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CENTRAL AND
EASTERN SYDNEY

An Australian Government Initiative

PALLIATIVE CARE AND END OF LIFE

2025 Needs Assessment

Funding Acknowledgement

Greater Choice for At Home Palliative Care – an Australian Government initiative

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Overview

The Central and Eastern Sydney Primary Health Network (CESPHN) has worked closely with key stakeholders to undertake a comprehensive needs assessment regarding palliative care and end of life services within the region. Key health needs, key service gaps and barriers and opportunities have been identified to better enhance the delivery of palliative care and end of life services and support in the CESPHN region.

Currently in Australia, 51% of all deaths occur in hospitals with an additional 30% in residential aged care homes (RACHs). Most Australians express the preference to die at home, however, only 17.3% of individuals die in their own homes.(1) Primary care providers play a vital role in providing coordinated care and ensuring individual preferences are met across all settings.(2) However, limited knowledge and awareness of such services and limited access to primary palliative care impacts the individuals' ability to access it. This places a strain on specialist services caring for patients who could be managed by general practitioners (GPs) and nurses, with on call specialist support.

Key health needs

Palliative care plays a crucial role in improving the quality of life for individuals with life-limiting conditions and ensuring a peaceful death for both patients and families. Those receiving palliative care at home experience improved quality of life, fewer hospital visits, and healthcare cost savings. Approximately 75% of all deaths are anticipated, meaning more individuals could benefit from palliative and end of life care. While people with complex health needs should have access to specialist palliative care teams, many can be supported by skilled GPs and nurses, easing the burden on specialist services.

The CESPHN region is undergoing significant demographic change. The region has a significant and growing ageing population, is also culturally diverse, with 40.7% of residents born overseas, and has areas experiencing high levels of socio-economic disadvantage.(3) Health indicator data highlights an increased need for palliative and end of life care, with conditions such as dementia, cancer, COPD and chronic kidney disease becoming more prevalent.(4, 5)

Key service gaps

Current utilisation of palliative care services highlights demands for these services is high, even though community awareness of palliative care services is low and referral to palliative care is often late or delayed. Other barriers contributing to reduced uptake include financial challenges, significant cultural factors, and reduced palliative expertise within the primary care workforce, particularly among GPs, where it can be difficult to find GPs willing to take on new patients coordinate palliative care and provide end of life home care.

Through extensive stakeholder consultation and analysis, eight priority action areas have been identified to improve access to key services and allow for effective delivery of palliative and end of life care across the CESPHN region. These include:

- community education and awareness raising
- advance care planning
- coordination and integration of care
- general practices with an extended role in palliative care
- digital health
- training and education
- advocacy
- community development

Purpose And Policy Context

CESPHN received funding under the Greater Choice for at Home Palliative Care measure, the objectives of the funding are to:

- improve awareness (workforce and community) and access to safe, quality palliative care at home and support end-of-life care systems and services in primary health care and community care
- enable the right care, at the right time and in the right place to reduce unnecessary hospitalisations
- generate and use data to support continuous improvement of services across sectors
- use available technologies to support flexible and responsive palliative care at home, including in the after-hours.

The intended outcomes of the grant funding are to:

- improve the capacity and responsiveness of services to meet local needs and priorities
- improve patient access to quality palliative care services available in the home
- improve coordination of care for patients, across health care providers and integration of palliative care services in their region.

The funding aligns with four of the seven goals under the National Palliative Care Strategy:

- improve appreciation of dying and death as a normal part of life
- enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services
- ensure appropriate and effective palliative care is available to all Australians based on need
- build and enhance the capacity of all relevant sectors to provide quality palliative care.

Methodology

A robust service review involved identification and consultations with key stakeholders, data collection and analysis, reporting and recommendations, and implementation and monitoring on palliative care needs within the CESPHN region.

Data collected

Data was collected through various channels to help understand palliative care needs within CESPHN. These collection techniques included:

- Australian Institute of Health and Welfare
- Australian Bureau of Statistics
- Surveys to primary care providers and CESPHN community members
- Community and professional discussions
- Meetings
- Observations
- Interviews with primary care providers and CESPHN community members
- Focus groups involving primary and palliative care providers
- Expert panels
- Service mapping

Stakeholder consultation approaches

To assess unmet palliative care needs in the CESPHN region, individual and small group consultations were conducted with a diverse range of stakeholders.

Consultations undertaken with health care providers were underpinned by the NSW Agency for Clinical Innovations Fundamentals for Palliative Care and best practice principles.(6) For a list of these please refer to Table 1 in Appendix A.

Consultations with community stakeholders were underpinned by selected best practice principles from the Australian Government National Palliative Care Strategy.(7) For a list of the selected principles please refer to Table 2 in Appendix A.

Stakeholder consultations

Participants discussed the gaps, opportunities and future strategies for the improving service quality and access to palliative care across the following areas and settings: primary care, community care, GP referrals and consults, shared care arrangements between local specialist, community palliative care and aged care providers, primary care workforce education and development, community engagement and education.

For a complete list of participants, please refer to Table 3 in Appendix B.

Analysis

Qualitative and quantitative information relative to palliative care services, service utilisation, gaps and unmet needs was collected, synthesised, and triangulated to identify key unmet palliative care needs and opportunities within the CESPHN region.

CESPHN Region

Population

In 2022, CESPHN's population was 1,555,706 with projections indicating significant growth by 2041. Currently, 14.9% of the estimated resident population is aged 65 years and over, and this proportion is expected to increase by 43.6% between 2024 and 2041. The most substantial growth will occur among older cohorts, those aged 80+ will increase by 113%. Within this group, people aged 85 years and over are expected to more than double, an increase of 101.8% over the same period.(5)

The growing elderly population highlights the urgent need for effective and sustainable palliative care services to address future demands. Proactively strengthening these services will ensure that the needs of the ageing population are met with compassion and efficiency in the coming years.

Table 1: Estimated population growth, CESPHN region, 2022-41

Age (years)	Population 2022	Population 2041	Increase (%)	Compound annual growth rate (%)
0-19 years	304,342	316,644	4%	0.2%
20-39 years	556,204	626,509	13%	0.6%
40-59 years	384,870	454,631	18%	1%
60-79 years	244,475	327,917	34%	2%
80 years+	65,815	140,404	113%	4%

Source: HealthStats NSW 2022

Diversity, ethnicity and multiculturalism

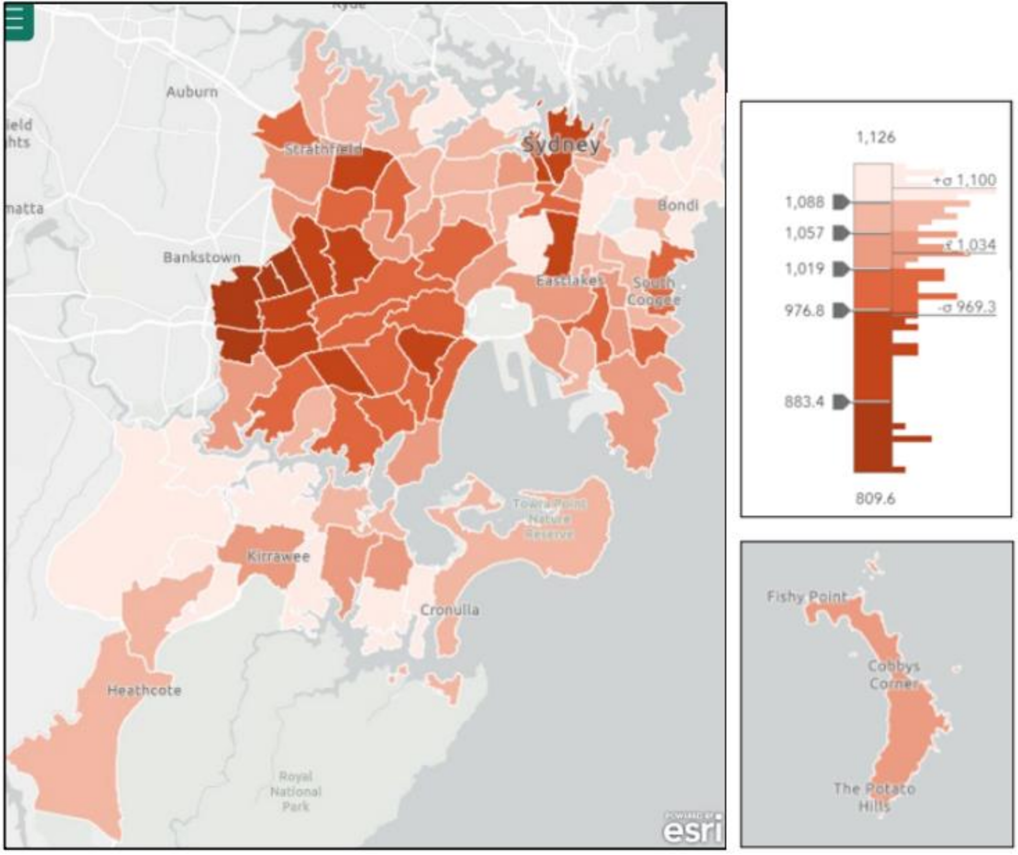
CESPHN has a diverse range of cultures across the region.

- 16,225 Aboriginal and Torres Strait Islander peoples (3)
- 14.5% of all same sex couples in Australia live in the CESPHN region.(3)
- 40.7% of the population were born outside of Australia.(3)
- Christianity is the main religious affiliation across the CESPHN region, followed by ‘no religious affiliation’ (36.1%) and Islam (4.6%).(3)
- 46.8% speak a language other than English at home.(3)
  - Top Languages:
    - Mandarin 17.2%
    - Cantonese 9.4%
    - Greek 8.7%
    - Arabic 8.2%
- Other commonly spoken languages spoken across the CESPHN region include Spanish, Italian, Vietnamese, Indonesian, Portuguese, Korean, Bengali, Thai, Macedonian, Hindi, Russian, French, Tagalog, Urdu and Japanese.(3)
- Refugees and asylum seekers: As at March 2022, a total of 451 people who came seeking asylum by boat and were granted a Bridging Visa E resided in the CESPHN region. Approximately 70.2% resided in Canterbury, 14.9% in Strathfield-Burwood-Ashfield and 14.9% in Botany.(8)

Socio-economic status

The overall level of advantage in the CESPHN region is above that of the Australian average as measured by the Australian Bureau of Statistics (ABS) Socioeconomic Indices of Advantage and Disadvantage.(8) Within the CESPHN region there is a gradient from east to west, with the western parts of the region relatively disadvantaged by national standards and the eastern areas relatively advantaged. However, this is not an even distribution, there are locations of considerable disadvantage as measured by factors such as low income, unemployment, and low English proficiency.

Figure 1: Index of Relative Socio-Economic Disadvantage (IRSD) in the CESPHN region by SA2, 2021



Source: ABS SEIFA, 2022

There are 32 statistical Area level 2s (SA2) with an Index of Relative Socioeconomic Disadvantage (IRSD) value below 1,000 indicating socioeconomic disadvantage. Almost one third of the most disadvantaged SA2s are in Canterbury. Other pockets of disadvantage are in Hurstville, Sydney Inner City, Kogarah - Rockdale, Strathfield - Burwood - Ashfield, Botany and Eastern Suburbs – South SA3s.(9)

There is clear evidence that people living with socio-economic disadvantage are more likely to experience poorer health outcomes.(10)

Death Literacy

In Australia, the Death Literacy Institute conducted studies and identified that people born outside of the country who do not speak English as their preferred language have lower access to palliative care and fewer completed Advance Care Plans.(11) They also found that:

- only 1 in 5 people know how to navigate the health system when someone is dying or trying to access aged care
- only 1 in 3 know how to navigate the funeral industry
- half of Australians are unaware of where to find information about palliative care, and only 22% know how to access it in their local communities.(11)

More broadly, in 2018, the National Health Literacy Survey conducted by the Australian Bureau of Statistics (ABS) found that overall:

- 26% of people reported finding it always easy to navigate the healthcare system,
- 60% reported finding it usually easy,

- 14% of people reported finding it difficult to navigate the healthcare system.(12)

An estimated 60% of Australian adults have low levels of health literacy, meaning they may not be able to effectively exercise their choice or voice when making decisions related to healthcare. Low individual health literacy is associated with higher use of health services, low levels of knowledge among consumers and poorer health outcomes.(13)

Health status

Individuals with life limiting diseases, illnesses and long-term conditions are more likely to require and use palliative care services. As the population ages and life expectancy continues to increase, the prevalence of people living with chronic and long-term conditions with the potential to increase demand for palliative care is also increasing.(4)

Dementia

The demand for palliative care for people living with dementia is expected to increase significantly in the coming years. Dementia, including Alzheimer's disease, was the leading cause of death in Australia in 2024, accounting for 9.4% of all deaths, increasing by 38.8% between 2015 and 2024.(1) Similarly, in NSW, dementia was the leading cause of death in 2024 resulting in 5,593 deaths.(1)

Between 2019-23, dementia was the leading cause of deaths in the CESPHN region, resulting in 4,927 deaths and a mortality rate of 62.4 per 100,000 population.(1, 12)

Based on national prevalence rates from 2022, an estimated 23,163 people aged 65 years and over in the CESPHN region are living with dementia, representing 15.4% of the local population aged 65 years and over.(13) These trends underscore the growing and sustained need for accessible, well-coordinated palliative care services for people living with dementia and their families across the CESPHN region.

Cancer

In 2022, it is estimated that around 49,996 people died from cancer in Australia.(14) In the CESPHN region, the cancer mortality rate is approximately 188.5 per 100,000 population. The age-standardised mortality rate for cancer has been decreasing over recent years, which is reflective of improvements in cancer detection and treatment.(14)

Chronic respiratory diseases and chronic heart failure

Chronic respiratory illnesses such as chronic obstructive pulmonary disease (COPD) and chronic heart failure often require palliative care to manage symptoms such as breathlessness, fatigue and pain. In 2022, COPD resulted in 2,514 deaths among NSW residents, equating to a rate of 22 per 100,000 population, compared with a lower rate of 14.4 deaths per 100,000 population in the CESPHN region.(5)

This pattern was also reflected in hospital activity, with NSW recording 17,290 hospital admissions for COPD in 2022–23, an age-adjusted rate of 157 per 100,000 population, increasing from 134 per 100,000 in 2021–22. In contrast, CESPHN recorded a significantly lower admission rate of 92.7 per 100,000 population. (5) Notably, the burden of disease was concentrated among older adults, with 76% of COPD hospital admissions occurring among people aged 65 years and over.(5)

A similar pattern was observed for heart failure, with 1,225 deaths recorded across NSW in 2022 (9.3 per 100,000 population), while CESPHN again reported a slightly lower rate of 8.8 per 100,000 population.(5) Despite comparatively lower rates, COPD and heart failure remained significant contributors to mortality within the CESPHN region, ranking as the fifth and eleventh leading causes of death respectively between 2019 and 2023.(12)

Chronic kidney disease

In 2022 in the CESPHN region, chronic kidney disease was responsible for an estimated 1,021 deaths, representing an increase from an average of 816.3 deaths per year recorded between 2011 and 2013.(5) Between 2019 and 2023, kidney failure ranked as the 19th leading cause of death in the CESPHN region, accounting for 679 deaths and a mortality rate of 8.6 per 100,000 population.(12)

Other neurodegenerative diseases

Integrating palliative care from the time of diagnosis can significantly improve the quality of life for people living with neurodegenerative diseases and their families. In 2023, neurological conditions were the underlying cause of 11,853 deaths in Australia, equating to a rate of 44 per 100,000 population and accounting for 6.5% of all deaths nationally.(16)

Among deaths where neurological conditions were the underlying cause, Parkinson’s disease accounted for 21% and motor neurone disease for 6.6%, highlighting the substantial burden associated with these progressive conditions and the importance of early palliative care integration.(16)

Rising rates of chronic disease

According to 2021 Census data, the estimated age-standardised prevalence rate of people reporting one or more long-term health conditions in the CESPHN region was 22.8 per 100 population.(17) Furthermore, it is predicted that by 2031, one in four people will be living with two or more chronic conditions. (23, 4) In the context of rising rates of life-limiting illness and chronic disease, combined with an ageing population, this highlights the importance of developing efficient and effective palliative care services and support within the CESPHN region.

CESPHN Palliative care services

Service providers

CESPHN covers the region of two Local Health Districts (LHD); Sydney LHD (SLHD) and South Eastern Sydney LHD (SESLHD) and includes two Local Health Networks; Sydney Children’s Network and St Vincents Hospital Network.

SLHD has four major hospitals:
- Balmain Hospital
- Canterbury Hospital
- Concord Hospital (offers a 20-bed inpatient palliative care unit)
- Royal Prince Alfred Hospital

SESLHD has five major hospitals:
- Prince of Wales Hospital (16 in-patient beds)
- Royal Hospital for Women
- St George Hospital (12 in-patient beds)
- Southerland Hospital (10 in-patient beds)
- Calvary Hospital Kogarah (20 in-patient beds)

Specialist community palliative care units

Both LHDs, Calvery and St Vincent’s Sacred Heart provide specialist palliative care community outreach services that complement their inpatient services. The Sydney Children’s Hospital Network at Randwick operates as a regional service, offering comprehensive palliative care support to children and their families, whether care is provided at home or during hospital admissions. These services are delivered by multidisciplinary teams led by dedicated palliative care consultants and nurses, who are available to assess symptoms and support general practitioners in managing the care of people with life-limiting illnesses in the community.

Teams are multidisciplinary in nature and complemented by a range of other support services. These supports include:

- Palliative care medical consultants
- Specialist palliative care nurses
- Social workers
- Pastoral carers
- Physiotherapists
- Occupational therapists
- Palliative care volunteers
- Bereavement and Psychosocial Support
- Home visiting teams
- Residential aged care facility visits
- Outpatient clinic appointments
- Recent addition of community facing supportive palliative care hubs for people living with non-malignant life limiting conditions.

After-Hours Support

In the CESPHN region, after-hours palliative care support is available through LHD specialist palliative care teams, which provide 24-hour specialist and nursing advice via telephone to support patients, residential aged care homes, and general practitioners requiring clinical guidance. In addition, people in the CESPHN region can access the NSW Health Palliative Care Helpline through the Healthdirect service, which offers after-hours support to anyone seeking palliative care assistance when regular services are unavailable.

Community palliative care nursing providers

Additional to hospital community palliative care outreach services, the CESPHN region includes a range of non-government, for-profit and not-for-profit home care nursing providers who offer supportive palliative care services. Larger providers in the region include:

- Hammond care
- Catholic care
- Uniting care
- Anglicare
- Regal care
- Baptist care

Service utilisation

In 2020, the NSW Government released a report analysing palliative care deaths between 2012 and 2019.(15) The report noted the following findings:

- Increased demand on health systems, driven by an ageing population and higher incidences of life-limiting illnesses. In the last month of life, emergency, and inpatient admissions more than doubled.
- Predictable population disease profiles could be benefiting from earlier intervention by palliative care services.
- A growing trend in palliative care use across all life-limiting illnesses, with cancer diagnoses remaining the most common.
- The median time from the start of palliative care to death has remained unchanged, this is 8-18 days for individuals with a cancer diagnosis and 4-5 days for individuals with a non-cancerous life limiting illness.

Place of death

In Australia, majority of deaths occur in hospitals or medical service areas. Similarly, 51% of deaths in NSW occurred in hospital or medical services setting and an additional 30.1% occurred in RACFs.(1)

Table 2: Place of death by region, 2019

Region	Home/residence (%)	Residential aged care facility (%)	Hospital/medical service area (%)	Other (%)	Unspecified (%)
NSW	17.3	30.1	51.0	1.5	0.1
Australia	14.8	29.5	50.1	1.4	3.4

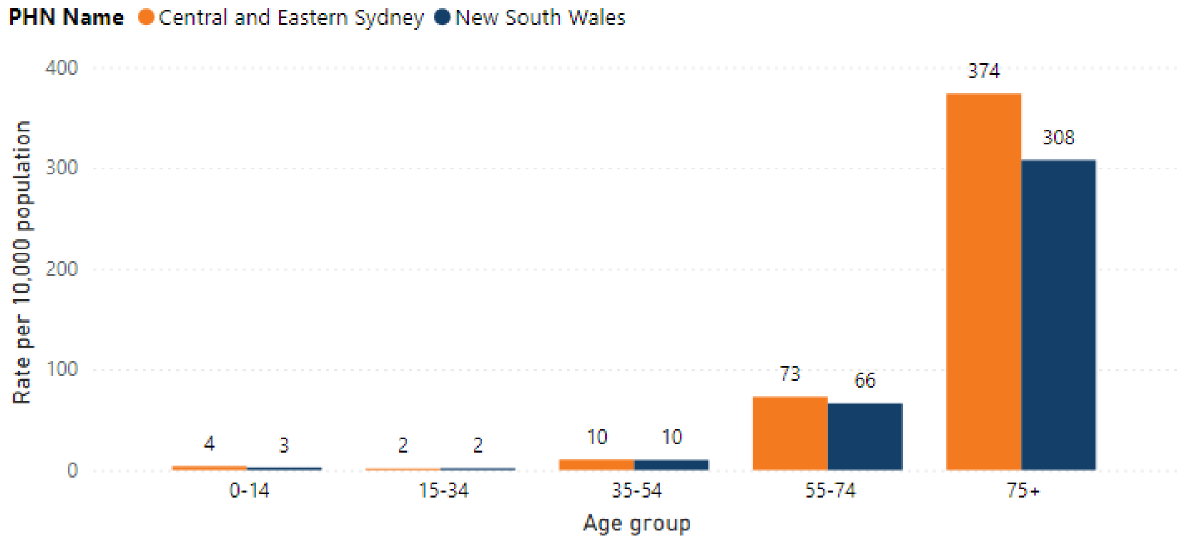
Source: ABS 2019

Palliative Care Hospitalisations

In Australia between 2015–16 and 2023–24, palliative care-related hospitalisations increased at an annual rate of 4.9%, double that of hospitalisations for all reasons (2.3%). In 2023–24, among the 107,500 palliative care-related hospitalisations more than half (55%) of hospitalisations ended with the patient dying in hospital.(2) In 2023–24, CESPHN had 6,978 palliative care-related hospitalisations.(2)

In 2023-24, CESPHN had higher palliative care hospitalisation rates compared to the NSW average (43.5 per 10,000 population and 42.3 per 10,000 population respectively). People aged 75 years and older had the highest rates of palliative care hospitalisations in both regions.(2)

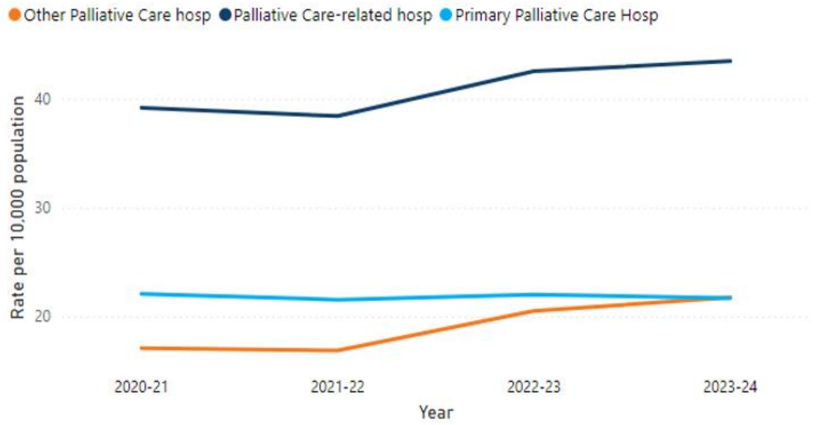
Figure 2: Rate of hospitalisations per 10,000 population by age group, CESPHN region, 2023-24



Source: AIHW 2025

Other palliative care hospitalisations have risen between 2020-21 and 2023-24, whereas primary palliative care hospitalisations have remained relatively stable during the same period.(2)

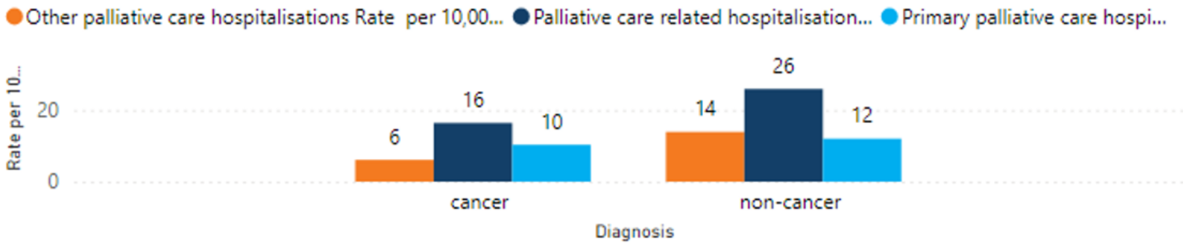
Figure 3: Rate of hospitalisations by hospitalisation type, CESPHN region, 2023-24



Source: AIHW 2025

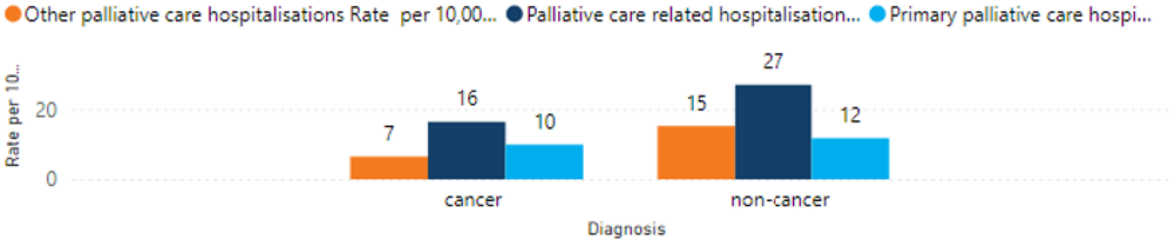
In 2023–24, NSW recorded a higher rate of palliative care-related hospitalisations among admissions for non-cancer life-limiting illnesses (26 per 10,000 population), a trend that was consistent with patterns observed in the CESPHN region.(2) This highlights the need for broader palliative care pathways to be implemented.

Figure 4: Rate of hospitalisations per 10,000 population by principal diagnosis, NSW, 2023-24



Source: AIHW 2025

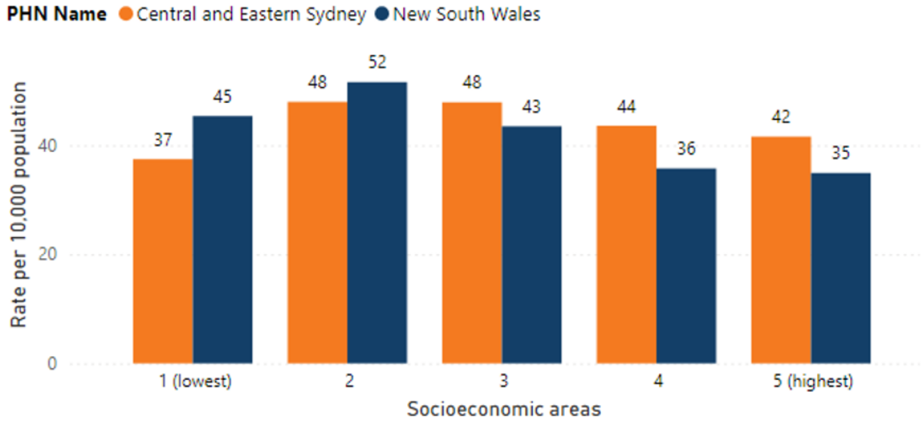
Figure 5: Rate of palliative care hospitalisations per 10,000 population by diagnosis, CESPHN region, 2023-24



Source: AIHW 2025

In 2023-24, palliative care hospitalisation rates varied slightly by socioeconomic status (SES) within the CESPHN region.(2)Whereas in NSW, rates where highest in low SES areas and lower in high SES areas, indicating that equity and access challenges may exist for some people when accessing palliative care services across the state.(2)

Figure 6: Rate of palliative care hospitalisations per 10,000 population by socioeconomic status (SES) areas, CESPHN region, 2023-24



Source: AIHW 2025

Specialist palliative care services

Data shows most specialist palliative care (SPC) consultations occur on average 15-days before death and passing. This time frame is considerably shorter than recommendations, which suggests at least 3-4 months of specialist palliative care provides the maximum benefit.(16)

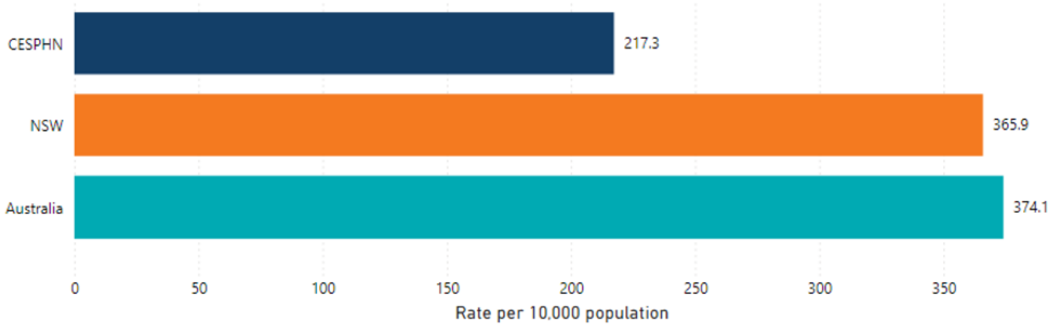
In 2019–20 in Australia, of the 52,105 people who received specialist palliative care (SPC) in the last year of life and died from predictable causes, 80% received SPC as inpatients, 26% attended outpatient clinics for consultations with palliative care specialists, and 23% had consultations with palliative care specialists or physicians.(16) Of the 35,158 SPC patients in Australia who died in hospital, 19% had lived in residential aged care during their last year; 82% of these were admitted in the final week. Among the remaining 81%, 63% were admitted in their last week. Similar patterns were seen in those not receiving SPC.(16)

Non-admitted palliative care patients

Non-admitted palliative care refers to services provided to patients who are not admitted to hospital, such as outpatient clinics, community visits, and day-only care. Non-admitted palliative care service events have been increasing nationally, reflecting a shift toward community-based care.

In 2023-24, CESPHN had a much lower rate of non-admitted palliative care service events (217.3 per 10,000 population), compared to NSW (365.9 per 10,000 population) and Australian rates (374.1 per 10,000 population).(2)

Figure 7: Rate of non-admitted palliative care patients per 10,000 population by region, 2023-24

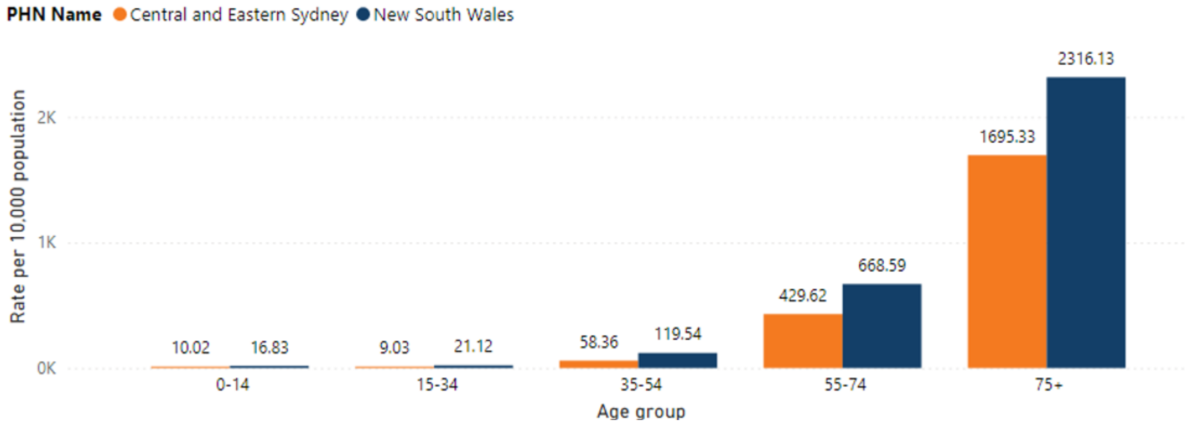


Source: AIHW 2025

In 2023-24, service event rates for non-admitted patient palliative care increased significantly with age, peaking in the 75 years and over age group. However, service event rates in the CESPHN region remained below the NSW averages across all age groups.(2)

Overall, CESPHN provided fewer non-admitted palliative care services per capita, despite similar age-related demand trends.

Figure 8: Rate of service events per 10,000 population for non-admitted patient palliative care, CESPHN region, 2023-24



Source: AIHW 2025

In 2023-24, NSW demonstrated higher service rates across all SES quintiles, while CESPHN had relatively even rates, with the highest in the most advantaged group (SES 5).(2)

Figure 9:Rate of service events per 10,000 population for non-admitted patient palliative care by socio economic areas, CESPHN region, 2023-24

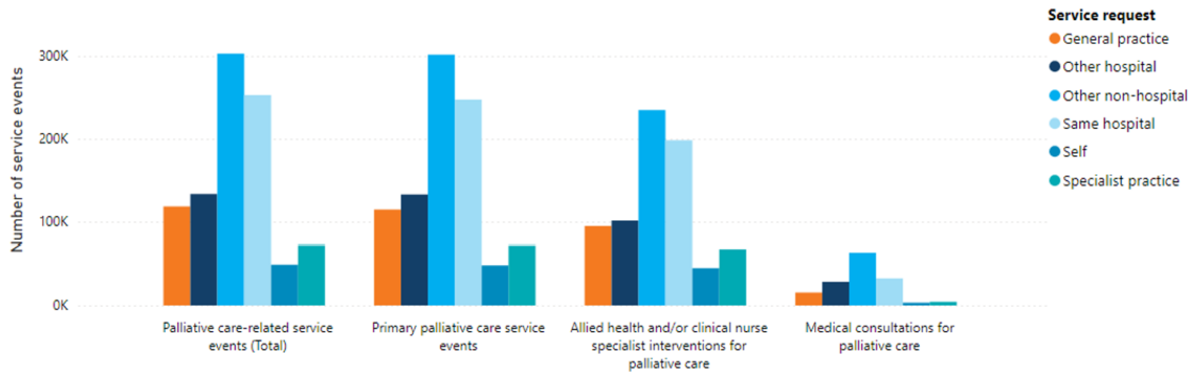
Source: AIHW 2025

Referral source for non-admitted palliative care patients nationally

In Australia in 2023–24, among the one million episode-level palliative care-related service events, over 1 in 3 referrals were from hospitals (24% was from the same hospital where service was provided and 13% from other hospitals) and almost 1 in 5 from medical consultations (12% from general practice, 7.1% from specialist practice).(2)

The first service events represent an umbrella category capturing all clinically relevant palliative care-related events, while the three subsequent service events are specific types of palliative care services (e.g., primary palliative care, medical, or allied health).(2)

Figure 10: Number of service events by palliative care service request source, Australia, 2023-24



Source: AIHW 2025

MBS Palliative care related service

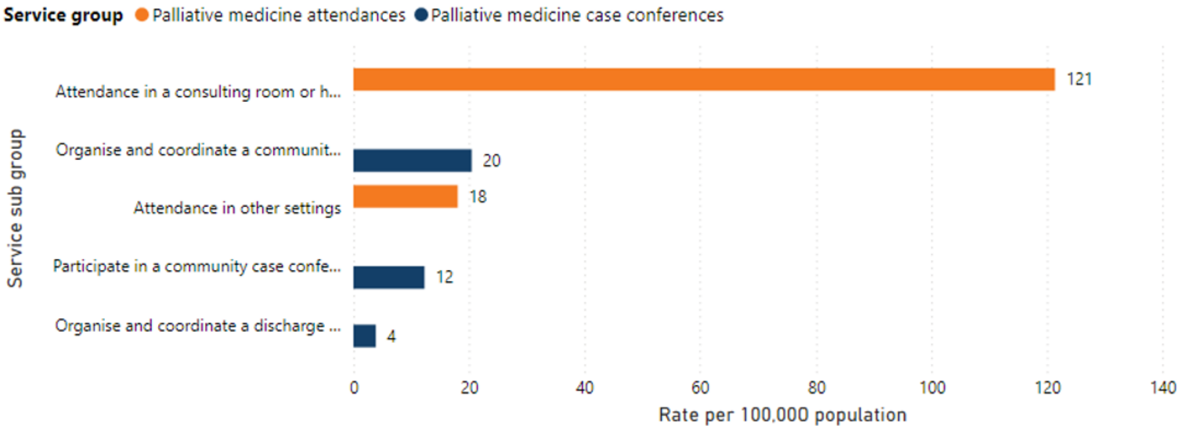
In 2023–24 in Australia, for MBS-subsidised palliative medicine attendances and case conference services delivered by palliative medicine physicians or specialists:

- 70,400 services were provided, averaging 4.9 services per person.
- 85% (59,800) of services were attendances in a consulting room or hospital, 3.3% (2,400) occurred in other settings, and 12% (8,300) were case conferences.(2)

Service volumes have declined from a peak of 90,600 in 2018–19 to 70,400 in 2023–24, representing an average annual decrease of 4.9%. This trend aligns with the reduction in the number of people receiving these services over the same period.(2)

In the CESPHN region, majority of services were attendances in consulting rooms or hospitals (121 per 100,000 population), with very few in other settings. Case conferences were rare, potentially indicating limited multidisciplinary coordination compared to direct clinical attendances.(2)

Figure 11: Rate (services per 100,000 population) by service group, CESPHN region, 2023-24



Source: AIHW 2025

Residential Aged Care Homes (RACH)

Residential aged care homes (RACHs) often face challenges in delivering palliative care due to high levels of multimorbidity, dementia, and functional disability among residents.(20)

In 2024, there were 10,975 residential aged care places across 149 RACHs in the CESPHN region.(17)

During 2022–23, CESPHN recorded 5,586 new permanent admissions to RACHs and 86% of exits from the RACHs occurred due to death.(18) In 2023–24, there were 2,597 exits from RACHs across the CESPHN region.(18) Of these exits, 95 individuals returned home or to the community, 60 were transferred to hospital, 130 moved to other residential care settings, and 167 exited for other reasons, including service termination, relocation outside the service area, or no reason recorded.(18) The remaining exits occurred as a result of death.(18)

While demand for palliative care in residential aged care is substantial, workforce capacity remains a key consideration in the delivery of high-quality care. General practitioners working in RACHs across the CESPHN region are supported to manage palliative care through access to LHD specialist palliative care outreach services, as required.

Anecdotally, palliative and end of life care training is increasingly recognised as essential for registered nurses and aged care workers. Increased uptake of effective training programs has shown to improve staff knowledge, skills, and attitudes towards palliative care in local RACHs, however, there remains scope for further improvement.

Furthermore, discussions with LHDs and disability advocates indicate that there are over 300 disability group homes within the CESPHN region. These are largely supported by disability support staff who may have limited knowledge and skills to deliver palliative care in the home setting. End of life care training is becoming increasingly recognised as essential for registered nurses and aged care workers, with growing uptake of effective training programs shown to improve staff knowledge, skills, and attitudes towards palliative care in local RACHs, however, there remains scope for further improvement.

Palliative care services from GP's

GPs play an important role in delivering palliative care in Australia, although the exact extent is challenging to quantify due to the lack of specific data collection. Data limitations include:

- A lack of nationally consistent, routinely collected primary healthcare data that specifically tracks palliative care services provided by GPs.(2)
- GPs use of general Medicare Benefits Schedule (19) items for chronic disease management and home visits when delivering palliative care.

Consultation with local GPs revealed the following challenges to providing palliative care:

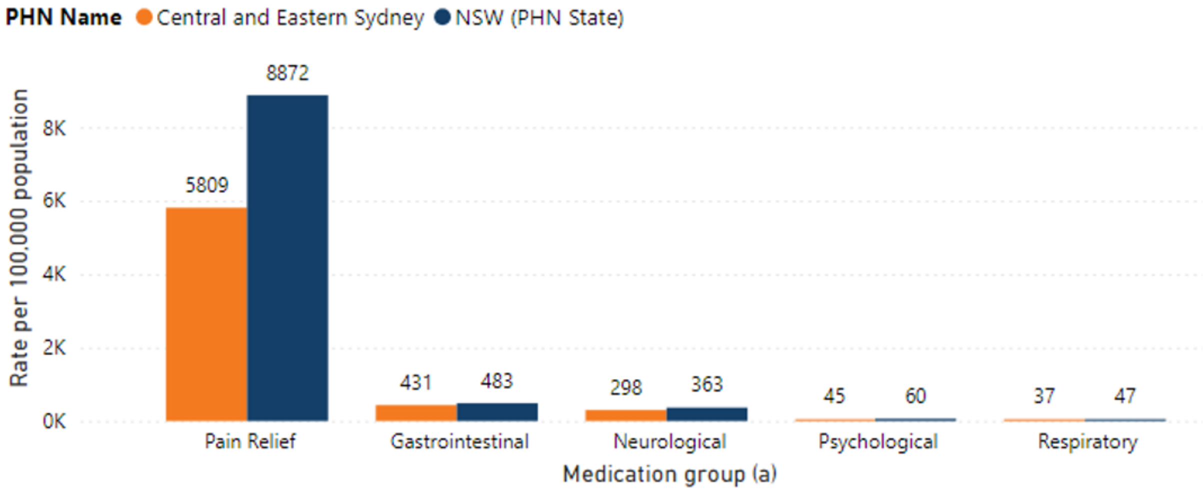
- Time demands in general practice and insufficient remuneration for home visiting.
- Communication with patients and their families about palliative care options and end-of-life decisions can be challenging, especially when patients are reluctant to engage in these discussions.
- Some GPs reported feeling they lack adequate training in palliative care, which can make managing complex symptoms and end-of-life care more difficult.(20)

Palliative care related medications

In Australia in 2023-24, general practitioners prescribed 90% of palliative care-related prescriptions. GPs were more likely than palliative medicine specialists to prescribe pain relief, conversely, specialists were more likely to prescribe for other symptoms.(2)

Within CESPHN pain relief dominates palliative care prescriptions, however prescription rates were considerably lower in comparison to those in NSW.

Figure 12: Rate of prescriptions per 100,000 population for PBS palliative care related medications, CESPHN region, 2023-24

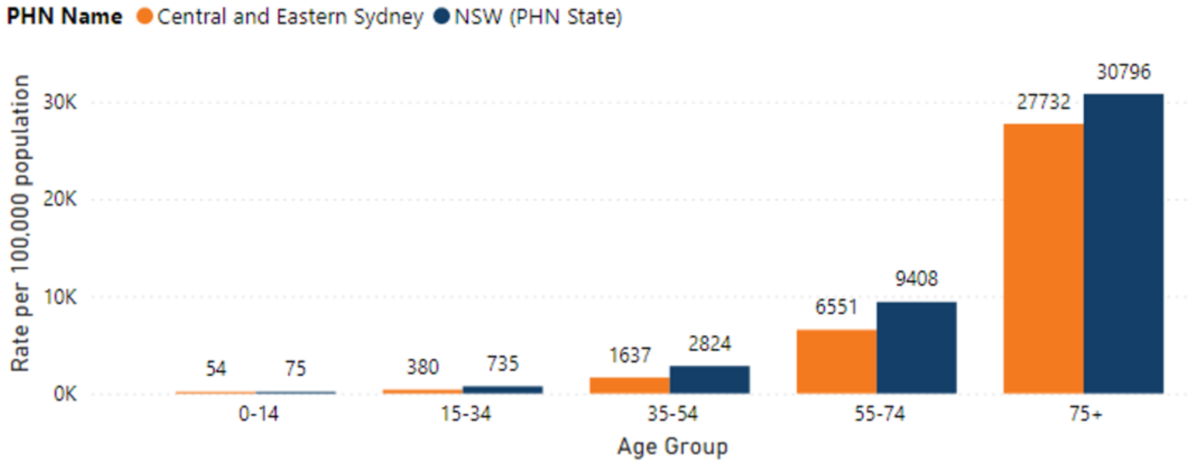


Source: AIHW 2025

Rates of prescriptions for PBS palliative care related medications are shown to rise with age, peaking in the 75 years and older age group, across both the CESPHN region and at the state level.(2)

This highlights an opportunity to focus GP education on palliative care principles, including anticipatory prescribing and effective symptom management.

Figure 13: Rate of prescriptions per 100,000 population for PBS palliative care related medications, CESPHN region, 2023-24



Source: AIHW 2025

End of Life Packages

Across NSW, end-of-life packages providing nonclinical packages of case management and home care services are available to support individuals who wish to die at home. These NSW Health funded packages can be accessed for 6 weeks at a time and are delivered to patients who are in the deteriorating or terminal phase of a life limiting illness or condition to assist them to remain at home for as long as possible.

Within the CESPHN region the combined number of end-of-life packages managed by LHDs in the CESPHN region each year totals more than 700, with demand for these packages exceeding capacity.

Voluntary Assisted Dying

Voluntary Assisted Dying (VAD) started in November 2023 in NSW. One of the key principles of voluntary assisted dying in NSW is a person's right to be supported to make informed decisions about their own medical treatment. This includes being provided with clear information about all available treatment options and likely outcomes, such as palliative care and other comfort focused approaches, for everyone seeking access to voluntary assisted dying-focused approaches, for everyone seeking access to voluntary assisted.(21)

Since the introduction of VAD in NSW, there were
- 398 VAD deaths reported between November 2023 and June 2024
- 1028 VAD deaths reported between July 2024 and June 2025.(21)

Education and awareness activities are in scope of the GCfAHPC, as part of the suite of general end of life education; however, VAD service delivery is not funded under GCfAHPC.

Palliative care needs

Patient needs

Quality palliative care needs include access to the following key supports:
- appropriate pain and symptom management
- effective advance care planning
- emotional, spiritual and psychological support
- support for people to meet cultural obligations
- counselling and grief support
- referrals to respite care services.(6, 7)

Discussions with CESPHN community stakeholders revealed:
- A lack of adequate knowledge of what palliative care is and what options are available in the community, particularly in the after-hours periods where some patients stated if in need of care they would default to the hospital emergency department.
- The misconception that palliative care is only for those who are at the end of their lives, when palliative care can be provided at any stage of a serious illness to improve quality of life and manage symptoms.
- An assumption that palliative care is expensive and concern around costs.
- Poor knowledge on how and where to start in documenting end of life plans and wishes.
- Poor knowledge and understanding of the wider death system, i.e. funerals, grief and loss.

Family and care giver needs

Family and care givers of palliative care patients are essential to an individuals end of life experience.

Feedback from carers of people with a life limiting illness have highlighted a lack of knowledge in relation to the range of helpful ways in which family and carers can support their loved ones. This includes the need for:

- helpful communication and training on how to provide care
- time out from caring through access to in-home or out-of-home respite
- timely information about avenues of financial support available and any associated entitlements
- opportunities to have their own physical, psychological and emotional needs addressed
- assistance with practical tasks to manage the load of caring
- timely access to support with grief and loss – such as counselling or participation in a bereavement support group.

Family and carers participating in local focus groups expressed

- a lack of knowledge on services and how to access be in not for LHD supports
- lack of confidence in discussing death and dying with a loved one, and how to go about initiating advance care planning discussions
- a lack of knowledge on how to go about support a person to die at home.
- greater need for practical knowledge and skills, such as coordinating care, navigating healthcare systems, and accessing community resources.

Healthcare provider needs

Primary healthcare providers interviewed and consulted with indicated they face several needs and challenges when delivering home based palliative care in community

- GPs and practice nurses highlighted the need to maintain a high level of up-to-date knowledge on end-of-life symptom management and the safe, appropriate use of palliative care medications.(1, 22)
- This pharmacological knowledge was also noted as a gap for general practice and RACHs nurses, who assess symptoms, and are required to administer medication, and monitor and document medication outcomes and report any side effects.
- Specialist palliative care teams reported a tendency for some GPs to refer palliative patients to specialist palliative care teams for less complex conditions that could be effectively managed by the GP either independently or with guidance and support.
- Specialist palliative care teams also identified a lack of GPs with a particular interest or expertise in palliative care limiting the workforce available to take on clients who do not have a regular GP.
- Specialist palliative care teams also noted that the limited number of GPs confident in palliative care creates challenges when trying to refer clients without an established primary care provider, further highlighting workforce capacity issues
- It was observed that some GPs would benefit from improved awareness of community palliative care services and referral pathways. This indicates a workforce development need, which could be supported through improved consumer resources, navigation tools, and targeted professional education.
- Access to more regular education and training opportunities to support the primary care workforce (GPs RACH registered nurses, practice nurses and aged care workers) was a noted request.
- Adequate staffing and skill mix was noted as a barrier to the delivery of effective palliative care for GPs in some RACHs. As was access to onsite palliative care medications and equipment to manage symptoms and provide comfort.
- Lack of coordination between services and clear patient pathways were mentioned as frustrations by health care providers and community and aged care workers.

Community needs

Increasing public awareness about the benefits of palliative care was noted as important to help ensure that more patients and families access these services and access them early in their illness.

Information attained from stakeholder consultations highlighted;

- inadequate community awareness of death and dying resulting in a perceived lack of acceptance of death generally, and a delay in planning for and transitioning to the final phase of life within the broader CESPHN community.
- a lack of palliative care volunteer support services and a need to integrate palliative care into broader health and community services, ensuring that it is accessible to all who need it.
- a need to engage communities more in discussions about death, dying, and bereavement to help normalize these topics and build supportive networks across the CESPHN region.

Barriers to access

Consultation with consumers, healthcare providers and the local palliative care community revealed the following key barriers to accessing palliative care in the CESPHN region.

Lack of awareness of services

Consultations identified that there is a need to strengthen community level palliative care promotion activities that address what palliative care is, and where and how people can access it. This includes:

- lack of knowledge amongst primary healthcare providers of local community based palliative care services.
- lack of access to service navigation tools for GPs and community to assist navigate palliative care services.
- lack of awareness of available for grief and bereavement.
- lack of awareness of after-hours palliative care supports.

Financial barriers

Understanding these costs and exploring available payment options can help families plan and manage the financial aspects of palliative care more effectively.

- Cost of care: the cost of palliative care can be a significant barrier for many families, particularly those from socio-economically disadvantages areas.(8) Costs can vary widely depending on several factors, including the setting, the level of care required, and the patient's specific needs.
- Funding Gaps: Access to non-clinical supports that help people remain at home at end of life is expected to improve with the rollout of the new Home Support Program’s End of Life Care Pathway coming into effect November 1, 2025.
- Remuneration: there are opportunities to strengthen GP engagement in palliative care by improving awareness and understanding of the MBS items already available for this work. Supporting GPs to confidently navigate and utilise these items may help make palliative care activities more cost effective and sustainable in general practice.
- Grief and bereavement impacts: Grief and bereavement can carry indirect costs, including long-term impact on mental health, productivity and community participation. While these costs may be more difficult to quantify, they remain significant for individuals and families experiencing them.(23)

- The Support at Home Program which commences November 1 could help address some financial barriers through its new End-of-Life Pathway, which offers up to $25,000 in funding over 12 weeks to support individuals at the end of life to remain at home for as long as possible.

Geographical barriers

As CESPHN is in a metropolitan area, coverage is quite good however some individuals with complex health issues, particularly the elderly and those living in RACH, may face difficulty traveling to specialist palliative care services.

Cultural barriers

As noted in the CESPHN demographic profile, CESPHN is home to a large number of diverse and multicultural communities. Multicultural communities may face many barriers to accessing palliative care services including:

- language barriers
- eligibility issues associated with visa status,
- cost of services with Medicare ineligibility,
- limited knowledge about services,
- unfamiliarity with and mistrust of health and support services,
- lack of provider cultural competence and responsiveness.(8)

Consultation with multicultural stakeholders revealed:

- Lack of awareness of information on how and where to find culturally appropriate palliative care support services in the CESPHN region.
- Issues with cultural sensitivity. It was identified that not all services are adequately tailored to meet the cultural and linguistic needs of diverse populations within the CESPHN region.
- Distinct cultural beliefs on palliative care across different multicultural communities contrary to western concepts of palliative care, death and dying.

Advance care planning

Advanced care planning can help people get their affairs in order, reduce stress and reduce rates of hospitalisation and length of stay, particularly in the last year of an individual’s life.(24) Despite the multiple benefits only 30% of Australians have a completed advance care plan.(25)

Common barriers to the uptake of advance care plans includes:

- lack of community awareness around what they are and how they can be used
- lack of infrastructure and time for discussions to be had
- limited workforce capacity and skills in addressing difficult end of life conversations.
- variability in patient attitudes, cultural differences
- clinician self-efficacy regarding establishing plans.

Advance care plans are completed in RACHs with mixed success. For example, a 2021 CESPHN RACH survey highlighted the following barriers faced by RACFs in preparing advance care plans for their residents:

- language and cultural’ at (32%)
- family and relative reluctance (29%)
- capacity - cognitive impairment, and mental illness preventing informed decision (9%)
- too early to discuss (9%).
- Other barriers identified include: too much information on admission; spiritual beliefs of staff.

Priority action areas

The following areas of action have been identified. For additional information regarding each priority action area, please refer to Appendix C.

Domain	SMART Goal	Measures / Indicators	Timeframe
Community Education & Awareness	Establish a regional palliative care collaborative with consumers, LHDs, councils and primary care to coordinate palliative initiatives.	TOR endorsed; membership confirmed; quarterly meetings held.	May 2026
	Deliver 30 public awareness activities as part of a regional palliative care campaign to reduce stigma and improve understanding.	Number of events; attendance; evaluation metrics; campaign reach.	Nov 2027
Advance Care Planning (ACP)	Deliver 6 community ACP workshops, reaching ≥100 participants and increasing confidence and understanding.	Attendance; pre/post confidence ratings; organisation participation.	Jun 2027
	Support 25 general practices to embed routine ACP discussions through QI and education.	Number of practices supported; documented ACP uptake; training records.	Dec 2026
General Practice Role in Palliative Care	Deliver 20 training sessions on the Support at Home - End of Life Pathway to increase homebased referrals.	Sessions delivered; GP attendance; referral patterns.	Jun 2027
Coordination & Integration of Care	Develop and publish a Support at Home - End of Life Pathway on SLHD and SESLHD HealthPathways.	Pathway completion; publication; stakeholder review.	Sept 2026
	Promote pathway awareness among GP practices.	HealthPathways page views; engagement metrics.	Dec 2027
Digital Health	Deliver 10 education sessions supporting My Health Record document upload and sharing.	Pre/post skill ratings; session attendance.	Nov 2027
Professional Education & Training	Deliver 10 CPD-accredited palliative care education sessions reaching ≥300 clinicians, achieving ≥70% knowledge gain and ≥90% satisfaction.	Attendance; survey data; evaluation scores.	Jun 2028
	Codesign and deliver 6 cultural safety sessions for LGBTQI+, multicultural, Aboriginal and Torres Strait Islander populations; train 100 providers; ≥80% confidence increase.	Attendance; pre/post confidence; codesign involvement.	Jun 2028
Community Development	Establish a formal palliative care collaborative with consumers and system partners to support integrated planning and community led palliative care improvement.	Collaborative established; TOR; membership; workplan.	Dec 2026

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List of Appendices

1. **Appendix A – Stakeholder consultation approaches**
2. **Appendix B – Stakeholder consultations**
3. **Appendix C – Priority action areas**

Appendix A: Stakeholder consultation approaches

Table 1. Health care providers

Stakeholder consultation approach	Definition
Shared decision making	Patient's values, goals and preferences are central to healthcare decisions made by the patient, their family, carers and clinicians.
Person-centred care	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 specialties 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.

Table 2 – Community stakeholders

Stakeholder consultation approach	Definition
Person Centred	Community perceptions in relation to understanding that palliative care is respectful of and responsive to individual's needs, preferences and values.
Death Literacy	Understand that communities varying levels of comfort discussing, and planning for, the dying process and death itself. Acknowledging and awareness around the reality of dying and death can help individuals to prepare for end of life in ways that are meaningful to them and their families.

Carers are valued and receive the support and information they need	Discussing and acknowledging the community health and wellbeing needs considered as a component of holistic palliative care, including bereavement support.
Care/ services are accessible	Community awareness and understanding are essential to ensure that care is accessible, respectful, culturally safe and appropriate according to need. Service navigation education is an essential element to ensure the accessibility.
Community engagement	Understanding community insight into specialist palliative care providers and that they have an important role to play across the health system in building the capacity of those providing palliative care, including people within the community, to ensure that people affected by life-limiting illnesses get the care they need. This helps to build compassionate communities that are self-sufficient.

Appendix B: Stakeholder consultations

Table 3. Stakeholder consultation participants

Stakeholder group	Participants
General Practice	• GPs, Practice nurses, Practice managers • Specialist and Community palliative care teams • SLHD and SESLHD, St Vincents Hospital Network, Sydney Children's Hospital Network, Calvary Health Care, Kogarah, War Memorial Hospital, Waverly.
RACHs and Disability group homes	• 6 of 149 RACHs in the CESPHN region • 5 Disability group Homes
Local Community Workshops	• 2 workshops with older people living in the community. • 2 workshops with people from local culturally and linguistically diverse communities. • 1 interview with a local Aboriginal and Torres strait Islander aged care provider service.
Local Community provider consultation	• 3 local aged care providers • 1 local disability providers • 3 local Councils • Other providers CESPHN local death system providers i.e., local death doulas, local memorial parks (cemeteries), funeral directors, and palliative care advocates.
Non-for-profit organisations	• Palliative care NSW
Expert panels	• CESPHN Palliative care advisory committee.

Appendix C: Priority action areas

Community education and awareness

The following actions have been marked to help strengthen community level awareness of what palliative care is, and where and how people can access it in the CESPHN community.

- Public awareness campaigns - raising awareness with community of what palliative care is encouraging early integration and better utilisation of services (community engagement activities and palliative care and end of life education seminars and workshops that normalise death and dying)
- Workshops designed to reduce stigma and change the perception of palliative care
- Development of an online palliative care service directory and consumer resources for general practice and the wider community
- Language and translation of information and resources
- Community events aligning with key dates i.e. palliative care week, dying to know day, advance care planning week e.g. workshops, film screenings, community conversations.
- Establishment of Death Cafes and community workshops on death literacy and advances care planning.
- Refinement and enhancement of palliative care referral pathways for accessing palliative care services

Opportunity exists to measure death literacy more specific to the CESPHN region using the Death Literacy Index (DLI), a comprehensive tool consisting of 29 items designed to assess various aspects of death literacy. The DLI evaluates four key subscales(11):

- Practical Knowledge: Understanding of practical aspects of end-of-life care, such as legal and financial matters.
- Experiential Knowledge: Personal experiences with death and dying, including caregiving and bereavement.
- Factual Knowledge: Awareness of factual information about death, dying, and end-of-life care options.
- Community Knowledge: Knowledge about community resources and support systems available for end-of-life care

Advance care planning

The following actions have been identified to improve awareness of what advance care planning and to help improve uptake advance care plans:

- advanced care plan workshops and education campaigns in the community to normalise advance care planning and end of life planning.
- promotion of advance care planning activities in general practice via an advance care planning toolkit featuring quality improvement activities for general practice.
- promotion of advance care planning activities in RACHs, and aged care community provider organisations (integration with workflows).
- Integration of advance care planning activities into other community programs e.g. healthy ageing hubs.

General practices with an expanded role in palliative care

The following actions have been proposed to help build leadership and strengthen access to quality primary care led palliative care in general practice.

- identify and support general practices willing to take on extended palliative care roles and responsibilities
- offer practice grants for practices to assist a small number of practices develop expertise and a leadership role in palliative care for their region.
- development and implementation of palliative care and end of life toolkits featuring quality improvement activities for general practice.
- deliver targeted training for the new Home Support End of Life Pathway ensuring GPs and practice nurses can assist implement palliative care in the home.

Coordination and integration of care

The following actions are proposed to assist coordination and integration of local palliative care services, reduce fragmented care and enable greater delivery home-based and community palliative care.

- review, development and enhancement of palliative care pathways in HealthPathways (SLHD and SESLHD HealthPathways)
- review and exploration of general practice clinical information systems for integration opportunities (automated uploading and sharing of patient information in MHR including transition of care documentation)
- facilitate telehealth consultations between specialists, GPs and RACHS.
- support for implementation of shared care models linking primary care, specialist palliative care teams and aged care providers.

Digital health

The following actions relating to care delivery, information sharing and data led improvements are proposed:

- education and training informing GP's, primary health care workers, RACH staff and consumers on how to navigate and upload documents into My Health Record.
- support for continued development of MHR and roll out of the MyHealth app which incorporate uploading and sharing of completed advance care plans
- expanded use of telehealth where appropriate, to make care more readily available and more efficient in both in hours and after hours

Training and education

The following training and education is proposed to strengthen primary care workforce capacity:

- provide training for GPs, practice nurses, RACHs staff in palliative care symptom management and end-of-life conversations (workshops, masterclasses, webinars and CPD events), this includes the following primary care provider groups:
- provision of cultural competency training to providers servicing priority populations (LGBTQI+, multicultural and Aboriginal and Torres Strait Islander peoples).
- provision of targeted dementia-care training and programs to improved awareness of dementia and palliative care community.

Advocacy

With the introduction of the new Home Support programs funding End-of Life Pathway, advocate for:

- system improvements that that enhance access to quality palliative care delivered in the home.
- equitable access to subsidised palliative and end-of-life care for all consumers
- adequate support for GPs and aged care community providers to provide palliative care in the home and in aged care settings.

Community development

With compassionate communities and public health approaches to palliative care beginning to build momentum foster collaboration local leadership through.

- partnering with key stakeholders; consumers, LHDs, local government and primary care providers to codesign and implement compassionate community initiatives
- development of community networks of volunteers and local organisations capable of providing practical assistance and companionship to those in need, strengthening grass roots capacity.
- establishment of community ambassadors within compassionate communities to identify local needs, connect people to services, and champion awareness of available supports.