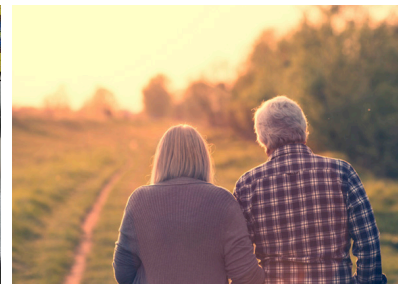
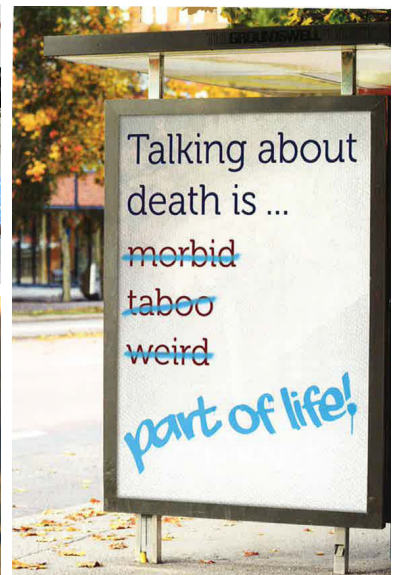


South Western Sydney Local Health District

Advance Care Planning, End of Life & Palliative Care Strategic Plan 2016 - 2021

Leading care, healthier communities



Health
South Western Sydney
Local Health District

Acknowledgement

The pictures in this Plan include photographs of patients, carers, family members, volunteers and staff. Our thanks are extended to all these people for their generosity.

We would also like to specifically thank a number of people and services:

- The Groundswell Project for permission to use the “Talking about death” bus stop poster
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January 2016





Foreword

Advances in medicine have meant that people are living longer, but the care of people at the end of their life has also become increasingly complex and can be difficult for people and families to discuss.

The *SWSLHD Advance Care Planning, End of Life and Palliative Care Strategic Plan 2016 – 2021* outlines the issues facing patients, families, carers, local communities and health care practitioners in meeting the needs of people with life-limiting illnesses and details the strategies planned to meet these challenges.

The plan addresses three aspects of end of life: the need for an earlier focus on advance care planning; providing optimal end of life health care and access to specialist palliative care for people with complex palliative needs and their families.

Clinicians have an important role in ensuring that each person and their family can plan ahead and consider their wishes at the end of life. This includes advance care planning, guardianship, enduring power of attorney and organ donation.

Building knowledge and awareness in the community about planning ahead and a community-wide approach to strengthening support to people at the end of life is considered an important part of the Plan.

A strong emphasis is also placed on professional development for clinicians in hospital, community and residential aged care settings, including the identification of clinical deterioration, supported by improved access to specialist palliative care consultation and services, stronger partnerships, governance and research.

This Plan provides the direction for change, and the actions that are needed, to ensure the best care and support is provided for people at the end of their life.

I would like to thank the many patients and carers, consumers, health professionals and organisations who have thoughtfully and generously contributed to the development of this Plan.

A handwritten signature in black ink, appearing to read 'Amanda Larkin', with a long horizontal line extending to the right.

Amanda Larkin
Chief Executive
South Western Sydney Local Health District



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1 Introduction

Death is an inevitable part of the human existence. However the experiences of patients and their families around death and the care they receive are variable. To address this concern, national and state governments have recognised that a stronger focus on end of life planning and care is required. This has included campaigns to encourage the public to participate in advance care planning, providing clinicians with tools to support identification and care of patients at the end of their lives and building capacity of specialist palliative care services to support patients with complex palliative care needs, their carers and other health professionals.

Managing patients with a life limiting illness is complex, complicated by multiple definitions, unclear roles and lack of tools and education. The diverse nature of south western Sydney communities adds further complexity. Poor knowledge of the health system, the multiplicity of euphemisms to describe death, variable English and literacy skills, multiplicity of cultural and religious beliefs, complex family dynamics, financial and economic constraints, past experiences of death, differing expectations about health outcomes and discussion and circumstances of death can complicate care.

This Plan provides a system-wide approach in addressing how health practitioners, in partnership with south western Sydney residents, can start the conversation around end of life and ensure that no matter where a patient is cared for they will receive optimal clinical care. Patients and their family will receive empathy and support in a manner that reflects the patient's needs and wishes. It addresses three critical areas of end of life in south western Sydney:

- **Advance care planning** is a recent concept and involves ongoing conversations between the patient, their family and treating doctor about their end of life wishes as their health condition and care needs change. As a normal part of ageing, it commences with annual screening and ongoing care provided to patients by their GP. It is also an essential part of comprehensive care provided by all health practitioners treating people with chronic and/or life limiting disease. This approach includes developing a will and appointing a power of attorney and enduring guardian. The Plan aims to build the capacity of all clinicians to understand and embed advance care planning into their practice and to build knowledge and understanding in local communities.
- **End of life care** is not the sole responsibility of palliative care specialists. Rather, it is the responsibility of all clinicians who are treating and caring for people with progressive life limiting disease with a focus on optimal care. The Plan recognises that most patients can be successfully cared for by their treating doctor with adequate training, the right tools and when required, access to a palliative care consultative service. The Plan provides guidance around the systems, processes and education that all clinicians require to build their capacity to meet patient needs.
- **Specialist Palliative Care Services** provide direct care to patients and families with the most complex needs; and consultative services to support other clinicians in providing end of life care. The Plan focuses on further developing these services in south western Sydney, including new models of care, and building the capacity of specialist palliative care services to strengthen care through research, education and teaching.

2 Planning Process

In September 2014, South Western Sydney Local Health District (SWSLHD) established a steering committee to guide development of a strategic plan. The committee included consumers and representation from generalist and specialist health services.

The planning process considered a range of factors, including policy, the demographic characteristics of the community, service demand and the views of key stakeholders including patients, carers and health and other service providers.

For this strategic planning process, interviews conducted with 100 local residents by the SWSLHD Palliative Care Service in 2012 – 2014, *Conversations, Stories & Reflections – What do they want us to hear?* provided a contemporary understanding of the views of people with palliative care needs and their carers. This was supported by feedback from local participants of the Palliative Care Home Support Packages (PEACH) Program. Consultation with professional health and community service providers and other stakeholders occurred through meetings, forums, surveys and letters. In addition, an Aboriginal Health Impact Statement has been completed for this Plan, indicating that consultation has occurred with Aboriginal stakeholders. Information from these consultations has informed this Plan.

The contribution of people with palliative care needs, carers, community members, staff and other service providers to this planning process has been extremely valuable and is gratefully acknowledged.

Consultation with:

- Consumers via the SWSLHD Community and Consumer Council
- Volunteers
- General practitioners
- Community and hospital pharmacists
- Residential aged care facilities
- SWSLHD hospital based staff – senior doctors, nurses, allied health and health promotion
- SWSLHD Community Health staff - nurses and nursing unit managers
- SWSLHD staff representing priority populations such as Aboriginal people, culturally and linguistically diverse communities and refugees
- Hospital and facility executives
- Specialist palliative care staff
- Local community organisations
- Pastoral carers
- Peak agencies i.e. NSW Cancer Council, Motor Neurone Disease Association
- SWSLHD committees
- Other local health districts, networks and NSW Ministry of Health agencies



3 Vision and Principles

Vision

The Plan responds to the SWSLHD vision of

**Leading care, healthier communities
with a focus on
quality health care and support for end of life care**

Principles

The principles informing this Plan and service development into the future are consistent with NSW Ministry of Health (MoH) directions around end of life,^{1,2} the *NSW Health Palliative Care Strategic Framework 2010-2013*³ and the *SWSLHD Strategic and Healthcare Services Plan*.⁴

1. Care is provided in the **most appropriate environment** possible in accordance with the needs of the patient and in consultation with them, their family and carers. These environments include home, residential aged care facilities and other health care facilities and the transition between these settings.
2. **Quality palliative care** is safe, effective, responsive, appropriate and evidence based
3. Health care will be **patient, carer and family centred** and responsive to the cultural and other needs of individuals, families and communities.
4. Care is **responsive to the needs** of the patient and their family.
5. The **health workforce has the necessary skills** in assessment and ongoing care of patients and is well supported in their practice.
6. Care is **holistic, integrated and coordinated** across primary and specialist health services and settings.
7. Care is **equitable**, with vulnerable populations and communities provided with additional support and assistance to access palliative care.
8. **Collaboration and teamwork** will occur across all health settings and include patients, community members and other service partners.
9. **Promotion** of palliative care is essential to building community capacity to understand death, dying and bereavement, respond to and support people with palliative care needs and their families and support decision making and problem solving.
10. **Advance care planning** requires initiation and continuing conversation involving the individual and their family and health care practitioners. It is an essential component of all health care.
11. Health **information and data** will be used to ensure quality health care is provided.

4 Policy and Planning Strategic Context

This Plan is underpinned by several concepts:

- Planning for end of life care ensures that people have the time and opportunity to consider their choices regarding their end of life care. Advance care planning encourages individuals to begin planning earlier in their life about how they wish to have care provided at the end of their life, including their preferences about health, personal care and treatment and who should make decisions on their behalf. Planning can occur early in adult life, when chronic disease is diagnosed or when prognosis changes or approaching the end of life.
- Providing care to people who are approaching the end of life is undertaken by a range of health professionals including the general practitioners, specialists from a wide range of medical disciplines, nurses, allied health professionals and palliative care specialists. Care can be provided in homes, clinics, residential aged care facilities (RACF), acute hospitals or specialist palliative care wards or units.
- Carers and family members are an integral part of care, ensuring that the broader range of needs of the individual are met. The demands on carers in particular can be significant. The broader community also has an important role in supporting individuals and families.
- Not every person approaching death will require access or treatment by specialist palliative care services. However a pathway to specialist advice is essential to comprehensive care.

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

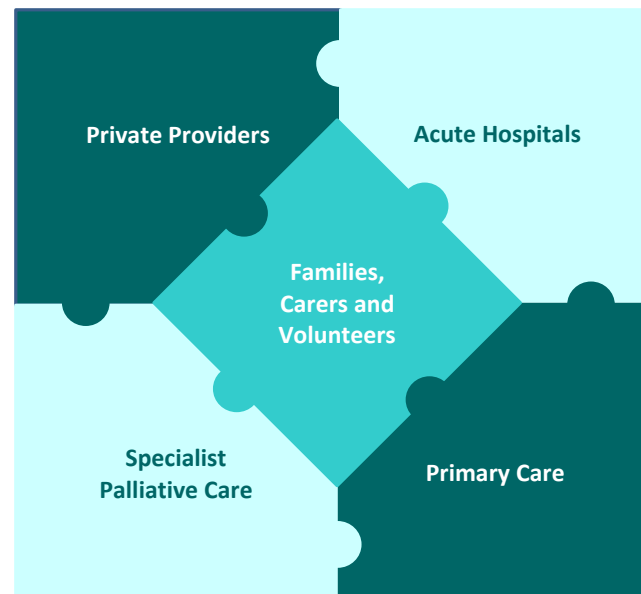
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process; intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until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

Source: World Health Organization 2002

The interplay of service providers and community members in meeting the needs of people at the end of life is reflected in Figure 1.



Figure 1: The Service Picture (Source: National Palliative Care Strategy 2010)



Australian and NSW governments and other agencies provide significant leadership through policy development and resources in planning ahead, improving end of life care and access to specialist services. The following summarises the strategic context, with detailed information in Appendix A. Terminology is described in Section 12. In policy it is used interchangeably, leading to confusion.

4.1 National Direction

The *National Palliative Care Strategy 2010* (NPCS) provides the overarching policy and planning context for palliative care in Australia covering specialist and generalist/primary health care.⁵ It has four goals: awareness and understanding; appropriateness and effectiveness; leadership and governance; and capacity and capability. The strategy is supported by guidelines on settings of care such as community and aged care facilities, and population groups such as Aboriginal people. These broader strategies reflect international directions.^{6,7} Palliative Care Australia (PCA) also provides national guidance through the *Standards for Providing Quality Palliative Care for all Australians*.⁸

The NPCS includes a focus on advance care planning and reflects a broader direction across government agencies, including the Departments of Health and Ageing, for people to plan ahead and talk with families about their wishes. The *National Framework for Advance Care Directives* draws attention to the importance of this issue.⁹ Other aspects of patient wishes are reflected documents such as the *Organ and tissue donation for transplantation in Australia 2014–2018 Strategic Plan*.¹⁰

4.2 NSW Direction

The *NSW Health Advance Planning for Quality Care at End of Life - Action Plan 2013–2018* sets the direction in decision making and advance care planning at the end of life.¹ It focuses on strategic partnerships with other government agencies and primary, acute and aged care sectors and seeks to

normalise advance care planning and improve end of life care by integrating patients' wishes into the management of chronic life-limiting illness.

The *NSW Government Plan to increase access to Palliative Care 2012-2016* sets the agenda for ensuring access to quality palliative care regardless of economic or social circumstances, geography or medical condition.² The Plan supports new partnerships and linkages between specialist and generalist services to support care for dying patients in the community and residential aged care settings. The four action areas are: expanded community based palliative care, especially in rural areas and for special needs populations; integration of primary care, aged care and specialist palliative care services; expanded support for families and carers; and extended capacity by enhancing existing palliative care services and building and using skills of the multi-disciplinary teams which provide such care.

These plans are supported by NSW policy including the *Palliative Care Role Delineation Framework*,¹¹ the *NSW Paediatric Palliative Care Planning Framework 2011-2014*,¹² the *Palliative Care Strategic Framework 2010-2013*,³ the NSW Agency of Clinical Innovation (ACI) *Palliative and End of Life Care - A Blueprint for Improvement*.¹³ *Increasing Organ Donation in NSW: Government Plan 2012* also has relevance with a focus on maintaining and strengthening existing Commonwealth strategies and new initiatives for NSW.¹⁴

NSW Government and Ministry of Health directions in 2015 include:

- *NSW Get it in black and white Campaign* to promote all aspects of planning ahead including completing Wills, Power of Attorney, Enduring Guardianship and eventually Advance Care Directives
- Release of the Aboriginal Wills Handbook and the Aboriginal Taking Care Of Business (Tcob) Resource
- Developing a *NSW Advance Care Directive*
- Roll out of NSW policies - *Resuscitation Plan* and *Verification of death and medical certification of death*
- Introduction of the Palliative Care Home Support Packages "PEACH" Program to care for people at end of life
- NSW Agency for Clinical Innovation (ACI) and the Clinical Excellence Commission have prioritised end of life care; and the *Palliative and End of Life Care* website has been launched
- Trials of the Health Professionals in Advance Planning and End of Life (SHAPE) Conversations Project

Additionally, the Australian Government introduced *Special Disability Trusts* for parents and immediate family members to plan for the future care and accommodation needs of a person with a severe disability.

Figure 2 following illustrates the NSW Health endorsed framework for managing patients approaching and reaching the end of life, with care for all but the most complex patients predominantly provided by general practitioners and medical specialists other than palliative care.

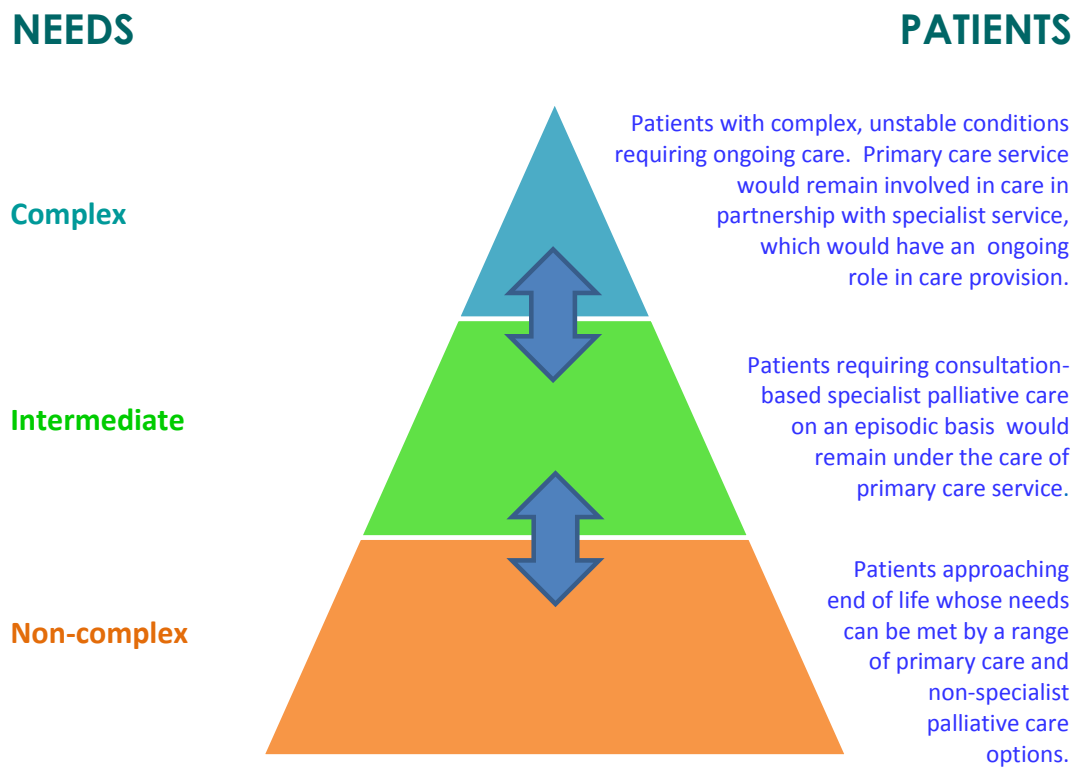
4.3 Local Health Direction

Local health services have given considerable attention strategically to end of life and palliative care. The SWSLHD Advance Care Planning and Care of the Dying Committee progresses implementation of



NSW directions in advance care planning and end of life care through health promotion, training and education and policy development. The Committee has action plans covering 2014-2015. Reflecting a broader concern about patient wishes, there is also an action plan focused on organ and tissue donation.¹⁵ Specialist palliative care needs have been considered in the *SWSLHD Strategic & Healthcare Services Plan*,⁴ *SWSLHD Cancer Services Strategic Priorities Plan*¹⁶ and in infrastructure planning for Liverpool, Campbelltown and Bankstown-Lidcombe hospitals.

Figure 2: Level of need within the population of patients approaching and reaching end of life



Source: NSW ACI *Framework for the Statewide Model for Palliative and End of Life Care Service Provision*, 2013¹⁷

South Western Sydney PHN Ltd (SWSPHN) has a role in increasing the efficiency and effectiveness of medical services for patients; and improving coordination of care. It does this by working with general practitioners (GPs), other primary health care providers, secondary care providers and hospitals to ensure improved outcomes for patients, a role previously provided by the South Western Sydney Medicare Local (SWSML). The SWSML Population Health Needs Assessment of the south western Sydney communities identified aged care and cancer (including palliative care) as priority health issues.¹⁸

The SWSLHD and SWSPHN Integrated Health Committee focuses on improving health in shared priority areas. Funding has been allocated to Healthcare Pathways to improve management of health conditions and referral to specialist services, with Palliative Care a priority area for pathway development. Other initiatives include development of integrated primary and community care centres (IPCCC), including at Oran Park, and technology assisted healthcare in Wollondilly Shire.

5 South Western Sydney

SWSLHD is responsible for providing health care to people living in south western Sydney. This covers the residents of Bankstown, Fairfield, Liverpool, Campbelltown, Camden, Wollondilly and Wingecarribee local government areas (LGAs).

5.1 South Western Sydney Communities

An estimated 921,718 people (12% of the NSW population) live in south western Sydney (Table 1).¹⁹

Table 1: Estimated Resident Population (ERP) of South Western Sydney, 2014 (ABS)

Local Government Area	2014 ERP	% of the Population
Bankstown	200,357	21.7%
Fairfield	203,109	22.0%
Liverpool	199,928	21.7%
Camden	67,084	7.3%
Campbelltown	156,572	17.0%
Wollondilly	47,084	5.1%
Wingecarribee	47,584	5.2%
SWSLHD	921,718	100.0%

1. Camden, Campbelltown and Wollondilly LGAs combined comprise the Macarthur Region, with an estimated total population in 2014 of 270,740 people i.e. 29.4% of SWSLHD residents

Source: Australian Bureau of Statistics, Estimated Resident Population 2014 (released 31 March 2015)

South western Sydney is characterised by considerable diversity including:

- a relatively young profile compared to the NSW population as a whole. There are 110,255 people aged over 65 years (12.2% of the population), with the largest proportion of older people in Wingecarribee LGA with 23.3% of residents aged 65+ years. Liverpool, Campbelltown, Camden, Wollondilly, Fairfield and Bankstown LGAs all having relatively small populations of residents in this age group. Of those aged 85+ years, only Wingecarribee (2.8%) and Bankstown LGAs (2.2%) exceed the NSW average (2.1%)¹⁹
- pockets of disadvantage measured by factors such as income, employment and educational status, particularly in Fairfield, Bankstown, Campbelltown and Liverpool LGAs (four of the ten most disadvantaged LGAs in metropolitan Sydney). At a local level, Claymore, Airs, Miller, Cartwright and Villawood are in the twenty five most disadvantaged suburbs in NSW²⁰
- public and private housing, with social housing predominantly in Bankstown, Campbelltown, Liverpool and Fairfield LGAs. There is also extensive residential aged care accommodation, with 5,769 residential aged care places (2012), with 51% located in Bankstown and Fairfield LGAs. The rate of residential aged care places is similar to the Australian Government target (87.1 places per 1,000); however there are fewer community places (packages) (20.3 places per 1,000)⁴
- some of the largest Aboriginal communities in metropolitan Sydney, with 13,070 residents identifying as Aboriginal and Torres Strait Islander peoples in 2011. The largest communities are in Campbelltown (4,729), Liverpool (2,676) and Bankstown LGAs (1,388). In comparison, Wingecarribee LGA has 802 residents identifying as Aboriginal people²¹



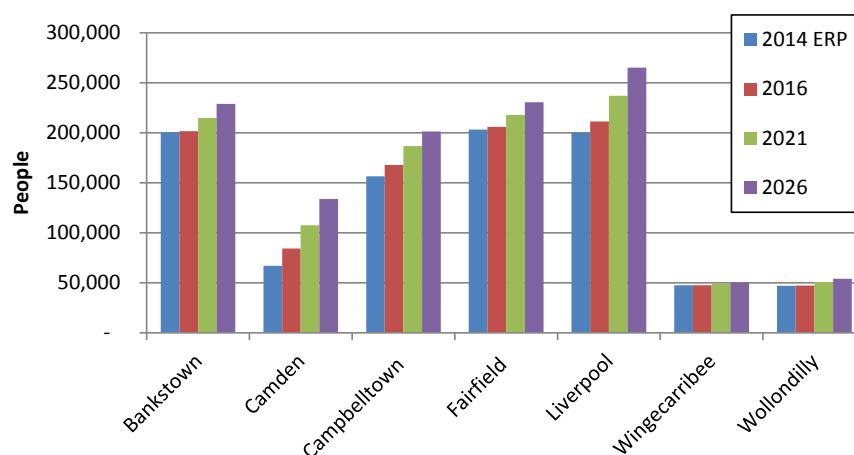
- rural communities including people in outlying towns and properties in Wollondilly and Wingecarribee LGAs. Although south western Sydney is considered highly accessible, these communities often have fewer services with poorer access to health and other services
- large culturally and linguistically diverse (CALD) communities with 36% of residents born overseas. Only 51% of families speak only English at home (compared to 73% for NSW) and in Fairfield, over 70% speak a language other than English at home. The most common languages other than English spoken at home are Arabic (spoken by over 74,000 people), Vietnamese (spoken by approximately 61,000 people) and Cantonese (spoken by over 19,000 people) ²¹
- a large refugee population, with over 9,200 humanitarian entrants settled locally in 2010 - 2014 i.e. 41 % of all humanitarian settlers to NSW ²²
- almost 48,000 local residents report a profound or severe disability requiring assistance with at least three core activities. Disabilities include intellectual or physical issues, may be congenital or acquired, and may be the result of a long term health issue or ageing. ²¹ One in 5 residents will be affected by a mental health condition at some stage
- over 77,000 local residents provide unpaid care to people with disabilities, chronic health problems or age related frailty. ²¹

5.2 Population Growth and Ageing

South western Sydney has experienced ongoing population growth and is one of the fastest growing regions in NSW. The most notable growth projected into the future will occur in Camden and Liverpool LGAs. Growth is driven by urban consolidation and new greenfield developments such as the South West Growth Centre. In the decade to 2021, there will be a projected 21% increase in the population with 1.06 million people living in the District. Approximately half of the growth will be in the southern parts of the District, including Wingecarribee LGA.

Figure 3: Population Projections for South Western Sydney, 2014 – 2026

Source: NSW Department of Planning and Environment 2014



By 2021, 14.6% of the population will be aged over 65 years, with projected growth greatest in those aged 70-74 years and 80+ years. Further, in the twenty years to 2031, it is projected that the number of those aged over 85 years will have increased by 155%. ²³

5.3 Facts about Mortality

Key facts about mortality:

- In Australia, the main causes of death are cancer and cardiovascular disease. Men die earlier than women with 91% of men and 95 % of women dying at age 50 years and over ²⁴
- 60-70% of Australians would prefer to die at home. Despite this, home deaths have declined and only about 14% of people die at home, 54% in hospitals and 32% in residential care ²⁵
- In 2013, 5,043 south western Sydney residents died ²⁴
- Over the past six years, there was a 9.9% increase in the number of deaths of south western Sydney residents. Campbelltown and Liverpool LGAs have seen the largest increase (24.7% and 16.6% respectively) ²⁴
- The death rate was above the NSW average in Campbelltown, Liverpool and Camden LGAs (ABS data).²⁶ Contributing to this problem are higher rates of health problems, lifestyle behaviours such as smoking and social determinants, such as poorer income and education.
- In 2013, 2,590 people (51%) died in a SWSLHD hospital, with the majority dying in an acute ward. Only 21.2% of these died in a palliative care unit/ward (NSW Health Information Exchange)
- In 2013, 236 local residents who died in their home received care from the SWSLHD Community Nursing Service, including the Specialist Palliative Care Nurses. A further 239 people who received advice from the specialist Palliative Care Service died in a residential aged care facility (RACF) ²⁷
- In 2013/14, there were 12,569 Palliative Care Specialist Service consults to patients of SWSLHD hospitals – 53% of these consults were provided by medical staff. A further 527 medical consults were provided to community patients ²⁷
- In 2012/13, about 81.3% of local residents treated in a subacute palliative care unit received their care in a SWSLHD hospital. Two hundred and eight residents were treated outside the District, mainly in hospitals in neighbouring LHDs. (NSW Health FlowInfo 2012)
- Cancer is a major driver of the need for palliative care services. In the decade to 2021, it is projected that the number of local residents with cancer will increase by 39%, with an increase in cancer deaths of 21%.²⁸ Demand will also be driven by non-cancer diseases e.g. stroke by 32%; respiratory diseases (including infections by 27% and chronic obstructive airways disease by 35%); gastroenterology problems (such as cirrhosis) by 36%; heart failure by 43% and renal failure by 26%. (NSW Health aIM2012, V2.2)
- In 2011, only 77 NSW residents donated their organs. ¹⁴

Key facts about end of life care:

- It is projected that in the ten years to 2021, palliative care subacute overnight inpatient separations for local residents will increase by 72.6% (Appendix C)
- A NSW survey indicated that the major concerns of SWSLHD staff were delays in identifying patients whose death could be anticipated; the lack of a formalised plan for symptom management; and gaps in symptom assessment processes and protocols for management of pain, agitation and delirium. Major challenges in managing end of life care were gaps in access to information about best practice in end of life care, access to medication, imprecise/insensitive terminology, poor communication and inability to recognise those who are dying. ²⁹



5.4 Priority Populations and Vulnerable Groups

Some communities have an increased risk of receiving poor health care and worse health outcomes. This includes not having an opportunity to think and talk with family and friends about their wishes regarding their health care at the end of their life, or missing out on receiving quality end of life care.

Aboriginal people and Torres Strait Islanders

Despite improvements, there is still a considerable difference in life expectancy between Aboriginal people and the total NSW population of 8.6 years for men and 7.4 years for women.³⁰ The mortality rate for Aboriginal people is 1.5 times higher than the rate for non-Aboriginal people with no significant change over the past 10 years. Leading causes of death for Aboriginal people (2003-2007) were cardiovascular disease (31%), cancers (21%) and injury and poisoning (12%). Australian data indicates that the number of palliative care-related separations was twice as high for Aboriginal people compared with non-Aboriginal people (34.6 and 19.5 respectively).³¹

Factors that can complicate end of life care include past experience and cultural beliefs around hospitals and death, lack of cultural sensitivity and understanding by service providers about the needs of Aboriginal people, importance of “going home”, the role of the extended family, financial barriers in supporting death and need for culturally appropriate religious and/or spiritual support. In the context of this complexity, it becomes even more important to ensure that generalisations are not made during care planning and ongoing care. Under identification of Aboriginal status results in poorer access to cultural and service supports, such as those provided by Aboriginal Liaison Officers and Aboriginal specific services and programs.

People from culturally and linguistically diverse backgrounds (CALD)

There are very significant cultural variations in experiences, beliefs, expression and understanding of dying, death and grief. This can also be affected by past experiences of trauma.³² In many cultures, the well-being of the family is of higher importance than the individual with implications for truth-telling and informed consent.³³ In turn, this poses ethical dilemmas about how care is to be delivered, further complicated by the need for translation into a community language. Taking this into account, more specific engagement with people from CALD communities is needed to improve their understanding of advance care planning and care at end of life, including palliative care.

Refugees and asylum seekers

South western Sydney is a major centre for humanitarian arrivals. Although the number with a life limiting disease is very small, refugees require additional support to navigate the complexities of the health system, are likely to have relatively few possessions and to have received suboptimal pre-arrival health care. Poor provider knowledge about entitlements to Medicare and lack of knowledge about local services further complicates their care. The dire financial circumstances of newly arrived refugees require services to be cost neutral i.e. available via Medicare.

Infants, children and young people

Although most types of cancer are relatively uncommon in children and young people, cancer was the leading cause of death in those aged 1-24 years (2002-2011), accounting for 11.8% (approximately 62 deaths per year) of all deaths in this age group in NSW.³⁴ Children, adolescents and young adults face unique challenges, either growing up through childhood with their illness or receiving a diagnosis of a life limiting illness as adolescents or young adults when they are undergoing significant physical and emotional change and independence. Uncertain illness trajectories, different physical and developmental stages which impact on care, the role of the family, complicated grief which includes siblings and transition for young people to adult services further complicates care.³⁵

While some children and young people are cared for by the Sydney Children Hospital Network (SCHN), increasingly families want their children home, requiring access to local health professionals with skills in working with children. In addition, a growing number receive their total care from SWSLHD. Potential for disjointed care, created by the number of services involved, and demand and need for specific paediatric expertise place additional demands on local health providers.



People with socio-economic disadvantage

There is no evidence that needs in disadvantaged communities are less than other groups; and given the social deprivation experienced across the life span, their needs are likely to be greater. Higher levels of chronic illness and earlier mortality for people with greater socio-economic disadvantage



suggest a need for a greater focus for equitable outcomes at the end of life, including consideration of the higher likelihood of dependent children given earlier death.³⁶ Nationally, people in areas with the lowest socioeconomic status account for a relatively higher rate of palliative care-related separations and higher proportion of palliative care related separations in public hospitals (23.7%).³¹

People with disabilities

The life expectancy of those with an intellectual disability has increased over the years, and the numbers and proportion living into old age are increasing. However, people with disabilities have higher age-specific mortality rates from health problems that are undiagnosed due to poorer access to primary and secondary prevention and medical services.

There is evidence also that palliative care decisions occur later in the course of an illness. Under-recognition of the need for palliative care given a history of significant life-long medical problems, diagnostic overshadowing (i.e. attributing symptoms to the disability, rather than looking for an underlying physical or mental health problem), inability to communicate suffering or pain (with potential causes overlooked), and pain insensitivity or indifference that complicates diagnosing an acute episode or deterioration in an existing condition contribute to this problem. Ethical issues including decision-making capacity and the impact on other residents in group home situations also need consideration.³⁷ Further complexity is created by variable understanding about death including their own mortality and that of others, and supporting death in group homes where the coroner will need to be involved.

People who are aged and those with dementia

Older people have a higher incidence of chronic conditions such as musculoskeletal, cardiovascular and respiratory diseases, cancer and other conditions which contribute to morbidity and disability. An aging population will require the additional support and accommodation provided through residential aged care facilities (RACFs) and community packages. Nationally, in 2012-13, there were about 226,000 permanent RACF residents with Aged Care Funding Instrument (ACFI) assessments and about 6% of these residents needed palliative care.³¹

Dementia prevalence rates are relatively low until the age of 70 years, where prevalence rates start to increase rapidly. By 2020, 128,238 NSW residents will have dementia.³⁸ Discussions about death and dying are *“complicated by the progressive nature of the disease and the eventual loss of capacity of the person with dementia to be involved in decisions about their care”*.³⁹ Communication, capacity, control, legal and ethical concerns and the impact of behavioural and psychological symptoms of dementia (the most common cause of strain for the family and staff) are considerable barriers and increase the difficulty in keeping the person home until death.

People aged less than 65 years

In 2008-9, people under 65 years accounted for 28% of all palliative care separations.⁴⁰ The rates for SWSLHD residents in 2012/13 were similar (26.1%). Coordination for local residents with degenerative diseases, principally Motor Neurone Disease, has improved through case conference meetings and palliative care involvement in the Liverpool Hospital Motor Neurone Disease Clinic. However, poor GP



knowledge about the benefits of early referral to specialist palliative care, the need for greater allied health involvement and stronger coordination are specific barriers to care.

Over 8,600 younger Australians live in residential aged care facilities (RACFs), including those with palliative care needs.⁴¹ In addition to the differing needs of younger adults, submissions to the 2015 Senate Inquiry into the adequacy of existing residential care arrangements available for young people reflect local concerns about RACF based care including unsuitability of the environment, staff skills geared to older people, isolation from the community, meeting care needs of their children, delays in access to care and lack of alternative care/accommodation options. Potential solutions include social investment funds, social housing, group homes and integrated care and support pathways.⁴²

People in rural areas

Nationally, residents of regional and remote areas experience poorer health than metropolitan people. Barriers to healthcare include distance from specialist units, fewer health care providers, geographic isolation, poor transport and time away from home for investigations and treatment. These barriers are experienced also by residents of Wingecarribee LGA. Compared to other people in SWSLHD, these residents make poorer use of inpatient subacute palliative care and approximately 54% travel outside SWSLHD for care. The number attending outpatient or specialist services in other parts of Sydney is unknown. Overall rural residents have an increasing likelihood of fragmented care.

Local residents treated outside the District

Although most local residents receive palliative care from a SWSLHD service, some receive inpatient and outpatient care in other parts of Sydney. In addition to Wingecarribee residents, this is particularly an issue for Bankstown residents, with 45% treated in a palliative care inpatient unit outside SWSLHD, compared to 18.7% of SWSLHD residents overall (NSW Health FlowInfo v13 2012/13). The SWSLHD Triple I Hub provides a first point of contact for local residents requiring assessment and care in the community. Variable discharge planning, with insufficient and untimely transfer of patient information to support care in community or hospital settings, poor knowledge about local services and inability to monitor care across all settings can lead to disjointed and substandard care.

People who live alone with no carer

Almost 18% of local residents live alone.²¹ Living alone is associated with lower levels of social and economic participation, a higher prevalence of mental health disorders, being older and of social isolation. It is also associated with a decreased likelihood of a home death regardless of previous choices and predicts admissions to hospital for symptom control and institutionally based death. Home-based palliative care services experience challenges in caring for residents without a primary caregiver. People living alone will experience more psychosocial distress, greater challenges around appropriateness of meals and safety and require more practical assistance and liaison regarding care (with increased time spent per visit).⁴³

Carers

Carers and other family members play a key role in supporting people with palliative care needs and advocating for services. Commonly reported carer concerns include lack of recognition and inclusion,



lack of consideration of their personal health needs by the health provider, health system fragmentation and cost (including for medications and other supplies). Locally, concerns focus on lack of knowledge and skills about palliative care and supporting the process of dying, lack of respite care, financial issues, lack of transport, variable knowledge about how to contact services and seek expert advice (particularly after hours), access to medications at discharge from hospital and lack of support groups. Inattentiveness by health professionals to the carer's needs and health, the impact of the burden of care and expectations that carers will meet increasing care needs are also issues. This includes consideration of children who play a significant role in caring, providing occasional or extended help, with resultant impact on educational and social outcomes.

Professional concerns focus on the variable involvement of carers and family in advance care and other planning around end of life, and managing expectations around end of life care.

People with non-malignant (non-cancer) chronic disease

Approximately 40% of palliative care separations nationally (and approximately 50% locally) are due to chronic health conditions such as heart disease, chronic obstructive pulmonary disease (COPD), renal failure and dementia. Compared to NSW, SWSLHD hospitals have a larger proportion of hospitalisations attributable to cardiovascular disease and dialysis.

Non-malignant (non-cancer) chronic diseases which may benefit from specialist palliative care support and advice include neuromuscular disorders (such as multiple sclerosis, motor neurone disease and Parkinson's disease), COPD, end stage organ failure, dementia and other illnesses where the person has reached the final stage of their disease. Despite good evidence of the benefits of palliative care, there are fewer referrals due to difficulty in predicting prognosis for non-malignant diseases, variable levels of resources and for some, a perception that referral is a sign of giving up.⁴⁴

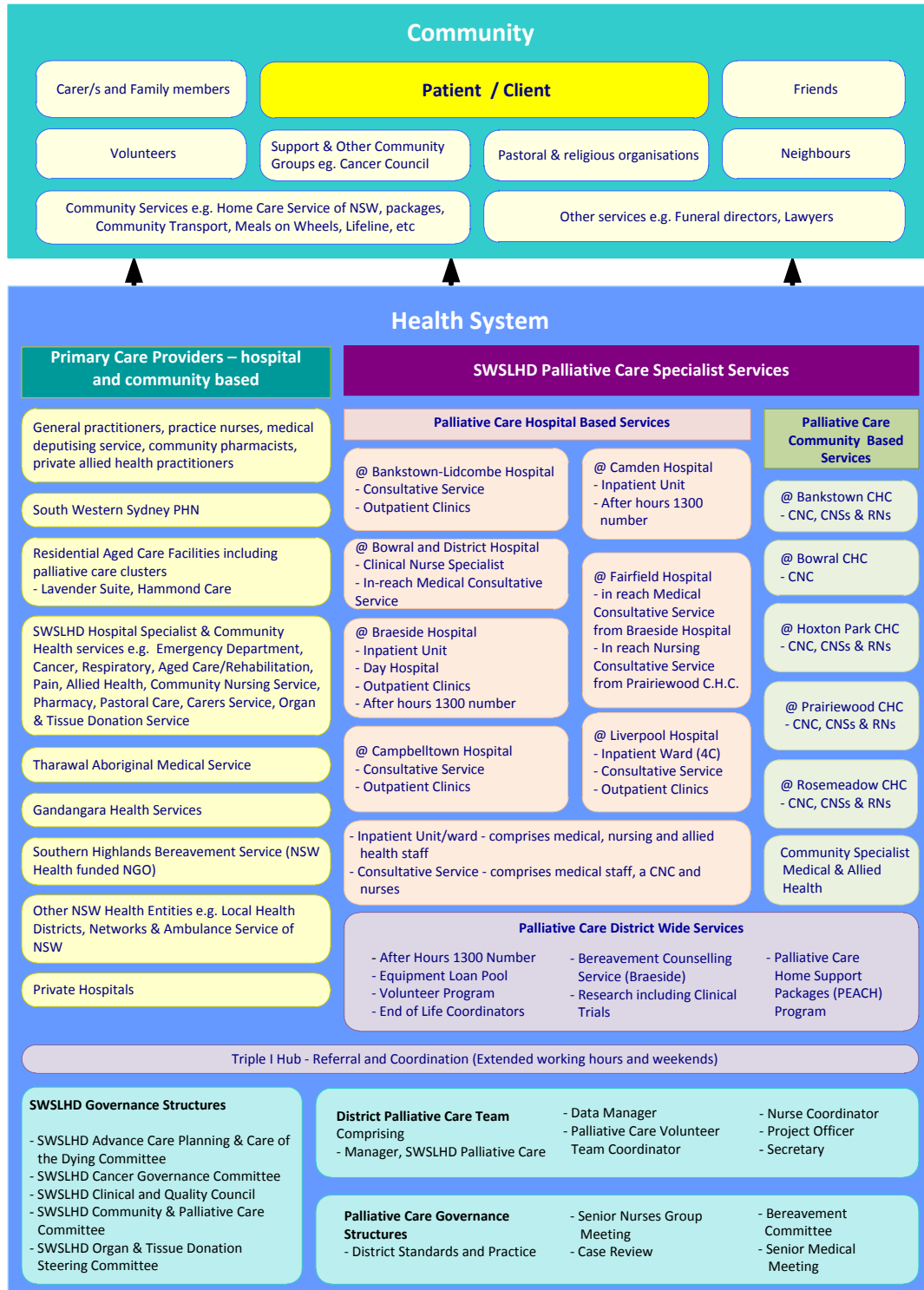
Other people with chronic diseases who may require additional support include:

- **People with mental health conditions** who have high rates of mortality and reduced life expectancy. Poorer health literacy, inadequate access to healthcare services, lack of attention to physical health problems and later diagnosis of life-threatening health conditions together with instability in housing, employment and income complicate care. In addition, many will live alone as they age without immediate family members who can support them at the end of their life
- **People with HIV and AIDS diagnoses** who are relatively small in number due to treatment advances including life-long medication changing the pattern and type of HIV associated illnesses. Sensitivity around sexuality, respect for relationships and confidentiality (including disclosure of HIV status to family after death, autopsy and involvement in medical research) and the impact of HIV-associated neurocognitive disorders (HAND) and HIV psychosis when consent and/or guardianship is sought are specific needs.

6 Current Service System

As indicated in the figure below, end of life care and support including specialist palliative care is provided by a diverse range of people across community and hospital settings.

Figure 4: The Service and Support System for south western Sydney residents





The individual at end of life is surrounded by carers, family, friends, neighbours, local religious supports, community support groups and volunteers. Each provides help, advice and emotional, physical and practical support. In turn, community organisations and businesses such as lawyers and funeral homes also have a role in supporting individuals and families.

6.1 Primary Care Providers

The health system has a significant role in ensuring that the treatment and care provided meets the individual's needs in a timely, comprehensive and coordinated manner. Central to community based care are General Practitioners (GPs) who provide holistic patient care, coordinate the patient's care, deliver medical and emotional support, advocate for the individual and refer to specialist services. Approximately 930 GPs work in the District, in solo and group practices and targeted services such as the Aboriginal Medical Service. They work in various settings with a range of health professionals including other primary carers such as nurses, pharmacists, allied health practitioners, ambulance staff and palliative care and other specialists.

Residential aged care facilities (RACFs) provide care to their residents in the final years of life including the last days. Lavender Palliative Care Suite, in Bond House in the Hammond Village at Hammondville, provides specialist palliative care in an RACF setting.

Non-government organisations provide counselling services to the community. This includes the Southern Highlands

Bereavement Care Service and Lifeline which receive targeted funding through the NSW Ministry of Health Non-Government Organisation Grant Program.

Recent Achievements in

South Western Sydney

- Supported development of **My Wishes website** providing residents and health professionals with information about Advance Care Planning
- **SWSLHD Advance Care Planning and End of Life Committee** established to drive District wide improvement
- **End of Life Coordinators** appointed to Liverpool, Bankstown, Campbelltown and Bowral Hospitals to enhance the consultative palliative care service and implement End of Life Plan programs
- **PEACH Program** winner in the Patients as Partners category of the 2015 NSW Health Awards
- **New services** including the Lavender Suite, Hammondville RACF with 9 designated palliative care beds (2012); 20 bed palliative care ward at Liverpool (2013); and the Palliative Care Home Support Packages (PEACH) Program (2013)
- **Council of Australian Government (COAG) funding** for Day Hospital services at Camden and Braeside Hospitals and RACF medical and nursing consultation and support (2011-13)
- Established **multidisciplinary clinics** at Liverpool Hospital for renal and motor neurone conditions
- Participated in **National Palliative Care clinical trials**
- Expanded the **volunteer program** into Bankstown-Lidcombe Hospital
- Grants to enhance the **Equipment Loan Pool** and to progress workshops supporting and educating carers
- **Carer and patient Interviews**
- Camden and Braeside Inpatient Units participated in the **National Palliative Care Outcomes Collaborative (PCOC)**.
- Appointed a **Community Development Officer** to promote Organ and Tissue Donation
- **Education** including *The ABC Of Palliative Care Nursing* and *Grief, Loss & Bereavement* and *Palliative Experience Palliative Approach (PEPA)* placements
- **Electronic medical record (eMR) rollout** across Community Health and the Liverpool Palliative Care Ward

In hospitals, clinicians provide treatment and care to children and adults with a range of health conditions, including chronic and complex health conditions. In most cases, these clinicians are responsible for supporting people during the last stages of their lives in hospitals.

Within the broader context of supporting patient wishes, the Organ and Tissue Donation Service facilitates donor's wishes and provides outreach and education to the community.

6.2 Palliative Care Specialist Services (PCS)

The SWSLHD Palliative Care Service (PCS) is a multidisciplinary service consisting of staff specialists, registrars, nurses, allied health professionals and volunteers. It has two main clinical roles:

- consultative assessment and advice to colleagues who are managing patients with complex symptoms associated with life threatening illness in community, hospital or residential aged care settings
- direct care to people with very complex pain and symptom management needs and complex end of life care for dying patients within dedicated palliative care units.

The PCS Services provide

- Pain control
- Symptom management
- Psychological and social support as needed
- Counselling for patients and families on request
- Bereavement care for families and carers
- Volunteers for clients in hospital or community settings
- Education for clinicians and undergraduate students in hospitals and the community
- Health promotion to the broader community.

The PCS works closely with primary community services such as GPs and community health nurses who offer continued support and care in a client's home and provide the day to day care and coordination. They also work with hospital staff during a hospital admission.

End of Life Coordinators work in several SWSLHD hospitals with responsibility for implementing the Care Plan for the Dying Patient (CPDP), facilitating quality care for the dying patient in the last few hours or days of their life.

Consultancy Services include a community based service which operates in each LGA led by a PCS clinical nurse consultant (CNC) and registered nurses (RN) working with primary health/community nursing team. There is access to a PCS staff specialist and registrar for home visits. The service is available to clients registered with the SWSLHD Palliative Care Service, including referred residents of RACFs.

“ (The clinician) took the time to talk to us, just having her listen and answer questions in a caring but honest way made all the difference. ”

– a carer from Bankstown LGA



Hospital based consultancy services and outpatient clinics are provided on-site at Bankstown-Lidcombe, Liverpool, Campbelltown and Braeside Hospitals; via part-time onsite nursing consultancy at Bowral Hospital; via inreach medical and nursing consultations to Fairfield Hospital; and inreach medical consultations to Bowral Hospital. These services are provided by staff specialists, CNCs, RNs and registrars. Specialist allied health hospital-based consultancy and outpatient clinics are also provided at Braeside Hospital.

There are also partnerships and participation in multidisciplinary team clinics and meetings including for Motor Neurone Disease, Pain and Renal Disease at Liverpool Hospital.

A District weekend and overnight medical on-call service is available to provide advice.

A **Day Hospital** operates two days/week at Braeside Hospital providing treatment and medical and allied health review for Palliative Care Service clients.

Palliative Care Inpatient Units and Ward are staffed by Palliative Care staff specialists, nurse unit manager, CNC and specialist nurses, a dedicated allied health team and volunteers. They include the:

- **Palliative Care Ward** at Liverpool Hospital with 20 acute beds for people known to the service requiring short term complex symptom control or terminal care. Admission criteria include:
 - Patients requiring access to acute services such as diagnostic imaging, interventional radiology and radiotherapy or services unavailable at other facilities e.g. pain team services, neurosurgery
 - Patients too unwell to be transferred to a palliative care unit due to risk of dying in transit or within hours of transfer and/or who have not yet psychologically accepted the need for a palliative care unit admission.
- **Palliative Care Units (PCU)** care for people who are known to the SWSLHD Palliative Care Service and require symptom control consistent with their goals of care including terminal care. Care may include the provision of medical interventions (e.g. intravenous antibiotics, intravenous fluids, blood products, enteral feeding), symptom relief (nasogastric tubes, pleural or peritoneal drains), and for the underlying life limiting illness (e.g. oral chemotherapy). However, as these units do not have after hours onsite medical coverage, and the focus of care is on the management of symptoms, it is important that clear goals of care are in place prior to transfer to a PCU. PCUs are not able to provide the required levels of care for acute unstable medical issues where this treatment is clinically warranted and in accordance with the patient's wishes. (e.g. neutropenic sepsis, acute cardiac issues) nor do they offer cardiopulmonary resuscitation. PCUs are located at Camden Hospital with 10 subacute beds for Campbelltown, Camden, Wollondilly and Wingecarribee LGA residents; and Braeside Hospital with 20 subacute beds, predominantly for Fairfield, Liverpool and Bankstown LGA residents. The units are designed to provide quiet peaceful environments and access to the outdoors, quiet spaces for patients and families, and also within the patient's room, beds for care givers to stay overnight if they wish.

Additional palliative care inpatient beds are planned to be opened as part of the Campbelltown Hospital Redevelopment Stage 1 in 2016/17.



Palliative Care Home Support Packages (PEACH) Program provides community-based services over the last seven days of life, enabling patients to die at home instead of in hospital. The “PEACH” Program is restricted to metropolitan LHDs.

The **After Hours 1300 Telephone Support Service** is provided for registered clients and their carers 24/7 days/week. Advice is provided through the Triple I Hub during extended business hours (7.00 am – 21.30 pm weekdays) and on weekends (8.00 am – 16.30 pm) and overnight by the Camden and Braeside Palliative Care Inpatient Units.

The **Bereavement Service** at Braeside Hospital provides specialist bereavement counselling across SWSLHD to family and friends of patients registered with the SWSLHD PCS. It also organises other supports for families and provides health professional education. There is no single District-wide coordinated bereavement service for patients of other services.

Palliative Care Volunteer Service comprises trained local residents who give their time to assist patients and their families/carers of the Palliative Care Service across the District, offering compassion, companionship and comfort. Operating 5 days/week, volunteers are supported by a Palliative Care Volunteer Coordinator. Volunteers operate at Bankstown-Lidcombe, Camden and Liverpool Hospitals and through community health centres at Bankstown, Bowral, Hoxton Park, Prairiewood and Rosemeadow. They also support activities such as fund-raising, assisting with memorial services and promotional events.

Research includes clinical trials of pharmacological and non-pharmacological interventions with a focus on improving symptoms and quality of life, including the type and way services are delivered in hospital or at home. The research program is led by a clinical academic.

Appendix B profiles palliative care services in greater detail.

“ We have a volunteer who sits with my partner, they sit and talk or sometimes they read. It’s a great support for my partner and for me. I know that my partner is with someone so I feel I can just pop out for a bit. ”

- a carer from Fairfield LGA



7 Issues

Following are the key issues that were identified in south western Sydney.

7.1 Awareness and Understanding

- Changing technology and advances in health care has meant that people live longer with greater expectations that health professionals will “cure” all health problems
- Community attitudes, beliefs and customs around death and dying. Death is a taboo subject for many in the community and health professionals, particularly for some cultural groups; exacerbated by a decline in experience and exposure to dying
- Changes in work/life balance and increasing emphasis on hospital and residential aged care has reduced individual and community capacity to care for and support people who are dying and their families
- Lack of standard terminology, multiple documents around advance care planning and end of life and variable understanding of the specialist palliative care role complicated by euphemisms for death can make management complex
- Poor uptake of advance care planning due to limited community and health professional knowledge, poor understanding of the law, confusion with euthanasia and around the best timing for initiating the discussion about terminal care
- Lack of policies and systems around advance care planning and directives (ACDs), poor visibility in the electronic medical record (eMR), family decisions overriding the ACDs and lack of attention to completed forms mean patient wishes are often ignored
- Lack of sustained focus in building community understanding about end of life
- Families are unaware of patient wishes about organ and tissue donation and resist donations due to myths and misconceptions; and often GPs do not discuss organ and tissue donation with patients

Summary of Key Issues

- Death still an issue of taboo
- Variable awareness of advance care planning
- Variable skills of health professionals in having “the conversation” about death
- Variable skills, understanding and compassion in caring for patients who are dying
- Lack of clarity around clinical roles
- Lack of tools to support care planning
- Lack of/low levels of specialist palliative care staff in hospitals and gaps in community settings including in growth areas
- Lack of choice to meet patient wishes to die at home
- Poor awareness of referral pathways
- Need for greater clarity around models
- Additional needs of people from CALD and Aboriginal communities and other vulnerable groups
- Underuse and under engagement with pastoral care
- Limited capacity of GPs to provide home visits and after hours care; and variable interest and knowledge

7.2 Appropriateness and Effectiveness of Care

In community settings:

- Delayed and sometimes inadequate communication between the hospital treating teams and primary health care practitioners particularly at re-referral, transfer of care and discharge
- Although some GPs are very interested in palliative care, others are not. Knowledge and skill in symptom and medication management is variable with care complicated by a lack of standard tools. There is also reduced interest by some GPs in home visits essential for people no longer mobile due to lifestyle decisions i.e. not wanting or able to work after hours and poor financial recompense. Medical Deputising Services go some way to meeting this need.
- Although some community nurses are highly experienced with good palliative care nursing, technical and communication skills, others have limited knowledge, interest or experience
- Delays and variable management of patients presenting through emergency departments
- Expectations that patients with palliative care needs will be cared for by PCS specialist staff only, whereas care is predominantly provided by general community nurses with specialist consultation
- Limited access to bereavement services for carers unknown to the palliative care service
- Residential aged care staff skill, knowledge and capacity to apply a palliative care approach and end of life care is variable. Technical knowledge and skills (e.g. reinserting a catheter and managing bowel obstruction), family request and difficulty getting a medical review are the most common reasons for transfer to hospital. ACD uptake is variable and ongoing promotion limited
- Difficulty in ensuring that death certificates are completed in a dignified and timely manner.

In acute hospital settings:

- The focus on curative care and uncertainty of the timing of death mean some clinicians do not recognise the symptoms of death or manage it appropriately. This is further complicated by a lack of tools to structure timely end of life planning, outline treatment goals and support recognition of the dying patient
- Beliefs that end of life discussions affect patient survival and variable confidence in structuring conversations about death mean that end of life decisions are left to family members.
- Variable culture of respect, compassion and dignity for the terminally ill
- Delayed and uncoordinated involvement of pastoral carers, with no shared understanding of the value of pastoral care and how to strengthen pastoral support of patients and carers

“People don’t understand how hard pressed people are, the exhaustion of grief is very tiring, the circumstances compound the problems and I’m not talking about the most care that is needed. I’m talking about general care and that is still exhausting. I’m worried that we’re only just keeping up while the situation is going well, what happens when his situation worsens that worries me, I want him home for as long as possible.”

– a carer from Wingecarribee LGA



- In older hospitals, lack of interview rooms, single rooms and carer facilities to provide privacy and respectful care. The viewing area at Bowral Hospital is less than ideal
- Formal review systems tend to be reactive (e.g. mortality review) rather than proactive
- Provision of medication on discharge and understanding of dosing regimens is variable
- Proposals for a freestanding community hospice at Bowral has the potential to impact on continuity of care, safety and links to existing services
- Conversations around organ and tissue donation occur inappropriately during end of life discussions and not by a trained requester.

“ Trying to find a doctor to come to the home was the biggest problem. I rang around to at least 12 practices in the area and none of them home visited. Finally we found a doctor who does home visits and we receive routine visits now. ”

– a carer from the Macarthur region

In access to and support from specialist palliative care services and palliative care units:

- Assessment, management and consultancy Specialist Palliative Care Services were generally highly regarded; however referral processes were poorly understood, with assumptions by some clinicians that patients with life threatening illnesses are always managed by the PCS
- Limited outpatient clinics with significant delays in access, particularly in the Macarthur region and Wingecarribee LGA (Appendix B). In all hospitals there is a need for increased involvement in multidisciplinary team meetings and coordination mechanisms to support care e.g. cancer, pain, renal and motor neurone disease. Projected population growth, particularly in the Macarthur region, will exacerbate this problem
- Access to PCS nurse and medical consultancy services in SWSLHD hospitals is unequal with no onsite palliative care nursing or medical consultancy services at Fairfield Hospital, and only a part-time nursing service and in-reach medical services at Bowral Hospital
- National and NSW models around care of people who are dying require all clinicians to manage these patients. This approach was not well understood by all clinicians
- Although relief of complicated pain has improved through the PCS collaboration with the SWSLHD Pain Service, there is poor knowledge outside of Liverpool Hospital about the service and access pathways
- Concerns about ensuring efficient, viable palliative care inpatient services across Campbelltown and Camden Hospitals with the planned opening of new Campbelltown palliative care specialist beds; and a lack of clarity around staffing, when the beds will open and how it will operate
- With the creation of specialist beds in acute hospitals, uncertainty about definitions and role of palliative care wards and units and of specialist palliative care physicians in accepting/managing patients in non-palliative care units (i.e. as outliers) on an ongoing basis



- Challenges in creating supportive environments in acute settings and building specialist palliative care nursing expertise in new specialist inpatient units
- For palliative care units, concerns about inequitable distribution across the District with delays to access units; and perceived inflexibility of units in not providing high flow oxygen, blood product and chemotherapy treatments or secure facilities for patients who wander
- Braeside and Camden Hospital Palliative Care Units participate in the Palliative Care Outcomes Collaboration (PCOC) and Liverpool is in the early stages. No service meets all benchmarks
- In the community, gaps in PCS nursing services, particularly in the Macarthur region, limited access to medical PCS expertise and limited-no access to specialist allied health service (Appendix B)
- Variable knowledge about and satisfaction with making a referral to the Triple I Hub
- Variable patient/carer knowledge about how to recontact the PCS and processes of dying
- Additional charges incurred by carers accessing this service; and variable quality of information provided during extended business hours via the 1300 number
- Capacity to reduce hospital presentations is restricted by the limited number of medical staff who can conduct outpatient clinics, undertake home visits including in RACFs, engage in shared care models and upskill the RACF workforce
- The “PEACH” Program strengthens care in the last week of life however there are a limited number of packages, until recently no coverage of Wingecarribee LGA, time limitations and a narrow access pathway
- Inadequate funding to ensure timely replacement and maintenance of patient equipment; and NSW Ministry of Health policies around oxygen provision are barriers to coordinated care



- Communication associated with transfer of patients across LHD boundaries is problematic, limited by poor understanding of local services, referral practices and no common eMR.
- Health literacy around palliative care including terminology, systems and treatment regimen is a barrier for many including people from a low socio-economic status, those with limited education or English skills and no carer support.

7.3 Leadership and Governance

The SWSLHD Advance Care Planning and Care of the Dying Committee provides high level advice and monitors activities in the provision of advance care planning and end of life care within SWSLHD. Progress has been hampered by a lack of dedicated project staff to implement the action plans and initiatives and variable interest and knowledge by clinical services.

Palliative care specialist expertise resides predominantly with the SWSLHD Palliative Care Service which structurally crosses two services - SWSLHD Cancer Clinical Stream and SWSLHD Community Health. The Service governance structure ensures professional standards and proactive leadership for parts of the system however:

- Palliative care medical and nursing leadership is not embedded in all facilities or key teams i.e. hospitals and Community Health. Access to specialist Palliative Care allied health leadership is variable
- Clinical governance, roles and relationships between specialist palliative care services and the generalist community nursing team are unclear
- Pockets of significant expertise/interest in research to improve symptom management and quality of life in the Palliative Care Service and some other specialities (particularly in medicine), however research is not embedded in the work of all Palliative Care staff and research benefits to improve care and service delivery are not fully realised. It has been difficult ensuring sustained approaches to building research capacity. There is a lack of an academic presence and educational focus needed for the development of new models of care.
- Information systems (and policy) do not always support continuity of care e.g. for patients with multiple admissions and discharges; and multiple information systems e.g. Powerchart, MOSAIQ are not available or accessible to all services
- NSW Health Information systems capture data about patients who are cared for and die in public hospitals. Most SWSLHD Palliative Care Services participate in the Palliative Care Outcomes Collaboration (PCOC) and National Standards Assessment Program (NSAP) and data are maintained on patients under the care of PCS staff. However, there are gaps in the range of data collection and reports useful for SWSLHD management and quality assessment e.g. information about patients with an advance care directive (ACD) or a resuscitation plan, patients requiring palliative care treated in acute settings or presenting to ED, etc. There is also a lack of objective data on quality of care provided by primary providers e.g. compliance with plans, use and compliance with validated tools
- Changing relationships with 3rd schedule facilities such as Braeside Hospital and non-government organisations offer opportunities and threats to integration and collaboration
- Consumer participation is marked by strong advocacy around advance care planning from the SWSLHD Consumer and Community (CCC) Participation structures (Facility Networks and the peak

Consumer Community Council), support for patients and families and fundraising by the SWSLHD Palliative Care Volunteer Program and formal consumer and carer's feedback about the health care provided. Consumers also participate in Community Health, Cancer and Advance Care Planning and Care of the Dying Patient Committees. Prior to 2010, there was a considerable CCC driven focus on advance care planning with numerous forums to raise community awareness, however sustaining this level of promotion and engagement proved difficult. Greater engagement is required with the community service sector around planning ahead, strengthening supports for people with terminal illnesses and building knowledge around end of life; and increased focus working with SWSLHD CCC structures.

There is also a SWSLHD Organ and Tissue Donation Committee which focuses on strategies to strengthen organ and tissue donation and retrieval.

7.4 Capacity and Capability

Development of the primary health workforce has predominantly focused on completion of advance care planning and end of life care on-line courses (through the SWSLHD Centre for Education and Workforce Development (CEWD); and the Program of Experience in the Palliative Approach (PEPA) courses, workshops and placements. Issues include:

- Models concentrating patient care to “specialist palliative care staff” are considered unsustainable in the medium-longer term, particularly given the growing and ageing community
- The SWSLHD Palliative Care Service is relatively small with most resources located within inpatient units. There is:
 - difficulty ensuring adequate medical coverage with many doctors working part-time
 - lack of specialist nurses in the community on weekends; and medical specialists after hours and on weekends
 - lack of a full range of specialist allied health, particularly in the community
 - gaps in the nursing workforce, an ageing workforce with demanding workload and burnout
 - inability of facilities with small teams e.g. Campbelltown Hospital to meet needs and demands
- Lack of focus on developing the skills of hospital clinicians in having a conversation with patients about their wishes, making clear plans and in identifying signs of imminent death
- Variable attention in ensuring that the knowledge and skills of the generalist health workforce in providing end of life care are balanced by compassion and promotion of dignity
- Managers knowledge and skills in how to support staff who are experiencing death and grief in the workplace and in their communities is variable
- Lack of targeted training and education for:
 - General Practitioners in palliative care including medication management
 - community nurses at a basic and advanced level supported by mentoring
 - community and hospital pharmacists around palliative care medications
 - support staff such as Aboriginal Liaison Officers and interpreters, including debriefing structure around difficult cases and discussions
 - front line staff such as administrative officers in communication around death
 - practice nurses in the community around end of life care and planning



- pastoral carers in palliative care issues and all staff about the impact of different religious and spiritual beliefs on patient care
- Variable use and capacity of private specialist services including private allied health professionals to deliver specialist services; and limited use of in-house expertise within RACFs
- No systematic approach to ensure that undergraduate or intern health professionals get wide ranging exposure to patients at the end of life
- Limited interest in Palliative Care as a profession, limited promotion of the profession and the longer term impacts of limited state-wide specialist recruitment programs, combined with individual concerns about distance of SWSLHD from Sydney central business district
- Around the electronic medical record (eMR), monitoring and assessment of service effectiveness is hampered by a complicated service system working across many settings with activity inadequately captured and without well-defined performance indicators and reporting. Although EMR expansion has strengthened clinical care and communication across SWSLHD, roll-out is still to occur for palliative care consult services at Bankstown-Lidcombe, Liverpool, Fairfield, Bowral and Braeside Hospitals (including the Braeside unit). In addition, GPs do not have access to the eMR in other LHDs or to the SWSLHD eMR (and hospital tests).
- Limited access for specialist medical staff to new technology e.g. tablets and limited use of telehealth for conferences or consultations with residents at home or in rural settings.



8 Service Development Directions

Building on policy, emerging models of best practice and research, consultations with stakeholders and the principles underlying this Plan, the following describes the models of care and directions that will guide service development, delivery and leadership in SWSLHD over the next five years.

The directions outlined in this Section and detailed in the Action Plan (Section 10) are structured around the four strategic directions in the *National Palliative Care Strategy 2010*.⁵

8.1 Awareness and Understanding

Health Promoting Palliative Care

Building on best practice in working with communities, attention will be given to strengthening the knowledge of local residents, agencies and health providers about death and dying and how to best support people with palliative needs and their families including into the bereavement phase. This may occur through working with local councils or building on existing approaches in NSW such as the NSW Cancer Council Speakers Program, Carers NSW Carer Representation Program and outcomes achieved from the SWSLHD Organ and Tissue Donation Community Development Project.

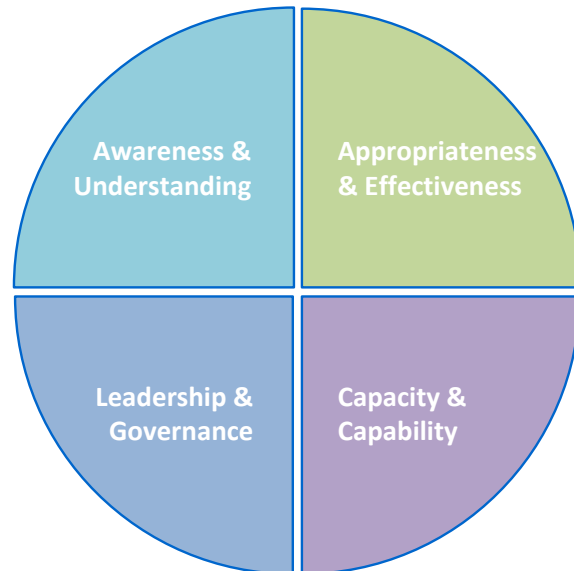
Additional attention will be given to communities who because of traditional beliefs or customs require a targeted response. This includes people from culturally and linguistically diverse backgrounds and Aboriginal people.

Advance Care Planning

The model for advance care planning to be developed into the future is:

- Health providers and staff will promote the adoption of advance care planning and directives to the wider community through varied communication medium (including newspaper articles, creation of a single SWSLHD website, promotion of NSW Government endorsed websites, talks, participation in broader NSW community campaigns such as *Get it in Black and White*) and working with community agencies and targeted groups including religious leaders. Opportunities to present at local industry forums which target relevant professionals e.g. lawyers will be pursued
- All clinicians will provide patients with multiple opportunities in community and hospital settings to consider and make decisions about their wishes and the way in which their health care will be managed at the end of their life; and will be encouraged to have these discussions with their families. Clinicians will provide patients with information about advance care planning including the forms which support decisions e.g. Advance Care Directives, NSW Ambulance Authorised

Figure 5: Strategic and Service Directions





Adult and Paediatric Palliative Care Plan. Assistance to complete the form will be provided where requested

- Patients will be encouraged to provide health practitioners with their documented decisions around end of life. In the community, patient decisions around end of life will be uploaded into the Australian Government Personally Controlled Electronic Health Record (PCEHR) and/or the individual's record in an RACF. In SWSLHD, the electronic medical record (eMR) and admission and discharge forms will be modified to enable clinicians to recognise and respond to patient's decisions for end of life care and to inform patient decision making
- General practitioners, staff in residential aged care settings and other health professionals in community settings and clinical staff in hospital settings will be supported in engaging in discussions around advance care and responding to patient choices through systematic education, standardised tools and policies which identify trigger points for discussion and action (including the 75 year old health check, diagnosis of a chronic disease, change in health status and admission to hospital or an RACF).

Advance Care Planning

Resources include

SWSLHD My Wishes @

<http://www.swslhd.nsw.gov.au/myWishes/>

SWSLHD Policy - Initiation and Management of Advance Care Planning processes PD 2013_035 (and approved medical records forms)

NSW Planning Ahead – information for everyone @

<http://planningaheadtools.com.au/prepare-a-will/>

NSW HETI and **CEWD courses** in advance care, palliative care and bereavement

NSW Ministry of Health End of Life Decisions, the Law and Clinical Practice - information for NSW health practitioners @

<http://healthlaw.planningaheadtools.com.au/>

Priority will be given to

- Working with SWSPHN to develop resources, expertise and approaches to strengthen knowledge around advance care planning and embed discussions about advance care directives into clinical practice
- Identifying SWSLHD clinical streams and services to implement advance care planning projects and initiatives, particularly in services treating people with chronic disease such as respiratory, cardiac and renal problems
- Progressively developing resources and skills and capacity to work with people from CALD backgrounds around advance care planning
- Providing education and promoting Aboriginal specific and generic tools through Aboriginal Health staff and use of Koori media
- Implementing the SWSLHD Organ and Tissue Donation Action Plan including implementing the SWSLHD Organ and Tissue Donation after Death Guideline

The SWSLHD Advance Care Planning and Care of the Dying Committee will progress the Advance Care Model.



Organ and tissue donation is another aspect of patient wishes. Donation of organs and tissue is an act of altruism that potentially benefits those in medical need and society as a whole. Although end of life care should routinely include the opportunity to donate organs and tissue, the duty of care toward the dying patient patients and their families remains the dominant priority of SWSLHD staff.

The decision of people who choose not to donate must always be respected and the family shown understanding for the decision. Priority will be given to ensuring that donations are managed in a manner consistent with the *SWSLHD Organ and Tissue Donation after Death Guideline* (SWSLHD_GL2014_020) and actions and strategies for the future are consistent with the *SWSLHD Organ and Tissue Donation Action Plan*.



End of Life Care

End of life care is the responsibility of all clinicians, commencing from diagnosis and including all care provided until the person's death. Priority will be given to ensuring that assessment, management and discussion around end of life occurs in a structured manner. Directions for end of life care will include:

- Identification that the patient is nearing the end of their life and decisions about ongoing care will be informed by NSW Ministry of Health policies such as *Recognition and Management of Patients*



who are Clinically Deteriorating

(PD2013_049) and *Using Resuscitation Plans in End of Life Decisions* (PD2014_030)

- Discussions will occur with patients and their families around end of life care. Formal consent decisions e.g. Advance Care Directives made by patients will be respected. Clinicians will be supported in engaging in discussions around end of life through systematic education, mentoring and promotion of standardised tools and policies which support decision making and identifying and managing end of life
- Patients and families will be asked in a systematic way about their pastoral care and other needs to ensure that their needs are respected and responded to comprehensively
- Patient wishes regarding the place of end of life care will be respected. Patients will receive quality end of life care irrespective of the setting. A range of strategies will be trialled and implemented to enable patients to remain in the community where feasible with access to Palliative care specialist advice
- Clinical and non-clinical staff (including health interpreters, Aboriginal health care workers and administrative staff) will be supported through education and debriefing in dealing with complex end of life situations including distressed families
- The *SWSLHD Care of the Dying Patient Plan* (CPDP) will be used by all clinical services in SWSLHD hospitals. Developed at Liverpool Hospital for use by health care specialities other than Specialist Palliative Care, it enables clinicians to care for the dying patient in the last hours/days of their lives in a holistic, supportive manner. It requires strong local governance to ensure staff education and training, regular audit and reporting, and staff focus groups to encourage feedback and reflection about care of the dying patient. It focuses on communication and attending to the religious, cultural and spiritual needs of the patient, the family and carers. It encourages staff to communicate and support the patient, carers and family on their fears and concerns before and after death. The main components of the CPDP are:
 - Initial assessment by prompting the nursing and medical team in an individualised plan of care and promoting comfort and dignity with an emphasis on symptom management, communication and cultural religious and spiritual needs
 - Ongoing assessment by prompting the multidisciplinary team to observe for any symptoms such as pain or agitation and address symptoms accordingly. Ongoing assessment also prompts the team in ongoing communication with the patient, carer and family about their fears, concerns, and cultural, religious and spiritual needs
 - Care after death by incorporating all clinical/policy needs of the organisation, the emotional needs of the patients, carers and family, care of the body after death and consideration of religious, cultural and spiritual needs at death.

End of Life Information can be

found at the ACI Palliative and End of Life Care – A Blueprint for Improvement Website @ <http://www.aci.health.nsw.gov.au/palliative-care-blueprint>

The SWSLHD Advance Care Planning and Care of the Dying Committee will progress the model in partnership with clinicians and facilities.

Reflections of a Clinician

Associate Professor Denise Lonergan was a doctor who provided caring, holistic and compassionate care to patients in South Western Sydney Local Health District. She died in 2012. In a letter to her patients, Denise wrote:

“ Over the years I have met many wonderful and inspirational patients. I feel I have developed a connection with each and every person it is often like we have become part of a family. I thank you for giving me the privilege of being part of your life. ”



At the presentation of the 2015 Dr Denise Lonergan Patient Care Award, Dr Louis McGuigan (Denise's husband and a Rheumatologist) reflected on Denise's approach to care for her patients at the end of life:

“ The path that awaits patients from the time they are told that they will die and their actual death is a lonely, frightening and uncertain one. Although palliative care is extremely helpful in lessening pain and suffering during this period.... other aspects are really important. To have people of importance still be interested in your care if you are the patient, to know that your welfare - physical, mental and emotional - is important to someone else and finally to know that your doctor is still interested in your progress while knowing that you will never be cured, allows these last days or months to be lived rather than endured.

To look into a patient's eyes and tell them bad news in a compassionate, honest and caring way and then not turn on your heels and walk away takes great courage, control and resolve. To know when to stop treatment and to have the honesty to share this decision takes maturity and humanity. To walk with patients down that lonely journey towards death and help make the rest of their lives meaningful and worthwhile is probably the most wonderful thing any doctor can do. ”

This approach to quality health care and support at the end of life reflects the vision for this Plan.



8.2 Appropriateness and Effectiveness of Care

Community Based Care

Referral pathways

To improve care in the community, Palliative Care Healthcare Pathways will be developed to support GPs in assessment and management of patients and referral to Community Nursing and specialist medical and allied health services.

The SWSLHD Triple I Hub will accept nursing referrals and coordinate care for community health nursing and specialist palliative care nursing. A specialist palliative care nurse (Senior Nurse) will review all palliative care referrals and followup (by phone) as necessary with the referring agent to ensure that patient needs are addressed and ensure safe transfer of care. Referrals for specialist palliative care medical assessment will be made directly to the Palliative Care Coordinating administrative staff at Camden (Macarthur and Wingecarribee) and Liverpool (Bankstown, Fairfield and Liverpool). Allied Health referrals are made directly to the local Allied Health services.

Priority will be given to developing the capacity of the Triple I Hub to accept and manage complex palliative care cases and provide high quality advice across extended hours including capacity to provide home visits.

Care provided by general practitioners and community primary practitioners

Enabling General Practitioners and others to provide effective care and support to patients with palliative care needs is essential for quality care. This includes recording of death in the community consistent with NSW policy around verification of death and certification. Priority will be given to:

- Trialling a GP Palliative Care Network at an LGA level which will support GPs interested in providing quality palliative care, accepting transfer of care from other GPs, etc. If successful, this approach will be extending across the District
- Developing shared care palliative care models with GPs providing most of the care, supported by ready access to specialists as needed
- Ongoing educational opportunities for GPs provided by the SWSLHD Palliative Care Service through annual in-service programs about symptom management and medication, and use of Program in the Experience of the Palliative Approach (PEPA) to provide GPs with an opportunity to work in palliative care units; and using existing formal meetings to reinforce these directions
- Strengthening the approaches used by GPs to advance care planning and exploring ways to involve practice nurses in advance care planning and ongoing care
- Providing education to community and hospital pharmacists about current palliative care medications, dosing regimens and side effects.

Care and case management by the SWSLHD Primary and Community Nursing Service

Community health nurses (CHNs) work within a cluster model of care which involves a small team of nurses. New nursing cases will be allocated to a CHN cluster at each centre. Oversight will be provided by a Palliative Care CNC who will identify any additional support needs to be provided by the specialist palliative care nursing team. At acceptance of referral and after the first visit, nursing staff (CHN



and/or specialist nurse) will provide clinical handover (the plan of care) to the GP. The referring specialist and GP will be advised of who is providing care, when the patient will be visited and contact details for the service 24/7.

Care and case management by the CHN will be supported by validated tools for the continual assessment/review of clients in collaboration with the carers; oversight and support by the PCS nursing team; regular formal case review attended by a PCS medical specialist, senior nursing staff and Nursing Unit Manager; clear processes for escalation; and joint case conferences involving the GP. Capacity of carers/family members to support the patient will be formally assessed and nursing staff will provide carers with information and education consistent with these needs.

Registered clients and their carers will have access to the Palliative Care 1300 After Hours telephone support service Monday - Friday, weekends and public holidays. Clients will experience seamless expert advice from the Triple I Hub during extended business hours and by the Palliative Care Inpatient Units overnight and on weekends. If the nursing team is sending the client to hospital, a protocol will be followed identifying which service/professional will contact ED (medical specialist, PCS nurse or Triple I Hub NUM) depending on time of referral and knowledge of the patient, prior to the patient's presentation to ED.

GPs and community nurses will encourage patients to have discussions about Advance Care and NSW Ambulance Planning with carers and families and to develop these plans. Priority will be given to strengthening governance and care by:

- Providing nurses with standardised tools to guide care supported by the expertise of PCS Nurses
- Ensuring that decisions to cease active medical care are made at a medical review by the multidisciplinary team comprising the PCS nurse and doctor, GP, CHN (and referring specialist where required) and include discussion with the patient and carer/s regarding the pathway for review and re-initiation of care
- Ensuring a consistent approach to case review of patients with palliative care needs including attendance by a PCS Specialist at Community Nursing Care Review Meetings. This includes a death review process for patients who have died in the community.

Role of the Specialist Palliative Care Service in Community Settings

The PCS CNC will provide palliative care nursing leadership, education and clinical governance for standards across the nursing team; lead research; analyse trends; work with the Nursing Unit Manager around palliative care nursing workloads and identification of nursing skills; provide consult services to local RACFs and assist with very complex cases.

Specialist Palliative Care registered nurses will work with CHN's through setting up the care plan, undertaking clinical review and working together as a team where the patient and/or carer require a joint home visit; provide urgent followup; and ensure effective clinical handover. Medical PCS specialists will undertake home visits on the request of the GP or treating specialist.



Priority will be given to:

- Strengthening the capacity of the specialist nursing team to support local CHNs to deliver quality palliative care, particularly in the Macarthur region
- Priority will be given to implementing “PEACH” packages and extending the program to Wingecarribee LGA
- Building allied health capacity in public and private sectors to provide specialist home based assessment and care
- Developing guidelines regarding provision of scripts by the PCS medical team for urgent community patients when the GP is unavailable.



Working with residential aged care facilities (RACF) and other providers

A medical and nursing consult service will be developed for RACF residents and Department of Veterans Affairs (DVA) patients to ensure appropriate care and avoid unnecessary ED presentations. Clinical discussion will occur with the GP and RACF Director of Nursing. Priority will be given to:

- Piloting a specialist palliative care RACF inreach service, potentially in partnership with SWSLHD Aged Care and Rehabilitation Services geriatricians, to prevent unnecessary presentations to ED. This will include on-site assessment and timely advice and education to RACF staff about management of complex symptoms
- Providing targeted education annually to RACF staff caring for these patients
- Working with RACFs to increase their capacity to manage the care of residents who are dying and build in-house expertise. This will include discussion with HammondCare and other facilities
- Supporting RACFs to strengthen their approaches in having advance care planning discussions with residents and families.



Bereavement support and counselling

Carers and family members will require information about dealing with death and grief and in some cases, may require counselling by specialist services. Priority will be given to

- Reviewing how bereavement services are organised in south western Sydney, including identifying bereavement counselling options (including private, non-government and not for profit), pathways for access and the most appropriate model for the future
- Ensuring that community nurses provide followup bereavement contact with carers/family members and information about bereavement services
- Developing capacity in each acute facility to acknowledge loss of loved ones through formal arrangements such as memorial services and remembrance cards
- Developing District resources which provide information for all carers and family members about coping with death.

Hospital Based Care

Streamlining Admissions

People with palliative care needs may need to present to an emergency department (ED) with complex symptom issues, particularly after hours and on weekends when the GP is unavailable. Attention will be given to streamlining access to specialist palliative care advice and/or admission under the most appropriate medical specialist. This may be a palliative care specialist or other primary care specialist. Priority will be given to:

- Providing existing PCS patients and carers with clear advice about accessing the 1300 number
- Providing GPs and CHNs with clear pathways to specialist PCS advice, supported by protocols focused on direct communication/comprehensive clinical handover with the ED prior to the patients presentation
- Scoping ED staff needs and response processes for accessing specialist PCS advice and strengthening referral pathways to the PCS Consultative Service (including via the on-call roster)
- Providing education to ED staff and developing appropriate care plans within ED
- Exploring innovative approaches to reduce unnecessary presentations and time in EDs such as trialling an ED bypass project; piloting the use of the Criteria for Screening and Triaging to Appropriate alternative care (CrISTAL) tool in EDs to define and identify patients at end of life; investigating use of or access to surgery or other beds for short term care; and trialling an After Hours PCS Nurse consultative service 7 days/week
- Promoting the Decision Assist Specialist Palliative Care and Advance Care Planning Advisory Services Phone Service to RACFs and the need to contact the GP or ED prior to sending the patient to hospital.

Inpatient care by the primary health care team

Most people will spend their last weeks of life in the community or in a general hospital ward. The Care Plan for the Dying Patient (CPDP) will be used in all hospitals to facilitate quality care for the dying patient in the last few hours or days of their life. Providing a multidisciplinary plan of care, it will focus on the patient's individual needs and the needs of their family/carers for support, information and education with the aim of improving outcomes for patients, families and carers and staff. Using



this tool, inpatients will be managed by their treating physician and will access the PCS Consultative Service for specialist nursing or medical advice, if required, regarding pain control and symptom management.

Following the death of a patient, the relevant service will undertake a death review to identify how care can be improved. In addition, as part of implementation of the CPDP process, regular ongoing randomised audit of deceased patient health records will be undertaken where a CPDP was commenced. This will enable identification of compliance issues and concerns with feedback to clinical services about issues identified with recommendations about ways to improve care.

Priority will be given to appointing an end of life coordinator/clinical nurse specialist at Fairfield Hospital to support implementation of the Care Plan for the Dying Patient, improve nursing care of patients at end of life in the hospital, streamline and facilitate care of patients through the ED, and strengthen access to specialist palliative care staff particularly at Braeside Hospital.

Inpatient care in hospitals without a palliative care ward or unit

Not every hospital will have or require a palliative care unit. In hospitals without a dedicated palliative care unit i.e. Bowral, Fairfield and Bankstown-Lidcombe Hospitals, where possible patients at the end of life will be clustered in a single ward; and where possible, single rooms will be utilised. The aim will be to provide patients with quality care and dignity at the end of life. Staff providing care in the ward will receive additional training so that they can provide good palliative care nursing, supported by access to specialist PCS nurses. Models of “hospital in the home” care will be explored by the PCS.

A cluster of palliative care beds in the Cancer Inpatient Unit is included in the Campbelltown Hospital Redevelopment Stage 1. Patients will receive care under Palliative Care specialists and Cancer nursing staff will receive additional training in palliative care.

Management of patients with palliative care needs transferred to Intensive Care Units (ICU)

To avoid unnecessary admissions of patients at the end of life into ICU, priority will be given to:

- In collaboration with ICU staff, identifying those groups of patients with palliative care needs who are inappropriately transferred to ICUs for ongoing management and identify options for improving the management of these patients. This includes the Medical Emergency Team (MET)
- Developing proactive palliative care models within ICU for appropriate patients to reduce ICU length of stay (LOS), reduce length of time being ventilated and improve quality of life of patients dying in ICU
- Using research on the CriSTAL tool to guide local policy and service development.

Referral pathways to the Specialist Palliative Care Service

Not every patient with a life limiting illness will require advice or ongoing care from a palliative care specialist. For patients who have not had prior contact with the Palliative Care Service (PCS), consultation services are available in most acute hospitals. Capacity to admit patients under the care of a palliative care physician into palliative care beds in an acute setting is limited to Liverpool Hospital. To improve referral pathways, the PCS will focus on:

- Developing and promoting clear referral pathways including referral criteria to specialist palliative care consultation services (including clinics) in hospital and community settings. This will include defining early referral to PCS consultation services
- Developing criteria for transfer to palliative care wards and units for patients with complex needs requiring direct care by the PCS
- Meeting with Cancer and Haematology specialists particularly at Liverpool and Campbelltown Hospitals to discuss the service model, clarify service availability, limitations and capacity to manage cases and to consider ways of strengthening links with general practice.

Following discharge from hospital, patients will be seen by the PCS Medical or Nursing specialist at the request of the treating specialist or GP. Patients may be seen in PCS outpatient/ambulatory clinics conducted on hospital sites or in the patient's home. Outreach clinics will be developed to improve physical access to services.



Photo from the Reflected Legacy Project

Inpatient care in palliative care wards and units

Not every patient will require admission to a palliative care unit. Every effort will be made to provide care in a setting that best meets the patient's needs and wishes. Settings of care include an inpatient palliative care unit/ward, the patient's home or an RACF.

Patients requiring management for complex and ongoing palliative care needs in an inpatient setting will be treated in a sub-acute palliative care inpatient unit at Camden or Braeside Hospitals or acute ward in Liverpool Hospital. Admission to these units will be consistent with the criteria outlined in Chapter 6. Patients in these wards and units will receive assessment and care from specialist medical,



nursing and allied health. Patients and families will also be supported by volunteers and pastoral carers. The PCS will focus on:

- Promoting how palliative care wards in acute settings operate and pathways to all PCS services
- Investigating models for strengthening after-hours medical coverage at Braeside and Camden Hospitals.

Transfer to community settings

To strengthen transfer of care, multidisciplinary/multiservice case conferences involving the patient and family will occur prior to discharge from hospital. Clear guidelines with a holistic focus, management plan and discharge letter will be developed to enable a smooth transfer of care to the General Practitioner and Community Nursing Service. If it is anticipated that the patient will die in the community, the discharging team will ensure that the GP is aware of the requirement for completing a death certificate and the value of discussing with the patient the use and completion of a *NSW Ambulance Authorised Adult (and Paediatric) Palliative Care Plan*.

To facilitate transfer and reduce readmissions and carer stress, developing a District approach to:

- provide a 3-5 day medication pack, with medication orders and medication lists for patients on discharge, with subsequent prescriptions to be obtained by the patient/carer from the GP
- provide people with palliative care needs in the community with access to costly non-Pharmaceutical Benefit Scheme (PBS) drugs and other consumables.

Palliative care (PCS) day hospital and outpatient clinics

Greater attention will be given to developing PCS outpatient clinics in hospitals and community settings closer to home. This will include a reorientation of the Braeside Hospital Day Hospital towards an outpatient model and improved use of existing ambulatory care units in acute hospitals and cancer centres. Nurse-led outpatient clinics will also be developed in community settings, such as in the Oran Park Integrated Primary and Community Care Centre and in other locations where an integrated approach to care can be implemented.

Closer collaboration will occur with the SWSLHD Cancer Services Wellness and Survivorship Centres so that PCS patients, where appropriate, can access education, group programs and support.



Collaborative outpatient clinics and multidisciplinary team (MDT) meetings

The PCS Consultative Team will participate in collaborative outpatient clinics/attend multidisciplinary team meetings conducted by other medical specialities. This will ensure that patients receive specialist advice irrespective of the specialty under which care is provided. Priority will be given to:

- Ongoing participation in the Liverpool Hospital Motor Neurone Disease Clinic and developing a model which can be implemented across SWSLHD, initially in Macarthur. The model will need to consider the role of community nurses in case coordination
- Ongoing partnership with the Liverpool Hospital Pain Service, with stronger promotion of District-wide pathways to access this specialist service; development of guidelines to address specific procedures and needs e.g. upper gastro intestinal related procedures, pelvic cancer pain; and monitoring of the impact of demand on operating theatre time
- Developing the Renal Palliative Care Supportive Service, including implementation of the hospital outpatients and outreach program to the community
- Developing partnerships with Cancer Specialists through attendance in MDT meetings, initially focused on brain tumours, upper gastro intestinal (GI), lung and head and neck
- Developing relationships with non-malignant chronic disease specialists such as respiratory and cardiology to better identify and coordinate services around patients with more complex needs.

In addition, the Haematology Service will strengthen end of life care for each patient by ensuring ongoing communication with General Practitioners.

Pathway to Oral Health Services

For patients with life limiting illnesses who are experiencing oral health problems which further complicate their care and add to their symptom burden, priority access to oral health services is required. A pathway to Oral Health Services for these patients will be developed.

Meeting the Needs of Priority Populations and Vulnerable Groups

Aboriginal people and Torres Strait Islanders

Building on initiatives in other Districts and SWSLHD successes in addressing the needs of Aboriginal people, services will be tailored to better meet the palliative care needs of Aboriginal people and their families. Priority will be given to:

- Seeking funding for employment of an Aboriginal health worker for Cancer and Palliative Care Services to support patients with palliative care needs. The Illawarra Shoalhaven/Cancer Council model is well regarded, involving direct service provision, building understanding of Aboriginal Health and other workers about local specialist services through structured visits to Cancer and Palliative Care Units, strengthening capacity to identify





- Aboriginal people and collaboration and consultation with local Aboriginal services
- Strengthening the knowledge and skills of PCS specialist staff and others providing palliative care in working with Aboriginal community members.
- Providing greater pre/post-interview support to Aboriginal Liaison Officers and other Aboriginal staff involved in supporting Aboriginal patients, partners and families around complex situations around death and bereavement; and in dealing with death in communities
- Strengthening linkages between the PCS and the Aboriginal Chronic Care Program to support Aboriginal patients transitioning to palliative care services
- Exploring ways to provide culturally appropriate accommodation to individuals and families and to support the desires of patients, where feasible, to return to Country.

Infants, children and young people

Infants, children and young people with palliative care needs are managed by a number of hospitals and various teams in each hospital. The priority will be on developing a model of care for infants, children and young people that comprehensively addresses their care and support needs and those of their parents and siblings. The model will include:

- Multidisciplinary/multiservice case conference before the child's discharge from hospital. Depending on the hospital, this may involve the SWSLHD PCS Medical Specialist, Sydney Children's Hospital Network (SCHN) Palliative Care Team, Community Nursing Service, relevant Paediatric Ambulatory Care Units, relevant Allied Health Service/Teams, the GP and family
- A "Team around the Child" approach which reflects collaborative team work between agencies and services working with families and children with complex needs. The team collaborates to create a clear management plan for the child and family that is flexible and responsive to their needs and enables self-management as appropriate to the family's skills and needs. The plan will be guided by the specialist paediatric care service or SWSLHD PCS as appropriate
- On discharge from hospital, develop capacity to provide access to medication for a longer period (1-3 months) consistent with SCHN
- A clearly identified referral/care pathway to services as the child's health needs change
- Timely referral to the SCHN specialist team including bereavement services, allied health and equipment loan pool and timely access to education and training as required
- Regular case review of the child's care. For children with longer term illnesses, clear processes for transfer of care/discharge and/or re-entry to services, supported by written information for parents. This includes consideration of young people who are transitioning to adult services
- A dedicated joint death review involving members of the treating team with the specialist PCS to identify how care can be improved. This will be supported by debriefing of staff involved with the care of the child or young person
- A District-wide paediatric governance committee to ensure that the model is implemented and address issues as needs arise. The committee will develop policies, quantify demand and need, identify capacity building requirements and support improved networking and partnership between SWSLHD Paediatric, Allied Health and Palliative Care Services with clear lines of communication to specialist palliative care services. A comprehensive clinical information system will be built on the eMR to capture information about children managed in south western Sydney by either SCHN or SWSLHD

- Adopting standardised forms for assessment, care planning and end of life/not for resuscitation (NFR) and ensuring that parents are aware of the Paediatric Resuscitation Plan (adopted by the Ambulance Service of NSW) in the management of children (consistent with NSW Ministry of Health Policy PD2014_030 *Using Resuscitation Plans in End of Life Decisions*)
- Employing the skills, sensitivity and contributions of Children's Hospital Westmead (CHW) Pain Medicine & Palliative Care and SWSLHD PCS volunteers to strengthen support for children and families
- Profiling and promoting local community support services appropriate for children and young people; with stronger advocacy role including collaboration with the SCHN around issues such as respite for young families.

People from culturally and linguistically diverse communities (CALD) including refugees

To improve care of people from CALD and refugee backgrounds, priority will be given to:

- Ensuring that PCS specialist staff have a good understanding of the cultural and religious beliefs and needs of CALD communities, and use available tools to support care e.g. NSW Refugee Health Service Appointment Translation Tool
- Working more closely with CALD community leaders around building knowledge about SWSLHD services and the value of advance care planning and including families in discussions
- Strengthening support for interpreters, particularly following complex and difficult interviews with patients and family members, and monitoring use of SWSLHD Health Language Services
- Increasing PCS staff awareness of refugee rights to Medicare funded services and capacity to support the comprehensive needs of refugees and asylum seekers.



People treated in other local health districts

To strengthen continuity of care of residents accessing services in other parts of Sydney, priority will be given to working collaboratively with neighbouring LHDs/networks to develop transparent referral pathways, provide timely advice, explore options to improve access to eHR and provide information about services available. Healthcare Pathways may provide a route for this to occur.

People in rural areas

To strengthen care in Wingecarribee and Wollondilly LGAs, priority will be given to providing additional specialist staff in hospital and community settings; developing a stronger culture of quality palliative care in hospital settings, including closer collaboration with services provided in the private hospitals; and developing capacity to use telehealth and other technology to improve care. In addition, the SWSLHD PCS will continue to provide opportunities to staff from rural LHDs to undertake placements and be open to developing networks to support rural staff.



People aged less than 65 years

To improve the care of younger adults, the focus will be on advocacy and working with NSW Ministry of Health and other entities to identify and trial innovative models of accommodation and care. This may include options such as group homes, clusters in RACFs or community based alternatives.

People with disabilities

The focus on improving care with people with disabilities will be to develop expertise in the SWSLHD Palliative Care Service on caring for people with disabilities, to consult with Ageing Disability and Homecare (ADHC), the National Disability Insurance Agency (NDIA) and peak organisations around best models of care and to adopt these models in SWSLHD.

People with Mental Health Conditions

The approach will be to consult this population, their carers and clinicians about ways specific needs and requirements can be met including consideration of Ministry of Health policies and guidelines; and upskilling palliative care volunteers about mental health issues to ensure that people with mental health conditions have more appropriate support.

Older people including those with dementia

GPs, staff in RACFs, geriatricians and other SWSLHD Aged Care staff are the primary clinicians who work with older people. With increasing numbers of people with dementia, palliative care staff need to strengthen their knowledge about comorbidity of dementia and delirium associated with complex end of life symptoms so that they can work more effectively in partnership with GPs, aged care providers and the South Western Sydney PHN. In addition, advance care planning needs to be incorporated into the processes at initial diagnosis of dementia and this can be incorporated into Healthcare Pathways for people with dementia. Opportunities to enable families who wish to care for an RACF resident at home in the last days of life with other emerging issues such as access to counselling for residents will be explored through a focus on advocacy.

8.3 Leadership and Governance

Leadership and governance will be strengthened by:

- Regular meetings between the PCS Manager and Community Health Director of Nursing to enhance oversight of the palliative care aspects of the community nursing service including service development and evaluation; and with the Braeside Hospital Executive Team to ensure effective continuity of care
- Finalising the management structure of the Palliative Care Service at a District and facility level and strengthening support provided to allied health staff
- Strengthening models and arrangements about patient and carer engagement, and community and volunteer participation and partnerships
- Working with and forming partnerships between the PCS and other clinical services, the SWSPHN, other hospital networks and non-government agencies to provide and develop services which meet the individual needs of people with palliative care needs



- A data and information management strategy which supports the implementation of this Plan and covers all aspects of end of life care (including post death support of carers). It will include actions which: identify the key performance indicators (KPIs); enable a single view of the patient record across SWSLHD hospital and community to support clinical decision making; support the uploading, rescinding or amending of authorised patient plans such as advance care directives, enduring power of attorney and authorised adult palliative care plan and access to documents held in other systems e.g. personally controlled electronic health record; support the transfer of paper based tools such as the Resuscitation Plan to an electronic tool; enable the timely transfer of information to GPs and other relevant health providers; support governance and research with capacity for regular reports on KPIs, flexible inquiry and audits of compliance with NSW and SWSLHD policy; build staff capacity to use data and information for service improvement; and access to health economics expertise to undertake cost benefit analysis of new models and service enhancement of redesign around end of life
- A formal plan for developing research capacity and capability, with stronger research leadership.

8.4 Supportive Initiatives to Build Capacity and Capability

The models will be supported by initiatives to build capacity and capability:

- Trialling innovative approaches to build capacity including opportunities for short term placements for SWSLHD staff in community palliative care; and integrated palliative models with colocation of specialist, GP and community nursing services e.g. Oran Park IPCCC
- Enhancing the PCS Consultancy and Community Services to ensure that irrespective of where a patient resides they can still access specialist advice when necessary; and strengthening supervision, mentoring and support
- Improving access to equipment through enhanced funding raising activities and by working with EnableNSW to improve access to oxygen and other equipment
- Identifying service deficits and developing formal business cases to address those gaps
- Providing targeted education and training opportunities to address identified needs (e.g. engaging in discussions around end of life, specific nursing care techniques) and which respond to care needs in each setting e.g. hospital, community and RACF. Those benefiting from this focus include GPs, practice nurses, specialist staff, community nurses, pastoral carers, volunteers, allied health practitioners, RACF staff and pharmacists
- Creating physical environments to support end of life discussions and care, particularly in older facilities
- Using validated clinical and other tools to support care from health professionals and carers
- Building capacity for the future and aiming to be a research leader in palliative care through development of a medical, nursing and allied health academic unit; and strengthening research through a comprehensive program of workforce development around research methodology, increased expectations for embedding research into practice, formally evaluating and reporting on initiatives, using research to drive new models, recruiting research and educational expertise to the SWSLHD Palliative Care Service
- Exploring opportunities to undertake research collaboratively with HammondCare, and investigating opportunities to expand models developed by HammondCare into SWSLHD.



Working with and caring for people with life limiting illness and families, particularly at the end of life, can be challenging and staff can be affected by grief and loss. It is the responsibility of managers to recognise this and promote support services. A focus will be on strengthening the capacity of all managers to support staff who are dealing with bereavement in the workplace or personally. This will involve updating managers and staff about local workforce support policies and programs such as the Employee Assistance Program (EAP) and holding forums and education sessions which focus on strengthening staff support in a team setting.



9 Implementation and Measuring Success

The Action Plan (Section 10) will be used to set the direction for improving care of people with palliative care needs and more broadly supporting local residents and clinicians in decisions around end of life. The strategies focus on the four key strategic areas:

- Awareness and understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability

A SWSLHD committee will be established to provide overarching governance for implementation of the Plan. It will be responsible for monitoring progress, formalising key performance indicators and identifying emerging issues and allocating actions as necessary.

Responsibility and time frames for each action or strategy is identified as are the broad indicators for success.

There are no specific National or NSW targets regarding advance care planning or palliative care. At a fundamental level, success of the models and strategies reflected in this Plan will be measured by completion of an action or strategy or effective roll-out of a new model. However, success can be measured at a broader population and service based level. Against each strategic direction, broad indicators have been identified to quantify the degree to which there is achievement of the extended vision of *quality health care and support for end of life care*. These indicators include many identified at a national level^{5 45} and will be refined as part of the implementation of this Plan. Potential indicators include:

Strategic Area	Potential Indicators
Awareness and Understanding	<ul style="list-style-type: none"> • Improvements in public awareness: number of people who have received education/information • Uptake and documentation of patient wishes: number of patients with an advance care directive (ACD) in the electronic medical record (eMR) or Personally Controlled eHealth Record; and residents of RACFs with an ACD • Completion of Advance Care/End of Life Education: number and proportion of health professionals • Compliance with the ACD: evidence in the eMR that the ACD and the end of life plan has been followed
Appropriateness and Effectiveness	<ul style="list-style-type: none"> • Outcome data and trends from relevant data collections: proportion of local residents with palliative care needs able to remain at home reflecting their wishes (including people living in a residential aged care facility); real-time feedback on patient experiences with care; timeliness of access to specialist services (including decision made, referral to and death); number of consults; transfers of care in the last week of life to intensive care; effectiveness of treatment of symptoms; category of death



Strategic Area	Potential Indicators
	<p>(expected/unexpected/diagnosis)</p> <ul style="list-style-type: none"> • Carer feedback through the National Standards Assessment Program indicates increased satisfaction with the SWSLHD Palliative Care Service; and decreased incidents around verification of death of patients in the community • Health care standards and accreditation: status against these standards including the National Standards Assessment Program for Palliative Care Services and the NSQHS standards • Access: feedback that care pathways are transparent • Use of NSW Health endorsed end of life tools by SWSLHD clinicians to guide clinical practice of care of people with palliative care needs; whether triggers to identify patients approaching the end of life were correctly used and applied; and whether the ACD or plan was enacted • Evidence of clear pathways and supports for people from priority populations; feedback from service providers and consumers from these populations
<p>Leadership and Governance</p>	<ul style="list-style-type: none"> • Completion/implementation of each strategy • Reporting and data systems support effective decision making • Consumer and Carer participation and engagement in service design and delivery • Policies, systems and governance structures: reflecting evidence and embedded in practice • Clear, well defined leadership and governance structures across management, clinical practice and research
<p>Capacity and Capability</p>	<ul style="list-style-type: none"> • Adequately skilled primary health workforce using recognised tools in practice • Increased research (as measured by number of trials, clinical research projects, trial participant numbers, grants, publications and higher degrees) and evidence of translation into practice – including increased consumer involvement in research • Manager and staff awareness of strategies to manage loss and pathways

10 Action Plan

Abbreviations

PCS – Palliative Care Service; HoD – Head of Department; GM – General Manager; PCH – Primary and Community Health; ACRS – Aged Care and Rehabilitation Service; ACPCoD – Advance Care Planning and Care of the Dying; SWSPHN – South Western Sydney PHN; CCC – Consumer and Community Council

Links - NSWPCP - NSW Government plan to increase access to palliative care; APQCP - Advance Planning for Quality Care at End of Life - Action Plan; ACI Blueprint ¹³

Strategic Direction 1: Awareness and Understanding				
	Actions	Responsibility	Time-frame	Link to NSW Plans
Goal 1 – Improve appreciation of death and dying as a normal part of the life continuum				
Develop an environment of Health Promoting Palliative Care				
1.1	Audit and compile a list of written and audio-visual resources about palliative care and terminal illness available through local libraries, community centres and the internet	PCS Project Officer	July 2016	APQCP O1 NSWPCP A1 and A3
1.2	Undertake a comprehensive literature review about the evidence around health promoting palliative care including consideration of “grey” literature	PCS Project Officer Partner: CONCERT Translational Centre	July 2017	APQCP O1
1.3	Develop and implement a detailed Health Promoting Palliative Care Plan which includes consideration of <ul style="list-style-type: none"> – Partnerships with local government and other agencies to trial community education in one LGA – An annual program of media releases 	PCS Manager Partner: Health Promotion	July 2018	APQCP O1
Strengthen uptake of advance care and other patient directives				
1.4	Levering off NSW Ministry of Health (MoH) awareness raising campaigns and revised advance care documentation, develop and implement a community communication strategy to increase knowledge about advance care planning (ACP) and uptake of advance care directives and enduring power of attorney. This will include: <ul style="list-style-type: none"> – An events calendar based on MoH promotional events – A media campaign focusing on advance care directives in annual health weeks e.g. palliative care week, seniors week – Targeted use of ethnic radio to reach targeted CALD communities – Collaborating with local services and agencies to develop comprehensive approaches – Promoting Aboriginal specific and generic tools through targeted collaboration with Aboriginal services and staff and use of Aboriginal media i.e. Koori Mail, Koori Radio and National Indigenous TV 	Chair, SWSLHD ACPCOD Committee Partner: Media Unit, Multicultural Health Service, Aboriginal Health Unit	Ongoing	APQCP O1



Strategic Direction 1: Awareness and Understanding				
	Actions	Responsibility	Time-frame	Link to NSW Plans
	<ul style="list-style-type: none"> - Discussion with and education of multicultural agencies and religious leaders - Promoting NSW Government endorsed web pages and promotional materials 			
1.5	<p>Work with South Western Sydney PHN to strengthen advance care planning including:</p> <ul style="list-style-type: none"> - Developing promotion materials regarding advance care planning for patient and other areas - Building the capacity of local GPs to incorporate ACP discussions into the 75 year old GP Health Check and other health checks and encourage patients to upload their completed ACD into the personally controlled electronic health record (PCEHR) - Developing Advance Care Directive Cards to alert health professionals that the patient has an ACD and promote its use to the public and health professionals 	<p>Chair, SWSLHD ACPCoD Committee</p> <p>Partner: SWSPHN</p>	July 2017	APQCP O1 and O2
1.6	Review SWSLHD policy, forms and educational materials to standardise advance care planning and end of life care terminology and definitions consistent with the NSW Ministry of Health	<p>Chair, SWSLHD ACPCoD Committee</p>	Dec 2016	APQCP 02
1.7	In partnership with IMTD and SLHD, develop processes which enable the upload of patient directives e.g. ACD, enduring guardian, etc. into the electronic medical record, facilitate revoking of previously uploaded documents and enable flagging/alerts to clinicians	<p>Chair, SWSLHD ACPCoD Committee</p> <p>Partner: IM&TD, SLHD, Braeside Hospital</p>	July 2016	APQCP 04 NSWPCCP A4
1.8	Incorporate advance care planning content (supported by targeted staff training) in admission and discharge hospital documentation, referral/ intake processes in community health (including Triple I Hub) and assessment and care planning processes	<p>Chair, SWSLHD ACPCoD Committee</p> <p>Partner: GM</p>	Dec 2017	APQCP 06
1.9	<p>Pilot new approaches to enable additional discussion with patients and their families about advance care planning including:</p> <ul style="list-style-type: none"> - Identifying SWSLHD clinical streams and services to implement ACP projects and initiatives - Focusing on SWSLHD outreach/community based services such as ACATs, community nurses and social workers to increase patient knowledge and support 	<p>Chair, SWSLHD ACPCoD Committee</p> <p>Partner: Clinical Directors, ACRS, PCS, CNS, Allied Health</p>	Dec 2018	APQCP 01

Strategic Direction 1: Awareness and Understanding				
	Actions	Responsibility	Time-frame	Link to NSW Plans
1.10	<p>Adopt innovative approaches (including use of targets) to strengthen the capacity of health professionals to support patients and families in effective advance care planning including</p> <ul style="list-style-type: none"> – Encouraging completion of <i>Introduction to Advance Care Planning</i> by front-line and medical records staff – Encouraging completion of <i>Advance Care Planning: Module 1 - Promoting Patient Wishes</i> about their Future by nursing, allied health and Aboriginal health staff – Participating in the roll out of the <i>NSW Health Supporting Health professionals in Advance Planning and End of Life (SHAPE) Conversations Project</i>, which includes education around end of life communications skills and mentoring, commencing with senior clinicians. 	Chair, SWSLHD ACPCoD Committee	Ongoing	APQCP 06 and APQCP 02
1.11	Promote <i>SWSLHD My Wishes</i> , <i>NSW Planning Ahead</i> and <i>NSW Health End of Life Decisions, the Law and Clinical Practice</i> websites to local clinicians, GPs and RACFs	Chair, SWSLHD ACPCoD Committee	Dec 2016	APQCP 01 and 02
1.12	Work with RACF Directors of Nursing to develop stronger approaches to advance care planning and compliance with resident wishes	Chair, SWSLHD ACPCoD Committee Partner: SWSPHN, RACFs	July 2018	APQCP 01 and 02
1.13	Progressively develop resources, skills and capacity to work with people from CALD around advance care planning	Chair, SWSLHD ACPCoD Committee Partner: Project Officer	Ongoing	
1.14	Monitor and evaluate progress and implement strategies to showcase endeavours and achievements in end of life and advance care planning	Chair, SWSLHD ACPCoD Committee	Ongoing	APQCP 03
1.15	Employ a SWSLHD project officer to support implementation of advance care planning initiatives within facilities and streams. An initial focus will be to work with clinical streams	Chair, SWSLHD ACPCoD Committee	July 2016	



Strategic Direction 1: Awareness and Understanding				
	Actions	Responsible Manager	Time-frame	Link to NSW Plans
1.16	Implement strategies consistent with the <i>SWSLHD Organ and Tissue Donation Action Plan</i> across south western Sydney to staff and patients, reflecting National and NSW guidelines and directions; and update the Action Plan as necessary	SWSLHD Organ and Tissue Donation Program Coordinators	Ongoing	APQCP O1 and O6
Improve end of life care				
1.17	Implement the <i>SWSLHD Care Plan for the Dying Patient</i> tool in all SWSLHD facilities, supported by staff education and training and ongoing audit	Chair, SWSLHD ACPCoD Committee Partner: GMs, End of Life Coordinators, SPC, Clinical Streams	Dec 2017	APQCP 03
Goal 2 - Enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services				
2.1	Develop a resource package (linked to a single website) for carers, families and community members to support people with palliative care needs and more generally people at the end of life. Include information about supports and services for carers	PCS Project Officer	Dec 2016	NSWPCCP A1
2.2	Strengthen the SWSLHD Palliative Care Volunteer Education Program by including a focus on building the capacity of volunteers to act as Ambassadors to promote end of life planning and access to palliative care services. Consider the role of volunteers in health promoting palliative care	PCS Volunteer Coordinator	July 2017	NSWPCCP A1 APQCP O1
2.3	Build the capacity of the SWSLHD Consumer and Consumer Council (CCC) and Networks to have a role in the promotion of Advance Care Planning and consumer choice documentation	SWSLHD CCC Manager	Ongoing	APQCP O1
2.4	Conduct a forum for local community agencies to increase awareness of advance care planning and palliative care services, outline future directions, and explore opportunities for partnerships and collaborations	PCS Manager	Dec 2016	NSWPCCP A1 and A2
2.5	Incorporate information about end of life and palliative care services and initiatives in SWSLHD promotional materials such as the SWSLHD District News, Patient Handbooks and Intranet Bulletin Board	PCS Manager and Chair, SWSLHD ACPCoD Committee	Ongoing	NSWPCCP A1
Alignment to other NSW Health System Frameworks: ACI Blueprint: Component 1, 2 and 10				

Strategic Direction 2: Appropriateness and Effectiveness				
	<i>Actions</i>	<i>Responsibility</i>	<i>Time-frame</i>	<i>Link to NSW Plans</i>
Goal 3 - Appropriate and effective palliative care is available based on need				
Strengthen access and referral to Specialist Palliative Care Services (PCS)				
3.1	Comprehensively profile services available to support patients with palliative needs, carers and family members	PCS Project Officer	Dec 2017	NSWPCP A1 NSWPCP A3
3.2	Develop consistent definitions around the role and functions of palliative care in acute settings including consultancy, inpatient care and follow up with transparent criteria for referral to Palliative Care Specialist Services in hospital and community settings	PCS Manager Partner: Cancer Services, GM, Chronic & Complex care	July 2016	NSWPCP A2
3.3	In collaboration with South Western Sydney PHN, develop Palliative Care Healthcare Pathways, providing information, tools and resources to GPs to support appropriate care of the patient with palliative care needs and referral to specialist palliative care services	PCS Manager Partner: SWSPHN	Dec 2016	NSWPCP A1 NSWPCP A2
3.4	Develop a referral pathway for all aspects of the Specialist PCS for residential aged care facilities including roles and responsibilities, access, documentation and promotion of the Decision Assist Telephone Advisory Line. Use this approach for Department of Veterans Affairs clients	SWSPHN, PCS Manager Partner: PCH, RACFs, DVA	July 2017	NSWPCP A1 NSWPCP A2
3.5	Develop a multifaceted strategy to support safe transfer of care including: <ul style="list-style-type: none"> - A referral pathway with criteria to specialist Palliative Care Services, including transfer to the community - Processes which support reflection on factors impacting on safe transfer of care e.g. medications, equipment, verbal clinical handover to GPs - Processes supporting transfer of care in holidays 	PCS Senior Medical Meeting	July 2016 Dec 2016 Dec 2016	NSWPCP A2
Improve Transfer of Care between all health providers				
3.6	Recruit palliative care expertise into the Triple I Hub to improve transfer and coordination of care to community services, improve support to the 1300 number and RACF triage. This will include enhancement to ensure 7 day/week coverage.	DON, PCH Partner: PCS	July 2016	NSWPCP A1 NSWPCP A2
3.7	In collaboration with the Ambulance Service of NSW and SWSPHN, implement the <i>NSW Ambulance Authorised Adult and Paediatric Palliative Care Plan</i> across south western Sydney	Chair, SWSLHD ACPCoD Committee Partner: NSW Ambulance Service, PCS, SWSPHN, RACF	July 2017	NSWPCP A2



Strategic Direction 2: Appropriateness and Effectiveness				
	Actions	Responsibility	Time-frame	Link to NSW Plans
3.8	In collaboration with other local health districts, networks and private hospitals, develop and implement strategies to support the smooth inter-District/Service transfer of patients with palliative needs. This will include regular promotion of the SWSLHD Triple I Hub, promotion of referral pathways to SWSLHD and other NSW LHD services and improved access to the eMR	PCS Manager Partner: PCS Development Officer Network	July 2019	NSWPCP A2 NSWPCP A4
Strengthen community based care and capacity to enable a quality death at home				
3.9	Implement the SWSLHD community model of community nursing palliative care across SWSLHD (as outlined in Section 8.4)	GM PCH Partner: PCS	Dec 2016	NSWPCP A1
3.10	Enhance the PCS Medical Team to support development of outreach/outpatient medical clinics in CHCs/IPCCCs, RACFs and patient homes; strengthen hospital avoidance; and improve medical governance of SWSLHD Community Nursing Service, the "PEACH" Program and RACF residents: <ul style="list-style-type: none"> - With a new registrar in Macarthur/Wingecarribee LGA as a high priority - Dedicated Staff Specialist medical community positions in Northern and Macarthur/Wingecarribee LGAS 	GM, Director Cancer Partner: PCS	Ongoing	NSWPC O2
3.11	Pilot an integrated palliative care model in the Oran Park IPCCC (or similar) with a stronger partnership and closer collaboration between community nurses, GPs and PCS specialists. GPs could become providers of choice.	GM, PCH Partner: PCS, SWSPHN	July 2019	NSWPCP A2
3.12	Develop and implement a District-wide Community Case Review Process for patients with palliative care needs. Initially, undertake a baseline assessment of all registered palliative care patients.	GM PCH, Manager PCS	July 2016	
3.13	Enhance Community palliative care specialist nursing service capacity initially in the Macarthur region to meet population growth; and in the medium term to Bowral to ensure full time weekday coverage	GM PCH, Manager PCS	July 2016 Dec 2018	NSWPCP A4
3.14	Develop a model for specialist allied health assessment and treatment in the community which: <ul style="list-style-type: none"> - Enables equitable access to multidisciplinary allied health across SWSLHD, initially focusing on Macarthur - Enhances services where gaps exist - Ensures practice occurs within a multidisciplinary community based team of CHNs, GP and the specialist palliative care team - Reduces staff isolation and ensures professional supervision and support - Includes a Memorandum of Understanding (MoU) 	Director Allied Health, Manager PCS	Dec 2017	NSWPCP A1

Strategic Direction 2: Appropriateness and Effectiveness				
	Actions	Responsibility	Time-frame	Link to NSW Plans
	outlining service provision if staff are hospital based			
3.15	Trial capacity building of private psychology services to provide quality interventions through the Medicare Chronic Disease Management Program. If successful, roll out to other professions	Manager PCS; GMs Liverpool & PCH	Dec 2016	NSWPCP A2
3.16	Trial the use of telehealth and tablets for community case conferencing and clinical management of patients	GM PCH	July 2018	NSWPCP A2
3.17	Continue participation in the Palliative Care Home Support Packages (PEACH) Program and evaluation and extend to Wingecarribee LGA	A/Director Strategic Projects	Dec 2016	NSWPCP A1 NSWPCP A2
3.18	Standardise documentation for the assessment and review of residents of RACFs and clients of Department of Veterans Affairs and the Dust Diseases Board	GM PCH; Manager PCS Partner: RACFs	Dec 2017	NSWPCP A2
3.19	Implement the NSW MoH <i>Verification of Death and Medical Certificate of Cause of Death Policy</i> (PD2015_040) to assist with deaths at home, including education, training and evaluation of effectiveness	GM and DON PCH; Partner: Manager PCS	2016 and ongoing	APQCP O4
Improve hospital based care				
3.20	Establish an on-site specialist palliative care nursing service to strengthen management and care of patients with palliative care needs and end of life care at Fairfield Hospital as a high priority	GM Fairfield Partner: PCS	Dec 2016	NSWPCP A4
3.21	Create appropriate environments in hospital settings for people with palliative care needs by: <ul style="list-style-type: none"> – Participating in clinical service planning for the Campbelltown and Bowral Hospital Redevelopments, Fairfield/Braeside Hospital Campus Master Planning and Bankstown-Lidcombe Hospital Service Planning – Exploring opportunities to develop hospital in the home capacity for longer term patients – Pursuing opportunities for minor capital works at Braeside and Camden Hospitals to meet the needs of wandering patients, bariatric patients, etc.; and at Bankstown-Lidcombe and Bowral Hospitals for private interview spaces particularly for end of life discussions and care – Investigating innovative ways of fostering and creating appropriate spaces to support carers – Improving the amenity of the Bowral Hospital Viewing Area – Where possible, clustering beds for people at the end of life in one ward/area in facilities without an onsite palliative care unit, with supportive 	GMs Partner: PCS	Ongoing	



Strategic Direction 2: Appropriateness and Effectiveness				
	<i>Actions</i>	<i>Responsibility</i>	<i>Time-frame</i>	<i>Link to NSW Plans</i>
	education to develop expertise around end of life, access to specialist consultation and a focus on a supportive culture for patients and families			
3.22	<p>Lead and/or participate in new models and trials of service delivery which focus on the care and management of people with terminal illnesses and which consider the best interests of the patient including:</p> <ul style="list-style-type: none"> – Implementing the SWSLHD Renal Palliative Care Supportive Service – Including Specialist palliative care expertise in multidisciplinary team meetings and clinics targeting chronic diseases such as Cancer, Renal, Motor Neurone Disease, Respiratory and Cardiac Disease. 	<p>PCS Medical staff/GMs Partner: GMs; Manager PCS; SWSLHD clinical services</p>	Ongoing	<p>NSWPCP A1 NSWPCP A2 APQCP O3</p>
3.23	<p>Improve access to SWSLHD Pain Service expertise required by patients with palliative care needs by</p> <ul style="list-style-type: none"> – Developing a Healthcare Pathway to the Liverpool Hospital Pain Service for people with palliative care needs and promoting across the District – Developing guidelines to address specific health problems where pain is a major factor – Monitoring the impact of demand on operating theatre lists and developing a business case to expand as necessary 	<p>Director Liverpool Pain Service Partner: HoD Liverpool, PCS</p>	Dec 2018	
3.24	Develop a pathway to Oral Health Services for patients with life limiting illness experiencing oral health problems	<p>Director: Oral Health Partner: PCS</p>	July 2017	
3.25	Review the medical model of care for people with palliative care needs managed by Cancer and Haematology Services to ensure understanding of referral pathways, patient criteria and identify opportunities for collaboration.	<p>PCS Senior Medical Meeting Partner: Cancer & Haematology</p>	July 2016	NSWPCP A2
3.26	Strengthen end of life care for Haematology patients by ensuring ongoing collaboration with GPs occurs	<p>Director Haematology</p>	July 2017	
3.27	Develop a model for Allied Health Palliative Care Specialist Consultative Services in hospitals	<p>Director Allied Health Partner: Manager PCS</p>	Dec 2017	NSWPCP A2
3.28	<p>Enhance PCS nursing, medical and allied health consultative services to provide consults and clinics at:</p> <ul style="list-style-type: none"> – Bowral Hospital – with additional nursing staff (and through medical outreach from Macarthur) – Bankstown-Lidcombe Hospital – with additional nursing, staff specialist and allied health staff 	<p>GMs, PCS</p>	Ongoing	NSWPCP A2

Strategic Direction 2: Appropriateness and Effectiveness				
	<i>Actions</i>	<i>Responsibility</i>	<i>Time-frame</i>	<i>Link to NSW Plans</i>
	<ul style="list-style-type: none"> - Campbelltown Hospital – with additional nursing and medical (which includes inpatient bed capacity) and allied health staff - Liverpool Hospital - with additional nursing and allied health staff 			
3.29	Strengthen approaches to the management of patients presenting at emergency departments (EDs) including scoping the response and needs of Ed staff for a Palliative Care Consult Service and trialling a Bypass Project at Liverpool Hospital	HoD PCS Liverpool, GM, Director Critical Care	Dec 2017	NSWPCP A4
3.30	Strengthen collaboration and partnerships with Intensive Care Services, including Medical Emergency Teams (MET), around management of patients at end of life	HoD PCS Liverpool, GM, Director Critical Care	Dec 2019	NSWPCP A4
3.31	Provide a comprehensive education program consistent with the Palliative Care standards and philosophy and underpinned by Essentials of Care, initially at Liverpool Hospital Palliative Care Inpatient Ward and extend to the Campbelltown Hospital palliative care inpatients beds when opened	PCS Nurse Coordinator PCS Senior Doctors	Dec 2016	NSWPCP A4
3.32	Strengthen care in palliative care units by: <ul style="list-style-type: none"> - Reviewing the Camden, Braeside and Liverpool Inpatient Palliative Care Units and Ward staffing profiles to ensure comprehensive nursing, medical, allied health and complementary services, including a role in servicing the community. - Undertaking a triennial review of admission criteria for patients who can be safely managed in Braeside and Camden Hospital Palliative Care Units, with education of other medical teams about revised criteria - Investigating models for improved after-hours medical coverage at Braeside and Camden Hospitals 	Clinical Manager Cancer, GMs, Manager PCS, PCS Medical Staff	Dec 2019 Dec 2018 & 2021 Dec 2018	NSWPCP A4
3.33	Scope, trial and evaluate the effectiveness of a weekend nurse consultative service at Liverpool Hospital	DON Liverpool, PCS HoD Liverpool, GM	July 2018	NSWPCP A4
Improve access to and management of medication in community and hospital settings				
3.34	Strengthen provision of medications to people with palliative care and end of life needs through: <ul style="list-style-type: none"> - Standardising the formularies used for palliative care patients available through SWSLHD hospitals - Developing a District-wide policy regarding the provision of Discharge Medications to patients at end of life and seek endorsement of the SWSLHD Drug Advisory Committee (DAC). This should 	PCS Senior Medical Meeting Partner: Chair, SWSLHD DAC Directors Pharmacy, PCS Senior Medical	July 2017 Dec 2016	



Strategic Direction 2: Appropriateness and Effectiveness				
	Actions	Responsibility	Time-frame	Link to NSW Plans
	include a policy outlining the requirement for authorisation by a palliative care physician <ul style="list-style-type: none"> – Making representations to the <i>NSW Review of the NSW Poisons Act and Regulations</i> for a legal framework to enable palliative care specialists to dispense Schedule 8 drugs to patients with palliative care needs – Developing guidelines for the PCS medical team for medication provision in urgent community cases 	Group	TBC Dec 2016	
3.35	Investigate opportunities to extend the scope of medication and consumables provision including: <ul style="list-style-type: none"> – Emergency access to medications through SWSLHD hospitals for community patients – Provision of non-PBS drugs (Section 100 – Highly Specialised Drugs Program) and consumables to patients in community settings 	GM PCH Partner: Manager PCS	July 2017	
3.36	Review capacity in each Pharmacy Department to provide patients and carers with palliative care needs prior to discharge with a list of medications and verification that this is correct and appropriate education. Develop business cases to enhance services where required	GMs; Director Cancer Partner: Directors Pharmacy	Ongoing	
Develop palliative care responses to the needs of priority populations and vulnerable groups				
3.37	Implement the paediatric model of palliative care across SWSLHD in partnership with the Sydney Children's Health Network; and give consideration to trialling the approach in one LGA prior to full implementation	Manager PCS Partner: Directors Paediatrics, Allied Health, GMs, SCHN	Dec 2017	NSWPCP A2
3.38	Develop and implement a comprehensive strategy to improve treatment and care of Aboriginal patients and families including: <ul style="list-style-type: none"> – Consulting with Tharawal Aboriginal Medical Service (AMS) and Gandangara Medical Services to identify and address issues in SWSLHD facilities – Strengthening processes which support identification of Aboriginal people in outpatient Cancer Services – Developing new pathways to access Aboriginal services and support – Strengthening linkages with the Aboriginal Chronic Care Program (ACCP) to support Aboriginal patient's transition to palliative care services – Employing a Cancer/Palliative Care Services Aboriginal health worker to support patients and families in inpatient, outpatient and community settings; and facilitate health promoting palliative 	Manager PCS Partner: Directors SWSLHD Aboriginal Health and Cancer Services, Tharawal AMS, Gandangara Health Services	Ongoing	NSWPCP A1 NSWPCP A2

Strategic Direction 2: Appropriateness and Effectiveness				
	<i>Actions</i>	<i>Responsibility</i>	<i>Time-frame</i>	<i>Link to NSW Plans</i>
	care and advance care planning in local communities (i.e. an Illawarra Shoalhaven LHD/ Cancer Council model)			
3.39	In collaboration with SWSLHD Aboriginal Health Services, local Aboriginal health organisations, SWSLHD Aged Care Services and the RACF sector strengthen support for Aboriginal patients and families by: <ul style="list-style-type: none"> – Investigating opportunities to create an Aboriginal cluster in a local RACF – Developing short term accommodation options near hospitals for carers and family members, including culturally appropriate facilities for Aboriginal families e.g. housing via Aboriginal Hostels Ltd (AHL) 	SWSLHD Aboriginal Health Unit Partner: ACRS, Manager PCS, Tharawal AMS, Gandangara Local Aboriginal Land Council, RACFs, AHL, GMs	Dec 2019	NSWPCP A1 NSWPCP A2
3.40	In collaboration with other SWSLHD services, identify long term accommodation and support needs of younger adults with palliative care needs; and advocate for and support initiatives by NSW Palliative Care forums and Government for improved community service and accommodation options	Manager PCS Partner: Director Cancer, NSW MoH	July 2017	NSWPCP A1
3.41	Strengthen the support provided to carers by <ul style="list-style-type: none"> – Reviewing the operation of the 1300 number and improving capacity to give highly specialised advice – Investigating availability of tools to assess carer capacity and capability to care for person with palliative care needs in the community and to maintain their own health – Innovating in delivery of information to carers e.g. information nights in ward and community settings – Providing specialist PCS staff with education, resources and tools in identifying carer needs and supporting carers – Working with local services to improve access to respite services – In the model for children, considering the needs of children who are carers/family members 	Manager PCS Partner: SWSLHD Carers Service, GM PCH, local agencies	Dec 2016 Dec 2016 Dec 2018 Dec 2018 Ongoing Dec 2017	NSWPCP A1 NSWPCP A3
3.42	Consult with NSW Ageing Disability and Homecare (ADHC), National Disability Insurance Agency (NDIA) and other relevant agencies about the needs of local residents with an intellectual or physical disability with palliative care needs and develop a plan to improve service delivery	Manager PCS Partner: SWSLHD ACRS, AD&HC, NDIA	July 2017	NSWPCP A1 NSWPCP A3
3.43	Consult with non-cancer chronic disease specialties to identify specific service development requirements	Manager PCS	Dec 2019	NSWPCP A1
3.44	Consult with SWSLHD Mental Health Services, consumers and carers and consider relevant NSW	Manager PCS Partner:	June 2017	NSWPCP A1



Strategic Direction 2: Appropriateness and Effectiveness				
	<i>Actions</i>	<i>Responsibility</i>	<i>Time-frame</i>	<i>Link to NSW Plans</i>
	Ministry of Health policies/guidelines to identify service development needs of consumers with mental health conditions	Mental Health		
3.45	<p>Develop stronger models for patients from CALD backgrounds and refugees by:</p> <ul style="list-style-type: none"> – Providing education to PCS staff and community nurses regarding refugee entitlements to free health care and support needs, the importance of interpreters and the role of the NSW Refugee Health Service – Including the Appointment Translation Tool (from the NSW Refugee Health Service website) for PCS outpatient clinics and home visits – Exploring with NSW Palliative Care and the NSW Ministry of Health translation of medications into key languages – Considering the impact of culture and literacy on new models 	<p>Manager PCS Partner: NSW Refugee Health Service, SWSLHD Health Language Service (HLS) and Multicultural Health Service</p>	July 2017	<p>NSWPCP A1 NSWPCP A2 NSWPCP A3</p>
3.46	Develop a District wide model for the palliative care management of people with motor neurone disease and related degenerative diseases including extending the service to other parts of SWSLHD	<p>HoD PCS Liverpool, Manager PCS, Director Complex Care</p>	July 2018	NSWPCP A1
3.47	<p>Strengthen the care of rural patients by:</p> <ul style="list-style-type: none"> – Formalising coordination of care arrangements with Southern Highlands Private Hospital (SHPH) – Monitoring the impact on patient care and services of Southern Highlands Community Hospice initiatives – Participating in discussions with rural health services about ways metropolitan services can strengthen care for rural residents through capacity building – Enhancing specialist nursing care services in the community 	<p>Manager PCS, Director Cancer Partner: SHPH</p>	<p>July 2016 Ongoing Ongoing Ongoing</p>	<p>NSWPCP A1 NSWPCP A2</p>
3.48	Strengthen Palliative Care Service knowledge and skills about people with comorbidities of dementia and complex end of life care and develop partnerships with the SWSLHD Aged Care and Rehabilitation Service (ACRS), Mental Health and SWSPHN to strengthen support for people with dementia including earlier advance care planning	<p>Manager PCS Partner: SWSPHN, ACRS, Mental Health</p>	Dec 2017	NSWPCP A1

Strategic Direction 2: Appropriateness and Effectiveness				
	Actions	Responsibility	Time-frame	Link to NSW Plans
Develop responses to equipment requirements for people living in their own homes				
3.49	<p>Improve provision of equipment in the community by:</p> <ul style="list-style-type: none"> – Reviewing SWSLHD guidelines for equipment prescribing and retrieval in the community to improve and simplify equipment management – Implementing strategies to ensure a sustainable Equipment Loan Pool for palliative care patients including fund raising activities for new and replacement equipment, maintenance of existing equipment, and regular audit of the quantum and range of equipment available e.g. concentrators – Advocating with EnableNSW to remove barriers in provision of oxygen to palliative care patients 	<p>Chair SWSLHD ELP Committee</p> <p>Partner: Manager PCS, GM PCH</p>	<p>July 2016</p> <p>July 2016</p> <p>Ongoing</p>	NSWPCC A3
Develop a coordinated and comprehensive response to bereavement				
3.50	<p>Strengthen bereavement responses to carers and family members by:</p> <ul style="list-style-type: none"> – Reviewing the SWSLHD Palliative Care Bereavement Service role and activities, identifying bereavement services available to local residents and considering a future model for bereavement (including potential to extend beyond PCS families) for SWSLHD in partnership with HammondCare – Developing formal processes at each facility to recognise the bereavement and loss of families – Developing stronger links and collaborative partnerships with the Southern Highlands Bereavement Care Service to build seamless high quality bereavement services 	<p>GM Hammond- Care/ Braeside</p> <p>Partner: SWSLHD Bereavement Service</p> <p>Manager PCS / Director PC Braeside, SHBS, GMs, ACPCOD Committee</p>	<p>Dec 2016</p> <p>Dec 2017</p> <p>July 2016</p>	
Expand support by volunteers to people with palliative care needs and their carers				
3.51	<p>Pursue opportunities to further develop the Palliative Care Volunteer Program by</p> <ul style="list-style-type: none"> – Developing a stronger presence within each LGA, initially focusing on Wingecarribee LGA and the Macarthur region – Exploring opportunities to broaden the Volunteer Program including a seven day/week extended hour service, telephone support, on-call support and aligning volunteers skills, interests and abilities with volunteer efforts – Providing volunteers with education about the needs of vulnerable populations e.g. people with mental health conditions 	<p>Manager PCS; Volunteer Coordinator PCS</p>	Ongoing	NSWPCC A1 NSWPCC A3
Alignment to other NSW Health System Frameworks: ACI Blueprint: Component 3, 4, 7, 8, 9				



Strategic Direction 3: Leadership and Governance				
	Actions	Responsibility	Time-frame	Links to NSW Plans
Goal 4 - Support the collaborative, proactive, effective governance of palliative care strategies, resources and approaches				
4.1	Establish a SWSLHD committee to provide governance and oversight of the implementation of this Plan	Chief Executive	July 2016	
4.2	Explore models for expanding patient and/or carer participation and involvement in the development, implementation and evaluation of palliative care and end of life services and projects	Manager PCS Partner: SWS Carers Network	Dec 2017	NSWPCP A3
4.3	Establish a Governance Network with effective lines of communication to specialist Palliative Care Services to ensure effective implementation of the SWSLHD Paediatric Model of Care and to address emerging issues with representation from relevant SWSLHD services, the Sydney Children's Hospital Network Palliative Care/Pain Service, a consumer and South Western Sydney PHN	Manager PCS, Director Paediatrics	July 2016	NSWPCP A2
4.4	Strengthen leadership and sustainability in palliative care education and research through: <ul style="list-style-type: none"> - Developing a Research Strategic Plan which incorporates capacity building (Strategic Direction 4) - Exploring opportunities to develop a Palliative Care Academic Unit including appointing a Palliative Care Chair/Professor in Medicine and Nursing in partnership with a university (potentially funded via SWSLHD Academic Unit competitive tendering) with capacity for allied health in the future - Applying for a competitive grants fellowship to encourage the best palliative care researchers to work in SWSLHD 	Manager PCS; Director Cancer, PCS HoDs, Director Clinical Trials	July 2016 Ongoing Ongoing	
4.5	Finalise the Palliative Care Management Structure through appointing: <ul style="list-style-type: none"> - Palliative Care Department Heads, Bankstown-Lidcombe Hospital and Camden and Campbelltown Hospitals (covering Macarthur/Wingecarribee) - a SWSLHD Manager/Director Palliative Care Service 	GMs, Director Cancer Partner: Manager PCS	July 2016 July 2016	
4.6	Review existing arrangements for the governance, supervision and professional development of allied health specialist palliative care staff in community and hospital settings	Director Allied Health Partner: Manager PCS	Dec 2016	NSWPCP A2
4.7	Strengthen Palliative Care volunteer governance with further development of policies, inclusion of the Volunteer Program Coordinator in the orientation of palliative care staff, greater clarity regarding roles, etc.	Manager PCS; Coordinator PCS Volunteer Service Partner: GMs, HR	July 2018	NSWPCP A1

Strategic Direction 3: Leadership and Governance				
	<i>Actions</i>	<i>Responsibility</i>	<i>Time-frame</i>	<i>Links to NSW Plans</i>
4.8	Develop a Palliative Care and End of life Information Technology and Data Management Plan which includes <ul style="list-style-type: none"> – Developing a single dashboard reporting on key performance indicators for palliative care and end of life – Reviewing and refining existing palliative care information systems to support patient care and to create reports to support service management – Building capacity of managers and clinicians to analyse and use performance data for service improvement 	PCS Manager, SWS IM&TD Partner :GM, community, SWSLHD Cancer, PCS Data Manager	Dec 2016 July 2017 July 2017	NSWPCP A4
4.9	Support Integrated Care initiatives in the SWSLHD Information Communications and Technology (ICT) Strategic Plan which enable shared access to health records across the NSW Health system	Director IM&TD	Ongoing	NSWPCP A4
4.10	Build on relationships with Braeside Hospital/HammondCare through <ul style="list-style-type: none"> – Establishing a formal SWSLHD PCS/Braeside Collaboration Meeting to address emerging issues in service delivery, communication and capacity building – Exploring opportunities for service development in SWSLHD – Building research collaboration 	PCS Manager Partner: Cancer Services, Braeside GM, Community Health Services	July 2016 Ongoing Ongoing	
Alignment to other NSW Health System Frameworks: ACI Blueprint: Component 5				



Strategic Direction 4: Capacity and Capability				
Actions		Responsibility	Time-frame	Links to NSW Plans
Goal 5 - Build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.				
5.1	Promote, encourage and host educational programs such as Program of Experience in the Palliative Approach (PEPA) for primary staff placements for experience in palliative approach	Manager PCS Partner: SWSPHN	July 2016 & Ongoing	PCPNSW O4
Build the capacity and capability of SWSLHD clinicians to provide appropriate care				
5.2	Progress roll-out of <i>Using Resuscitation Plans in End of Life Decisions PD2014_030</i> form and policy with training	GMs	Dec 2017	
5.3	Participate in the AMBER care bundle evaluation and if successful, roll out recommendations	Director Clinical Governance, GMs	Dec 2016	APQCP A3
5.4	Complete SWSLHD research into the Criteria for Screening and Triaging to Appropriate Alternative care (CriSTAL) objective assessment and definition of the dying patient and: <ul style="list-style-type: none"> - If effective, utilising the tool to support end of life decisions. - Implementing a project to assess the value of combining CriSTAL with supportive advance care education from a palliative care nurse with the patient and family 	Director ICU Liverpool Partner: PCS	Dec 2018	
5.5	Collaborate with the SWSLHD CEWD and/or the NSW Health Education and Training Institute (HETI) to develop an education program for front line administrative staff on dealing with distressed families	Chair ACPCoD Committee Partner: Director Workforce and Development (including CEWD), HETI, PCS	Dec 2017	NSWPCP A4
5.6	Develop formal systems in care planning for end of life to enable debriefing of patient support staff such as Aboriginal Liaison Officers, Interpreters and Administrative Officers	Chair ACPCOD Committee Partner: Director Workforce (including EAP), SWSLHD Aboriginal Health Services, Health Language Services	Dec 2016	

Strategic Direction 4: Capacity and Capability				
	Actions	Responsibility	Time-frame	Links to NSW Plans
5.7	Conduct a biannual Introductory Palliative Care Education Program targeting hospital and community pharmacy interns; and updates for more experienced pharmacists on high risk drugs	Staff Specialist PCS Partner: Pharmacy	Dec 2016	NSWPCP A2
5.8	Strengthen community nursing care by : <ul style="list-style-type: none"> – Developing guidelines for community nurses to support detailed planning and patient review including triggers where care needs may change; and indicators for escalation i.e. seeking specialist nursing or medical advice – Implementing validated tools for nursing health status assessment and review which consider acuity, status and changing needs i.e. PCOC phase changes, Karnofsky Performance Status (AKPS) Scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) 	PCS Nurse Co-ordinator Partner: Manager PCS, DON PCH	Dec 2016	NSWPCP A1
5.9	Develop and implement a formal education program for staff providing palliative care in the community including: <ul style="list-style-type: none"> – An advanced nursing skills in palliative care for the Specialist Palliative Care nurses – Orientation and education to Triple I Hub staff about palliative care services and call centre advice – A community based palliative care competency framework – An orientation program for new Community Health Service nurses about palliative care – A hierarchy of supervision, mentoring and support of community nurses by palliative care specialist nurses which ensures skills are aligned to required competencies – An orientation program for allied health staff 	PCS Nurse Co-ordinator Partner: Manager PCS, DON PCH, Nurse Educators, CNCs, Director Workforce & Development (including CEWD), Director Allied Health & Project Officer PCS	July 2016 Dec 2016 July 2017 Dec 2017 July 2018 July 2018	NSWPCP A1 and A4
5.10	Develop capacity within the eMR to have co-case management of community patients	GM PCH	July 2016	
Build the capacity of general practitioners and practice nurses to deliver care				
5.11	In partnership with the South Western Sydney PHN, strengthen the capacity of general practitioners and other staff to manage patients with palliative care needs and refer to specialist services via: <ul style="list-style-type: none"> – Developing Palliative Care Healthcare Pathway referral and management guidance, tools and resources (4.3) – Conducting a rolling program of professional education sessions, including a focus on Schedule 4 and 8 drugs and legal issues. Include attention to overseas trained doctors – Providing opportunities for experiential learning 	SWSPHN, SWSLHD Pathways Team Partner: Manager PCS & PCS Senior Medical Staff	Dec 2017 July 2017 July 2017	NSWPCP A1 and A2



Strategic Direction 4: Capacity and Capability				
Actions		Responsibility	Time-frame	Links to NSW Plans
	<p>and reflection</p> <ul style="list-style-type: none"> – Trialling a Palliative Care Network for GPs interested in treating patients with palliative care needs and increasing their expertise. The Network would provide advanced support to GPs and include a model for shared care 		July 2017	
Build the capacity and capability of staff in residential aged care facilities and Department of Veterans Affairs (DVA) service providers to deliver care				
5.12	Undertake a literature review to identify and inform models for RACF service delivery and advice	PCS Project Officer Partner: Manager PCS, HoD PCS	July 2018	NSWPCP A2
5.13	Explore opportunities with RACFs to reduce unnecessary transfers to hospital of patients with palliative care needs. This may include fostering jointly funded programs and/or outreach SWSLHD medical/nursing teams to provide palliative care advice to RACFs	Manager PCS Partner: SWSPHN, RACFs, Hammond-Care, ACRS	Ongoing	NSWPCP A2
5.14	Advocate to relevant government agencies to improve end of life care around issues such as home based care for RACF residents who wish to die at home; and improved models and training for providers caring for patients of DVA and other government agencies at end of life	Nurse Coordinator PCS Partner: PCS Medical Team, DON PCH	Ongoing	
Build stronger relationships, understanding and capacity in meeting patient needs for Pastoral Care				
5.15	<p>Building on initiatives to strengthen SWSLHD governance for pastoral care, develop a comprehensive approach to pastoral care and end of life including:</p> <ul style="list-style-type: none"> – Contributing to the updated policies on pastoral care including a review of processes to ensure the accurate and timely identification of patient requirements for pastoral care – Including information about the SWSLHD model of palliative care in the SWSLHD Pastoral Care Education Framework – Orientation and Continuing Education Programs – Providing education and resources for SWSLHD staff about the role of pastoral carers, commencing with units with a large palliative workload; supported by targeted education about emerging religions 	Director Allied Health Partner: PCS, End of Life Coordinators	Dec 2018	

Strategic Direction 4: Capacity and Capability				
	Actions	Responsible Manager	Time-frame	Links to NSW Plans
Develop the capacity and capability of Specialist Palliative Care Service				
5.16	Develop a reasonable workload predictor tool for community palliative care specialist nursing staff and use this to determine workloads	DON PCH, Manager PCS Partner: SWSLHD DON&M	July 2018	NSWPCP A1
5.17	Provide education and training to palliative care specialist nursing staff in mentoring and supervision	Nurse Coordinator PCS	July 2019	NSWPCP A4
5.18	Build the specialist palliative care nursing, medical and allied health workforce through a focus on succession planning supported by: <ul style="list-style-type: none"> - An Advanced Palliative Care Practice Education Program for specialist palliative care nurses - Opportunities to be seconded to higher grades or work on special projects - Short term placements in hospital or community settings - Encouragement to undertake post-graduate qualifications - Participation in PEPA courses 	Manager PCS Partner: DON's, PCS Nurse Coordinator, PCS Staff Specialists, Director Allied Health	Ongoing	NSWPCP A4
Strengthen undergraduate education and training				
5.19	Provide enhanced opportunities for undergraduate clinical placements for nursing, allied health and medical students in primary and specialist palliative care services	PCS HOD's, CNCs, NUMs Partner: Director Allied Health	Ongoing	NSWPCP A4
Implement the Palliative Care Research Plan (Linked to Action 4.4)				
5.20	Appoint a clinical trial nurse in a tenured position funded through research grants to increase clinical trial capability	Manager PCS; Director Cancer; Director Clinical Trials Partner: Ingham Institute	July 2017	
5.21	Develop research capacity to participate in and lead palliative care research through strategies focusing on: <ul style="list-style-type: none"> - CNCs and CNSs through partnerships with Centre for Applied Nursing Research (CANR) covering issues such as ED presentations, "PEACH" Program evaluation and identification of carer capacity - Allied health practitioners through collaboration with the Chair Allied Health and other research bodies - Medical staff and registrars/interns via mentoring, 	Manager PCS & Director Clinical Trials Partner: PCS Nurse Coordinator, Directors Allied Health & Cancer, DONs, CANR, Ingham	Dec 2019	



Strategic Direction 4: Capacity and Capability				
	<i>Actions</i>	<i>Responsible Manager</i>	<i>Time-frame</i>	<i>Links to NSW Plans</i>
	supervision, structured participation in research and presentations in conferences	Institute		
5.22	<p>Grow an evidence based practice and research culture across the PCS through a formal program of:</p> <ul style="list-style-type: none"> - Developing shared values around research - Incorporating explicit expectations in staff roles about evaluation, participation in research, presentations and publications - Including research as an agenda item into governance structures e.g. meetings - Mentoring within and across professions and education in practical research and translational skills - Encouraging staff to enrol and complete post-graduate education in clinical practice or research - Recognition of achievement 	<p>Manager PCS & Director Clinical Trials Partner: CANR</p>	July 2020	
5.23	Implement strategies to increase the capacity of consumers to successfully engage in research as participants and as part of the research team	<p>Manager PCS & Director Clinical Trials Partner: PCS Senior staff, SWSLHD CCC</p>	Dec 2018	
Strengthen support for staff coping with grief and loss				
5.24	<p>Strengthen the capacity of managers to support staff in coping with grief and loss by:</p> <ul style="list-style-type: none"> - Conducting a forum with Aboriginal staff to provide information, education and practical skills in managing the emotional impact of death in the workplace, family and community and to identify the best ways to support these staff into the future (e.g. supervision, policy, debriefing sessions, etc.) - Conducting an education session for interpreters about working with complex deaths, family dynamics and the Employee Assistance Program's role - Trialling an education/debriefing session for managers about supporting staff who are experiencing grief - Providing clear information to staff and managers about entitlements to Family and Community Service Leave; and ways to support staff including support for Aboriginal staff in funeral leave 	<p>Director Workforce and Development (including EAP and District HR) Partner: Directors Aboriginal Health Services, Health Language Service, Human Resources, Manager PCS</p>	<p>Dec 2016</p> <p>Dec 2017</p> <p>Dec 2018</p> <p>Dec 2018</p>	
Alignment to other NSW Health System Frameworks: ACI Blueprint: Component 6				

11 Appendices

Appendix A: Policy and Planning Directives

National Palliative Care Strategy 2010⁵ - provides the overarching policy and planning context for palliative care in Australia, covering specialist and generalist/primary health care. The strategy has four goals: *awareness and understanding* via an improved appreciation of dying and death as a normal part of the life continuum and enhanced community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services; *appropriateness and effectiveness of care* based on need; *leadership and governance* which supports collaborative, proactive, effective governance of national palliative care strategies, resources and approaches; and *capacity and capability* for all relevant sectors in health and human services.

National Framework for Advance Care Directives⁹ - provides guidance on policy and best practice about advance care directives. It is primarily intended for regulators, including legislators and policy makers in governments and parliaments, and administrators of advance care planning programs in health and aged care sectors. It outlines the key ethical and practical aspects of ACDs.

Standards for Providing Quality Palliative Care for all Australians⁸ - provides national guidance in palliative care practice. These standards represent a whole-of-sector approach to ensuring high quality, needs-based care at the end of life. The standards are currently under review.

Australian Government Guidelines for a Palliative Approach in Residential Aged Care⁴⁶ - aims to help practitioners in applying a palliative approach in a residential aged care facility. It guides appropriate practice, subject to the clinician's judgement and the patient's preference in each individual case.

Australian Government Guidelines for a Palliative Approach for Aged Care in the Community Setting⁴⁷ - target health professionals providing palliative care to older people in the community, including GPs, community nurses, care workers and organisations providing support for people being cared for at home.

National Consensus Statement: essential elements for safe and high-quality end-of-life care⁴⁵ - describes the essential elements for delivering high quality care in hospital settings with guidance around the systems, processes and structures for delivering that care. It aligns with the *National Statement around Recognising and Responding to Clinical Deterioration*.

National Consensus Statement: Essential Elements for Recognising and Responding to Clinical Deterioration⁴⁸ - describes essential elements for prompt and reliable recognition of, and response to, clinical deterioration in acute health care facilities in Australia.

NSW State Health Plan: Towards 2021⁴⁹ - provides a strategic framework which brings together NSW Health's existing plans, programs and policies and sets priorities across the system for the delivery of 'the right care, in the right place, at the right time'. The directions in the plan focus on keeping people healthy, providing world class clinical care and delivering truly integrated care.

The NSW Government Plan to increase access to Palliative Care 2012-2016² - sets the NSW agenda for ensuring access to quality palliative care regardless of economic or social circumstances, geographical location or medical condition. The Plan supports new partnerships and linkages between specialist and generalist services to support care provision for dying patients in the community and residential aged care settings. It focuses on four action areas: expanded community based palliative care, especially in rural areas and for special needs populations; integration of primary care, aged care and specialist palliative care services; expanded support for families and carers; and extended capacity of palliative care services in NSW



by enhancing existing palliative care services and using and building skills of the multi-disciplinary teams which provide such care.

NSW Health Advance Planning for Quality Care at End of Life - Action Plan 2013–2018¹ - provides direction for implementing advance care planning in the NSW public health system, including strategic partnerships with other government agencies and primary, acute and aged care sectors. It seeks to normalise advance care planning and improve end of life care by integrating patients' wishes into the management of chronic life-limiting illness.

Palliative Care Role Delineation Framework (GL2007_022)¹¹ - provides consistent, common language to describe and differentiate health care services. It facilitates strategic planning at area, regional and state levels, and support program and service level evaluation, quality and research.

NSW Planning Framework 2011-2014 (GL2011_014)¹² - outlines a plan for paediatric palliative care development and identifies existing paediatric palliative care services and opportunities to improve paediatric palliative care in NSW.

NSW Palliative Care Strategic Framework 2010-2013³ - addresses planning, service standards, data and evidence based practice. It requires each health service to develop a palliative care service plan.

Dementia Services Framework 2010-2015⁵⁰ - targets health, community and residential services to assist with planning and development of dementia services and programs. It includes a focus on palliative care for people with dementia.

Coroners Cases and the Coroners Act 2009 (PD2010_054)⁵¹ - provides medical practitioners, health care workers and managers in the public health system with specific information about the Coroners Act 2009; and medical practitioners, nurses and midwives, health care workers and administrators with direction and guidance about reportable deaths to the NSW Coroner

Death - Management of Sudden Unexpected Death in Infancy (PD2008_070)⁵² - relates to the management of sudden unexpected infant death. Aspects of management described include diagnosis of the cause of death and support of the surviving family members.

Using Resuscitation Plans in End of Life Decisions (PD2014_030)⁵³ - describes the standards and principles relating to appropriate use of Resuscitation Plans by NSW Public Health Organisations for patients 29 days and older. A Resuscitation Plan is a medically authorised order to use or withhold resuscitation measures and which documents other aspects of treatment relevant at end of life.

Deaths - Perinatal - Hospital Procedures for Review and Reporting of Perinatal Deaths (PD2011_076)⁵⁴ - describes the procedures for review of perinatal deaths occurring in hospitals and reporting of these deaths to the NSW Maternal and Perinatal Committee

Death - Verification of Death and Medical Certificate of Cause of Death (PD2015_040)⁵⁵ - outlines the processes for the assessment and documentation to verify death (previously referred to as extinction of life), and the medical certification of death of patients within the NSW Health System. It describes the roles of medical practitioners, registered nurses/registered midwives and qualified paramedics employed by NSW Health in assessment and documentation when patients die within the NSW Health system.

Deaths - Reporting of Maternal Deaths to the NSW Department of Health (PD2005_219)⁵⁶ - requires reporting of all maternal deaths to the NSW Maternal and Perinatal Committee that reviews morbidity and mortality.

Guidelines for the End-of-Life Care and Decision Making (GL2005_057)⁵⁷ - sets out a process for reaching end-of-life decisions. This process promotes communication among the treating team and with patients

and families, compassionate and appropriate treatment decisions, fairness, and seeks to safeguard both patients and health professionals.

Advance Care Directives (NSW) - Using (GL2005_056)⁵⁸ - assists health professionals in discussing advance care planning with patients, and clarifies how to use an advance care directive as part of that process.

Agency for Clinical Innovation Palliative and End of Life Care A Blueprint for Improvement¹³ - provides a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers. It emphasises the need for an integrated approach to care whereby relationships between specialist palliative care providers and care providers across all settings of care are fostered. It seeks to enhance networks of support, to build skills and competence in providing care to those approaching and reaching the end of their lives across all care settings and seeks to better support patients, families and carers along the way.

SWSLHD Initiation and Management of Advance Care Planning Processes (SWSLHD_PD 2013_035)⁵⁹ - guides staff about their responsibilities regarding advance care planning and to establish mechanisms that will allow a more systematic approach across SWSLHD. This includes common forms and protocols, inclusion of ACP-related documents in medical records, education programs and information resources.

SWSLHD Organ and Tissue Donation after Death Guideline (SWSLHD_GL2014_020)⁶⁰ - outlines the process and procedures and the role responsibilities associated with organ donation after brain death and circulatory death, donor referral criteria, patient management, criteria for the declaration of death, care of the patient and family and the phases of organ retrieval. It is consistent with the Human Tissue Act 1983 and NSW Health policy directives.





Appendix B: Specialist Palliative Care Service (PCS) Staffing Profile

Community Based Services							
Service	Bankstown LGA	Fairfield LGA	Liverpool LGA	Macarthur Region LGAs	Wingecarribee LGA		
Clinical Nurse Consultant	✓	✓	✓	✓	✓		
Clinical Nurse Specialists/RNs	✓	✓	✓	✓	x		
Bereavement Counselling	✓ - Braeside (District-wide from Braeside Hospital)						
Specialist Allied Health	✓ - SW X – Psychology, OT and Physio	✓ - SW*, OT* and Physio* X - Psychology	✓ - SW*, OT* and Physio* X - Psychology	✓ - SW X – Psychology, OT and Physio	X – Psychology, SW, OT and Physio		
Equipment Loan Pool	✓						
Volunteers	✓	✓	✓	✓ - Camden	✓		
Hospital Based Services							
Service	Bankstown -Lidcombe	Braeside	Fairfield	Liverpool	Campbell-town	Camden	Bowral
End of Life Coordinators	✓	X	X	✓	✓	X	✓
Consultative Service – On site	✓ - medical ✓ - nursing	✓ - medical	X	✓ - medical ✓ - nursing	✓ - medical ✓ - nursing	✓ - medical ✓ - nursing	✓ - nursing
Consultative Service - Inreach	X	X	✓ - medical	X	X	X	✓ - medical
Outpatient Clinics	✓	✓	X	✓	X	✓	X
Day Hospital	X	✓	X	X	X	X	X
Palliative Care Ward	X	X	X	✓ (20 beds)	X	X	X
Palliative Care Unit	X	✓ (20 beds)	X	X	X	✓ (10 beds)	X
Specialist Allied Health	X	✓ - SW, Psychology OT, SP, Physio, DT and Dietician	X	✓ - SW, OT, Physio, Psychology DT and SP	X	✓ - SW and Physio	X
Volunteers	✓	✓	X	✓	X	✓	X

* Allied Health outreach into the community provided from Braeside. Abbreviations include Social Worker (SW), Occupational Therapist (OT), Physiotherapist (Physio), Diversional Therapist (DT) and Speech Pathologist (SP)

1. Inpatient beds to be opened at Campbelltown Hospital in 2016/17; Inpatient Specialist Unit proposed for Bankstown-Lidcombe Hospital Clinical Services Plan
2. Access to generalist allied health in most hospitals, but very limited in community
3. Profile indicates dedicated palliative care specialist positions

Appendix C: Palliative Care Needs – Projecting Future Demand

Table 2: Palliative Care overnight separations (seps), bed days and average length of stay (ALOS) - demand by SWSLHD residents 2010/11 (actual) and projected to 2016/17 and 2021/22

Hospitals	2010/11			2016/17			2021/22		
	Seps	Bed days	ALOS	Seps	Bed days	ALOS	Seps	Bed days	ALOS
Bankstown/Lidcombe	47	338	7.2	63	599	9.5	72	670	9.3
Braeside	347	6,506	18.7	437	5,741	13.1	520	6,806	13.1
Fairfield	1	11	11.0	0	5	12.2	0	5	12.2
Liverpool	80	925	11.6	126	1,423	11.3	159	1,735	10.9
Camden	211	2,888	13.7	353	4,581	13.0	447	5,762	12.9
Campbelltown	17	110	6.5	13	160	12.7	16	205	12.6
Bowral	4	20	5.0	23	272	11.7	28	321	11.6
Other NSW Public	164	2,270	13.8	231	3,057	13.2	260	3,440	13.2
Private	1	28	28.0	1	16	13.0	1	16	13.1
Interstate	1	1	1.0	2	17	9.7	3	27	9.4
Grand Total	873	13,097	15.0	1,251	15,871	12.7	1,507	18,987	12.6

Source: NSW Ministry of Health SiAM 2012 V2.2

NB: Braeside Hospital average length of stay (ALOS) has reduced since 2010/11

Artwork by Flutter Lyon Ink-Pressing





12 Terminology

Advance care planning Advance Care Planning involves ongoing conversations between patients, their families and their treating health professionals introduced gradually over a period of time which enable planning ahead for potential deterioration in future health when that person becomes unable to make decisions about their own treatment and care. It involves eliciting that person's choices, wishes and values and how these affect preferences for care and goals of treatment.¹

Advance care plan An advance care plan is the documented outcome of an advance care planning process. Like an advance care directive, it also records preferences about health and personal care and treatment goals. However, it may be completed by discussion or in writing and it may be made by, with or for the individual. If a health professional, a family member or someone who knows the person well makes an advance care plan on the person's behalf, the known preferences of the person should be recorded. Advance care plans, like advance care directives, can capture a competent person's wishes about treatment and care at end of life. Where an ACP documents the known wishes of a competent person, they should be considered in the same way, according to common law standards, as an advance care directive. Where advance care planning has never been able to include the person's wishes due to lack of capacity, the ACP should be consulted as part of determining treatment and care decisions that are in the best interests of the patient.⁶¹

Advance care directive An advance care directive is a type of advance planning tool that can only be completed by a person with decision making capacity. Advance care directives record decisions or value statements that describes a person's future preferences relating to medical treatment, to be used in circumstances where the person loses capacity. A Person Responsible cannot complete an advance care directive on behalf of another person. However a Person Responsible may participate in advance care planning. An advance care directive is valid when: it has been made voluntarily by a capable adult; it is clear and unambiguous; and it extends to the circumstances at hand. Advance care directives are legally enforceable in NSW.⁶¹

Health promoting palliative care Health promotion aspires to an integrated approach where health is viewed as part of a wider pattern of life. The Ottawa Charter for Health Promotion focuses on building public policies that support health, creating supportive environments, strengthening community action, developing personal skills and reorienting health services. When applied to palliative care, the goals are to: provide education and information for health, dying, and death; provide social supports—both personal and community; encourage interpersonal reorientation; encourage reorientation of palliative care services; and combat death-denying health policies and attitudes.^{62 13}

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

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process



- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life e.g. chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁶³

Palliative approach

The term “palliative approach” has developed particularly within the aged care sector over the last nine years but may be applied in any setting where needs arise. This approach is primary palliative care provided by generalist and specialist primary providers.

When a person’s condition is not amenable to cure and the focus is on quality care and quality of life they should have appropriate, holistic, early identification and assessment of symptoms and management plans developed. Intervention for the person’s illness/condition may also still be appropriate and may be provided concurrently with a palliative approach.

The primary goal of a palliative approach embraces the goal of improving the person’s level of comfort and function and to address their psychological, spiritual and social needs.

Primary carer

The primary carer is generally in the close kin network of the patient. The primary carer can be the patient’s spouse, child, another family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient e.g. the administration of medications. They provide the primary support role for the patient at all levels of need.⁶⁴

Primary generalist provider

In the context of end of life care, a primary care provider is the first contact medical, nursing or allied health professional, who undertakes an ongoing role in the care of patients with a life threatening illness. The substantive work of a primary generalist provider is not in the care of people who are dying, however they include: general practitioners; community nurses; allied health professionals; pharmacists; residential aged care facilities staff; staff caring for people with developmental disabilities; staff of mental health units; health professionals in acute care hospitals; and trained volunteers.

Primary care services provide on-going support from diagnosis through to the death of the patient. Primary care services should aim to identify developing symptoms and refer patients to specialist palliative care providers when the patient’s needs exceed their services capability.⁶⁵



Primary specialist provider In the context of life threatening illness, primary specialist providers include specialist teams that have first contact and in general their substantive work is not in palliative care. Services include but are not limited to: oncology; renal; cardiac; respiratory; and geriatrics.⁶⁵

Specialist palliative care provider Specialist palliative care providers include medical, nursing or allied health professionals recognised as a palliative care specialist by an accrediting body, has specialist palliative care qualifications or who substantively works in a specialist palliative care service.

A palliative care specialist has the specialist knowledge skills and expertise in care of people living with a life threatening illness and their families and carers, including the management of complex symptoms, loss, grief and bereavement.

Specialist palliative care Specialist palliative care services are optimally provided by a multi-disciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including a person's home, acute hospitals, residential aged care facilities, hospices and palliative care units.

Specialist palliative care providers include medical specialists, nursing specialists, allied health professionals, volunteers, pastoral care workers and counsellors recognised as palliative care specialists by an accrediting body or are working substantively in a specialist palliative care service if an accrediting body is not available.

A palliative care specialist provider has specialist knowledge, skills and expertise in the care of people living and dying with a life threatening illness, their families and carers. This includes the identification, assessment and management of complex symptoms, end of life care and grief and bereavement. Specialist palliative care services may work in various ways:

- Provide direct care to referred patients with complex needs requiring specialist palliative care interventions in the acute hospital setting, a person's home or a specialist palliative care unit
- Provide consultation based services to patients being cared for by primary care providers within an acute hospital, a community nursing facility or a person's home
- Provide shared care arrangements with other primary or specialist providers
- Provide support, education and training to providers and services providing a palliative approach and or end of life care.
- Undertake and disseminate research about people and their families/carers with life threatening illness, the dying process and grief and bereavement
- Promote and increase awareness of the broad definition of palliative care to the general community and general health sector.

13 Acronyms

ACD	Advance Care Directive	ICT	Information Communications and Technology
ACFI	Aged Care Funding Instrument	IMTD	Information Management and technology Division
ACI	Agency for Clinical Innovation	IPCCC	Integrated Primary and Community Care Centres
ACPCoD	Advance Care Planning and Care of the Dying	KPI	Key Performance Indicator
ACRS	SWSLHD Aged Care & Rehabilitation Service	LGA	Local Government Area
ADHC	NSW Ageing Disability and Homecare	LOS	Length of Stay
ADL	Activities of Daily Living	MET	Medical Emergency Team
ALOS	Average Length of Stay	MND	Motor Neuron Disease
APQCP	Advance Planning for Quality Care at End of Life - Action Plan	MDT	Multidisciplinary Team
CALD	Culturally and Linguistically Diverse	NDIA	National Disability Insurance Agency
CCC	Consumer and Community Council	NFR	Not for resuscitation
CEWD	Centre for Education and Workforce Development	NGO	Non-Government organisation
CHN	Community Health Nurse	NSWPCP	NSW Government Plan to increase access to palliative care
CNC	Clinical Nurse Consultant	PCA	Palliative Care Australia
CNS	Clinical Nurse Specialist	PCH	SWSLHD Primary and Community Health
COPD	Chronic Obstructive Pulmonary Disease	PCS	Palliative Care Service
CPDP	Care Plan for the Dying Patient	PEACH	Palliative Extended And Care at Home
DVA	Department of Veterans Affairs	PEPA	Program of Experience in the Palliative Approach
ED	Emergency Department	PCOC	Palliative Care Outcomes Collaboration
eMR	Electronic Medical Record	RACF	Residential Aged Care Facility
FTE	Full Time Equivalent	RN	Registered Nurse
GM	General Manager	SCHN	Sydney Children's Hospital Network
GP	General Practitioner	SLHD	Sydney Local Health District
HAND	HIV-associated neurocognitive disorders	SWSLHD	South Western Sydney Local Health District
HETI	Health Education and Training Institute	SWSPHN	South Western Sydney PHN Ltd.
HIV/AIDS	Human Immunodeficiency Virus Infection and Acquired Immune Deficiency Syndrome	Triple I	Intake, Information and Intervention
HoD	Head of Department		



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