Document Administration

Revision History

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WESTERN NSW LOCAL HEALTH DISTRICT

23 Hawthorn Street
DUBBO NSW 2830
PO Box 4061
DUBBO NSW 2830
Phone: +61 2 6841 2222
Fax: +61 2 6841 2225
www.wnswhd.health.nsw.gov.au

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Our Commitment to Palliative Care

- Palliative Care is multidisciplinary and is an integral part of our work across the Western NSW Local Health District.

- People with an advanced life limiting illness will have access to quality care to meet their needs delivered by trained generalist staff who are supported by specialist palliative care services.

- People with an advanced life limiting illness will have support to spend as much time as possible in their own home and community. Outpatient follow-up will be provided where possible in local community settings, or by using Telehealth and other technologies, to avoid unnecessary travel and burden on patients and families.

- Patients and families will experience care that is coordinated across all settings with other medical, health or community care providers.

- The Palliative Care we offer will be culturally appropriate.

Scott McLachlan
Chief Executive
Definitions

Advanced Life Limiting Illnesses;

Advanced life limiting illnesses are conditions that can be reasonably expected to lead to the death of a person within the foreseeable future. The term encompasses cancer and non-cancer illnesses which are expected to shorten a person’s life\(^1\).

End of Life Care;

End of life care is used in this Plan to mean the care provided to a person during the period of time when they are living with an advanced, progressive life-limiting illness. This period may be identified by clinicians asking themselves the question: “Would you be surprised if the person died in the next 12 months or so?”\(^2\).

Generalist Clinicians;

Generalist clinicians include general practitioners, community nurses and allied health professionals, staff in multipurpose services and residential aged care facilities. In the context of this plan it includes health care providers whose central work is outside of palliative care.

Model of Care:

Defines the way health services are delivered by outlining best practice care and services for a person or population group or patient cohort as they move through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place\(^3\).

Needs Based Care:

Refers to care based on the unique needs of patients and their families and carers. Frequent reassessment ensures that care and support can be adjusted as people’s needs change\(^4\).

Palliative Care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering.\(^5\) Palliative Care is not limited to the final weeks of a person’s life.

Palliative care may be provided by specialist palliative care clinicians or generalist clinicians including a person’s general practitioner in their local community. Care provided by generalists is often referred to as ‘a palliative approach’ to care.

Specialist Palliative Care:

Specialist palliative care describes services provided by a multidisciplinary team of specialist palliative care clinicians who have expert knowledge and skills in the care of people living with an advanced life limiting illness, in particular in the management of complex symptoms\(^6\).

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1. Palliative Care Australia
2. Framework for the Statewide model of Palliative and End of Life Care Service Provision, Agency for Clinical Innovation, 2013
3. Framework for the Statewide model of Palliative and End of Life Care Service Provision, Agency for Clinical Innovation, 2013
6. Framework for the Statewide model of Palliative and End of Life Care Service Provision, Agency for Clinical Innovation, 2013
1. Introduction

1.1. Background

There were 50,661 deaths in NSW in 2011. There were approximately 2,500 deaths in Western NSW LHD\(^7\). According to specialist opinion approximately 75% of deaths follow an anticipated course and evidence indicates that many of these people would benefit from the support of a palliative approach to their care. Approximately 1,530 people within the LHD would benefit from end of life care each year\(^8\).

Palliative Care provides treatment and care for people with advanced life limiting illnesses and supports their families and carers. It neither hastens nor postpones death, but affirms life and approaches dying as a normal process.

'End of Life' care generally refers to care provided to a person with an advanced life limiting illness in the last year of their life. Caring for people leading up to their death has always been at the core of Palliative Care practice.

Palliative and end of life care practices evolved historically within hospices and have over the last decade been adapted to other settings where many predictable deaths occur, such as residential aged care facilities and acute hospitals, or at home.

Community expectations about quality care for someone experiencing an advanced life limiting illness have continued to evolve rapidly in the last 20 years. There is now a clear demand by the whole community for people at the end of life to have access to care that matches the complex and ever-changing needs that they encounter.

The variety of settings in which palliative and end of life care occurs and the wide range of life-limiting illnesses, provide challenges to providing good care for people at end of life. Limited resources require careful coordination to achieve the goals of care – optimising quality of life including physical, emotional, spiritual, social, sexual, and financial aspects of life.

Palliative and end of life care is an important component of medical and surgical care, emergency and intensive care, aged care, chronic care and paediatric services. Palliative and end of life care is therefore ‘everybody’s business’.

Effective networks involving generalist clinicians (including general practitioners, allied health professionals and community nurses), and specialist palliative care teams are able to

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\(^7\) Centre for Epidemiology and Evidence, NSW Ministry of Health. Accessed and analysed by Epidemiology, Research & Evaluation Unit, Population health Directorate, WNSWLHD, 02 11 2014.

\(^8\) Based on assumption that 50% of people who die from non cancer deaths and 90% of people who die from cancer deaths in Western NSW LHD are people who would benefit from palliative and end of life care.
provide supportive care to people with advanced life limiting illnesses in their community. Advance care planning activities are best commenced and coordinated by the range of health care providers who are involved in supporting a person with an advanced life limiting illness. These activities include determining with the person, and their family, their goals of care and wishes for care at the end of their life, including the preferred location of care.

1.2. Purpose of this Plan

The purpose of this Palliative and End of Life Care Plan (‘the Plan’) is to guide the development of services across the Western NSW Local Health District (LHD) over the next three to five years. The scope of the Plan is inclusive of both palliative and end of life care and includes services provided to all age groups, in all care settings, by a broad range of health service providers including both generalist and specialist palliative care service providers. This plan will guide and support managers of health services across the Western NSW LHD and assist the Palliative Care Clinical Stream to develop services in a way that best meets the needs of our population.

The Plan will contribute to the development of a cohesive and integrated District-wide service that is aligned with Australian and NSW Health directions. The overarching goal of the Plan is to ensure that Western NSW LHD residents have access to quality care based on assessed need and as close as possible ‘to home’ or their place of choice.

This Plan provides the platform for developing a comprehensive model of care for palliative and end of life care services within the LHD. It describes some of the challenges and drivers for change and identifies key action areas aligned to the five strategic priorities of the Western NSW LHD Strategic Health Services Plan.

1.3. Strategic Context of this Plan

Several NSW, National and District plans have been reviewed to inform the development of the Palliative and End of Life Plan. These include:

- NSW State Plan
- NSW State Health Plan
- The NSW Rural Health Plan
- The Western NSW Local Health District Strategic Health Services Plan
- The NSW Government plan to increase access to Palliative Care 2012-2016
- The NSW Health Palliative Care Role Delineation Framework (GL2007_022)
- The NSW Agency for Clinical Innovation’s (ACI) Diagnostic Report to inform the Model for Palliative and End of Life Care Service Provision, February 2014
- The ACI Framework for the Statewide Model for Palliative and End of Life Care Service Provision (May 2013)
- National Palliative Care Australia key reference documents - Standards for Providing Quality Palliative Care for all Australians, Palliative Care service provision in Australia: A planning guide; A Guide to Palliative Care Service Development: A population based approach (2005)
- The National Palliative Care Consensus Statement (2011)
- Palliative Care NSW Policy Paper (2012)
1.4. Consultation process
A Steering Group, including specialist clinicians, was convened to oversee the planning process. The group has met several times to establish the scope of the Plan and the planning methodology.

The initial stages of planning included data analysis and a literature review. A workshop was held in Dubbo on 5 September 2014 to progress the development of the Plan. Participants of the workshop included representatives from the Agency for Clinical Innovation, Clinical Excellence Commission, Aboriginal Health, Hammond Care, Lourdes Hospital, general practitioners, LHD managers, specialist palliative care clinicians and generalist clinicians. The workshop participants provided a series of suggestions and recommendations regarding the direction of the plan.

1.5. Planning principles
The following principles, adapted from the Agency of Clinical Innovation\(^9\) have guided the development of this Plan:

<table>
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<tr>
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<tr>
<td>Patient and family centred Care</td>
<td>Care that is delivered in accordance with the wishes of the patient and family</td>
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<tr>
<td>Population and Needs based care</td>
<td>Services are planned based on population distribution and disparities in health status between different population groups and clinical cohorts are addressed</td>
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<td>Networked care provided on the basis of assessed patient and carer needs</td>
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<tr>
<td>Care as close to home as possible</td>
<td>All people approaching the end of their life in NSW should be able to access care as close to their home as possible</td>
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<tr>
<td>Accessible</td>
<td>People approaching the end of their life have access to local primary care clinicians, and networked access to specialist palliative care services based on assessed need</td>
</tr>
<tr>
<td>Equitable</td>
<td>Access to needs based care regardless of age, diagnosis, geography, culture</td>
</tr>
<tr>
<td>Integrated</td>
<td>Primary services, specialist acute services and specialist Palliative Care services are integrated to enable seamless patient transfer based on needs assessment and clear referral and access protocols</td>
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<td>Safe and effective</td>
<td>Care meets the Australian Safety and Quality Goals for Health Care:</td>
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<td>• That people receive health care without experiencing preventable harm</td>
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<td></td>
<td>• That people receive appropriate evidence-based care</td>
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<tr>
<td></td>
<td>• That there are effective partnerships between consumers and healthcare providers and organisations at all levels of healthcare provision, planning and evaluation.</td>
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\(^9\) Framework for the Statewide Model of Palliative and End of Life Care Service Provision,
2. Profile of Western NSW LHD

Western NSW is the second most sparsely populated LHD area in NSW, with just over one person per square kilometers (271,000 people, 250,000 square km). Around one-third of the Western NSW population is resident around Orange (including Parkes and Forbes); one-third in Dubbo and surrounding Local Government Areas (LGAs); 17% in Bathurst; and the remainder in the ‘North West’ and ‘Remote’ LGAs.

Population growth in Western NSW has been minimal over the past five years – 2.0%. Areas closer to Sydney have grown, while those beyond Dubbo have declined. The largest growth is in the 65+ ages; low future population growth is forecast.

Western NSW LHD has a large proportion of Aboriginal and Torres Strait Islander people – 11.1% of the population\textsuperscript{10}. Approximately 56% of the Aboriginal people in the LHD are aged 24 years or younger. The proportion of Aboriginal people living in communities increases from the south eastern to north western and remote areas of the District.

Socio-economic indicators largely step in the same direction, with people living in the south east areas being least deprived and those living in the North West and remote areas being most deprived. Health outcome statistics tend to follow the same trajectory. Aboriginal people continue to show disadvantage across all social determinants – education, employment, housing, household income, and incarceration – with health outcomes remaining unacceptably low compared to non-Aboriginal people.

For non-Aboriginal residents of Western NSW there is still a negative health gradient by remoteness. This is much less when compared to the gradient with Aboriginal residents included\textsuperscript{11}.

3. Death and life limiting illness

Dying has changed dramatically over the past century in Australia with the annual death rate per 1000 people having halved. People are less likely to die at a young age, but life expectancy at 85 years has changed very little. Death is more likely in older age groups (two thirds being 75 years and older) and is usually a result of chronic and degenerative diseases. Death is also more predictable and more likely to occur over a longer period of time\textsuperscript{12}.

Premature mortality measures deaths that occur before the age of 75 years. The causes of premature mortality in Western NSW reflect those of NSW as a whole. Around one-third are attributed to cancer, a quarter to circulatory diseases (coronary heart disease, ischaemic stroke, peripheral vascular disease, and congestive heart failure), ten per cent to injuries, and 7% to respiratory disorders. Overall, these causes make up about 80% of all premature mortality.

Despite a decline in cancer mortality and an increase in survival over time, one in two Australians will develop cancer and one in five will die from it before the age of 85\textsuperscript{13}. The most common cancer cause of death for both men and women in Australia is lung cancer.

\textsuperscript{10} NSW Ministry of Health Populations database (SAPHaRI) Accessed: 12.8.2014
\textsuperscript{11} Western NSW Health Needs Assessment, 2013
\textsuperscript{12} Dying Well: Grattan Institute Report No. 2014-10, September 2014
\textsuperscript{13} AIHW & AACR. Cancer in Australia: an overview 2012. Cancer series no. 74. Cat. no. CAN 70. Canberra: AIHW, 2012
Prostate cancer in men and breast cancer in women is next, followed by bowel cancer (colon and rectal cancers) in both men and women. Based on 2008 data, projections for cancer incidence in Western NSW LDH indicate a 33% increase by 2021 (2003 people per year with a cancer diagnosis)\(^\text{14}\). This trend is consistent with predictions for NSW as a whole.

Although the rate of death due to circulatory diseases continues to decline, the total circulatory disease burden is expected to increase over the next few decades due to the ageing population, better survival with the disease, and the increase in diabetes prevalence. Based on estimates from self-reported cardiovascular disease from the Health Survey\(^\text{15}\), 20% of the Western NSW population aged 15 years and over has existing disease. This is markedly higher than the NSW average.

Chronic obstructive pulmonary disease (COPD) results in airflow restriction causing progressive breathlessness. The Western NSW rate of self-reported COPD is 6.4% of all adults aged 45 years and over, which is significantly higher than the NSW rate of 5.7%. Within Western NSW the gradient follows that of smoking prevalence, lowest in the eastern areas of the LHD and highest in remote areas.

Whilst cancer, circulatory disorders, injuries and respiratory diseases account for the greatest number of premature deaths, several other chronic illnesses also result in premature death or death at an age greater than 75 years. These conditions include but are not limited to dementia, motor neuron disease and multiple sclerosis.

The life expectancy in Aboriginal people was estimated to be from seven to nine years fewer than for the general population in both males and females\(^\text{16}\). Aboriginal people have an earlier onset and higher prevalence of most chronic illnesses including cardiovascular disease, diabetes, renal disease and respiratory disease\(^\text{17}\). Aboriginal people have a 7% higher incidence of cancer than the NSW population overall (9% higher in men, 6% higher in women)\(^\text{18}\).

Chronic disease illnesses often have different trajectories. People who die from cancer often have a period of relatively high function following their diagnosis, followed by a rapid decline prior to their death. Others slowly lose function with intermittent periods of acute illness prior to their death. In contrast people with conditions such as dementia are more likely to experience longer periods of poor quality of life prior to their eventual death\(^\text{19}\).

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\(^{14}\) *Cancer incidence and mortality in Western NSW LHD*. Cancer Institute NSW. Presentation by Professor Jane Young, 2012

\(^{15}\) NSW Population Health Survey (SAPHaRI). Centre for Epidemiology and Evidence, NSW Ministry of Health


\(^{18}\) *Cancer in Aboriginal Peoples: Incidence, Mortality and Survival*. Cancer Institute NSW, 2012

\(^{19}\) *Dying Well*: Grattan Institute Report No. 2014-10, September 2014
4. What does a good death look like?

Dying well is dependent upon the quality of life experienced as a person's health deteriorates and good end of life care. A good death meets a person's physical, psychological, social and spiritual needs and provides support for the carers and family. People generally want to die comfortably at home or in a home-like environment. As death approaches some people may change their mind, preferring to die in a hospital or hospice setting. What is critical is that people have a choice. In rural areas many people equate dying in their local community hospital with dying at home, close to their family and in their local community. The principle of dying in ‘a place of choice’ has a particular meaning for Aboriginal people, this is the concept of going ‘home to country’.

The Australian Commission on Safety and Quality in Health Care has engaged health consumers and carers, and experts in the field of end of life and Palliative Care to explore the safety and quality issues associated with end of life care. The National Consensus Statement: essential elements for safe and high-quality end-of-life care describes ten essential elements for delivering safe and high-quality end-of-life care in Australia. These are summarised in Figure 1.

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21 Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians, Palliative Care Australia, Position Statement.
Figure 1: Overview of the 10 essential elements in the Consensus Statement

**PROCESSES OF CARE**

1. **PATIENT CENTRED CARE**
   Patients are part of decision making about end-of-life care

2. **TEAMWORK**
   Clinicians work together to provide end-of-life care

3. **GOALS OF CARE**
   Clear goals improve the quality of end-of-life care

4. **USING TRIGGERS**
   Triggers identify when patients need end-of-life care

5. **RESPONDING TO CONCERNS**
   Clinicians get help to rapidly respond to patient suffering

**ORGANISATIONAL PREREQUISITES**

6. **LEADERSHIP & GOVERNANCE**
   Policies and systems for end-of-life care

7. **EDUCATION & TRAINING**
   Clinicians have the skills and knowledge to provide end-of-life care

8. **SUPERVISION & SUPPORT**
   Clinicians providing end-of-life care are supported

9. **EVALUATION & FEEDBACK**
   The quality of end-of-life care is measured and improved

10. **SUPPORTING SYSTEMS**
    Systems align with NSQHS Standards to improve outcomes
5. Palliative and End of Life Care Services

Palliative Care may start early in the course of an illness and evolve as a person approaches the end of his or her life. Palliative Care can be provided in a range of settings and can involve doctors, nurses, allied health professional, families, carers and volunteers. They will often work in networked teams to ensure people receive high quality care.

These networks include generalist and specialist clinicians working in the community and in hospital setting, community support services and aged care services. One of the greatest challenges is ensuring people across NSW are able to access palliative care as close as possible to their home and family23.

Elements of Palliative Care include:

- Relief from pain and other distressing symptoms
- Enhancement, as far as possible, of quality of life
- Psychological and spiritual care
- Support to help people to live as actively as possible
- Assistance for families coping with illness, death and bereavement24

Generalist clinicians deliver the majority of palliative care and end of life care within the LHD. They utilise the referral triggers of Palliative Care Australia (2005) to refer to specialist palliative care when the patient’s needs exceed the capacity (knowledge, resources and facilities) of the primary care providers and/or, when there is exacerbation of a previously stable symptom.

Specialist palliative care services operate within a consultative model of care and are coordinated, predominantly, by specialist palliative care nurses. Specialist palliative care medical support is provided by fly-in, fly-out physicians and a part time staff specialist in Orange. The degree of specialist support currently provided to generalist clinicians is variable across the LHD.

The core roles of the specialist palliative care nurses are to:

- Provide recommendations and support (including a plan of care) to generalist clinicians working with patients
- Assist and support advanced care planning discussions and activities with patients and their families
- Liaise with metropolitan palliative care teams, when required, to assist in addressing complex patient’s care needs
- Provide education and training for health care providers on palliative care to maintain and increase competency and confidence in inpatient, aged care and community settings

Specialist palliative care nurses and generalist clinicians are supported by two palliative care clinical nurse consultants (CNCs) based in Bathurst and Dubbo. The CNC at Bathurst supports specialist palliative care nurses in Bathurst, Orange, Parkes and Forbes. The CNC at Dubbo supports specialist palliative care nurses in Dubbo, Mudgee, Walgett and Bourke.

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23 NSW Government plan to increase access to palliative care: 2012-2016

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

World Health Organisation
In addition to their clinical leadership role the CNCs are available for direct support to generalist clinicians.

Specialist palliative care medical support in Dubbo is provided by a ‘fly in – fly out’ service. Patients are able to access a specialist outpatient clinic and consultations via telehealth to more rural locations. This service from Royal Prince Alfred Hospital in Sydney also provides telephone support for the specialist palliative care nurses in Dubbo and the region. In Orange, specialist palliative care medical support is provided three days per week by a locally based clinician. This is complemented by a long-standing relationship with Sacred Heart Palliative Care Service in Sydney who provide ‘fly in – fly out’ monthly clinics.

There are five palliative care specific beds located at Lourdes Hospital in Dubbo. All other facilities within the Western NSW LHD have a number of single rooms that provide a private environment for people requiring end of life care. Many small hospitals in the region have rooms with specific equipment which has been donated by the local community to support people towards the end of life.

In recent years a number of allied health professionals have been employed specifically in palliative care. Palliative care social workers provide services in Bathurst and Orange and palliative care occupational therapists provide services in Bathurst, Orange, Parkes and Forbes. Where access to these professionals is not available, services are provided by generalist clinicians.

People receiving palliative care services within much of the LHD can receive additional support at home towards the end of their life. The Ministry of Health, as part of a three year initiative, have provided additional community support for people who wish to die at home. These ‘packages’ of care complement and link with the specialist palliative care services and aim to reduce hospital admissions. The Hammond Care Consortium (comprising Hammond Care, Sacred Heart Health and Calvary Health Care Sydney) successfully tendered to provide the packages. Care packages are available to seven LHDs in NSW including Western NSW LHD. Use of the packages commenced in January 2014 in the Bathurst and Orange areas. To the end of May 2015, 58 packages had been deployed in the LHD. The palliative care service is supported by small groups of volunteers in a range of locations across the LHD.

**Paediatric Palliative Care Provision “The Pop up Model” – A Shared Care Model**

Consistent with the *Paediatric Palliative Care Planning Framework 2011-2014*, the Western NSWLHD supports the “Pop up Model” when a child requires palliative care support. This ‘virtual Pop up Team’ is formed when the need arises, providing collaborative support consisting of local hospital and community service providers, GPs and paediatric and palliative care services supported by metropolitan specialist paediatric palliative care teams.

**Primary Care**

NSW Ambulance “Authorised Palliative Care Plans” provide further support for people receiving palliative care at home or in an aged care facility. With assistance from health care providers plans can be completed by the person or their carers and their medical officer (most often their GP) and lodged with NSW Ambulance. This plan then provides direction and support for Ambulance Officers to administer specific clinical support consistent with the person’s wishes, including their wish to die at home. Plans can be developed for children and adults.
Paramedic Connect is a collaborative between NSW Ambulance and NSW Health to increase paramedic engagement whilst also increasing access to health services in rural and remote communities. Following a pilot phase, this program is now involved in 'taking care to people with chronic illness' in the form of health promotion, primary health care and emergency care.

Bereavement support is provided by the specialist palliative care nurses in partnership with generalist clinicians. In the more isolated western region of the LHD a trained volunteer provides general support by telephone from Dubbo on average one day per week. This position is supported by the palliative care CNC based in Dubbo.

People identified as experiencing complicated grief are referred to appropriate, available services including professional counsellors, mental health services and Non-Government Organisations including the National Association for Loss and Grief.

6. Utilisation of Palliative and End of Life Care Services in Western NSW LHD

The majority of palliative and end of life care services are provided in the community or in an ambulatory care setting. In 2013/14, 16,519 non admitted occasions of service were documented as part of a palliative care clinic or as palliative care in a general clinic. Only one percent of the occasions of service were documented as medical services. This data does not include services provided by general practitioners.

Due to changes in data coding and reporting, reliable trended activity is not available. Whilst the quality of non-admitted data has improved significantly over the last few years, actual palliative care activity is likely to be higher than that reported particularly medical services due to different coding practices.

Between 2008/09 and 2012/13 there were 2145 admissions of residents of Western NSW LHD to hospitals within Australia for palliative or end of life care, requiring a total of 25013 bed days. There has been an increase in documented admissions over the period, ranging from 198 in 2008/09 to 577 in 2011/12. However this is likely to reflect improved coding rather than an actual increase in activity. The majority (92%) of these admissions were to facilities within the LHD and 62% of all admissions resulted in death in hospital.

Graph 1 illustrates an increasing trend in palliative care admissions to hospitals within the LHD between 2008/09 and 2013/14. There has been a decrease in bed days between 2011/12 and 2013/14. This data is likely to be an underestimate of true activity due to coding inconsistencies including timely type changing of people categorised initially as an acute admission.

Most admissions for palliative care to facilities within the LHD are local residents (92%) and six per cent are people identifying as being of Aboriginal or Torres St Islander decent. During the period, there were few children recorded as being admitted for palliative care.
Admissions were to hospitals throughout the LHD, ranging from the major referral centres to small rural hospitals and multipurpose services. The largest volumes of admissions were to Lourdes Hospital, Bathurst Hospital and Orange Hospital. However, collectively, the district and small rural hospitals and MPSs provide the majority of palliative care inpatient services in the LHD.
Graph 2: Western NSW LHD separations for palliative care 2008/09–2013/14 by hospital type
7. Challenges

The key strategic issues and challenges facing palliative and end of life care services in Western NSW are inter-related, and are summarised in the following section. These issues and challenges were identified during a workshop with palliative care specialists, clinicians, managers and non-government care providers held in September 2014.

Not surprisingly issues and challenges raised are consistent with those identified in key informing documents including the NSW Government Plan to increase access to Palliative Care 2012-2016 (NSW Health), The framework for the Statewide Model of Palliative and End of Life Care Service Provision (ACI, 2013) and Dying Well (Grattan Institute, 2014).

For the purpose of this document issues and challenges have been grouped under broad headings:

- Access
- Fragmentation of services
- Reliance on acute care facilities
- Culturally appropriate care
- Support for carers
- Education and training
- Transport and access to equipment.

7.1 Access to Palliative and End of Life Care

Historically the focus of palliative care services has been 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 children, adolescents and young adults.

Of the people in NSW who die of cancer, approximately two thirds receive specialist palliative care. Similar numbers of people die from other conditions where death is predictable; however ten percent of these people receive specialist palliative care in their last year of life\(^{25}\). Palliative Care Australia has estimated that 90 per cent of cancer patients and half of non-cancer patients could benefit from palliative care services.

\(^{25}\) The NSW Government plan to increase access to increase access to Palliative Care, 2012-2016
The challenge of providing access to palliative and end of life care close to home is compounded by the dispersed population, large distances between small communities and large centres, the difficulty and costs of accessing transport and accommodation services and the limited locally available health resources in small communities.

Specialist palliative care services within the LHD are predominantly relatively small nurse-led teams. The distribution of specialist clinicians also varies across the district and apart from one medical officer based in Orange who specialises in palliative care; the District is reliant on fly-in fly out palliative care physicians.

Access to specialist services, is therefore constrained and is generally not available out of normal business hours. Access to home and community care packages is also limited.

Timely access to palliative and end of life care services is also dependent upon comprehensive assessment and referral to appropriate services – ‘right place, right time, right team’. Often the recognition that a person is dying does not occur until the very late stages of their illness, preventing the mobilisation of appropriate services and limiting the time people and their carers have to come to terms with and make choices in relation to the approaching death.

People with life limiting illnesses and their families are not always aware of available services. There is also a limited understanding of what palliative care means, resulting in reluctance to be referred to these services. Clinicians may also be unclear about service options for their community.

The availability and role of Advance Care Planning is not widely understood. Communication systems are required to ensure that these plans can be available to all care providers.

### 7.2 Fragmentation of services

Palliative care and end of life care is complex because death and dying is the core business of multiple professional and non-professional stakeholders across a range of services. They often have conflicting views on what constitutes good end of life care and who requires specialist palliative care services. These issues can be exacerbated within a rural setting because of the fragmentation of care across settings (primary care, health care facilities, government and non-government agencies and communities).
Most of the care provided to people approaching the end of their lives is provided by generalist clinicians or other medical specialists. Generalist primary care services within the LHD are provided by general practitioners, community nurses, allied health professionals and community support services provided by public community support agencies and non-government organisations. The engagement of general practitioners is often a challenge in rural areas due to their busy work commitments in the larger centres and the shortage of general practitioners in small rural communities. This reduces their capacity to engage in shared care arrangements for patient care.

In Western NSW LHD, specialist palliative care nurses are employed by Lourdes Hospital and Health Service under a Service Level Agreement with the LHD. Integration with the remainder of specialist services is at times problematic and their scope of practice is not aligned to that of the LHD services. For example the Lourdes Palliative Care Service does not provide services to children or people residing in residential aged care facilities in Dubbo.

7.3 The reliance on acute care facilities for end of life care

According to the NSW Government Palliative Care Plan 2012-2016, most people in Australia say they want to die at home. However, only 16% of people actually do. Approximately 20% die in a hospice, 10% in a residential aged care facility and over half die in acute care hospitals. There are several contributing factors to this reliance on hospital settings including access to specialist and community palliative care services, the lack of after-hours services in the community and the availability of carers to provide 24 hour care for people who are highly dependent. Additionally hospital and community services do not coordinate systems to move people between hospital and home settings in response to changing needs.

Palliative care services actively work to support the choices of people at end of life and their caregivers to receive the care and support that they need in the place of their shared preference. However, more can be and needs to be done to promote quality of life and support care at home, not just for the last days of life, but over the whole ‘end of life’ timeframe. For many people and their families, anxieties about their capacity to manage caring for a dying person at home and the extent and responsiveness of services often shape attitudes about whether home is a safe, comfortable and appropriate place to be as death approaches. 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.

The lack of access to 24 hour support services, difficulties accessing general practitioner services and the trend away from general practitioner home visits to surgery consultations has resulted in emergency departments becoming defacto primary care services for people in many rural areas.

Acute care services with their emphasis on patient flow and acute disease management and cure are not always ‘palliative friendly.’ Staff are not always aware of contemporary end of life care including advance care planning and may be uncomfortable with talking about dying with patients and carers. Failure of acute care staff to identify people requiring palliative and end of life care may prevent appropriate referral to specialist palliative care services.

Anecdotal information from clinicians within the Western NSW LHD suggests that people living in small communities often consider dying within their local hospital as ‘dying at home’. Many small hospitals within the LHD have rooms that have been furnished and decorated by the community to provide a comfortable end of life environment.

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26 The NSW Government plan to increase access to increase access to Palliative Care, 2012-2016
7.4 Culturally Appropriate Care

Historically, local services have provided a ‘one service fits all’ approach. With an increasing cultural diversity of our communities, services need to be responsive to the different beliefs, values and customs of people requiring services.

7.4.1 Aboriginal Population

Providers of palliative and end of life care need to focus on providing care that meets the cultural needs and practices of Aboriginal people in their communities. For inpatient care this will include:

- Ensuring the size of room(s) encourage and accommodate extended family and kinship groups over long periods of time
- Provide direct access to adjacent outdoor areas to enable care to be provided outside (day and night) over extended periods of time
- Providing unencumbered capacity for ceremonial and cultural activities before and after death

7.4.2 Culturally and Linguistically Diverse Populations

The Western NSWLHD has a culturally and linguistically diverse population (CaLD) who may also require palliative care support. Palliative care service providers can help address the palliative and end of life care needs of CaLD people by the use of professional interpreting services in accordance with health guidelines and provide information about palliative care in the person’s preferred language using resources that are available online through organisations such as Palliative Care Australia (PCA).

Apart from family members, people who require access to translation services may contact the Rural Health Interpreter Service on 1800 674 994. Interpreters will often need to provide telephone services in rural areas, however the use of telehealth services including visualisation should be considered.

7.5 Support for Carers

Carers are frequently the ‘backbone’ of care provision in end of life care. Whilst most people want to die at home, significant support is required to enable this to occur. The main support is informal care by partners, children, parents and friends. Informal care, care by the carers, is associated with financial, social, time and health costs. Carers face considerable pressure during such a time. The ratio of people who need a carer to the number of people who have one is falling28. Already, a significant proportion of dying people do not have a live-in carer. This is increasingly the situation in rural areas as younger people frequently migrate to larger centres to seek education and career opportunities.

Often carers face considerable waiting periods to access support through carer packages and home-based care. There are also limited respite services available for carers, particularly those provided in the home. The support offered by community care workers under the Hammond Care Consortium packages assists with this however each package is limited to 48 hours of care, and the initiative is only funded for a three year period to date.

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7.6 Education and Training
Access to education, training and ongoing clinical professional development is particularly problematic for health staff and primary care providers living in rural areas. The specialist palliative care service across the Western NSW LHD is committed to providing ongoing education to generalist health care providers to assist them in caring for their community members at the end of life. This is delivered in a planned approach at a range of locations to provide optimal access for clinicians.

7.7 Access to Equipment and Information Systems
Timely access to equipment is an important aspect of enhancing quality of life for people in their last year and also to support people who are dying at home. However supplying equipment is sometimes difficult when people live in rural and remote communities. A particular issue is the supply of hospital beds. A system for renting beds has been introduced within the LHD rather than borrowing hospital beds, the uptake has been limited due to availability and cost factors for local health services.

Transportation of equipment to homes usually becomes the responsibility of health service staff or the laundry service. Some of the existing equipment is dated, and in less than optimal condition.

Currently several stand-alone information systems are used by different providers of palliative and end of life care services. This prevents effective sharing of information and data between generalist clinicians and specialist palliative care services and does not support quality initiatives involving the benchmarking of activity with other services. The collection of data on available systems is also inconsistent and incomplete making available data unreliable for planning and monitoring purposes.

8. Future directions

Proposed Model of Care
The Agency for Clinical Innovation (ACI) has developed a high level framework to inform the development of a comprehensive model of care for Palliative and End of Life Care service provision across NSW.

Taking a framework approach to service delivery achieves three key outcomes by:

- Describing a ‘network’ of services to support people approaching and reaching the end of life
- Describing minimum expected levels of accessibility of palliative and end of life services to the people of NSW
- Ensuring best practice care is provided safely and meets required standards and quality.
This Framework guides the future model of palliative and end of life care for the services we provide in the Western NSW LHD and will provide a roadmap for developing and improving our services.

Three key priorities have been identified across a range of policy and strategic documents:

1. Caring appropriately for people approaching the end of life – identification of preferred place of care, better care coordination, patient focused, goal directed care and advance care planning and access to competent and supported primary care providers
2. Caring for people with complex needs related to life-limiting illnesses – needs-based assessment and referral, management of refractory pain or other symptoms, management of complex social or psychological distress
3. Care for those who are dying – impeccable symptom management, communication and care and support for the family.

Underpinning the ACI Framework for Palliative and End of Life Care is a population health approach. This approach proposes that the target population be conceptualised as falling within three broad sub-groups, based on the complexity of their needs (Figure 2) and care to be provided by appropriate services to meet those needs.

**Figure 2: Adapted model of level of need within the population of patients with a life limiting illness**

- **Groups**
  - A: Primary care
  - B: Intermediate care
  - C: Complex care

- **Needs**
  - Primary care
  - Intermediate care
  - Complex care

- **Patient movement between levels**

It is important to note that people with advanced life limiting illnesses require assessment and frequent re-assessment as their needs, and the needs of their carers, are likely to change over time. The above figure illustrates how patients can move between groups as the complexity of their needs change, however many people with advanced life limiting illnesses are successfully cared for by primary care providers who are well resourced to meet their needs.
The *Guide to Palliative Care Service Development* developed by Palliative Care Australia (2005) provides a generic template for a collaborative, inclusive model that incorporates care provided by primary and specialist palliative care providers.

Primary care providers in the context of the planning framework include general practitioners, community and hospital based clinicians (doctors, specialists in other areas of practice, nurses, allied health staff and staff working in residential aged care facilities). This group of clinicians are usually the first point of contact for a person with an advanced life-limiting illness, and are responsible for a large proportion of palliative and end of life care.

For the purpose of developing a model of care in our District, the NSW Palliative Care Role Delineation Framework\textsuperscript{30} has been modified to better reflect the structure and role of specialist palliative care services within Western NSW LHD. The Framework presented below (Figure 3) has been tailored to describe the relationship between specialist palliative care and primary care services. The specialist palliative care services at Bathurst, Orange and Dubbo provide resources and support for specialist services in other locations including Mudgee, Parkes, Forbes, Walgett and Bourke.

**Figure 3:** A Networked approach for the care of people approaching and reaching the end of life in Western NSW LHD

All people diagnosed with an advanced life limiting illness, as a minimum, require access to primary care providers who have knowledge and skills to promote optimal quality of life in the care of people with an advanced life limiting illness. The needs of the person with an advanced life limiting illness, primary carers and family, balanced with an assessment of their individual and collective strengths and limitations, are the criteria used to determine access to appropriate levels of support and care.

Specialist palliative care services may be required to assist the person with an advanced life limiting illness at times when they experience problems or needs beyond the capabilities of

\textsuperscript{30} NSW Department of Health, 2007
the primary care provider or service. For most people this is likely to be episodic need for specialist care, provided in partnership with their primary care team. A person in these circumstances may expect to access specialist services on a number of occasions while receiving ongoing care from their primary care providers.

All health professionals have a responsibility to advocate for and contribute to the care of people toward the end of life. Fulfilling this 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 may 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 substantially focussed 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 the specialist skill, knowledge and qualification in the field of palliative care.

The extensive use of inpatient services and emergency departments in the last year of life by people whose deaths are clinically expected is particularly relevant in rural areas where access to supportive services is at times prohibited due to geographic and social factors. A recent report from the Bureau of Health Information\textsuperscript{31} found that when comparing the percentage of the population who attend an emergency department at least once a year, people with a cancer diagnosis in the last 12 months, did so at double the rate (39%) than the general NSW population (19%). Anecdotally, clinicians report that people with non-cancer chronic illnesses are also more frequent attenders at emergency departments.

Thus there is the need for a networked and integrated model that is based on an agreed understanding of the needs of those approaching the end of life, which provides accessible and timely specialist support for the generalists and informal primary carers who deliver most of the care. Specialist palliative care services will support and complement the care provided by primary care services on a needs-basis. The specialist service will provide support and expert advice in a ‘shared care’ arrangement with primary care teams for people who have complex or unstable symptoms or those who have high level needs.

**Strategic Directions for Palliative and End of Life Care**

The following section details key initiatives for implementation over the next five years. These initiatives are aligned to the Strategic priorities of the Western NSW Local Health District Strategic Health Services Plan

\textsuperscript{31} Bureau of Health Information. *The Insights Series: Emergency department utilisation by people with cancer* Sydney (NSW); BHI; 2014.
Developing a coherent Western NSW system of care

**INITIATIVE:**

1. Establish a Western NSW LHD Palliative Care Clinical Stream to:
   a. Monitor quality and efficiency of services for people in the last year of life
   b. Evaluate existing and proposed services with the Triple Aim Framework

   Develop a workforce plan to address existing service gaps and grow a sustainable specialist palliative care workforce.

2. Explore the feasibility of a centralised referral system to specialist palliative care services across Western NSW LHD

3. Realign palliative care services provided by Lourdes Hospital and Community Services with LHD teams to ensure consistent scope of service and provide children and residents of aged care facilities with access to specialist palliative and end of life care

4. Review existing information systems and agree preferred option/s to promote timely and accurate data recording and allow the sharing of information between providers

**MEASURING SUCCESS:**

i. Clinical Stream established

ii. Minutes provided to Operations Directorate

iii. Communication / governance processes in place

iv. Key focus areas identified / prioritised and implemented

v. Workforce plan developed

vi. LHD information system agreed and implementation plan developed

**Partners:**

- Executive Lead
- Generalist clinicians
- Private practitioners and specialists
- Non-Government Organisations
- Medicare Locals / Primary Health Care Organisations
- Aboriginal Community controlled Organisations
- Community members
- LHD Communications & Engagement Directorate
Supporting high performance primary care

**INITIATIVES:**

1. Strengthen the networked model of care in Western NSW LHD by:
   - Advance Care Planning (ACP) – promote / share / support all clinicians to implement ACP
   - Multidisciplinary care – develop care models to support people towards the end of life
   - Support the development of 24 hour specialist palliative care advice for carers and families

2. Enhance community based palliative and end of life care services in the Western NSW LHD:
   - Integration of primary care, aged care and specialist palliative care services
   - Strengthen existing partnerships with general practitioners and build on the LHD integrated care strategy to develop multidisciplinary generalist palliative care in rural communities
   - Work in partnership with NSW Ambulance to support ongoing use of authorised palliative care plans and Paramedic Connect.
   - Build the capacity of generalist clinicians (nursing, allied health and general practitioners) to effectively contribute to high quality end of life care
   - Support the promotion of new on-line resources, symptom management and clinical guidelines

3. Explore the feasibility of integrated data systems to facilitate the sharing of clinical information between generalist and specialist clinicians

4. Community Education Strategy
   Liaise with both internal and external stakeholders to develop education sessions for both clinicians,

**MEASURING SUCCESS:**

i. Increased percentage of appropriate referrals from generalist staff
ii. Increased percentage of appropriate referrals for people with non-cancer illnesses
iii. Percentage of generalist clinicians with training in end of life and palliative Care
iv. ACP education conducted and location
v. Sharing of Advance Care Plans across providers
vi. Decreased Emergency Department presentations and decreased avoidable admissions
vii. Number of clinicians who have attended end of life and palliative care education
viii. Evidence of multidisciplinary care plans (audits)
ix. Decreased length of stay in hospital prior to death
x. Decrease in hospital-based palliative care deaths

**Partners**
- Generalist clinicians
- Chronic Care and Connecting Care clinicians
- HICT
- ACI
- CEC
- PHO
- LHD Aged Care team
- LHD Patient Flow team
- Residential Aged Care Facilities
- LHD Communications & Engagement Directorate
- NSW Ambulance Service
Closing the Aboriginal Health Gap

**INITIATIVE:**

1. Strengthen partnerships between palliative care providers and Aboriginal Community Controlled Health Services to increase access to available services and decrease duplication

2. Partner with Aboriginal health workers to facilitate delivery of culturally appropriate services

**MEASURING SUCCESS:**

i. Clinicians from Aboriginal Community Controlled Health Services participating on the Palliative Care Clinical Stream

ii. Aboriginal health workers participation in multidisciplinary team meetings (snapshot survey)

iii. Attendance of Aboriginal health workers at palliative care education events

**Partners:**

- Aboriginal Community Controlled Health Services
- Primary health care Aboriginal health workers
- Specialist palliative care
- Bila Muuji
- LHD Communications & Engagement Directorate
**Improving the patient experience**

**INITIATIVE:**

1. Improve the end of life and palliative care experience in:
   a. Aged care settings
   b. Inpatient facilities

2. Engage and support volunteers to provide carer and patient support

3. Promote community awareness regarding ‘what is palliative care’, what services are available and advance care planning

4. Develop a performance monitoring framework for palliative and end of life care services including key performance indicators and monitoring systems

**MEASURING SUCCESS:**

- Decreased admissions to emergency departments of people from RACFs
- Development of a LHD wide volunteer program
- Community education provided on ‘what is advance care planning?’
- Key performance indicators agreed
- Monitoring system established

**Partners:**

- WNSWLHD Health Councils
- DOHA – training to support the Palliative Care Toolkit
- Residential Aged Care Facilities
- Western NSW LHD Aged Care
- MPS Aged Care:
  - Operational managers
  - Health Service Managers
  - Nurse Unit Managers
- PEPA
- Community groups
- LHD Communications & Engagement Directorate
Living within our means

**INITIATIVE**

1: Review of existing funding and funding allocation to identify opportunities for service development using a Program Budgeting and Marginal Analysis (PBMA) approach. This approach can also be used to provide a basis for judging where to allocate new money or resources.

**MEASURING SUCCESS:**

I. Number of palliative care doctor Telehealth consultations

II. Number of palliative care nursing Telehealth consultations

III. Number of multi-disciplinary care planning meetings in palliative care network

IV. Percentage of attendees to meetings compared to base membership in terms of reference

V. Program or service budget used to inform future resource allocation

VI. Impacts of moving resources examined to determine what might increase total benefits

**Partners:**

- Telehealth Manager
- Primary health care clinicians
- Specialist Palliative Care clinicians
- Metropolitan specialist Palliative Care clinicians
- Lourdes hospital and community team
9. Implementation of Plan

Implementation of the Plan will be overseen by the Palliative and End of Life Care Clinical Stream. This stream will have representation from Specialist palliative care clinicians, Health Service Managers, Primary Care Providers (including GP's) in a collaborative approach to delivering the key initiatives identified in this plan.