



Sydney  
Local Health District

# Specialist Palliative Care Service Strategic Plan

2024–2029



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# Acknowledgement of Country

Sydney Local Health District acknowledges that we are living and working on Aboriginal land. We recognise the strength, resilience and capacity of Aboriginal people on this land. We would like to acknowledge all of the traditional owners of the land and pay respect to Aboriginal Elders past and present.

Our District acknowledges *Gadigal*, *Wangal* and *Bediagal* as the three clans within the boundaries of the Sydney Local Health District. There are about 29 clan groups within the Sydney metropolitan area, referred to collectively as the great *Eora Nation*. *Always was and always will be Aboriginal Land*.

We want to build strong systems to have the healthiest Aboriginal community in Australia.

Together under the Sydney Metropolitan Partnership Agreement, including the Aboriginal Medical Service Redfern and in collaboration with the Metropolitan Local Aboriginal Land Council, Sydney Local Health District is committed to achieving equality to improve self-determination and lifestyle choices for our Aboriginal community.

## *Ngurang Dali Mana Burudi* – A Place to Get Better

*Ngurang Dali Mana Burudi* — a place to get better, is a view of our whole community including health services, Aboriginal communities, families, individuals and organisations working in partnership.

### Our story

Sydney Local Health District's Aboriginal Health story was created by the District's Aboriginal Health staff.

The map in the centre represents the boundaries of Sydney Local Health District. The blue lines on the map are the Parramatta River to the north and the Cooks River to the south which are two of the traditional boundaries.

The *Gadigal*, *Wangal* and *Bediagal* are the three clans within the boundaries of Sydney Local Health District. They are three of the twenty nine clans of the great *Eora Nation*. The centre circle represents a pathway from the meeting place for Aboriginal people to gain better access to healthcare.

### The Goanna or *Wirriga*

One of Australia's largest lizards, the goanna is found in the bush surrounding Sydney.

### The Whale or *Gawura*

From June to October pods of humpback whales migrate along the eastern coastline of Australia to warmer northern waters, stopping off at Watsons Bay the traditional home of the Gadigal people.

### The Eel or *Burra*

Short-finned freshwater eels and grey Moray eels were once plentiful in the Parramatta River inland fresh water lagoons.

Source: Sydney Language Dictionary



### Artwork

*Ngurang Dali Mana Burudi* — a place to get better

The map was created by our Aboriginal Health staff telling the story of a cultural pathway for our community to gain better access to healthcare.

Artwork by Aboriginal artist Lee Hampton utilising our story.

# Foreword

Palliative Care is a major service and strategic priority for the Sydney Local Health District (the District). Helping people with life-limiting conditions to maximise their quality of life or ensuring comfort at the end of life, means that palliative care has become an essential component of modern health care services. It is important to ensure that our health system supports individual preferences and is inclusive of everyone who is involved. Palliative care is holistic care that supports people nearing the end of their life to live as well as possible until their death. Palliative care is delivered by a diverse workforce across a range of settings from primary care through to generalist and other specialty services, including Specialist Palliative Care. The provision of education and training by Specialist Palliative Care services ensures equity of access for people with complex needs.

All people require evidence-based and person-centred care at the end of their lives, and it is recognised that appropriate care should be based on appropriate need. Equally, palliative care is not available to all people for reasons of awareness, socioeconomic status, workforce, accessibility and engagement. Aboriginal people, in particular, are impacted by unique factors such as intergenerational trauma, cultural dislocation, oppression, and systemic racism that influence their decision making around end of life care considerations. In addition, other groups of people are historically under-served including people from culturally and linguistically diverse backgrounds, people living with disability, homelessness and people with mental health issues. Palliative care has also traditionally been associated with patients who have a cancer diagnosis; and consideration needs to be given to non-cancer and chronic care cohorts as people live longer.

The Sydney Local Health District *Specialist Palliative Care Service Strategic Plan 2024–2029* sets out our vision to meet the needs of our health service when responding to people with life limiting conditions, over the next five years. The District is proud to announce this Strategic Plan as the first, formalised Plan for our Specialist Palliative Care Service; which has been developed against the NSW Ministry of Health *End of Life and Palliative Care Framework 2019–2024* and the Agency for Clinical Innovation (ACI) *End of Life and Palliative Care Blueprint for Improvement*.

This Strategic Plan aims to create a renewed drive for people and services to work together in providing accessible, high-quality end of life and palliative care. This includes working in partnership with people receiving the care, their families and carers. The Plan sets our priority areas for improvement where people and our service must work together to enhance support and care for people at the end of life. The key priorities of the plan are: person centred care; recognition and support for families and carers; access to care providers across all settings who are skilled and competent in end of life and palliative care which is well-coordinated, integrated and equitable.

Our Plan is consistent with the Strategic Directions of NSW Health and Sydney Local Health District's Strategic Plan, keeping people healthy, providing world class clinical care and delivering truly integrated care. The Plan provides a framework for us to work towards meeting our community's current and future health needs in relation to end of life and palliative care, and enables us to strategically work with our partners to support high-quality, evidence-based care across the District.

**Dr Teresa Anderson AM**  
Chief Executive  
Sydney Local Health District

**A/Professor Ilona Cunningham**  
Clinical Director of Cancer  
Services and Palliative Care  
Sydney Local Health District

**A/Professor Ghauri Aggarwal**  
Deputy Clinical Director of Cancer  
Services and Palliative Care  
Sydney Local Health District

## Our vision

Excellence in health and healthcare for all.

‘We see a world where quality palliative care is available for all, when and where they need it’<sup>1</sup>

## Our mission

Work with our communities to promote:

- Co-designed and co-produced health policy, plans, new service models and research studies.
- Improvements in the social and environmental factors that sustain health.
- A healthcare system that is responsive to equity concerns.
- Best practice prevention, health promotion and health protection programs and strategies.
- Care in the community delivered close to where people live.

Ensure that the community has equitable access to the highest quality consumer and family-centred care that is:

- Integrated, timely, culturally safe and competent, evidence-based and efficient.
- Provided by a highly skilled compassionate workforce who are committed, accountable, supported and valued.
- Supported by leading-edge research, education, and medical and information technologies.
- Supportive of the healthcare of populations in other local health districts, states, and territories across Australia and in other countries.

# Introduction

Palliative care is defined as ‘a crucial part of integrated, people centred health services; relieving serious health related suffering, be it physical, psychological, social or spiritual’<sup>4</sup>. End of life care refers to the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death and usually has higher support needs at this time<sup>1</sup>.

According to the World Health Organisation, palliative care<sup>2</sup>:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s 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.

Throughout this document, the term ‘palliative care’ will cover both end of life and palliative care. End of life and palliative care is also referred to as EoLPC. The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include one or more of a range of formal and informal supports. People with more complex needs should be able to access care provided by Specialist Palliative Care services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. The type of care that is provided by these services is defined as ‘specialist palliative care’<sup>1</sup>.

It should be noted that while not everyone will need this level of care, Specialist Palliative Care providers have an important role to ensure provision is available and accessible for advice and guidance if and when needed.

How people approach the end of their life is highly individual and a deeply personal experience. As people enter this phase of their life, they, their families and carers should be able to make decisions about the care they want, how it is delivered, and the places and circumstances it is provided, no matter where they live, their condition, age or who they are. All individuals should have access to the best possible end of life and palliative care. Our Service aims to not only improve access to the best possible EoLPC, but also to encourage people to talk more openly about death and dying as a normal part of life.

Palliative care, while originally associated primarily with the diagnosis of cancer, is appropriate for anyone with life-limiting illnesses including other chronic conditions, dementia, and non-malignant degenerative diseases.<sup>3</sup> People receiving palliative care have been shown to have fewer hospitalisations, shorter lengths of stay when they are hospitalised, and reduced visits to emergency departments<sup>4</sup>. Those receiving EoLPC at home have been shown to have increased quality of life and reduced need for hospital-based care<sup>5</sup>, providing cost-savings for government.

This Strategic Plan has been developed through an inclusive Sydney Local Health District executive, staff, consumer, carer and community consultation process. The ACI *End of Life and Palliative Care Blueprint for Improvement* and other District enabling plans were reviewed, including current population demographics, and hospital and community activity. Further detail on the planning framework is documented in the appendices.



The ACI Fundamentals underpinning End of Life and Palliative Care will be used as reference to underpin this Plan as noted below.

**Shared decision-making:** The patient’s values, goals and preferences are central to healthcare decisions made by the patient, their family, carers and clinicians.

**Person-centred care:** The patient’s physical, psychological, social and spiritual issues are assessed and managed to support communication, coordination of care and decision making for patients, families and carers.

**Integrated cohesive care:** Using a holistic approach, management and advance care planning is assessed across different specialities and care settings. Communications and documents are shared between the patient, their family, carers and clinicians.

**Cultural capability:** Based on equity, autonomy, empowerment and trust, this focuses on humane and seamless care with an emphasis on living and cultural respect.

**Digital health technology:** Connecting the patient, family, carers and healthcare providers to support end of life and palliative care service delivery across different specialities and care settings.

**Governance:** This provides processes and mechanisms including agreed leadership and accountability underpinned by appropriate policies and procedures.

**Quality improvement:** Regular local review and improvement processes support good clinical practice and service development.

**Data evaluation and monitoring:** This checks the quality of care and guides improvements in local models of care and their implementation in practice through the collection and monitoring of data.

# The engagement process

## Internal Palliative Care Service consultation

A total of 47 people participated in the Specialist Palliative Care Service planning day in October 2022, including medical, nursing and allied health clinicians. Specialist Palliative Care participants were divided into five groups to discuss the gaps, opportunities and future strategies for the service areas of: inpatient care; community care; consults; partnerships with collaboration (including Primary Care); education and workforce.

Ideas and issues were discussed and documented to inform this Plan.

## Stakeholder consultation

Consultation was conducted with the Ministry of Health, Health and Social Policy Branch, Sydney Local Health District Senior Executive and stakeholders listed right.

This process enabled the prioritisation of strategic goals and the accompanying operational/ implementation processes.

## Review

A draft version of the Strategic Plan was reviewed by the District's Planning Department, Specialist Palliative Care Service Executive and then released in draft form for feedback from key internal stakeholders.

## SLHD clinical stakeholders

Specialist Palliative Care Services  
 Cancer Services  
 RPA Virtual Hospital  
 Renal Medicine and Urology  
 Outreach Services  
 Aboriginal Health  
 Gastroenterology and Liver Services  
 Allied Health Services  
 Aged Health Rehabilitation and Chronic Care Services  
 Respiratory Medicine and Critical Care  
 Cardiovascular Services  
 Neurosciences  
 Pharmacy  
 Pastoral Care  
 Central and Eastern Sydney Primary Health Network  
 Women's Health, Neonatology and Paediatrics

## SLHD non-clinical stakeholders

Senior Executive  
 Planning  
 Digital Health and Innovation  
 Finance  
 Workforce  
 Director of Corporate and Clinical Services  
 Mental Health  
 Carers Program  
 Community Participation Manager  
 Balmain Hospital  
 Canterbury Hospital  
 Volunteer Program  
 Integrated Care and Population Health  
 Public Health  
 Disability Inclusion and Strategy

# The need for end of life and palliative care

Approximately 75% of all deaths are expected (such as people living with cancer or end-stage renal disease) and might benefit from the provision of EoLPC<sup>6</sup>

People receiving palliative care have been shown to have fewer hospitalisations, shorter lengths of stay when they are hospitalised, and reduced visits to emergency departments<sup>4</sup>

Those receiving EoLPC at home have been shown to have increased quality of life and reduced need for hospital-based care, providing cost-savings for government<sup>5</sup>

Most health professionals are not aware that Specialist Palliative Care is available to all people with a life-limiting condition, regardless of diagnosis

There is an increasing need for Aboriginal people to access Specialist Palliative Care Services, related to their high rates of premature mortality<sup>13</sup>

Demand for palliative care will increase by 50% by 2035 and double by 2050 due to ageing population and chronic disease<sup>8</sup>

Nearly 50% of deaths occur in the acute hospital setting, despite an increased policy focus on supporting people to die at home or in the place of their choice<sup>9</sup>

40% of people who die in hospital still do not receive palliative care<sup>8</sup>

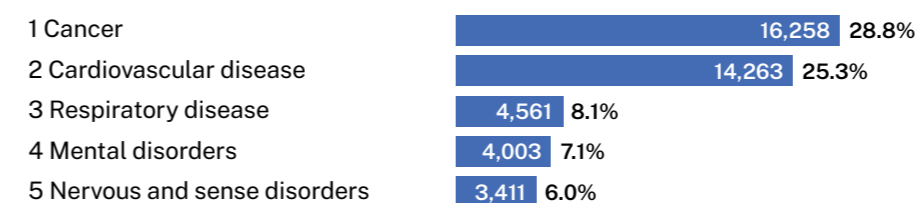
Only 36.8% of older Australians accessing health services in NSW had an advance care directive documented in their health record<sup>10</sup>

From 2006–21, there has been a 38% increase in cancer diagnoses in NSW

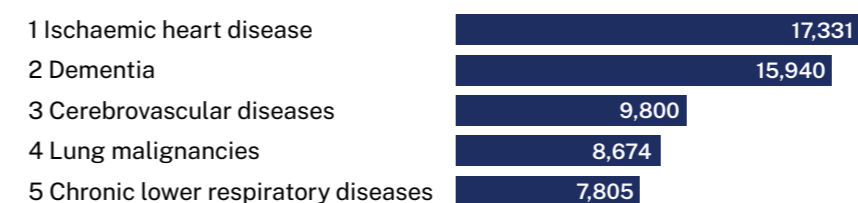
Some causes of death have increased, including from mental health conditions, nervous and sense disorders (including Alzheimer's Disease) and endocrine diseases (including diabetes)<sup>15</sup>

From 2010–16 there was significant growth in the number of people accessing Specialist Palliative Care Services with a primary diagnosis of respiratory failure (203%), end stage kidney disease (118%) and cardiovascular disease (103%)<sup>11</sup>

## Top five causes of death in NSW in 2021<sup>16</sup>



## Top five causes of death in Australia in 2021<sup>12</sup>



# Sydney Local Health District profile

**17.4%**

projected population growth rate 2022–36

**1%**

Aboriginal population in 2021<sup>12</sup>

**34%**

born in a non-English-speaking country in 2021

**11%**

increase in the over 65s population in 2011–21

**9%**

increase in the population aged 35–64 in 2011–21

**147,097**

have a mental health problem that will require care

**28,000+**

live with a disability<sup>16</sup>

**6,000+**

experiencing homelessness<sup>17</sup>



The District's population is expected to reach 732,733 people by 2026 and 819,540 people by 2036<sup>11</sup>

The highest non-English-speaking populations are in the Canterbury, Burwood and Strathfield Local Government Areas<sup>13</sup>.

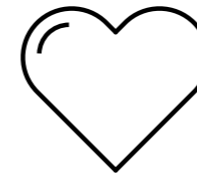
The most common non-English languages are Chinese, Arabic, Greek, Korean, Italian and Vietnamese

New cases of cancer are expected to increase from 2,967 in 2016 to 3,943 in 2026<sup>20</sup>

By 2036 there will be 65% more older persons aged over 70 years living in the District – a total of 42,976 extra older persons<sup>11</sup>

Almost one in three people aged 65 years and over lives with three or more chronic diseases and 40% will be a non-cancer diagnoses<sup>15</sup>

In 2021, there were 3,313 deaths in SLHD, with 2,489 estimated as expected deaths that may benefit from the provision of palliative care services<sup>17</sup>



48% of adults report being overweight or obese which can result in cardiovascular disease, endocrine and gastrointestinal problems, and some cancers<sup>17</sup>

In 2019–20, cardiovascular related disease deaths in SLHD were 99.7 compared to 114.7 per 100,000 population in the state. This includes deaths from CHD, HF, PVD, and stroke<sup>17</sup>

In 2018–20, deaths related to renal diseases were 43.6 compared to 49.4 per 100,000 population in the state<sup>17</sup>. This is higher for persons aged 75 years and over, Aboriginal people, and those living in most disadvantaged areas.

There are a number of other priority populations which require targeted responses. This includes Culturally and Linguistically Diverse (CALD) and non-English speaking populations and people living with disability.

In 2019–20, deaths related to COPD were 99.6 per 100,000 in SLHD compared to 152 per 100,000 population in the state<sup>17</sup>

There are over 4,700 older people living in Residential Aged Care Facilities (RACFs)



# Services at a glance

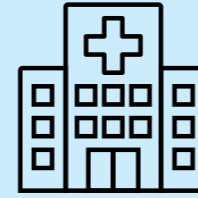
Specialist Palliative Care Services in Sydney Local Health District are arranged within a model encompassing hospital consultancy, inpatient, ambulatory and community palliative care.

The Service is underpinned by emerging research and evidence for best practice principles. These services are responsible for EoLPC for both cancer and non-cancer patients who have been diagnosed with life-limiting disease and/or complex needs.



## Specialist Palliative Care

Services are provided across the breadth of care settings.



Hospital palliative care departments at Royal Prince Alfred (RPA) and Concord Hospitals provide inpatient and consultation care



Dedicated inpatient palliative care beds:

- 6 acute beds at RPA
- 20 sub-acute inpatient beds at Concord Centre for Palliative Care
- 4 acute beds at Concord Hospital

Community medical and allied health services across the District

Residential Aged Care Facility (RACF) clinical nurse consultant services to 56 aged care facilities, home to approximately 4,700 older residents

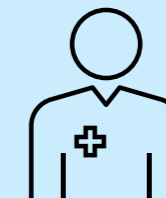
Hospital consultative services to Balmain Hospital, Canterbury Hospital and District Mental Health Services

Outreach services are provided to Dubbo and Lourdes Hospital, Dubbo



RPA Virtual Hospital provides care to patients in their homes which includes the Sydney District Nursing (community nursing) Service, the Chronic Disease Palliative Care Service and the Virtual Care Centre

- Core services include:
- Clinical palliative and end of life care to support patients at home
- Multi-disciplinary Chronic Disease Palliative Care Service
- 24/7 Palliative Care Advice Line for patients and their family/carers
- RACF (afterhours) Advice Line



Community nursing services are divided into 'zones' based on Health Centre locations: Eastern Zone includes Redfern, Marrickville and Canterbury, and Western Zone includes Croydon and Concord

Dedicated palliative care volunteer program is available across the District

Bereavement counselling services are available for bereaved clients post patient-death



# Challenges

## Changing policy environment

Federal and State Governments recognise the need to improve EoLPC service provision<sup>3</sup>. There have been a number of policy changes with a shift to include initiatives to achieve greater choice for palliative care at home, in aged care settings and completion of advanced care planning. For example, the *Australian Government Royal Commission into Aged Care Quality and Safety Report* highlighted key recommendations for EoLPC. These challenges highlight the importance of having a coordinated approach to the provision of EoLPC in the context of an evolving policy environment.

## Consumer, carer and family expectations

Most people express a preference to die at home. There is a challenge to shift the focus of EoLPC into community-based settings to meet the expectations of people living with a life-limiting illness, their families and carers. This requires a change in focus in the provision of Specialist Palliative Care consultancy services to support people in all settings. Historically also, carers and families have often not been considered in care planning. Their role needs to be considered as a component of holistic palliative care; respecting their health, wellbeing and capacity to participate in decisions.

## Population changes

As the population ages and chronic disease complexity increases, demand is growing for quality care at the end of life. The District's Specialist Palliative Care Service model facilitates service provision and skill diversity to meet the challenge of growing demand for services. There is, however, increasing overlap of palliative care and chronic care cohorts which can result in challenges to integrate multiple stakeholders providing care at different points along the patient journey.

## New complex Models of Care and technology advancement

New models of care include a shift from cancer to non-cancer patient groups, drug therapy advances, an increase in sub-specialties such as renal supportive care and integration with chronic care programs. Models of care are becoming increasingly complex and challenging. Virtual care innovations in Specialist Palliative Care include myVirtualCare to support secure virtual consultation rooms between clinicians and patients, and remote monitoring using wearables, tablet devices and telehealth platforms, enabling the provision of care in the community and rapid assessment and triage.

## Impact of COVID-19 Pandemic

The COVID-19 pandemic had a major impact on staffing levels/workforce. Staff leave and isolation requirements reduced available staffing across the service. Staff fatigue and burnout reduced service efficiency. The Pandemic also impacted Specialist Palliative Care Service provision with patients accessing hospital-based services less frequently and the temporary modification of outpatient (telehealth)/community based services.

Throughout this period, Sydney District Nursing continued to deliver in-home nursing care to palliative patients, unless a preference for virtual care was identified.

These challenges resulted in prioritising the development and use of digital health solutions to support and complement face to face clinical roles; and has been supported by the District as an additional service delivery model.

## Workforce

The Sydney Local Health District Specialist Palliative Care Service utilises the *Palliative Care Service Development Guidelines 2018* (PCSDG) as a best practice reference source for workforce planning. The PCSDG 'believes that it is important to be aspirational and set high expectations for the development of palliative care services across Australia'. The District endeavours to plan workforce development around national benchmarks, within a constrained funding environment. Current workforce challenges include medical and nursing staff shortages and reduced access to specialist trained clinicians across medical, nursing and allied health.

## Voluntary Assisted Dying (VAD)

Voluntary Assisted Dying means an eligible person can ask for medical help to end their life. The person must be in the late stages of an advanced disease, illness or medical condition. A person is required to meet all criteria outlined in the legislation to be eligible to receive VAD. The Parliament of New South Wales passed the *Voluntary Assisted Dying Act 2022* (the Act) on 19 May 2022. The Act will allow eligible people the choice to access voluntary assisted dying in NSW from 28 November 2023.

For our District, VAD has been supported in the following ways:

- Implementation of a District VAD Advisory Committee. The purpose of this Committee is to:
  - Govern implementation of the requirements of the Act and the associated Access Standard, including development of pathways of care.
  - Ensure that the requirements of the legislation are met and that clinicians have education and support to provide VAD services.
  - Meet obligations for documentation and the reporting of process and outcomes as required by the legislation and NSW Health Policy.
- Implementation of facility specific VAD Support Teams, which has a responsibility for local facility implementation.

# Specialist palliative care strategic principles

End of life palliative care is a universal human right



1

## Care is person centred

People approaching the end of life, their families and carers are partners in their own care and decision making.

Consistent approaches for end of life care practices are achieved through partnerships across all settings and care providers.

Patients, families and carers provide feedback about their experiences and outcomes and are involved in planning, designing and evaluating services.

EoLPC service design and provision is flexible and responsive to diverse preferences, values and needs of our patients, carers and community.

Open communication occurs between patients, carers, their families and treating teams regarding their care to encourage self-management.



2

## There is recognition and support for families and carers

Carers and families play an integral role in providing EoLPC.

Carers and families receive personalised, responsive, culturally safe and competent, evidence-based, integrated care that truly matters.

Carers and families are supported by access to information, resources and bereavement services.



3

## There is access to care providers across all settings who are skilled and competent in end of life and palliative care

All staff model CORE values with a focus on continuous improvement and a respectful culture of high performance.

Staff are supported by a district wide workforce strategy.

All staff can access EoLPC content in their training and education.

There are strong links between Specialist Palliative Care and generalist providers.

There is recognition and response to EoLPC needs across all settings.



4

## Care is well-coordinated and integrated

Care providers can recognise triggers for when consultation with, or referral to, Specialist Palliative Care is needed.

Service gaps and improvements are identified and responded to through digital district wide performance, quality and activity reporting.

Clinical care and information sharing is integrated across acute, community and GP primary care settings.

Coordinated data collection tools and methods are utilised for service development across all settings.



5

## Access to quality care is equitable

EoLPC is a universal human right.

Population groups who require additional support can access culturally safe EoLPC services responsive to their unique needs.

Increased awareness of the service is achieved through community engagement.

Innovative ways to deliver and improve care and support across community and acute settings are explored.

Home-like environments are available for patients, families and/or carers within the hospital setting.

Community leaders, cultural groups and Aboriginal communities are central to delivery of personalised, cultural and spiritual care in response to patient needs and preferences, including for priority groups.

# 1 Care is person centred



## Strategic goal:

Care is provided based on the unique, holistic needs and preferences of the person receiving care.

People receiving care should have control over their own health, enabling them to make appropriate decisions about their care facilitated by care providers<sup>19</sup>. The care provided should be based on the unique needs and preferences of the individual as an equal partner in decisions relating to their care and treatment<sup>21</sup>. This requires an EoLPC person centred system where people, their families, carers and support networks have access to the services and supports they need, in a way that is flexible, adaptive and provides choice and control<sup>20</sup>.

### What you told us (stakeholder consultation)

There are opportunities to partner with patients, families and carers to understand their experience when making decisions about their own care.

Personalised care includes creating more home-like environments when patients, families and carers stay in hospital.

Preferences and needs change over time, and may depend on the setting, access to information, culture, and acceptance of this information.

There is support to enable patients, families and carers to make choices and care decisions.

### Why this is important<sup>19,21</sup>

Embodies respect, compassion, support and responsiveness to the needs, experience, diversity and preferences of our patients.

Encourages patients to be more involved in decisions about their care so they receive services and support that are appropriate for their needs.

Strengthens clinical safety and quality for patients because they are better informed about their care.

Positively impacts on patient's health outcomes.

Places patients and their families at the centre of decision making to get the best outcome.

### Progress already made

Local and state-wide services provide after-hours advice and support for palliative care patients, their families and carers, and health professionals.

District wide launch of advance care plans, end of life care tools or other similar documents to communicate a patient's preferences regarding their care.

Implementation of the End of Life (EoL) packages to support patients with a progressive life-limiting illness or condition with daily living assistance and/or the option to die in their own home or to remain home for as long as possible.

Refurbishment of existing palliative care facilities, to provide a home away from home for patients, their families and carers.

Enhanced access to Specialist Palliative Care support for residents in aged care facilities within the District.

Engagement with the VAD Advisory Committee to support patient-centred approaches and choices in the end of life.

### Objectives

#### 1.1 Involve people approaching the end of life, their families and carers as partners in their own care and decision making.

- Ensure our patients, families and carers have timely access to information at the point of care which is tailored to their understanding.
- Raise awareness of services available to enable patients, families and carers to find the support they need to live will at the end of life.

#### 1.2 Support partnerships in the development of consistent approaches for end of life care practices, for example with the aged care, community and primary care sectors and non-government organisations

- Ensure all services and facilities meet and exceed National Safety and Quality Health Service Standards, National Palliative Care Standards, and other relevant standards in care.
- Promote advance care planning and end of life care tools as standard practice across the District to identify, document and implement preferences for care.
- Strengthen communication between national, state/territory and local palliative care networks.
- Build partnerships to inform community expectations and perceptions on death and dying.

#### 1.3 Involve people approaching the end of life, their families and carers in planning, designing and evaluating EoLPC services

- Extend patient, carer and community engagement in patient safety, quality improvement, education, ethics and research.
- Involve consumers in model of care developments, research projects, and policy decision making as active participants in health.
- Provide culturally appropriate EoLPC programs for the Aboriginal community.
- Provide targeted EoLPC programs for CALD communities and priority populations.

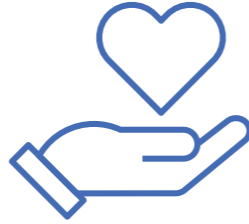
#### 1.4 Develop measures that allow individuals, families and carers to provide timely feedback about their experiences and outcomes (patient reported outcome measures (PROMs), and patient reported experience measures (PREMs))

- Develop palliative care specific PREMs/PROMs to capture patient, family and carer experience across all care types to provide patients with direct and timely feedback about their outcomes.
- Continue to collect and use PCOC data to report on patient outcomes of symptom prevalence and symptom distress.

### Signs of success

- Patients, families, and carers become active partners in their care, and have the knowledge to make informed decisions.
- Service is culturally welcoming, safe, and responsive to the diverse cultural needs of our community.
- Aboriginal people are identified when they access our service and receive culturally safe and clinically appropriate high-quality care.
- Increased completion rate for advance care plan and incorporation of end of life care tools for Specialist Palliative Care patients.
- Increased measures of Specialist Palliative Care against National Safety and Quality Health Service Standards, National Palliative Care Standards.
- Patients, families and carers have positive experiences of care with high Patient Reported Measures survey response rates.
- Patient and carer feedback is incorporated into safety and quality improvements.
- Service design and models of care reflect patient, family and carer input and feedback.
- Ongoing monitoring of PCOC data and relevant quality improvement based on results.
- Implementation of VAD/Specialist Palliative Care process pathway and support for individuals accessing VAD.

## 2 There is recognition and support for families and carers



### Strategic goal:

Families and carers are included in decision-making in the planning and provision of care; and are recognised, valued and supported.

Families and carers play a pivotal role in EoLPC. Uniquely, carers can be both providers and recipients of care and, historically, carers' needs have often not been considered in care planning<sup>3</sup>. It is essential their role is recognised, valued, and supported. It is important they are involved in the planning for and provision of care, and they receive quality services and support. This includes personal and home care, counselling and respite<sup>20</sup>. Focus on these areas will achieve care outcomes that matter most to them<sup>19</sup>.

### What you told us (stakeholder consultation)

There are opportunities to increase palliative care knowledge in the community and primary care.

Families and carers have a need for readily available consumer resources.

There is an opportunity to expand the memorial service.

Carers are often the recipients of information rather than patients, and often require further support.

### Why this is important<sup>20</sup>

Recognises that families and carers have an active role in provision of holistic care for patients, which affect health outcomes.

Enables health providers to work with families and carers to better understand their needs, optimise support and provide the right care, at the right time in the right place.

Improves health literacy, self-management, service navigation and engagement to EoLPC services.

Supports the grieving process to reduce risk of prolonged grief disorder and subsequent poor health, psychological and social outcomes.

### Progress already made

Development of digital health platforms to enable families and carers to access health information.

Publication of information brochures for patients, families and carers.

Improved access to EoL community home packages to support care provided by families and carers.

Implementation of the caring@home packages to support families and carers to help manage EoL symptoms for a patient at home.

Improved access to bereavement and psychosocial support services for people experiencing ongoing, complex grief.

### Objectives

#### 2.1 Develop systems to integrate the role of families and carers in EoLPC

- Enhance access to targeted resources to help navigate the system, including accessing services and local support networks.
- Enhanced access to 24-hour phone support, overnight care and access to medication and equipment.
- Support the provision of flexible respite care (e.g. in-home, short-and long-term respite) to enable care at home and prevent unnecessary hospitalisations.

#### 2.2 Develop standard resources to support families and carers including multicultural resources

- Partner with Diversity and Strategy Hub, CALD advisory groups, Aboriginal Health and Population Health to identify resource needs for all key population groups.
- Use clear and easily understood language and resources when communicating with families and carers, to support patient care.
- Work with internal, external, and non-government organisations to develop tailored resources to promote understanding of death, dying and bereavement.
- Procure and adapt District resources in response to health literacy needs, including the use of interpreter services when needed.

#### 2.3 Improve access to bereavement support for families and carers

- Expand memorial service/remembrance event across the District through involvement of all facilities.
- Develop standardised policies and/or procedures around grief and bereavement practices for all families and carers.
- Strengthen referral and escalation pathways to support families and carers experiencing ongoing, complex grief.
- Develop programs and partner with local bereavement providers to extend bereavement support in the community.
- Expand education and capacity building for health professionals to better recognise and refer people with bereavement needs.
- Develop tailored bereavement support for Aboriginal people.
- Develop tailored bereavement support for priority populations, including bereaved parents.

### Signs of success

- Increase in positive reporting of the experience of 24-hour phone support, overnight care and access to medication and equipment.
- Increased access to tailored resources and support available for families and carers in the home and/or community settings.
- Aboriginal specific worker engagement with families and carers.
- Carers are identified in the patient's clinical record to facilitate decision-making about treatment and care.
- Publication of translated information resources for identified CALD groups.
- Increased uptake of interpreter service for consultations with CALD patients and families.
- Memorial service available at four sites across the District.
- Publication of standardised procedure around grief and bereavement practices for the District, including for priority population groups.

# 3 There is access to care providers across all care settings who are skilled and competent in caring for people requiring end of life and palliative care



## Strategic goal:

People affected by a life-limiting illness will have access to high quality services across all care settings to help them make informed decisions about their care.

Some people approaching the end of life have straightforward and predictable needs which may be met by providers not based in a Specialist Palliative Care Service. However, it is critical these providers can access Specialist Palliative Care Services for advice and guidance if and when needed. These specialist services play an important role in not only the delivery of quality care but building the capacity of other providers of palliative care<sup>3</sup>. In this way people receive more coordinated clinically appropriate care in their choice of setting<sup>19</sup>.

### What you told us (stakeholder consultation)

There is increasing need for standardised care across all clinical groups and settings using collaboration and education.

There is an opportunity to improve the quality care provided by generalist staff, including primary health providers, in adopting the palliative care approach.

There are opportunities to up-skill senior staff, such as master classes.

Staffing enhancements, workload management processes and succession planning will optimise clinical care provision.

Coordination of research across services and sites will drive excellence in clinical care.

### Why this is important

Increases the capacity of Specialist Palliative Care Services to meet future needs for EoLPC<sup>3</sup>.

Enhances service delivery and shared decision making in the community, within homes, in rural and remote locations and in RACFs in response to individual preferences<sup>19</sup>.

Enables patients and families to remain at home as much as possible and/or die within their preferred place of death<sup>5</sup>.

Strengthens succession planning to manage increasing service demands resulting from ageing workforce and shortages of trained clinical staff in Specialist Palliative Care<sup>3</sup>.

Supports timely, equitable access to high quality EoLPC services; reducing unwarranted hospital admissions, carer stress, and promoting functional independence and quality of life.

Improves timely advance care planning and goal/priority setting.

### Progress already made

Enhancements to the palliative care workforce – medical, nursing, allied health, Aboriginal health.

Initiatives to address gaps in specialist health services to support people with life-limiting illnesses such as cancer, late-stage chronic illness or degenerative conditions.

Flexible funding pool, which allows districts and networks to address palliative care needs specific to their communities.

Implementation of support for education through grants/scholarships.

Enhanced partnerships with aged care services and primary care, for example, increasing access to Specialist Palliative Care services for RACFs via the Comprehensive Palliative Care in Aged Care Measure (CPCiAC).

## Objectives

### 3.1 Develop a Sydney Local Health District workforce strategy for EoLPC, which identifies and addresses needs across the district.

- Support leaders to guide the workforce to meet current and future service demands, through robust performance and development management processes.
- Develop workforce succession planning and professional development pathways, in response to current and future needs.
- Maintain a strong focus on the safety, wellbeing and resilience of staff, and support strategies for staff retention.
- Ensure a safe, supportive and healthy work environment for staff through workplace initiatives.

### 3.2 Enhance investment in the EoLPC workforce.

- Integrate workforce modelling and develop benchmarking tools informed by performance, quality and activity reporting measures to project future requirements.
- Develop sustainable staffing models inclusive of appropriate staffing and mix, capable of delivering high quality EoLPC services in response to current and future workforce demands.
- Recognise and support the role of specialist and non-specialist palliative care providers to support people with life-limiting illnesses.
- Develop a workforce of champions across all clinical settings, focused on advance care planning and end of life care.
- Recognise and expand the role of volunteers to provide timely, equitable support based on compassion and respite for people with life limiting illnesses.
- Implement the role of an end of life care coordinator to optimise end of life care.
- Expand the role of non-denominational pastoral care services to provide holistic palliative care support.

- Support staff in secondment and/or research opportunities.
- Strengthen consultative and educative roles fulfilled by Specialist Palliative Care Services to non-Specialist Palliative Care Services.

### 3.3 Advocate for increased EoLPC content in clinicians' training and education

- Develop sustainable strategies to support staff education, knowledge and skills to deliver EoLPC services, including podcasts and education modules.
- Recognise the role and promote uptake of the Program of Experience in the Palliative Approach (PEPA), focusing on EoLPC education and knowledge development for the general workforce.
- Utilise the Indigenous Program of Experience in the Palliative Approach (IPEPA).
- Develop mechanisms to improve staff development opportunities, including accreditation or other quality improvement activities.
- Develop staff digital capability through access to relevant training and technology resources.
- Include EoLPC modules in staff training and induction.
- Enable staff access to evidence-based information regarding recognition of clinical deterioration and dying, and when to escalate.

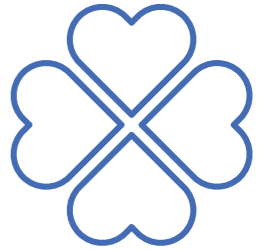
**3.4 Work collaboratively with Commonwealth and other partners to promote training and education on EoLPC for people in the primary, aged care, not for profit and private sectors.**

- Strengthen partnerships and collaboration with the Central Eastern Sydney Primary Health Network (CESPHN), aged care, not for profit and private sectors to foster education and training opportunities for non-specialist palliative care staff.
- Develop a 'Community of Practice' to support collaboration around current evidence-based practice for EoLPC, identify education opportunities, develop learning resources, and support clinical innovation.

**Signs of success**

- Expansion of the dedicated Specialist Palliative Care volunteer program across the District.
- Expansion of the dedicated Specialist Palliative Care pastoral care program across the District.
- Implementation of an end of life care coordinator role.
- Staff completion of current Performance Development Reviews in PAT.
- Reduction in unplanned leave.
- Improved self-reported rates of health and wellness amongst staff, including staff retention.
- A positive workplace culture where staff feel valued, included and engaged.
- Up-skilling of clinicians from non-Specialist Palliative Care Services in the management of EoLPC.
- High participation of learning and development programs, PEPA, IPEPA, quality improvement activities and research.
- Increase in number of staff presenting on EoLPC at District, state, national and international conferences.
- Development of podcasts and online education modules.
- Staff are digitally literate and are skilled and confident in the use of new technologies and systems.
- Implementation of Specialist Palliative Care 'Community of Practice' group.

# 4 Care is well coordinated and integrated



**Strategic goal:**

Care pathways, including pathways for transitions between settings and over the course of the dying process, enable people to receive coordinated and integrated palliative care, tailored to their needs across the healthcare system.

Everyone works together to create a consistent experience of Specialist Palliative Care across care settings. Strengthening existing networks for information sharing can help services learn from each other regarding the best ways to improve the quality of palliative care. Integrated care encourages shared clinical accountability for clinical outcomes, supports staff to work at their full potential and scope of practice, and alleviates staff fatigue and burnout. This enhances a person's experience by streamlining their navigation of the system and providing a seamless experience across the continuum of care<sup>22</sup>.

**What you told us (stakeholder consultation)**

There is an opportunity to improve coordination and timeliness of referral, admission/intake, discharge planning and transfer pathways.

Integrated care through standardisation of District Specialist Palliative Care Service governance, structures, referral processes and standards of practice is important.

There is an opportunity to improve integrated care with GPs through shared knowledge of communication access points, clinical information and transfer of care pathways.

Streamlined pathways to refer patients with EoLPC needs through existing platforms, including Centrelink, Housing, Public Guardian, NDIS are beneficial.

There is a need for consistent and accessible clinical documentation across all care providers using digital health platforms.

**Why this is important<sup>19, 21</sup>**

Facilitates access to safe, high quality palliative care from a range of service providers and settings.

Integrates services to reduce patients experiencing fragmentation, duplication, gaps and delays in their care.

Strengthens communication, collaboration and partnerships between providers at local levels - improving care experiences, enhancing care pathways and shared care arrangements thus optimising resources and reducing unnecessary hospitalisations and length of stay.

**Progress already made**

Enhanced partnerships with aged care services, primary care, and non-government organisations

Service improvement projects, including improved support for palliative care volunteers and carers.

Digital health solutions to assist patients and their families access Specialist Palliative Care to supplement generalist services.

Establishment of multidisciplinary Specialist Palliative Care teams to support patients, their families and carers in all settings.

Delivery of palliative care education workshops to clinicians working in Emergency Departments and Intensive Care Units.

Increased utilisation of prognostication tools (for example, SPICT), to facilitate timely early access to Specialist Palliative Care Services.

Collaboration and coordination of data collection/ outcome measurement through the roll out of Palliative Care Outcomes Collaboration (PCOC).

Palliative care specific Sydney District Nursing triage tool implementation (PC-ace Redesign).

Specialist Palliative Care clinicians access to clinical information across varied ICT platforms (Meditech/ ACD in EMR).

## Objectives

### 4.1 Develop resources to help care providers recognise triggers for when consultation with, or referral to, specialist palliative services is needed

- Implement a Standards of Practice Committee to provide governance and oversight for palliative care policies and guidelines.
- Utilisation of end of life care tools to support recognition of the EoL and dying phase.
- Support and facilitate the recognition and delivery of palliative care in Emergency Departments
- Implement nursing and allied health led palliative care clinics to supplement the multidisciplinary service and optimise timely referral to Specialist Palliative Care.
- Strengthen multidisciplinary Specialist Palliative Care provision to RACFs, including emphasis on advance care planning.
- Establish standardised chronic care referral pathways across the areas of RPA Virtual Hospital, community-based chronic care teams, Specialist Palliative Care and hospital based ambulatory care clinics.

### 4.2 Work with digital partners to identify ways to improve EoLPC data collection across NSW

- Improve eMR clinical documentation through ICT enhancements, supporting seamless transition and equitable access to digital clinical information throughout the patient journey.
- Implement Ministry of Health palliative care minimum data sets across the District to evaluate current practice, develop benchmarking, and inform continuous quality improvement.
- Implement a dedicated EoLPC data analyst role to support the development of quality indicators and benchmarking.
- Establish partnerships with eHealth (for example, End of Life Care Solutions Project) to monitor and improve palliative care workflow.
- Standardise PCOC data collection processes, including engagement and sponsorship from leads.

### 4.3 Promote increased information sharing between care providers across settings through the development of standardised documentation and tools relevant to EoLPC

- Implement a dedicated palliative care discharge planner/case manager role to support the transition of patient care between settings and across LHDs.
- Increase access to and usage of the MyHealthRecord platform.
- Standardise both intra-service and inter-service discharge and referral documentation tools.

### 4.4 Work with Commonwealth partners to further develop shared priorities in EoLPC, such as in the disability, aged and primary care sectors. This includes supporting linkages between Specialist Palliative Care services and primary health services

- Collaborate with the CESP HN to support the implementation of priorities in delivering care close to home.
- Develop shared care partnerships with afterhours GP Services.
- Enhance timely access and escalation pathways to Centrelink, Housing, Guardianship Tribunal and NDIS financial/care supports to share EoLPC provision
- Increase visibility of existing services and/or develop programs to support people living with disability, homelessness and people with mental health issues to access EoLPC services.
- Further develop GP eReferrals to District Specialist Palliative Care Services.
- Strengthen relationships with other Specialist Palliative Care Services across local health districts

## Signs of success

- Implementation of a Standards of Practice Committee for the Service.
- Implementation of nurse and allied health led palliative care clinics.
- Specialist Palliative Care provision to RACFs is multidisciplinary.
- Publication of models of care, inclusive of integration with other specialities.
- Continued partnerships with external networks through the SDO network
- Embed state-wide minimum data sets and PCOC across the District.
- Streamline pathways for admission and discharge of patients with EoLPC needs.
- Increased uptake of the MyHealthRecord platform.
- Streamlined access and escalation pathways to Centrelink, Housing, Guardianship Tribunal and NDIS financial/care supports to share EoLPC.
- Increase in number of people living with disability, homelessness and people with mental health issues accessing EoLPC services.
- Increase in GP eReferrals to Sydney Local Health District Specialist Palliative Care Services.
- Increased confidence of community care providers to deliver the palliative care approach, with robust systems to support referrals back to Sydney Local Health District Specialist Palliative Care Services.

# 5 Access to quality care is equitable



## Strategic goal:

People affected by a life-limiting illness have access to the care they need, when and where they need it; enabling flexible access and resourcing to provide quality care.

The goal of palliative care is to ensure people live as well as possible for as long as possible. All cultures experience death and have their own unique traditions when dealing with bereavement. Preferences for care may be influenced by culture, spirituality, past experiences and community norms and practices. To improve access to quality care, EoLPC providers need to ensure cultural safety in all services<sup>3</sup>.

### What you told us (stakeholder consultation)

There are opportunities to enhance access to pastoral care, volunteer services, rehabilitation and allied health across all sites/services.

There is a need to enhance community Specialist Palliative Care services to provide equitable care to people <65yrs who are not eligible for NDIS and people who wish to die at home.

Equitable care focuses on vulnerable populations including those in group homes/with a disability, homeless persons, children and young adults.

Equitable access to equipment will support home based Specialist Palliative Care.

Equitable access to specialist inpatient palliative care would be enhanced through allocation of a dedicated palliative care ward at RPA.

Access for Aboriginal patients can be improved.

Access for CALD patients can be improved.

### Why this is important<sup>18,19</sup>

Underpins equitable provision of culturally safe and individualised care based on personal needs and preferences.

Strengthens additional support in accessing EoLPC for priority populations and vulnerable groups.

Considers the demographic attributes unique to each community in the design and delivery of care rather than simply increasing the number of services available.

### Progress already made

Collaboration with local communities to improve the cultural awareness, safety and competency related factors for Aboriginal people with EoLPC needs, including enhancements of dedicated Aboriginal Health Workers in palliative care.

Dubbo outreach increases service access for rural and remote palliative care patients.

Use of preferred language GPs for CALD patients.

### Objectives

#### 5.1 Ensure services and support are culturally safe and responsive to the unique needs of people and population groups who require additional support in accessing EoLPC services

- Investigate an Aboriginal return to country support plan and/or assist family reunion in place of care.
- Engage with the Diversity Program and Strategy Hub to deliver culturally appropriate, responsive and safe EoLPC for priority population groups.
- Develop sustainable multi-literacy resources, including podcasts, radio dramas, or pamphlets to support engagement and understanding of EoLPC.
- Support innovative new workforce roles, such as bilingual community educators, peer support workers, cultural support and extend workers.
- Implement education programs and training for staff to increase confidence and engagement when providing care for priority populations and groups, for example, homelessness, mental health, and disability.

#### 5.2 Strengthen referral pathways to Specialist Palliative Care teams, and increase awareness, knowledge and access of services

- Promote palliative care service information and initiatives using the MyHealthPathways platform.
- Streamline the provision of information and access to the District Specialist Palliative Care Service to providers outside of the District where appropriate, including NGOs and disability residential service providers.
- Streamline the provision of end of life care for specialty cohorts e.g. Yaralla House, Chris O'Brien Lifehouse, and the Sydney Children's Hospital Network.
- Launch the Specialist Palliative Care Sydney Local Health District intranet page, including provisions for priority populations and groups.

#### 5.3 Explore alternative ways care and support can be delivered across community and acute settings including consideration of appropriate design of spaces, technology and equipment

- Enable equitable access to inpatient Specialist Palliative Care across the District through the establishment of a dedicated 15-bed palliative care ward in RPA.
- Investigate enablers and barriers to the commencement of palliative care day therapy program/centre.
- Enhance the provision of rapid response services to meet care needs in the community
- Enhance community palliative care services for residents in group homes.
- Expand support for young families who have a life-limiting condition across all care settings.
- Develop a sustainable model to procure and distribute dedicated palliative care equipment in a timely, equitable manner.

### Signs of success

- Publication of multi-literacy/CALD resources, including podcasts, radio dramas and pamphlets.
- Increase in staff receiving education and training for EoLPC for priority populations.
- Increase in 'hits' for EoLPC resources and information on MyHealthPathways platform.
- Launch the Sydney Local Health District Specialist Palliative Care Services intranet page.
- Establishment of a dedicated 15-bed palliative care ward in RPA.
- Establishment of RPA Virtual Hospital for palliative care.
- Increase in access to Specialist Palliative Care by young families who have a life-limiting condition across all care settings (longer term accommodation for young families)
- Increased uptake of services which are culturally safe, culturally competent, and responsive to the needs of priority groups.
- Increased staff confidence to deliver care for priority population groups.
- Digital health, including telehealth and virtual care, are part of business as usual.
- Group activities in areas of EP, psychology, and support groups



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# Implementation and monitoring

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Each clinical service within the District Specialist Palliative Care Service will develop an annual operational plan with specific strategies and actions to achieve the priorities of this Strategic Plan. This will be a living operational plan that will be updated to reflect changes in service provision, lived experience needs, and the policy landscape.

The implementation of this plan will be monitored by the Specialist Palliative Care Executive. The committee will develop an annual report on progress.

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# Glossary

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**End of Life and Palliative Care** A crucial part of integrated, people centred health services; relieving serious health related suffering, be it physical psychological, social or spiritual. End-of-life care refers to the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death and usually has higher support needs at this time<sup>2</sup>.

**Complex Palliative Care** There is no standard definition of complexity in palliative care; rather a series of potential indicators of complex needs, including number, severity and changing nature of need, alongside the interaction of multiple needs across different domains (physical, psychological, social and spiritual)<sup>6</sup>. Where patients require 'complex palliative care support' this often describes the needs of patients accessing Specialist Palliative Care.

**Specialist Palliative Care** Care provided by specialist palliative care (Specialist Palliative Care) services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care.

**Voluntary Assisted Dying (VAD)** An eligible person can ask for medical help to end their life. The person must be in the late stages of an advanced disease, illness or medical condition. If a person meets all the criteria and the steps set out in the law are followed, they can take or be given a voluntary assisted dying substance to bring about their death at a time they choose. The substance must be prescribed by an eligible doctor. 'Voluntary' means the choice must be the person's own. Only the person who wants voluntary assisted dying can ask for it. It is against the law to pressure someone to ask for voluntary assisted dying. The NSW legislation has safeguards in place to make sure the person is protected<sup>23</sup>.

**Advance Care Planning** The process of planning for future health and personal care, whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their decisions<sup>24</sup>.

**Advance care directive** A written advance care planning document completed and signed by a competent adult (i.e. a person-driven document). In Australia, advance care directives are either recognised by specific legislation (statutory advance care directive) or common law (non-statutory advance care directive). Advance care directives can record the person's preferences for future care, and/or record the appointment of a substitute decision-maker to make decisions about the person's health care<sup>24</sup>.

**Family and carers** The term family includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets). Carers may include family members and other members of their community (such as close friends and neighbours) who the person agrees to being involved in their care<sup>24</sup>.

**Person with a life limiting illness** The term life-limiting illness is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease. The term person living with a life-limiting illness also incorporates the concept that people are actively living with such illnesses, often for long period of time, not simply dying<sup>22</sup>.

**MyHealthRecord** A secure digital place to store health information like vaccinations, scripts and emergency contacts. It is available to all Medicare Card holders and is accessed via MyGov. My Health Record is private and can only be seen by the individual and healthcare providers.

# References

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- 21 Luckett et al, 2014. *Elements of effective palliative care models: a rapid review*, BMC Health Services Research, 14:136
- 22 NSW Health website
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# Appendix

## The Planning Framework

The Plan aligns with the expectations of a number of enabling plans, and broader health goals in NSW, including *Future Health 2022–2032*, and *Value Based Health Care*. Our Strategic outcomes, goals and objectives align with the *Sydney Local Health District Strategic Plan* focus areas.

The Plan’s analytic base derives from an analysis of current and projected activity using nationally endorsed palliative care planning tools and literature to understand best practice and emerging evidence. Documents used in this process include:

### ***Clinical Principles of End of Life and Palliative Care 2021***

This guideline identifies the clinical principles that underpin the delivery of high quality, accessible and appropriate EoLPC for people in NSW. It includes the key actions to be undertaken by NSW Health services and their partner organisations to meet the priorities identified in the *NSW Health End of Life and Palliative Care Framework 2019–2024*.

### ***National Palliative Care Standards 5th Edition 2018***

The Standards have been developed to be used by Specialist Palliative Care services to support the delivery of high quality EoLPC for the person receiving care (the person), their family and carers. The Standards are divided into two categories: Care Standards, which describe the systems and enablers necessary to deliver high quality clinical care; and Governance Standards, which describe expectation in regard to quality management, quality improvement and benchmarking.

### ***Palliative Care Service Development Guidelines 2018***

These Guidelines communicate the expectations of Palliative Care Australia for the range of EoLPC services that should be available to people living with a life-limiting illness, their families and carers. They also address workforce and system capabilities required to deliver an effective network of palliative care services using a population-based and geographic approach to service planning.

### ***National Palliative Care Strategy 2018***

This document provides an overarching vision for EoLPC in Australia: that people affected by life-limiting illnesses get the care they need to live well. It includes six principles fundamental to good EoLPC expected to be demonstrated in all service delivery, quality improvement, policy and research development activities. It also includes the core goals of: understanding; capability; access and choice; collaboration; investment, data and evidence and accountability.

### ***NSW Health End of life and Palliative Care Framework 2019–2024***

This framework sets out the vision and future direction for palliative and end of life care for people across NSW. The Framework describes how people and services can work together to provide accessible, high quality end of life and palliative care. The Framework reflects wide engagement with stakeholders, health professionals and community members.

### ***ACI End of life and Palliative Care Blueprint for Improvement***

The Blueprint provides a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers across all care settings. The Blueprint 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. Development was informed by research-based evidence and developed through consultation with more than 1200 clinicians, service managers, researchers, consumers, their families and carers.

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