

South Western Sydney Local Health District



# End of Life and Palliative Care Strategy to 2028

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## Foreword

Delivering high quality end of life and palliative care services to meet the needs of the diverse and rapidly growing community of south west Sydney is a key priority of South Western Sydney Local Health District (SWSLHD).

SWSLHD has long been considered a leader and innovator in palliative care service delivery, designing, and delivering evidence-based programs which are responsive to the needs of patients and their families and carers, beyond the traditional sphere of cancer-related care. A strong focus on translational research and building the evidence base has enabled SWSLHD to offer a comprehensive suite of services to the community, across inpatient and community settings and in partnership with other care providers. Our end of life care services, including care in the last days of life, has also significantly developed, enhancing the way in which all people are cared, regardless of their age, illness or engagement with treatment.

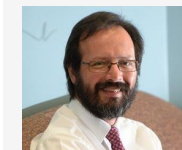
The *SWSLHD End of Life and Palliative Care Strategy to 2028* has been developed to align with the NSW Framework for End of Life and Palliative Care 2019 – 2024 and builds upon the successful implementation of the [SWSLHD Advance Care Planning, End of Life and Palliative Care Plan 2016 -2021](#) and the range of initiatives implemented across services through the [Transforming Your Experience](#) (TYE) program. It addresses the end of life and palliative care needs of all people from newborns to those who have lived a long life and recognises that deaths may be unexpected, or able to be planned well in advance.

Approximately 200 people have contributed to the collaborative development of this plan, including community members, staff and partner services across primary care, the residential aged care sector and community care providers.

The *SWSLHD End of Life and Palliative Care Services Strategy to 2028* will guide the allocation of resources and development of services, systems and supports to meet the end of life and palliative care needs of the community.



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## Plan on a Page

<b>SWSLHD Vision</b>	Leading safe, sustainable care for healthier communities		
<b>Core Values</b>	<b>Collaboration</b>	<b>Respect</b>	<b>Transforming Your Experience</b>
	<b>Openness</b>	<b>Empowerment</b>	
<b>Aim</b>	<i>To provide the communities of south west Sydney with access to high quality, accessible end of life and palliative care services which are responsive to the diversity of individual needs, circumstances, and goals of care</i>		
<b>Key Priorities</b>	1. Communities are compassionate and support people to prepare for and manage end of life	2. Care is person-centred	3. There is recognition and support for families and carers
	4. There is access to care providers across all settings who are skilled and competent in end of life care and palliative care	5. Care is well coordinated and integrated	6. Access to quality care is equitable
<b>Key Performance Indicators</b>	<ul style="list-style-type: none"> <li>• Increase in the number of patients with Advance Care documents recorded in the eMR</li> <li>• Increase in the number of medical and nursing inpatient specialist palliative care consultations (face to face and virtual)</li> <li>• Increase in separations from dedicated Palliative Care inpatient units (once additional capacity is available)</li> <li>• Increase in Occasions of Service in community end of life and palliative care services</li> </ul>	<ul style="list-style-type: none"> <li>• Increase in the number of specialist medical outpatient palliative care consultations (face to face and virtual)</li> <li>• Increase in the number of medical specialist palliative care home visits</li> <li>• Increase in the number of specialist palliative care nursing consultations to RACF residents</li> <li>• Increase in Occasions of Service within Renal Supportive Care program</li> <li>• Increase in Occasions of Service within Neurodegenerative Supportive Care program</li> <li>• Increase in Occasions of Service through the Aboriginal Specialist Palliative Care and End of Life Care service</li> </ul>	<ul style="list-style-type: none"> <li>• Utilisation of PEACH Program</li> <li>• Increase in proportion of PEACH Program recipients who die in their preferred place of death</li> <li>• Increase in utilisation of Ministry of Health Out of Hospital Packages (End of Life)</li> <li>• Increase in the number of Palliative Care volunteers</li> <li>• Increase in the number of Palliative Care volunteer occasions of service</li> <li>• Number of people referred to VAD Care Navigator service</li> <li>• Number of people who have died using VAD prescribed substance</li> </ul>

## Introduction

In 2021, 5,877 residents of south west Sydney died. Despite the impact of COVID-19 on health care services, the number of deaths in the region has remained relatively steady since 2011, with some increase in line with population growth<sup>i</sup>.

Across NSW, the most common causes of death are cancer, cardiovascular disease, respiratory disease, and injury/poisoning. This shows that whilst some deaths are sudden and unpredictable, the majority were a predictable outcome resulting from diagnosis of a life-limiting condition. What this data does not reflect is that the majority of people who die are in the older cohorts (the life expectancy of a person born in south west Sydney in 2020 is 84.2 years). Most older people are living with a range of chronic and complex conditions which make their later years challenging in terms of health and independence. Deaths of babies and children are relatively rare<sup>ii</sup> but are extremely difficult for families and services, requiring specialist involvement.

Since 2016/17, an average of 2,700 people have died each year in a SWSLHD hospital, with the remainder dying generally in a Residential Aged Care Facility (RACF) or community setting. On average, people who die in hospital have a longer length of stay than other patients (11.2 days compared to 3.3 days in 2020/21)<sup>iii</sup>. This data shows the need for staff across the community, RACF and hospital settings to be skilled in caring for people as they near the end of their life, including the last days of life.

Specialist palliative care services provided by SWSLHD are available to support patients experiencing complex symptoms and circumstances. However, most people will receive the majority of their end of life and palliative care from the broad range of other clinicians working across the health system, including community services and the aged care sector.

As such the *SWSLHD End of Life and Palliative Care Strategy to 2028* seeks to articulate the way in which health and support services operating in south west Sydney will collaborate to ensure the delivery of proactive, high quality care to people as they approach the end of their life or as they require additional care and support to manage their condition. It is important to note that whilst all people living with a life limiting condition are vulnerable, there are some groups within the community who experience additional challenges in accessing the services they need. These groups include Aboriginal people, people from culturally and linguistically diverse backgrounds, children and young people (and their families) and people living with dementia and/or disability.

This Strategy reflects the NSW government and SWSLHD commitment to the delivery of a broad range of end of life and palliative care services to meet the diverse needs of the community, beyond the scope of specialist palliative care services.

## The End of Life and Palliative Care Legislative and Policy environment in Australia and NSW

The environment around end of life and palliative care is rapidly changing. The following provides a brief snapshot of the policy and legislative context in which end of life and palliative care services will be provided as at 2023.

The [National Framework for Advance Care Planning Documents \(2021\)](#) represents the commitment of the Australian and state and territory governments to support all people to consider and provide direction on their future care, if they choose to do so. The Framework outlines ethical considerations and best practice principles which will support uptake of a shared language and common approach to advance care planning and provide a pathway toward mutual recognition of Advance Care Directives across state and territory borders.

In relation to clinical service provision, the [National Palliative Care Strategy 2018](#), the [National Palliative Care Standards 2018](#) and the [National Palliative Care Standards for All Health Professionals and Aged Care Services 2022](#) clearly articulate and promote a vision for compassionate and appropriate palliative care (specialist and generalist) in the Australian context. There is a focus on ensuring delivery of care that is person-centred and age-appropriate, with concentrated effort on delivering equity for people who may be especially vulnerable or at risk. Also at a national level is the [National Consensus Statement: Essential elements for safe and high quality end of life care](#), describing 10 essential elements for the provision of end-of-life care in settings where acute care is provided.

Within NSW, the [NSW End of Life and Palliative Care Framework 2019 – 2024](#) sets out the vision and future direction for palliative and end of life

care for people across NSW. The Vision described in the Framework is that “All NSW residents, their families and carers have access to and receive the best possible end of life and palliative care, based on their individual needs.” This care places the person at the centre, where their preferences, values, beliefs, and dignity are respected, and quality of life matters most. The *SWSLHD End of Life and Palliative Care Strategy to 2028* is aligned with the NSW Framework.

The Agency for Clinical Innovation (ACI) has developed the [Clinical Principles for End of Life and Palliative Care Guideline](#) to support good quality, evidence-informed practice and improvement in the provision of end of life and palliative care in NSW. This is supplemented with the [Blueprint for Improvement](#) that has been developed to provide a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers.

### Voluntary Assisted Dying

From 28 November 2023, across NSW, [voluntary assisted dying \(VAD\)](#) will be embedded within each Local Health District's services, consistent with the [Voluntary Assisted Dying Act 2022](#). The Act requires that all patients be informed about all options available to them, including palliative care and other treatment options, in line with their goals of care.

A person's decision to seek information about, or access to, VAD has no impact on the person's access to high-quality palliative care.

## **Aligning with the Planning Context in SWSLHD**

Service planning in SWSLHD reflects an integrated approach across population groups and clinical areas. As such, this Strategy should be read in conjunction with other key planning documents, including the SWSLHD Older Persons and Rehabilitation Plan, [Aboriginal Health Plan](#), [Multicultural Partnership Strategy](#) and the [Disability and Carers Strategy](#).

## **Current End of Life and Palliative Care service system in south west Sydney**

The following diagram represents the complex service environment in which end of life and palliative care services are provided to the

community of south west Sydney. There is a clear reliance not only on services provided by SWSLHD, but also by a range of partner care organisations including General Practitioners, RACF, private hospital and health services, community care providers and the non-government (NGO) sector.

End of life, specialist and generalist palliative care services are delivered across a broad range of settings by medical, nursing, and allied health professionals, working closely with families, carers and consumers/patients, as well as external agencies.

The diagram below provides a high -level representation of the current end of life and palliative care service system in south west Sydney.

Partner Services	South Western Sydney Local Health District Services	
General practitioners, practice nurses, medical deputising services	Specialist Palliative care hospital-based-services	
South Western Sydney PHN	Hospital Volunteer program	
Residential aged care facilities including palliative care clusters- Lavednder Suite, Hammond Care	Aboriginal palliative care program	
Tharawal Aboriginal Medical Services	<b>Bankstown-Lidcombe Hospital</b> <ul style="list-style-type: none"> <li>Medical, nursing and social work consultative service</li> <li>Outpatient clinics</li> </ul>	<b>Bankstown-Lidcombe Hospital</b> <ul style="list-style-type: none"> <li>Medical, nursing and social work consultative service</li> <li>Outpatient clinics</li> </ul>
Gandangara Health Services	<b>Bowral &amp; District Hospital</b> <ul style="list-style-type: none"> <li>Medical and nursing consultative services</li> </ul>	<b>Fairfield Hospital</b> <ul style="list-style-type: none"> <li>Nursing consultative service</li> <li>Medical consultative service (in-reach from Braeside Hospital)</li> </ul>
Southern Highlands Bereavement Service (NSW Health funded NGO)	<b>Liverpool Hospital</b> <ul style="list-style-type: none"> <li>Palliative care inpatient ward</li> <li>Medical and nursing consultative service</li> <li>Outpatient clinics</li> </ul>	<b>Campbelltown Hospital</b> <ul style="list-style-type: none"> <li>Medical and nursing consultative service</li> <li>Outpatient clinics</li> </ul>
Other NSW Health entities. E.g. Local Health Districts, Network and	<b>Braeside Hospital</b> <ul style="list-style-type: none"> <li>Palliative care inpatient unit</li> <li>Outpatient clinics</li> <li>After-hours 1300 number</li> <li>Bereavement counselling service</li> </ul>	
Private Hospitals	<b>Other SWSLHD Services including all medical subspecialities, critical care and paediatrics, providing care and services for people with life limiting conditions.</b>	
My Aged Care	Specialist Palliative care community-based service	
Carer Gateway	Palliative care nursing	
Community Pharmacists	Medical outreach	
Private specialists	Allied health outreach	
Private allied health services	Community Volunteer program	
	Residential Aged Care Facility nursing service	
	Aboriginal palliative care program	
	End of Life and Palliative Care packages	
	Palliative Care Support Program (PEACH)	
	MOH Out of Hospital End of Life packages	
	Generalist Palliative care community-based services	
	Community Nursing	
	Triple I: referral and coordinatoin 1300 number (extended hours and weekends)	
	Other programs	
	Renal supportive care	
	Neurodegenerative supportive care	
	End of life coordinators	
	Community outreach geriatrics services	



## Demand for End of Life and Palliative Care services in south west Sydney

Population growth and ageing will result in significant additional demand for end of life and palliative care services in south west Sydney to 2028. In addition, the range of treatment options currently available for conditions such as cancer, respiratory disease, heart disease, liver disease, kidney disease and complex neurological conditions are resulting in people living longer with chronic conditions. This range of patients will ultimately require access to end of life, generalist and/or specialist palliative care services, which will vary in duration and complexity depending on the individual need and goals of the patient and their family/carers.

## Significant Achievements from the SWSLHD Advance Care Planning, End of Life and Palliative Care Strategic Plan 2016 – 2021

Significant achievements since 2016 are described in line with the *SWSLHD Advance Care Planning, End of Life and Palliative Care Strategic Plan 2016 – 2021*, and include:

- Establishing a SWSLHD Advance Care Planning (ACP) Coordinator Position to improve the uptake of Advance Care Directives and compliance with directives across the District
- Embedding advance care documents within the electronic medical record (eMR)
- Building staff capacity to develop Advance Care Directives (ACD), supported by a Masterclass Program led by the University of Technology, Sydney
- Creating a new Community Development/Health Promotion Officer role to promote Advance Care Planning in the community (particularly targeting hard to reach groups and groups with low participation in ACP) and promoting awareness of end of life and palliative care services and service availability
- Enhancement of inpatient and community palliative care nursing services across the District, including after-hours nursing and dedicated specialist palliative care nursing for people living in RACF and creation of Clinical Nurse Educator positions to support workforce development and the delivery of high quality, safe services

- Enhancement of medical staffing, including establishing a medical palliative care presence at Bowral and District Hospital, improving equity of access to services
- Developing specialist capacity in the support of adolescents and young people with palliative care needs
- Enhancement of allied health staffing across clinical psychology, social work, occupational therapy, speech pathology, physiotherapy and dietetics in hospital and community settings
- Developing virtual care capability to improve accessibility and responsiveness
- Expansion of the Palliative Care Home Support (PEACH) program to provide additional packages
- Improved coordination with NSW Ambulance to provide improved care for people at end of life and palliative care patients who require emergency assistance
- Introduction of End of Life Care packages to support people to remain at home
- Establishing the Renal Supportive Care and Neurodegenerative Supportive Care Programs to provide tailored support to people living with end stage kidney disease and end stage neurological conditions and development of a program to support people with end stage liver disease
- Establishment of an Aboriginal Palliative Care Worker position to improve access of Aboriginal people to palliative care, and by association, cancer services
- Refurbishment of hospital facilities to provide improved amenity in palliative care spaces
- Development and expansion of research programs in collaboration with SPHERE, including the Stamford University Quality Improvement Collaboration (ongoing)

## Planning for the Future

Building on the considerable success in implementing the previous plan, SWSLHD has consolidated a Strategy for delivery of end of life and palliative care services to 2028. The following sections outline the aim and principles which underpin the way care will be delivered in the future and describe key priority areas of focus.

### Aim

*To provide the communities of south west Sydney with access to high quality, accessible end of life and palliative care services which are responsive to the diversity of individual needs, circumstances, and goals of care*

### Key Priorities for Future Service Development and Enhancement

After a comprehensive consultation and review process, SWSLHD has chosen to adopt the five priorities articulated in the [NSW End of Life and Palliative Care Framework 2019 – 2024](#), as described below. SWSLHD has added an additional priority to reflect the need to focus on development of compassionate communities and community development and engagement in relation to attitudes towards death and dying.

Within this document, strategies may be identified as being the following:

<b>SD</b>	Service Development
<b>SE</b>	Service Enhancement
<b>TYE</b>	Transforming Your Experience

## Principles for the delivery of end of life and palliative care to people in south west Sydney

The following set of principles are based on the [Blueprint for Improvement](#), developed to provide a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers. Additional principles have been added to reflect the themes from consultation undertaken for the development of this plan.

The following principles underpin how the end of life and palliative care services will be developed and delivered for the community of south west Sydney by 2028:

- The diversity of cultural and religious/spiritual beliefs around death and dying are understood and acknowledged
- Death is understood as a normal part of life
- Care is patient, family and carer centred and provided at the right time, at the right place
- Care is provided based on agreed goals and assessed needs
- Patients, families, and carers have access to local and networked services to meet their needs
- Care is high quality, evidence-based, clinically and culturally safe and effective
- Care is integrated and coordinated across the continuum of service providers and service settings
- Care is equitable
- Staff are well supported, educated and trained to deliver care and contribute to development of the evidence base
- Strong leadership and governance ensure excellence in service delivery

## Priority 1: Communities are compassionate and support people to prepare for and manage end of life

*Compassionate Communities are communities in which all people, regardless of their personal circumstances or history, play a stronger role in the care and support of people as they age and at the end of life. Compassionate Communities recognise that death is a normal part of life and support those around them to prepare for the end of life and to experience a positive death.*

By 2028, SWSLHD will implement the following strategies in collaboration with partners, creating Compassionate Communities across south west Sydney to enhance community awareness and understanding of death and dying:

1.1 Develop and implement [Compassionate Communities](#) programs in partnership with community groups, government agencies and the non-government sector (SD)

1.2 Broaden the scope and range of palliative care health promotion and health education programs delivered across the District, with a focus on improving death literacy (SD)

1.3 Develop awareness of Advance Care Planning and uptake of Advance Care Plans and Directives in community, hospital, RACF and specialist disability accommodation settings (SD)

## Priority 2: Care is person-centred

*Care should be based on the unique, holistic needs and preferences of the person receiving care. It should respect their preferences and their dignity. The individual, their families and carers are equal partners in the decisions relating to their care and treatment. Provision of care should be based on assessed need and be flexible in response to the person's changing needs and preferences.*

By 2028, SWSLHD will implement the following strategies to enhance the delivery of person-centred care for people at end of life and palliative care patients:

- 2.1 Utilise patient and carer reported outcome and experience measures in hospital and community settings to inform service delivery (TYE) (SD)
- 2.2 Improve delivery of and participation in clinical trials (SD)
- 2.3 Progressively establish a seven day per week, multidisciplinary, community-based end of life and palliative care service, with the capacity to provide rapid response (SE)
- 2.4 Improve access to loan equipment to support patients to be discharged and to remain at home (SE)
- 2.5 Provide complementary therapies as a core component of end of life and palliative care services to improve the patient experience, including virtual programs (TYE) (SD/SE)
- 2.6 Expand the provision of multidisciplinary services within Renal and Neurodegenerative Supportive Care and further develop the services available for people with end stage liver disease (SE)
- 2.7 Improve access to pharmaceutical and non-pharmaceutical interventions for pain and other symptom management in hospital and community settings, including:
  - Acute and interventional pain management services
  - Chronic pain management services
  - Timely access to affordable and appropriate medication and medication delivery devices for people in the community (SE)
- 2.8 Review the delivery of 24-hour telephone based palliative care support across the District and develop new models as required (SD/SE)
- 2.9 Adopt the successful collaborative Supportive Care service models for people who are frail aged, have dementia and/or are living with end stage chronic disease, with an initial focus on cardiac and respiratory failure (SD/SE)
- 2.10 Review, update and promote resources available in relation to culture and religion to support SWSLHD staff to provide appropriate care (SD)
- 2.11 Implement the NSW state-wide framework for safe and appropriate access to voluntary assisted dying services, including development of care navigation and consultancy services (SD/SE)

### Priority 3: There is recognition and support for families and carers

*Families and carers play a pivotal role in the end of life and palliative care service system. It is essential their role is recognised, valued, and supported. Health services should support families and carers to be involved in planning and providing care, and to access the services they need to carry out this role.*

By 2028, SWSLHD will implement the following strategies to improve recognition of and responsiveness to the needs of families and carers across all end of life and palliative care services:

3.1 Expand the capacity of multidisciplinary psychosocial and family/carer support services to assess needs and facilitate access

to appropriate information, education and supports across inpatient and community settings (SE)

3.2 Develop and implement a SWSLHD Bereavement Services Model of Care to standardise service delivery and improve equity of access (SD/SE)

### Priority 4: There is access to care providers across all settings who are skilled and competent in caring for people requiring end of life and palliative care

*End of life and palliative care can be delivered in multiple settings. It must be supported by a skilled and competent workforce*

By 2028, SWSLHD will implement the following strategies to build the capacity and capability of staff in clinical and support roles across all services to recognise and respond to the needs of people who are dying and their families and carers:

4.1 Provide a broad range of education and training opportunities to develop the minimum core competencies of all staff in providing generalist palliative care, end of life care and last days of life care (SD)

4.2 Provide a broad range of education and training opportunities to develop the skills of all staff in developing and documenting ACP and ACD (SD)

- 4.3 Strengthen and grow the Palliative Care Volunteer workforce to deliver a broad range of programs in hospital and community settings (SD)
- 4.4 Provide scholarships to develop the skills of nursing and allied health staff in end of life and palliative care (TYE) (SE)
- 4.5 Enhance the multidisciplinary specialist palliative care workforce across inpatient and community settings (SE)
- 4.6 Establish Academic positions across Palliative Care and End of Life Care (SE)
- 4.7 Investigate new collaborative Models of Care to support primary care such as GP Shared Care and GP Case Conferencing to complement existing education and training programs (SD/SE)

## Priority 5: Care is well coordinated and integrated

*People needing end of life and palliative care may receive care from multiple services across a number of settings. Care should be delivered in an integrated and well-coordinated manner with seamless transitions between services and settings*

By 2028, SWSLHD will implement the following strategies to improve the coordination and integration of end of life and palliative care services across all service providers and care settings:

- 5.1 Facilitate digital solutions to enable the sharing of information with NGOs and private providers delivering partnership and shared care programs (SD)
- 5.2 Review and update HealthPathways for end of life and palliative care in response to service redesign and service enhancement (SD)
- 5.3 Review how SWSLHD End of Life and Palliative Care services interface with services provided through external programs such as the National Disability Insurance Scheme, My Aged Care, Department of Veterans' Affairs and the Dust Diseases Board, to ensure patients have access to the care they need (SD)
- 5.4 Develop a SWSLHD Community End of Life and Palliative Care Model of Care to facilitate the introduction of new services and incorporate a coordinated approach to service delivery (SD/SE)
- 5.5 Strengthen coordination and integration of care between SWSLHD services and the Aged Care sector (RACF and community care providers) (SD)



## Priority 6: Access to quality care is equitable

*There can be significant variation in access to end of life and palliative care services across south west Sydney. There are groups across south west Sydney who need greater support to access end of life and palliative care services.*

By 2028, SWSLHD will implement the following strategies to enhance access to high quality end of life and palliative care services, with a focus on meeting the identified needs of community groups who experience barriers to accessing services:

- 6.1 Develop a standardised approach to providing last days of life care across hospital facilities within the One Service: Multiple Sites Framework (TYE) (SD)
- 6.2 Further develop the Aboriginal Specialist Palliative Care and End of Life Care service (SD/SE)
- 6.3 Increase the use of virtual care to support patients and families in the community, including the use of digital patient interactions (virtual care appointments) and remote care and monitoring tools (SD)
- 6.4 Establish additional specialist palliative care inpatient capacity across SWSLHD (SE)
- 6.5 Expand access to the End of Life Care Coordinator service in hospital and community settings with a view to delivering a seven day per week, extended hours service (SE)
- 6.6 Pilot a Care Navigator role in end of life care, with a particular focus on people from culturally and linguistically diverse communities (TYE) (SD/SE)
- 6.7 Document and promote the existing networks and pathways to support families of children with a life limiting condition across SWSLHD inpatient and community services and integration with the Sydney Children's Hospital Network and other services (SD/SE)
- 6.8 Develop specialist palliative care and end of life services for adolescents and young adults (SD/SE)
- 6.9 Redesign the way end of life care is delivered to people with an intellectual or cognitive disability (SD)
- 6.10 Develop community based palliative care clinics, including nurse practitioner led, nursing led and/or multidisciplinary clinics to reduce the need to travel to hospital-based outpatient appointments (SD/SE)
- 6.11 Develop and implement a standardised Inpatient Specialist Palliative Care Model of Care across inpatient units and consultation and liaison services within the One Service: Multiple Sites Framework (SD/SE)

## Implementation and Monitoring

The *SWSLHD End of Life and Palliative Care Strategy* will be implemented progressively to 2028.

The End of Life Committee (the Committee) will have overall accountability for the implementation of the Plan. However, responsibility for implementing individual strategies will be shared across facilities and services working in collaboration with patients, carers/families, the community, and partner organisations.

The Committee will provide regular progress reports to the SWSLHD Clinical Quality Council, Executive Leadership Team, and the Board to allow continuous monitoring of Plan implementation.

Monitoring and reporting will be consistent with key performance indicators (KPIs) listed below. It should be noted that as new services are established and quality improvement and/or research programs are implemented, additional activity will result and further qualitative and quantitative KPIs may be developed and reported.

- Increase in the number of patients with Advance Care documents recorded in the eMR
- Increase in the number of medical and nursing inpatient specialist palliative care consultations (face to face and virtual)
- Increase in separations from dedicated Palliative Care inpatient units (once additional beds are created)
- Increase in Occasions of Service in community end of life and palliative care services
- Increase in the number of specialist medical outpatient palliative care consultations (face to face and virtual)
- Increase in the number of medical specialist palliative care home visits
- Increase in the number of specialist palliative care nursing consultations to RACF residents
- Increase in Occasions of Service within Renal Supportive Care program
- Increase in Occasions of Service within Neurodegenerative Supportive Care program
- Increase in Occasions of Service through the Aboriginal Specialist Palliative Care and End of Life Care service
- Utilisation of PEACH Program
- Increase in proportion of PEACH Program recipients who die in their preferred place of death
- Increase in utilisation of Ministry of Health Out of Hospital Packages (End of Life)
- Increase in the number of Palliative Care volunteers
- Increase in the number of Palliative Care volunteer occasions of service
- Number of people referred to VAD Care Navigator service
- Number of people who have died using VAD prescribed substance

Additionally, the [Palliative Care Outcomes Collaboration](#) reports will continue to be used by specialist palliative care inpatient units to monitor the implementation of best practice care and enable benchmarking between sites.

At the recommendation of the Committee adjustments to the strategies contained within this plan may be made, to respond to changes in the operating environment and emerging opportunities.

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<sup>i</sup> [HealthStats NSW - Deaths, all causes](#)

<sup>ii</sup> [HealthStats NSW - Deaths in children](#)

<sup>iii</sup> Ministry of Health, FlowInfo v2.1, 2023

## Key terminology

As noted in the [NSW End of Life and Palliative Care Framework 2019 – 2024](#), the terms ‘end of life’ and ‘palliative care’ hold different meanings to different people. The following table provides an outline of the key terminology used in this Strategy.

Term	Description
<b>Compassionate Communities</b>	Compassionate communities are a core part of public health approaches to palliative care, end of life care and bereavement.... (They are) communities which play a much stronger role in the care of people at end of life and their families and carers through illness, dying, death and bereavement. Compassionate communities draw from the Compassionate City Charter, which describes 13 social changes to the key institutions and activities of cities to create a city which “publicly encourages, facilitates, supports and celebrates care for one another during life’s most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care.” <sup>iii</sup>
<b>Advance Care Planning</b>	Advance Care Planning involves individuals thinking about what care they would like should they find themselves in a position where they cannot make or communicate decisions about their treatment or care. It can include the individual talking with family, carers and/or health professionals, developing an Advance Care Plan, appointing an Enduring Guardian, or making an Advance Care Directive. An Advance Care Plan can be made by the individual or together with people that they trust and/or who are important to them. Where the individual is not able to make decisions, the Advance Care Plan can be made by their family with a health professional. An Advance Care Plan is not a legal document.
<b>Advance Care Directive</b>	An Advance Care Directive is a way an individual can document what health care treatments they would like to have or refuse, should they find themselves in a position where they are unable to make or communicate decisions about their treatment and care. An Advance Care Directive in NSW can be spoken or written, there is not a specific form. An Advance Care Directive can only be made by an adult with decision-making capacity and if it is valid, it must be followed. Health professionals and Persons Responsible have no authority to override a valid Advance Care Directive.
<b>End of Life Care</b>	<p>The care delivered to improve the quality of life for people who have a life limiting illness, as well as their families and carers. End of life care ensures the appropriate support and palliative needs are provided to the person, so they live as well as possible until their death. It recognises end of life care is the responsibility of everybody.</p> <p>It is noted that some clinicians consider end of life care to be last days of life care (see below)</p>
<b>Last Days of Life</b>	<p>This term implies that the patient is actively dying. This includes patients who have had a long illness and also those for whom a sudden illness or injury will result in a terminal outcome.</p> <p>The last days of life are a critical time in the care of a patient and their family/loved ones to ensure a high level of patient comfort and care delivery in accordance with the patients/families goals and wishes. Care should be delivered within the framework of the <a href="#">Last Days of Life Toolkit</a> and will primarily involve generalist services, supported by specialist palliative care for the management of complex symptoms as required.</p>

<p><b>Palliative Care</b></p>	<p>The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.</p> <p>Palliative care:</p> <ul style="list-style-type: none"> <li>• provides relief from pain and other distressing symptoms;</li> <li>• affirms life and regards dying as a normal process;</li> <li>• intends neither to hasten or postpone death;</li> <li>• integrates the psychological and spiritual aspects of patient care;</li> <li>• offers a support system to help patients live as actively as possible until death;</li> <li>• offers a support system to help the family cope during the patient's illness and in their own bereavement;</li> <li>• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;</li> <li>• will enhance quality of life, and may also positively influence the course of illness;</li> <li>• 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</li> </ul>
<p><b>Specialist Palliative Care</b></p>	<p>Care given to patients with complex, unstable symptoms or high needs by either medical, nursing or allied health professionals who have formal specialist palliative care qualifications and often work exclusively within interdisciplinary teams with other palliative care health professionals. Specialist palliative care services can provide direct care to people and their families as well as provide education and advice to other clinicians providing end of life care. Not all people with a life-limiting illness require specialist palliative care services.</p>
<p><b>Generalist Palliative Care</b></p>	<p>Care given to all patients with a life-limiting condition, their families and carers by all healthcare providers from diagnosis to last days of life<sup>iii</sup>.</p>
<p><b>Supportive Care</b></p>	<p>Supportive care involves an interdisciplinary approach, integrating sub-speciality medicine and palliative care services, and encompassing advance care planning and end of life care<sup>iii</sup></p>