Palliative Care

Needs Assessment Update

December 2025

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NEPEAN BLUE MOUNTAINS
An Australian Government Initiative

Wentworth Healthcare
Blue Mountains | Hawkesbury | Lithgow | Penrith

Update December 2025

We acknowledge the traditional custodians of the lands on which we work and pay our respect to Aboriginal Elders, past, present and emerging. The Darug, Gundungurra and Wiradjuri people are acknowledged as the traditional owners of the land in our region.

Cranes are a sacred bird in Japan that are a symbol of living a long life (a ‘thousand years’). Legend says that in making a thousand origami cranes your wish will be granted. Sadako Sasaki, a young Japanese girl who contracted leukaemia from the atomic bomb dropped on Hiroshima in 1945, made over a thousand paper cranes in her journey with the illness. Through Sadako’s story, the paper crane has become a symbol of hope, determination, and peace.

Read more about Sadako’s story and the paper cranes here:
theelders.org/news/story-sadako-sasaki-and-hiroshima-peace-cranes
sadakosasaki.com

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EXECUTIVE SUMMARY

The Nepean Blue Mountains Primary Health Network (NBMPHN) is pleased to present our 2025 Palliative Care Needs Assessment update, detailing the health and service needs of the Nepean Blue Mountains (NBM) region for palliative care.

The needs assessment consists of two key components – an analysis of the health and service needs of our local population, and an assessment of the gaps and priorities that will support planning opportunities to address the palliative care needs in the region.

The NBM region has an increasing ageing population leading to increased demand for local palliative care services. People living in the Blue Mountains, Hawkesbury and Lithgow areas experience significant barriers to accessing palliative care services, which are centered around the Penrith area.

A range of providers are involved in the delivery of palliative care services which include general practitioners, pharmacists, allied health professionals, palliative care physicians and nurses and end of life doulas. It is expected that there will be an increase the number of death doulas* as the role becomes more recognised as a valuable support for people at end-of-life.

Whilst recently the region has received an uplift of palliative care services to support people in residential aged care homes (RACH) and during the after-hours period in the community. The palliative care needs assessment identified gaps in access and equity of services especially in more rural areas of the region, variable continuity of care - particularly in the after-hours period, lack of knowledge and awareness of available services, cultural responsiveness and system level capacity challenges which are contributing to inequitable and fragmented palliative care delivery.

Key recommendations for improving palliative care in the NBM region include:

- Integrated care pathways strengthening the collaboration between palliative care providers, utilising digital integration and shared communication systems.
- Responsive home-based support with expanded service coverage including in the after-hours period.
- Increased access to education and training for health professionals and community.
- Improved communication channels with established clearer pathways between health professionals.
- Opportunities to increase collaborative practices ensuring structured feedback mechanisms and documentation.
- Single point of contact creating a centralised referral hub for all palliative care services.
- Enhanced infrastructure and resources with increased palliative care beds supporting equitable distribution of services across the region.
- Development of models to support culturally appropriate care recognising diverse needs of priority population groups.

This needs assessment update will support prioritising activities that improve access to safe, quality palliative and supportive care in the community as part of Greater Choice for At Home Palliative Care program.

**Death doulas provide valuable non-medical, holistic support to people who are dying and their families, but it is important to note that death doulas are not currently a regulated profession in Australia.*

BACKGROUND

In June 2022, Wentworth Healthcare, provider of the Nepean Blue Mountains Primary Health Network (NBMPHN), commissioned Synergia to conduct a palliative care needs analysis for the Nepean Blue Mountains (NBM) region. This assessment is an update to our needs analysis for palliative care as part of the Greater Choice for at Home Palliative Care program. The aim of this needs assessment is to increase our understanding of palliative care services in our region and the need for these services. The findings from our palliative care needs assessment update will support our goals for improving the efficiency, effectiveness and coordination of health services for people in our region. The palliative care needs assessment process was supported by survey findings, desktop and data analysis and consultation with key stakeholders in the NBM region.

While the Australian Government Department of Health, Disability and Ageing has contributed to the funding of this material, the information contained in it does not necessarily reflect the views of the Australian Government and is not advice that is provided, or information that is endorsed, by the Australian Government. The Australian Government is not responsible in negligence or otherwise for any injury, loss or damage however arising from the use of or reliance on the information provided herein.

INTRODUCTION

The Palliative Care Needs Assessment Update has been informed by our Needs Assessment 2025, Annual Report 2025, Palliative Care Needs Analysis Survey and the Palliative Care Needs Analysis 2022.

In 2025 we conducted a survey comprised of 29 questions, which received a total of 50 responses from across all four local government areas (LGAs) in our region – Blue Mountains, Hawkesbury, Lithgow and Penrith. Our respondents provided considered feedback from different perspectives, including general practice, allied health, community and specialists. Outcomes from this consultation process are outlined within this needs assessment.

An important element of our needs assessment is our continued close collaboration and regular engagement with our Palliative Care Advisory Committee (PalCac). The PalCac has representatives from the NBM Local Health District (NBMLHD), community health, local general practitioners, residential aged care homes (RACHs), NSW Ambulance and community representatives. Our PalCac provides expert advice and guidance on an integrated and coordinated approach to support people to receive quality palliative care services at home in our region. We acknowledge and appreciate the ongoing support of our PalCac representatives.

We would like to acknowledge our funding as part of the *Greater Choice for At Home Palliative Care – an Australian Government Initiative*.

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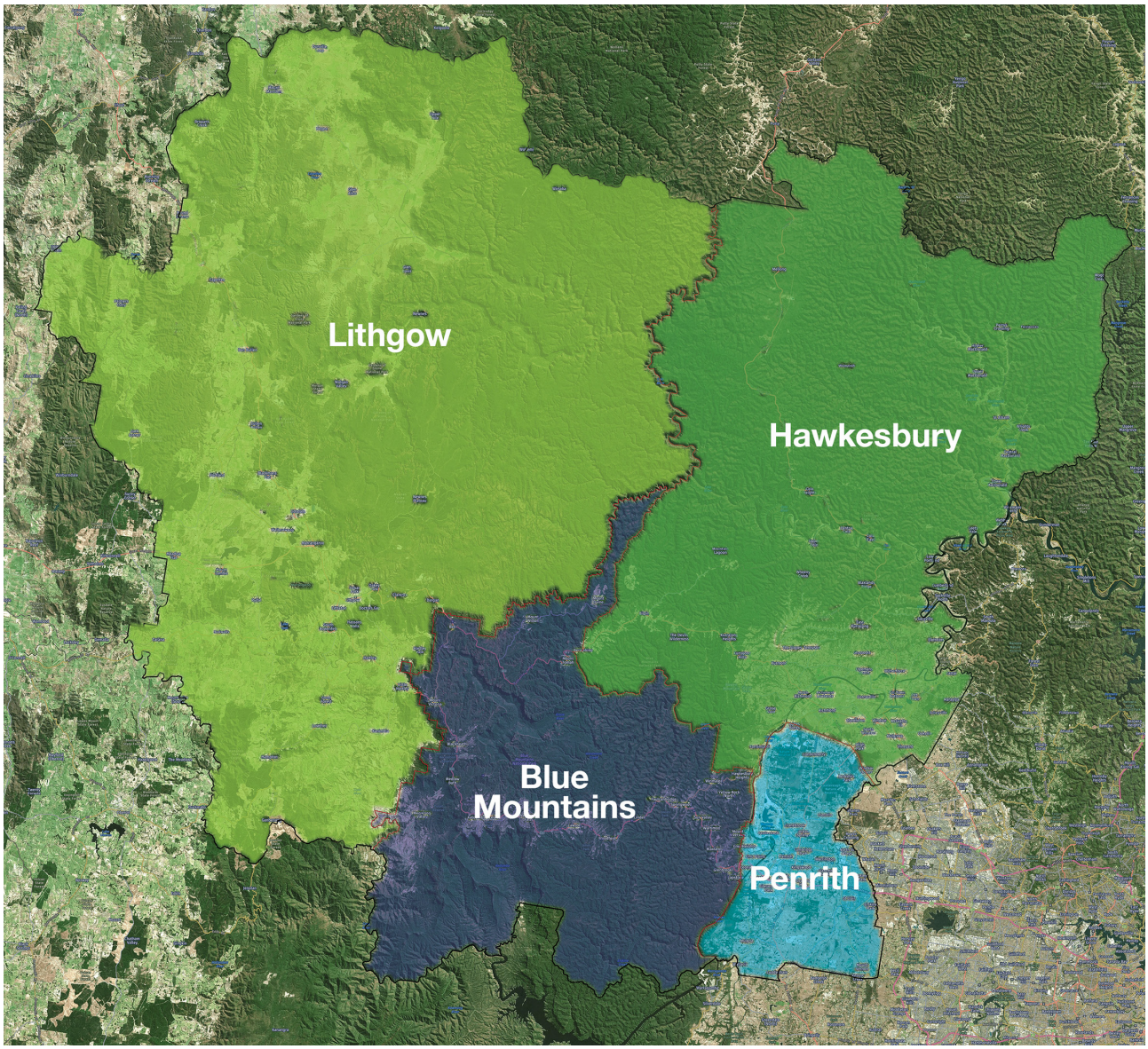
HEALTH NEEDS ANALYSIS

The NBM region has an ageing population. We are responsible for improving the health and wellbeing of people living in the NBM region. The current population of 396,996 projected to reach 452,747 by 2041. The projected growth in the older population aged 65 years and older will significantly increase the demand for local palliative care services. Currently 16.43% of the NBM population is over 65 and this is expected to increase to 22.33% by 2041, slightly lower than the NSW expected increase of 22.58%[1].

As demand for palliative care in our region is projected to rise, deaths per year are also expected to increase from 2,240 in 2022 to 3,500 by 2041.[2] Major challenges remain in the coordination of palliative services, with limited capacity and capability in the healthcare workforce, frequent delays in referrals and a lack of integrated electronic shared care plans. Key findings from recent consultations with stakeholders highlight the need for earlier engagement in palliative care and better accessibility to general practitioner (GP) services. Additionally, a low rate of advance care planning documentation particularly in RACHs contributes to gaps in care coordination.[2]

Nepean Blue Mountains region



Geography

The NBM region covers an area of 9,123 square kilometers, consisting of urban, rural, and regional areas. The traditional owners of these lands are the Wiradjuri people (Lithgow), the Darug people (Blue Mountains, Penrith and Hawkesbury), the Gundungurra people (Blue Mountains) and the Darinjung people (Hawkesbury).

- The Blue Mountains LGA covers 1,431 square kilometres, with approximately 74.8% of the area designated as protected land, 99% of which is in the World Heritage-listed Blue Mountains National Park.
- The Hawkesbury LGA spans 2,775 square kilometres, with 72.5% protected land and 18.1% of the protected area being covered by one of three national parks.
- The Lithgow LGA spans 4,512 square kilometres of which 12% is part of a national park.
- The Penrith LGA is the smallest LGA of the region at 404 square kilometres. Only 7.9% of the area is protected land, with 2% of the area covered by national park.

Demography

The Blue Mountains is home to a community of over 78,800 people. Almost 3% of the Blue Mountains population identify as Aboriginal and Torres Strait Islander peoples and 17.3% were born overseas.

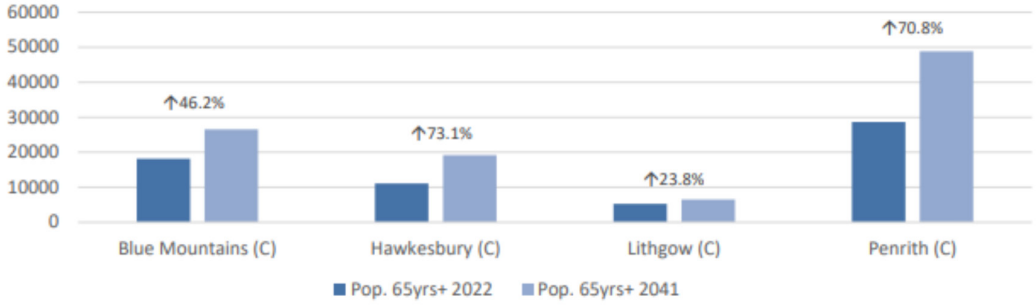
Hawkesbury LGA is home to 68,704 residents living in urban and rural communities. Around 4.8% of the population identify as Aboriginal and Torres Strait Islander peoples and over 13% of the population were born overseas.

Lithgow is the largest LGA of the region but sparsely populated by less than 21,000 people. Lithgow has the highest percentage of the population who identify as Aboriginal and Torres Strait Islander peoples at 7.7%, and the lowest percentage of people born overseas at 10.1%.

The Penrith LGA has the highest population density of the region, home to more than 228,661 people that reside across 36 suburbs. Aboriginal and Torres Strait Islander people make up approximately 5.0% of the Penrith population and 23.1% were born overseas.

For people living in the Blue Mountains, Hawkesbury and Lithgow areas there can be significant barriers to accessing healthcare services, which are centered around Penrith. This is exacerbated by the significant size of the region. Limited transport options, and workforce shortages reduce access to GPs and RACHs. The NBMLHD provides approximately 44 palliative care services across the four LGAs[3].

Figure 1: Nepean Blue Mountains region



Health Determinants

The NBM region comprises four LGAs with diverse geographical characteristics. The region has a higher proportion of Aboriginal and Torres Strait Islander peoples compared to the NSW average 4.7% vs 3.4%. The region also has a diverse cultural makeup. In 2021, 19.7% of residents were born overseas, lower than the state average of 29.3% for New South Wales. English language proficiency varies across the region. Penrith LGA has the highest proportion of residents who report that they "speak English not well" or "not at all" (2.2%).[2]

According to ABS data, individuals with limited English proficiency face greater challenges in accessing healthcare, employment, education and other essential services. The region's Socio-Economic Indexes for Areas (SEIFA) scores indicate levels of disadvantage: Lithgow has the highest level of disadvantage with a score of 935, followed by Penrith (991), Hawkesbury (1026), and the Blue Mountains (1048). The region faces socio-economic disparities, with some areas experiencing extreme disadvantage, especially affecting access to health services.

Each LGA has its unique characteristics and demographics, which impact health and access to services in the NBM region which include palliative care services.

Health Status

The median age at death in Australia for males is 79.6 and for females is 84.6 years, which is higher than the NBM region reported in Table 1.[4]

Premature deaths are deaths that occur at a younger age, which in this report are deaths among people aged under 75. Table 1 indicates the number and percentage of premature deaths compared to total deaths. Premature deaths represent almost 40% of total deaths in our region.

Potentially avoidable deaths (PADs) are a measure of health system performance, where deaths occur among people aged under 75 that are avoidable in the context of the present healthcare system. PADs include deaths from conditions that are potentially preventable through individualised care and/or treatable through existing primary or hospital care. PADs are classified using nationally agreed definitions.[5] The total number of PADs in our region was 443, which is approximately 17% of total deaths.

Table 1. Death due to all causes in 2023 in the NBM region[6]

	Total deaths	Population	Median age at death	Premature deaths* (aged under 75)	Premature deaths % of total deaths	Potentially avoidable deaths	Potentially avoidable deaths % of total deaths
Males	1,324	194,909	77.8	568	42.9	257	19.4
Females	1,234	197,463	82.5	390	31.6	186	15.1
TOTAL	**2,557**	**397,372**	**79.8**	**957**	**37.4**	**443**	**17.3**

The leading causes of death are based on underlying causes of death and classified using an AIHW-modified version of *Becker R, Sivli J, Ma Fat, L'Hours A, Laurenti R. 2006. A method for deriving leading causes of death. Bulletin of the World Health Organization 84: 297–304*. ICD-10 codes from the International Statistical Classification of Diseases and Related Health Problems, a medical coding system developed by the World Health Organization (WHO), are presented in parentheses. The majority of deaths in our region are from coronary heart disease (10.9%) followed by dementia (6.4%) then cerebrovascular disease (5.3%).

Table 2. Top ten causes of death 2019-2023 in the NBM region

Cause of death (ICD-10 codes)	Deaths	Percent of all causes
Coronary heart disease (I20–I25)*	1,328	10.9
Dementia including Alzheimer's disease (F01, F03, G30)**	775	6.4
Cerebrovascular disease (I60–I69)*	644	5.3
Lung cancer (C33, C34)***	602	4.9
Chronic obstructive pulmonary disease (COPD) (J40–J44)	522	4.3
Diabetes (E10–E14)*****	396	3.2
Colorectal cancer (C18–C20, C26.0)***	393	3.2
Heart failure and complications and ill-defined heart disease (I50–I51)*	304	2.5
Pancreatic cancer (C25)***	253	2.1
Breast cancer (C50)***	251	2.1
All causes	**12,205**	**100.0**

*Diseases of the circulatory system**
*Mental and behavioural disorders (F00–F99)***
*Neoplasms****
*Diseases of the respiratory system (J00–J99)*****
*Endocrine, nutritional and metabolic diseases (E00–E90)******

Palliative Care-related Hospitalisations and Events

Palliative care-related hospitalisations refer to those episodes of admitted patient care where palliative care was a component of the care provided during all or part of the episode. These hospitalisations can be divided into two groups, depending on how they are identified in the hospital data:[7]

1. Primary palliative care hospitalisations: with a recorded care type of palliative care, and
2. Other palliative care hospitalisations: with a recorded diagnosis of palliative care, but the care type is not recorded as palliative care.

Table 3. Data provided for palliative care-related hospitalisations in NBM region and principal diagnosis.

Age Group	Primary palliative care hospitalisations		Other palliative care hospitalisations		Palliative care related hospitalisations	
	Number	Percent	Number	Percent	Number	Percent
Cancer	361	44	187	34	548	34
Non-cancer	452	56	627	66	1,079	66
TOTAL	**813**	**100**	**814**	**100**	**1,627**	**66**

Palliative care-related service events refer to non-admitted patient care service events where the primary clinical purpose or treatment goal is optimisation of the quality of life of a patient with an active and advanced life-limiting illness. These service events must contain therapeutic/clinical content and result in a dated entry in the patient's medical record. They can be divided into three groups, depending on how they are identified in the non-admitted patient care data:

1. Primary palliative care service event: non-admitted patient care service event with a recorded care type of palliative care.
2. Medical consultation for palliative care: non-admitted patient care service event.
3. Allied health and/or clinical nurse specialist intervention for palliative care: non-admitted patient care service event.

Table 4. Data provided for admitted patients in NBM region and age group for 2023-2024

Age Group	Admitted patient palliative care – Number of hospitalisations
0-14	42
15-34	36
35-54	115
55-74	585
75+	850
TOTAL	**1,627**

In-patients may have multiple service events per admission.

Table 5. Data provided for non-admitted patients in NBM region and age group for 2023-2024

Age Group	Non-admitted patient primary palliative care -Number of service events
0-14	162
15-34	118
35-54	298
55-74	1,188
75+	1,473
TOTAL	**3,243**

Table 6. Data provided for NBM region for 2023-2024 for hospitalisations and service events

Socio-economic areas*	Admitted patient palliative care – Number of Hospitalisations	Non-admitted patient primary palliative care – Number of service events
1	329	875
2	258	547
3	461	830
4	350	597
5	227	393
TOTAL	**1,627**	**3,243**

*Socioeconomic areas = 1 (lowest) to 5 (highest)

The SEIFA Index of Relative Disadvantage (IRD) is one of the ABS's SEIFA indexes. The relative disadvantage scores indicate the collective socioeconomic status of the people living in an area, with reference to the situation and standards applying in the wider community at a given point in time. Socioeconomic status is based on the geographical region in which a person usually resides.[8]

Palliative Medications

In Australia there were 1,446,833 medications prescribed, with 455,020 in NSW. In NSW in 2023-2024 the majority of medications prescribed for palliative care were for pain relief, through 374,544 prescriptions. The next most prescribed medications were for gastrointestinal symptoms with 40,658 prescriptions and neurological symptoms with 30,708 prescriptions. Respiratory and psychological medication were the other major medications prescribed during that time. GPs were the most frequent prescribers for all types of medication. In 2023-2024 in the NBM region there were 24,569 prescriptions for palliative medications for just over 8,000 people representing 3.1 prescriptions per person. This represented only 1.7 % of prescriptions in Australia for that year.[8]

Table 6 provides information about palliative care-related prescriptions from the Palliative Care Schedule under the Pharmaceutical Benefits Scheme (PBS), the Repatriation Pharmaceutical Benefits Scheme (RPBS) and the characteristics of people who received them over the period 2023–24. Overall, in Australia during 2023–24:

- 1.4 million palliative care-related prescriptions were provided to 474,000 people, equating to 3.1 prescriptions per person
- 1.1 million palliative care-related prescriptions were for pain relief, representing 79% of all prescriptions
- GPs prescribed 90% of palliative care-related prescriptions

Table 7. Palliative care-related medications from PBS Palliative Care Schedule and people receiving them, by NBM region and medication group, 2023-24

Medication group	Number of people	Number of prescriptions	Prescriptions per person
Pain Relief (Anti-inflammatory and antirheumatic products, non-steroids)	2,282	4,217	1.8
Pain Relief (Opioids)	1,468	6,514	4.4
Pain Relief (Other analgesics and antipyretics)	3,080	10,391	3.4
Pain Relief (Subtotal)	**6,830**	**21,122**	**3.1**
Gastrointestinal	629	1,632	2.6
Neurological	457	1,424	3.1
Respiratory	45	245	5.4
Psychological	56	147	2.6
TOTAL	**8,017**	**24,569**	**3.1**

Population with Special Needs

There may be inequities to receiving palliative care services for people in rural and regional communities, culturally and linguistically diverse communities (CALD), for Aboriginal and Torres Strait Islander peoples, LGBTIQA+ communities and people with disabilities. Outcomes from the palliative care survey demonstrated the majority of respondents reported they had not experienced inequities for people accessing palliative care services from these priority populations. However, for those who described the inequities experienced, they reported that:

- Group homes lack registered nurse (RN) support for administering breakthrough medication and end-of-life care.
- Healthcare resources are often inflexible, limiting person-centred approaches that require adaptability.
- Services need to be more inclusive, particularly for CALD populations, migrants and pensioners.
- People with low health literacy, non-English speakers, those from non-English speaking backgrounds and those without family support, face additional barriers in navigating and receiving support and access to services
- Remote patients face difficulty accessing respite care workers who are unwilling to travel. Transport to respite care is limited, with poor public transport options (e.g. Hawkesbury area).
- Some individuals are “asset rich but cash poor” (e.g. those owning farms), leading to low eligibility for financial assistance with home help.
- Patients with chronic conditions or who are immunocompromised are sometimes forced to attend hospitals despite needing home visits.

Recommendations to better support access for priority population groups involve:

- Providing NDIS-funded short-term RN packages for end-of-life care.
- Strengthening education and funding to support equitable service delivery.
- Providing care based on individual need, not restricted by resources or strict systems with greater flexibility across all care settings.
- Increasing services beyond Penrith to ensure equitable geographic coverage.
- Improving access to respite care and transport for carers and patients.
- Offering equitable financial assistance for those in need.
- Providing social workers, interpreting services and translators to assist CALD and vulnerable populations.
- Strengthening the GP-patient relationship to coordinate and personalise care.
- Consider language when referring to palliative case, using terms such as chronic care, comfort care and end-of-life care where appropriate, to reduce stigma and fear

SERVICES NEEDS ANALYSIS

Workforce Mapping

General practitioners

GPs contribute significantly to the palliative care of patients.[9] However, more support is needed for GPs delivering palliative care. A key barrier for GPs delivering palliative care is a lack of funding, particularly appropriately funded palliative care specific MBS item numbers.[10] As of November 2023, new MBS Level E consultation items are available for longer consultations, allowing for better management of patients with palliative and end-of-life care needs.[11] There is also specific remuneration for GPs providing palliative care services within RACHs, however this needs to be appropriate with the complexity of care required for individuals living in RACHs. According to RACGP – General Practice: Health of the Nation report, approximately 14% of GPs work in RACHs and only 1% of GPs (surveyed) main type of practice was residential aged care.

Pharmacists

Community pharmacists can be remunerated for undertaking palliative care services related to medication management. The Pharmaceutical Society of Australia offer the ASPIRE Palliative Care Foundation Training Program, which was offered in 2025 to equip pharmacists with essential palliative care skills. The RACGP aged care clinical guide (Silver Book) for GPs acknowledges the role of pharmacists in providing team based palliative care as a member of the multidisciplinary palliative care team for patients.[12]

Allied health professionals

The Medical Benefits Scheme has several items for funding palliative care activities that are being undertaken in the primary healthcare setting by allied health professionals. This includes Aboriginal health workers or Aboriginal and Torres Strait Islander health practitioners, dietitians, mental health workers, occupational therapists, physiotherapists, podiatrists, psychologists and speech pathologists, who can all be involved in a patient's palliative care provision.[13]

Palliative care physicians and nurses

In 2022, there were 335 palliative care physicians and 3,700 palliative care nurses employed in Australia, mostly in hospitals. In NSW in 2023, there were 124 palliative care physicians and 1,134 nurses.[14] On average physicians worked 36 hours per week (including 29 clinical hours). Palliative care nurses worked on average 34 hours (including 31 clinical hours).

End-of-life doulas

An end-of-life or death doula can support a person who is palliative and their family and carers in a non-clinical role, from diagnosis or decline through to the death and bereavement. The doula role can complement the health professional's role and they can assist community and social services to work alongside clinical services.[15]

Types of services provided by death doulas

The time and services provided by death doulas vary according to the needs of the family and dying person. A doula can assist for many months, depending on the circumstances. There are a range of services that a doula can provide during pre-death, active dying and after death[16], including:

- Assisting to navigate the health system and accompanying the person and/or family to appointments
- Advocating for a person's end-of-life wishes
- Providing in-home respite for carers
- Advance care planning discussions and documentation
- Documenting end-of-life wishes
- Planning a funeral or rituals
- Assisting with companionship and activities that bring the person comfort
- Supporting spiritual and/or cultural wishes
- Non-clinical task coordination
- Supporting grief and bereavement after death.

Training and projected numbers

There are 299 end-of-life doulas in NSW, however this could be higher as not all doulas complete the four-day intensive training. The potential number of doulas in 2030 is projected to be 438 in NSW. NSW has the highest number of death doulas in Australia. As the role becomes more recognised, death doulas could potentially complement clinical services.[15]

There are different training courses for death doulas depending on interests and needs.[17] Each of them builds on the material from the previous course. Some are free and others incur costs with different organisations offering specific training.

Death Literacy Survey

Death literacy is the knowledge and skills that people need to make it possible to gain access to, understand and make informed choices, about end-of-life and death care options. People and communities with high levels of death literacy have context specific knowledge about the death system and the ability to put that knowledge into practice.

The Death Literacy Survey (DLS) provides a means to measure and research public health palliative care initiatives, including those under the umbrella of Compassionate Communities, by exploring the ways in which community members' knowledge and practice are enhanced through these initiatives.

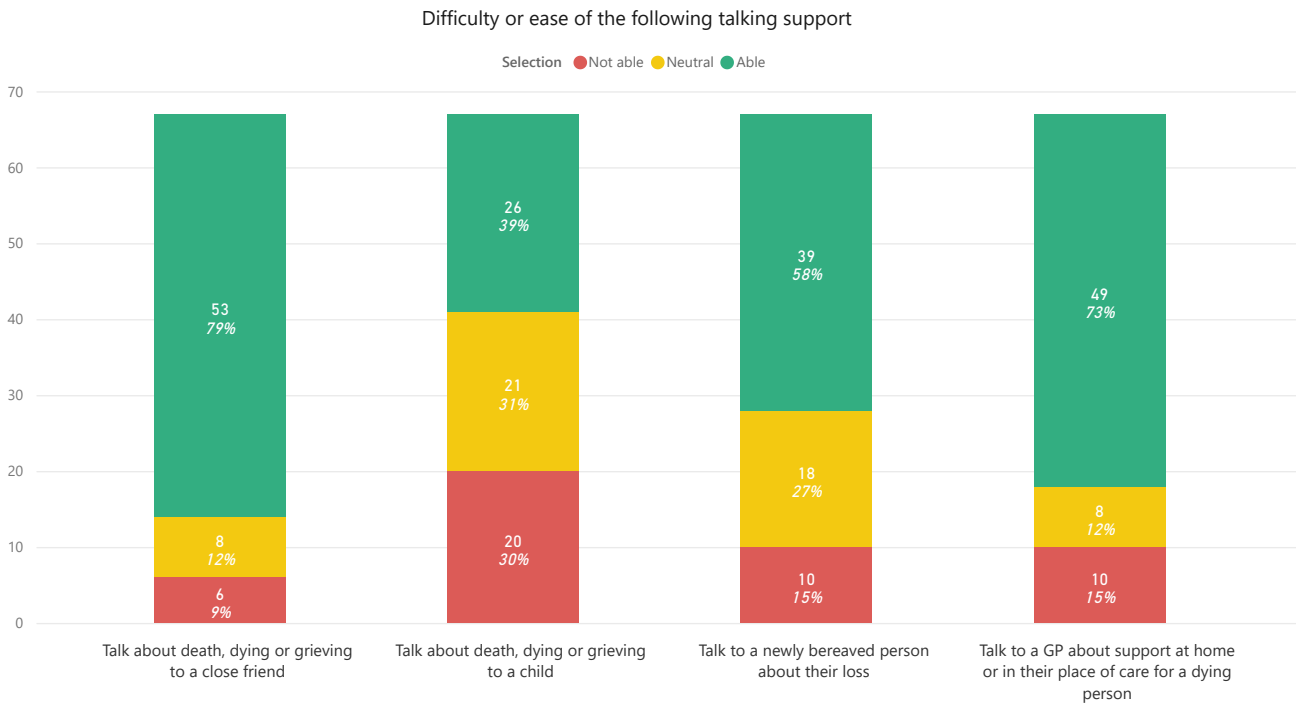
The DLS consists of four subscales:

1. Practical knowledge (talking support and hands-on-care)
2. Experiential knowledge
3. Factual knowledge
4. Community knowledge (community support groups and accessing help)

The DLS can be used as a tool for determining the current level of death literacy in a community, organisation or nation, to help in targeting of interventions and the impact of interventions to address gaps in death literacy and/or build on existing strengths. This can contribute to knowledge of successful strategies and interventions in the end-of-life field.[18]

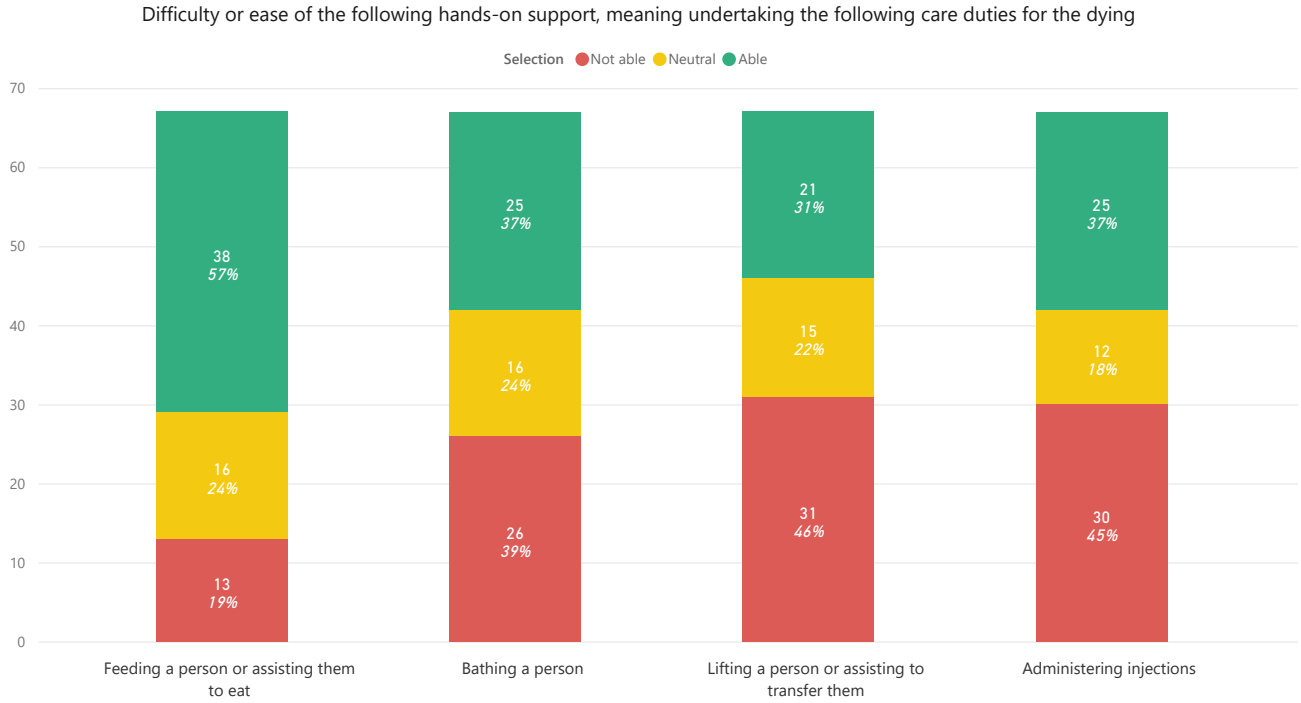
We distributed the DLS throughout our community and received 67 responses. DLS responses were received from Blue Mountains (30), Penrith (17), Hawkesbury (10) and out of our region (10). More respondents reported they have a Power of Attorney (26%) compared to an Enduring Guardian (24%), followed by having an Advance Care Directive (15%).

Figure 2. Talking to others about death and dying



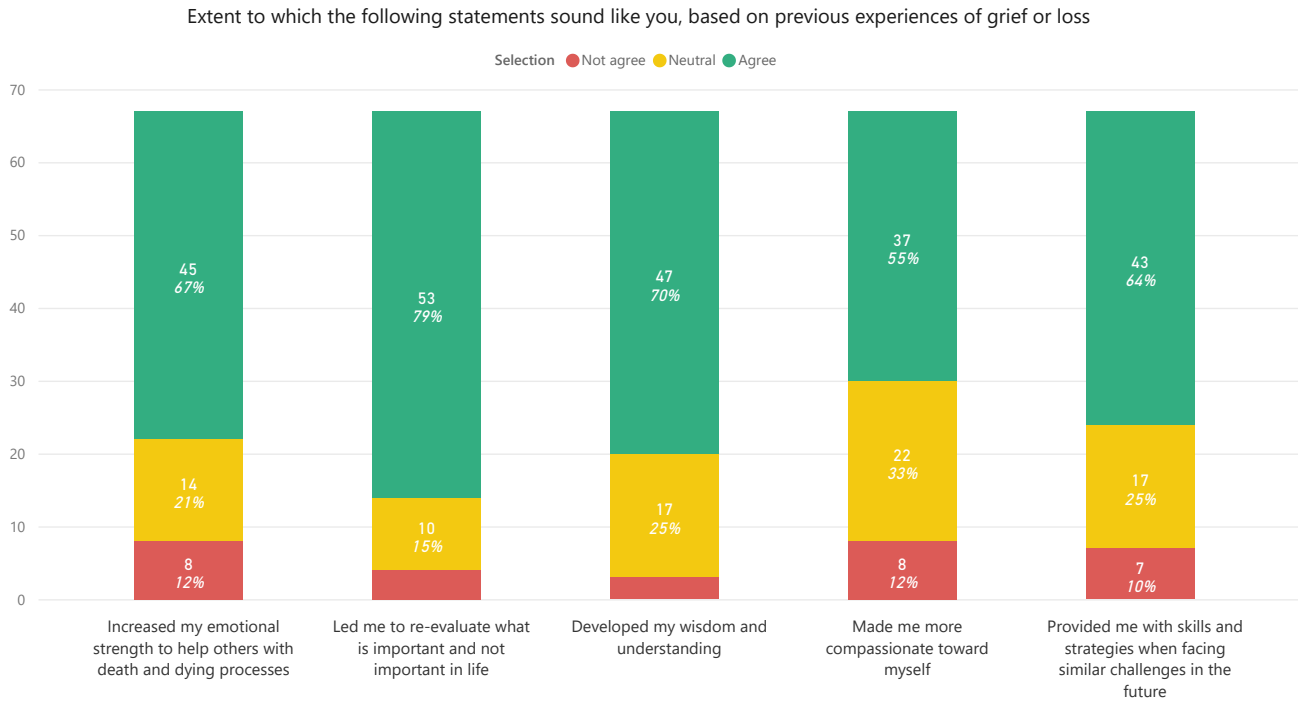
The majority of respondents felt more comfortable talking about death, dying or grieving to a close friend and talking to a GP about support at home, compared to talking about death to a child.

Figure 3. Providing support



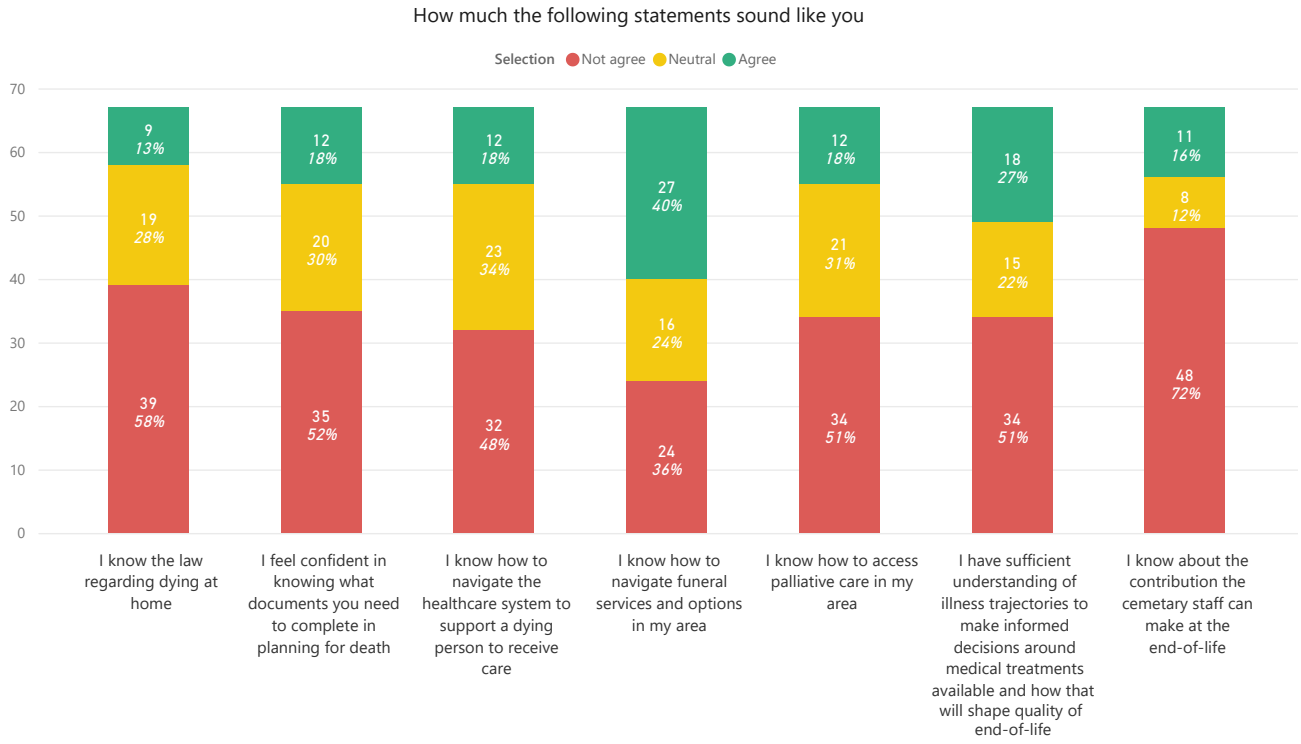
More respondents felt comfortable assisting a person to eat compared to bathing a person, administering injections and lastly transferring a person.

Figure 4. Experience and impact of grief and loss



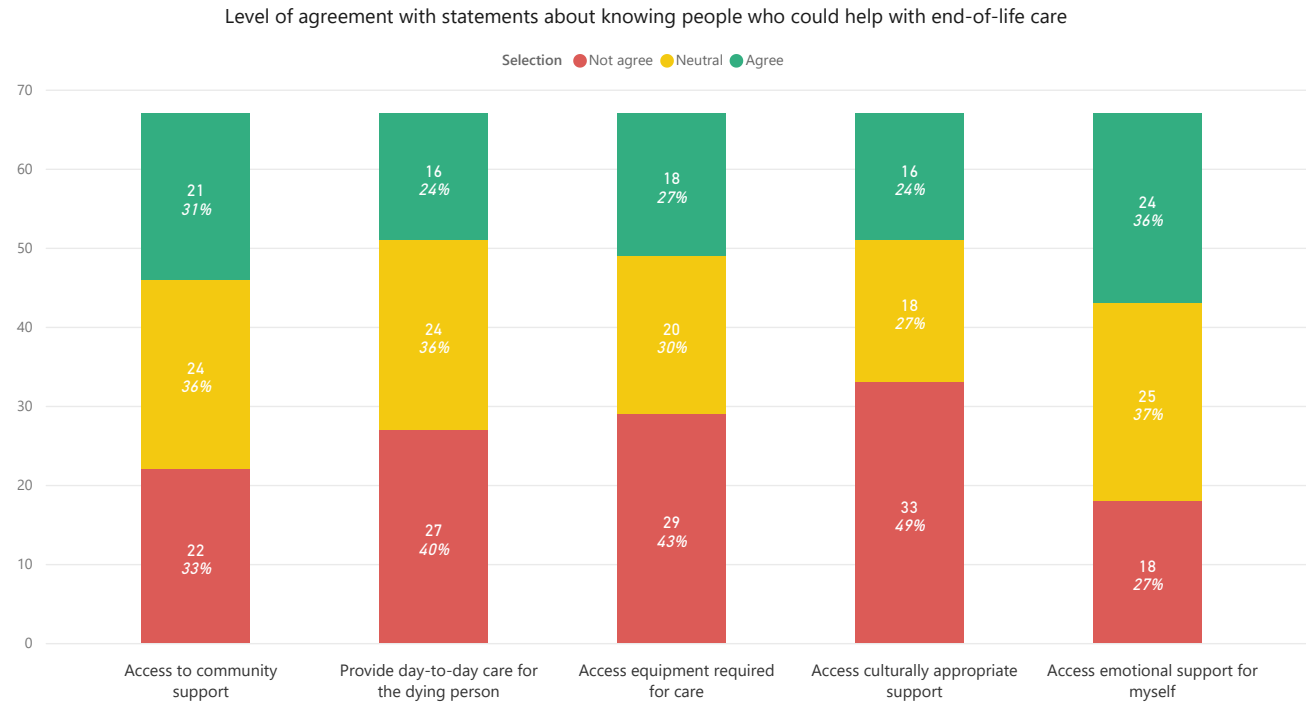
The majority of respondents indicated a more positive effect following their experience of grief and loss, with noted increased emotional strength, development of wisdom and understanding, increased compassion and skills in facing similar challenges in the future.

Figure 5. Navigating the system



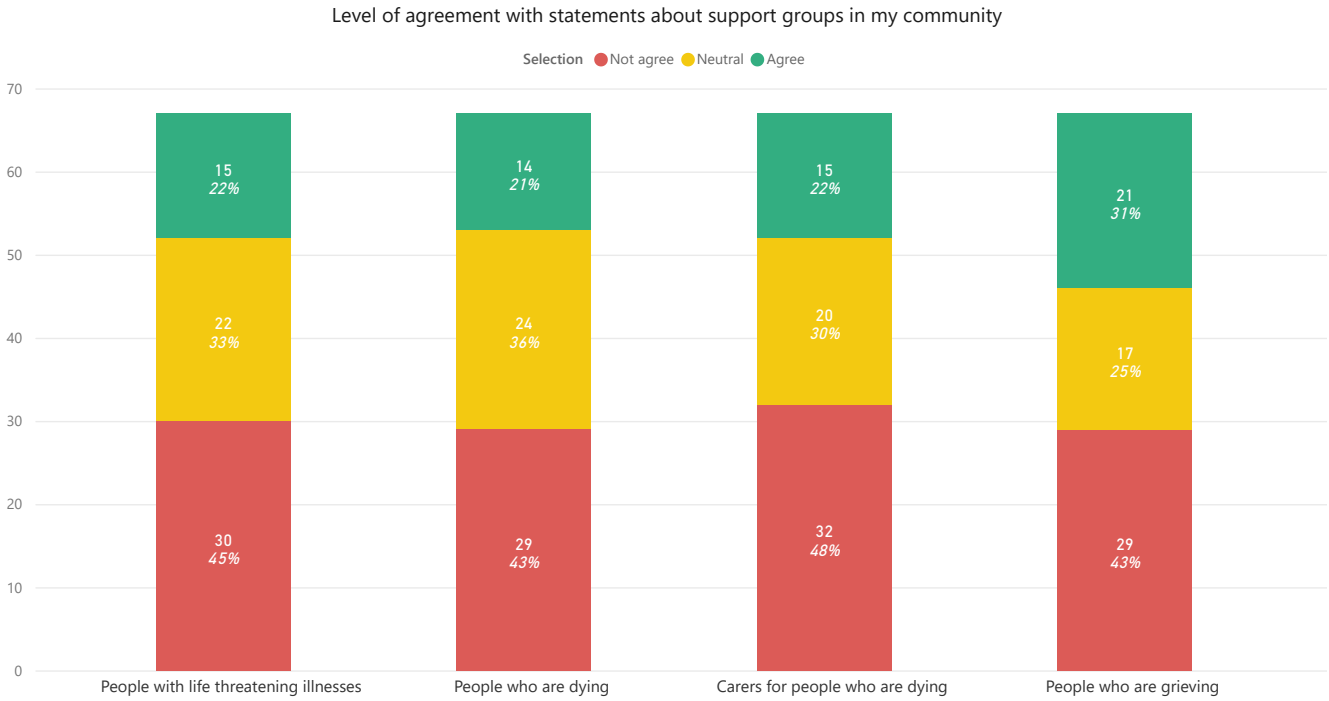
The results from navigating the system were quite poor with many respondents indicating they know less about the law regarding dying at home, navigating the healthcare system or funeral services. Many respondents did not know how to access palliative care in their area and did not have sufficient understanding of illness trajectories to make informed medical decisions.

Figure 6. Understanding who can assist with providing end-of-life care



Some respondents knew how to access community support, equipment, culturally appropriate support and personal emotional support, however this area needs further attention.

Figure 7. Support groups



More respondents knew about support groups in the community for people who are grieving compared to those for people who are dying.

Advance Care Planning

Advance care planning is the process of developing plans for your health and personal care that respect your values, beliefs, and preferences. It is important to have a plan in place so you are in control of what happens to you, if you are unable to express your wishes and preferences for care and treatment. The recommended advance care planning process includes understanding any health and ageing issues that you may be susceptible to, thinking about your values and wishes for care and treatment, discussing these with your family, friends, and/or your treating healthcare team, identifying your Person Responsible or Enduring Guardian who can make decisions on your behalf and completing an Advance Care Directive to capture your preferences for care and treatment. An Advance Care Directive is sometimes called a living will and is the formal outcome of your advance care planning conversations. It is legally binding and the best way to ensure your wishes for treatment and care are respected by those closest to you.

The majority of Australians (82%) agree that advance care planning can help others make the right decisions for themselves, and can help reduce confusion, stress and anxiety (79%). The majority are open to talking about advance care planning (73%). Locally, 90% of our survey respondents think it is important for people to have an up-to-date advance care plan or Advance Care Directive.

However, most Australians are not fully prepared for future healthcare decisions. Only one-third have engaged in some form of advance care planning, with just 6% having completed a formal advance care directive and 13% having formally appointed a substitute decision maker.[19] Recommendations to help increase advance care planning conversations in our region include education and awareness, discussing during the 75+Health Assessment when visiting your primary healthcare professional and aligning this with appropriate funding for general practice.

Figure 8. The distribution of who Australians talk to about their advance care plans

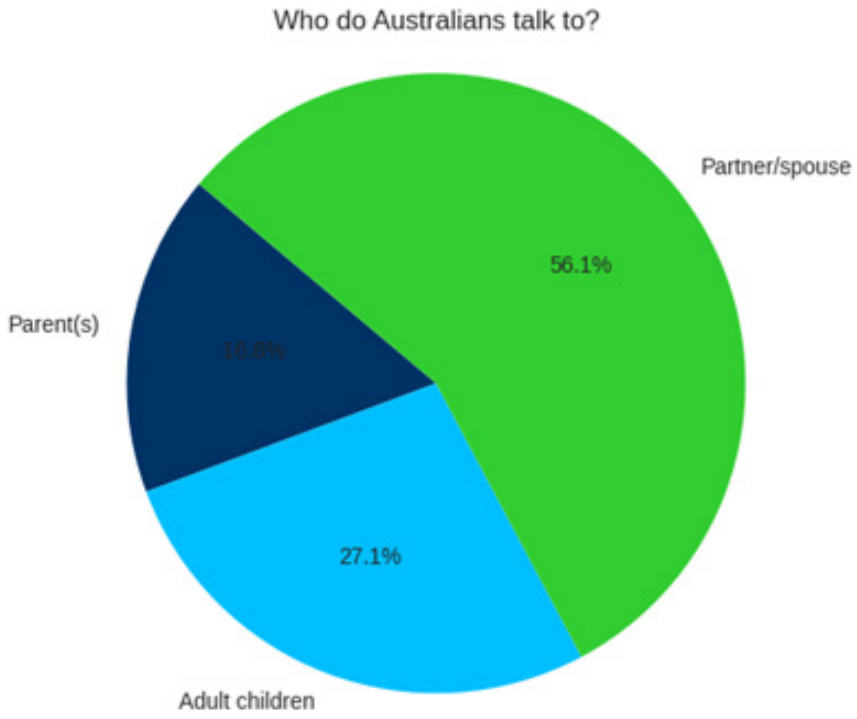
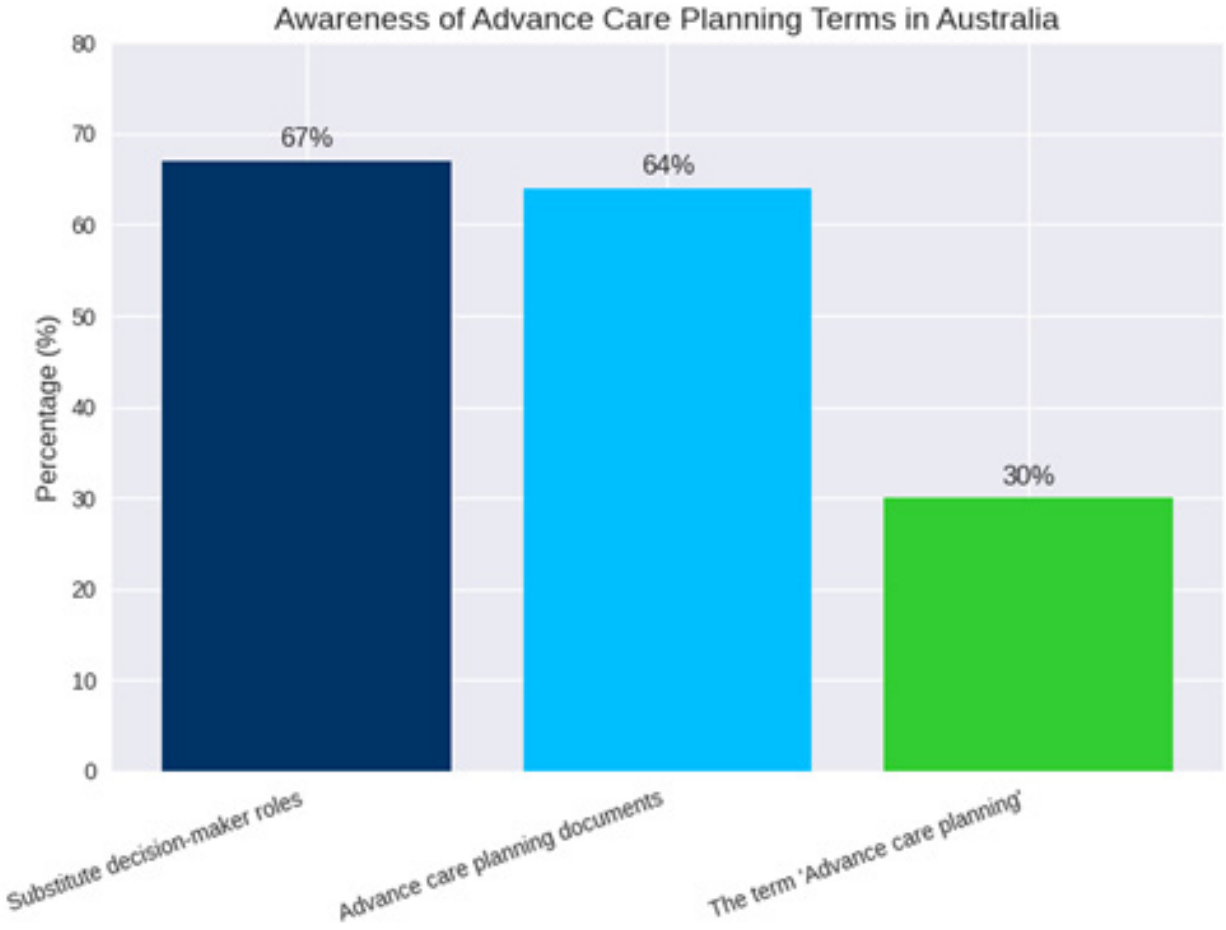


Figure 9. Awareness of advance care planning terms in Australia



The main reasons stopping Australians from undertaking advance care planning:

- It is not a priority – 36%
- Unsure how to do it – 34%
- Have not had the time – 19%
- Too expensive to do – 19%
- Requires input from multiple people – 16%

Although Australians do not have high rates of advance care planning conversations, they do talk about the medical treatments they do or do not want, their wishes and preferences for future healthcare, important documents and the things that are important to them when they are close to the end-of-life.

A 2021 multicentre audit by Advance Care Planning Australia that examined the prevalence of Advance Care Directives or documented advance care plans found that approximately 30% of older people had an advance care document. The audit found that most of these were not Advance Care Directives and the prevalence was higher in aged care facilities (47%) than in acute hospitals (15.7%) and, surprisingly, just 3.2% in general practice.[20]

Advance Care Directives NBM region

There has been a steady increase in the number of advance care planning documents uploaded to the NSW Health electronic medical record (eMR) across the NBMLHD since 2023. This increase is likely multi-factorial, due to an increase in the promotion of advance care planning in the community, along with a review of the process for asking for and uploading documents to the eMR.

HealthPathways

HealthPathways is a free online clinical decision support tool for healthcare professionals intended to be used during patient consultations. It provides information on how to assess and manage medical conditions, and how to refer to services available in the area.

Table 8. Most popular palliative care page views 2024-2025 in the NBM region

Page title	Views
NSW Ambulance Authorised Care Plans	114
Palliative Care Nursing	103
Adult Palliative Care Assessment	97
Advance Care Planning (ACP)	75
Palliative Care Advice	71
Issuing a Medical Certificate of Cause of Death	64
Nausea and Vomiting in Palliative Care	64
Sleep Disturbance in Palliative Care	37
Symptom Control in Palliative Care	37
Cachexia and Anorexia in Palliative Care	30
New Palliative Care Patient	30
Palliative Care Support	28

There were 48 Pathways for palliative care with a total of 1,101 views for the 2024-2025 period.[21]

My Health Connector

The My Health Connector directory is a free online local directory of services available to the community. It features a dedicated search category for accessing services and support for end-of-life care. During the year 2024-2025 there were 367 service type impressions for 'end-of-life' and 379 health condition impressions for 'palliative care'. An impression is counted for each distinct service type of health condition. Of the top 10 pages by impressions, 'Nepean Palliative Support' was sixth with 10,124 impressions. This demonstrates both the usefulness and need for this local directory for our community, so people can easily access the support and service information they need.

Palliative Care Beds in our Hospitals

- **Nepean Hospital** – six beds on a mixed medical ward; a dedicated specialist Nepean Palliative Care Unit with funding to open 12 beds initially due to commence services in early 2027.
- **Springwood Hospital** – three beds in a generalist ward, rooms refurbished for palliative care patients with family space and kitchenette.
- **Katoomba Hospital** – two beds in a generalist ward, rooms refurbished for palliative care patients with family space and kitchenette.
- **Lithgow Hospital** – no specific bed allocation, but two rooms refurbished for palliative care patients when needed, with family space and kitchenette.
- **Hawkesbury Hospital** – three notional beds, in a mixed medical ward.[22]

Service Mapping

These professional palliative care support services are provided in the home, based in the NBM region and delivered by local service providers (source: NBM HealthPathways).[21]

NBMLHD provide the end-of-life care package for people who are:

- Experiencing functional decline and in the deteriorating or terminal phase of a progressive life limiting illness/condition.
- Any age, although the packages generally do not cater for the specific needs of children. Instead, they are there to support parents/caregivers in their caring role.
- Requiring non-clinical home care services to be able to manage at home for as long as possible. Has a carer/family member that requires non-clinical home care services to support the patient to die at home or to remain at home for as long as possible.
- Known to the NBM Palliative Care Service.

Nepean Cancer and Wellness Centre:

- Provides patients and GPs access to an end-of-life and palliative care coordinator. Specialist triage, assessment and referral to the services and resources with a palliative care medical consultant for GPs.
- Works across community and hospitals to support the patient journey between settings and facilitates discharge planning, including accelerated transfer home for end-of-life care.
- Out-of-Hospital Care Packages (non-clinical).
- Telehealth/telephone support is available in all LGAs during working hours. Palliative care (medical) consultant is on-call 24 hours per day, all year, providing medical advice for nursing staff and GPs.

Lemongrove Community Health Centre – Chronic and Complex Service:

- Referral required. Services are available to adults living in the NBM region, with chronic and complex health conditions. Virtual care (telehealth) is available at this service. People under 18 years are eligible for palliative care (however not available in Hawkesbury).

Lithgow Community Health Centre:

- Provides palliative care and support to people with a life-limiting or terminal disease (such as advanced cancer, end-stage heart, lung or kidney disease, or motor neurone disease) at home, in hospital, at a cancer care centre or in aged care.
- A referral from a GP or specialist is required to see a palliative care doctor or attend our palliative care clinics.

Other Community Health Centres:

- St Clair Community Health Centre – referral required during business hours. Virtual care (telehealth) is available at this service. Palliative care is offered through Lemongrove Community Heath Centre.
- Springwood Community Health Centre - Referral required during business hours. Virtual care (telehealth) is available at this service. Palliative care is offered through Lawson Community Health Centre.

As part of our Greater Choice for at Home Palliative Care measure, we developed an information sheet for residents in our region that outlines the services that can provide support to those needing or receiving palliative care title Live Well with Palliative Care.

Specialist Nurse-led Palliative Care In-reach into Residential Aged Care Homes

Table 9. Number of referrals received 2024-2025 in the NBM region

LGA	Number of referrals	Percentage
Blue Mountains	77	14%
Hawkesbury	127	24%
Lithgow	14	3%
Penrith	310	59%
Total	**528**	**100%**
Period: 1 October 2024 to 30 September 202522		

Of the last 86 deaths, 80 (93%) have occurred in residential aged care homes with 6 (7%) occurring in hospital.

After Hours Palliative Care Service

This after-hours service is a pilot project to determine the best model for NBMLHD. Currently, only patients known to community palliative care in all four LGAs can access the service.

The after-hours service complements the day service and is available for palliative care patients from 4:00pm - 8:30am, seven days a week including public holidays. It offers phone and video support, with both proactive calls to people in the evening by a palliative care registered nurse, employed by the palliative care service in NBMLHD who has access to the medical record.

The pilot was launched 21 July 2025 and will be evaluated before 30 June 2026, to determine the model going forward.

Table 10. Number of calls during 2025 in the NBM region

LGA	Calls	Percentage
Blue Mountains	121	28.3
Hawkesbury	18	4.2
Lithgow	36	8.4
Penrith	251	58.8
Other	1	0.2
Total	**427**	**100**
Period: 1 July 2025 to 30 October 202522		

The number of patients supported over the 4-month period since the pilot commenced is 124. The total number of calls received is 427 with the average number of calls per month being 85. Of these, 47.3% are calls received with 52.7% follow-up calls. The outcome for the majority of calls (88%) is providing information, reassurance and clinical advice for people remaining at home.[22]

Service Gaps

The respondents to the palliative care survey ranged in their experience with providing clinical care to both palliative and end-of-life care, reflecting the backgrounds of responses, from health professionals to community. The types of palliative care service or support provided ranged from in-practice, home visits or a combination.

In terms of awareness levels of the training available for health professionals on palliative and end-of-life-care, almost half (44%) of those who responded were aware, with the remainder unsure or were not aware of available education. Education or training that is available covered a wide range of options including universities, HealthPathways, NBMLHD, End of Life Directions for Aged Care (ELDAC), Pharmaceutical Society of Australia (PSA), Australian Primary Health Care Nurses Association (APNA), End of Life Essentials, The Health Education and Training Institute (HETI), Palliative Care Australia, Palliative Care NSW, Palliative Volunteer Scheme, The Palliative Care Curriculum for Undergraduates (PCC4U), Program of Experience in the Palliative Approach (PEPA), Primary Health Networks and The Royal Australian College of General Practitioners (RACGP).

Additional palliative or end-of-life care education and/or training that our stakeholders would like to have available include:

- local services and referral pathways
- medication management and symptom management
- communication skills – having difficult conversations with families, communication toolkit
- support for family
- practical training – phases and transitions of palliative care and end-of-life planning and end-of-life stages e.g. dementia
- cultural sensitivity in palliative care
- community palliative care, connecting with allied health providers and working with palliative care nurses
- death literacy
- hospice information

The majority of respondents had a good understanding of who currently provides palliative care and end-of-life services in our region, which ranged from NBMLHD, community health, aged care providers, GPs, nurses, volunteer services, health care providers, hospitals and specialists. However, when it relates to who provides in-home palliative care services in our region, 20% of respondents were unsure, 27% were not aware and 29% were aware of some services. Therefore, only one quarter of respondents felt confident in their awareness of in-home palliative care services in our region.[23]

Coordination and Integration of Services

Health service delivery is optimised if it is well integrated and coordinated. How well the health services, and community services communicated with each other in relation to the delivery of palliative care varied in our region, with 22% of respondents citing quite well to extremely well, compared to 31% citing not at all well to not very well. 47% of respondents were neutral. Only 14% of respondents believed there was sufficient access to palliative and end-of-life care services in the region, with 48% unsure and 38% insufficient.

Survey respondents were asked to recommend how communication between health and community services could be improved, with the following collated responses listed in order of the most frequently mentioned:

1. Digital and shared communication systems

- Establish a shared online platform for GPs, LHDs and community services.
- Enable electronic messaging/email updates and short emails after each visit or care plan change.
- Provide ambulance and other services with electronic access to care plans and Advance Care Directives.
- Ensure LHD and GPs have access to current digital health records.

2. Structured feedback and documentation

- Improve discharge summaries and ensure they are timely and detailed.
- Send brief written updates or letters to GPs after visits or medication changes.
- Provide consistent feedback loops after hospital discharges and community visits.
- Share summaries of visits and recommendations directly with GPs.

3. Collaboration and case conferencing

- Conduct joint case reviews and case conferences, especially for palliative care patients.
- Foster open regular communication directly between providers and consider multicultural perspectives in communication.
- Promote round-table discussions, working groups and community forums to share knowledge.
- Encourage more collaboration between nursing homes, hospitals, pharmacies and community services.

4. Education and awareness

- Offer regular seminars/webinars to update GPs on new services.
- Strengthen education and networking opportunities to build relationships between primary and specialist teams.
- Increase awareness of local services through referral directories, posters, newsletters and outreach.
- Provide quarterly updates/newsletters with referral processes and procedures.
- Adopt a biopsychosocial and holistic model rather than a purely medical one.

There were some mixed experiences as some respondents indicated that communication already works well in their organisation and a few felt no improvement was needed with good correspondence occurring. Others noted loss of effective systems (eg. PEACH packages, NSW Health 1800 intake line). There were also some concerns about time constraints for GPs and unclear instructions from carers were raised.[23]

Efficiency and Effectiveness of Health Services

Survey respondents identified some of the current challenges to people receiving palliative and end-of-life services, outlining some of the key barriers and gaps in our region.

Access and equity:

- Patients often enter via emergency departments instead of direct palliative pathways.
- Limited home-based supports available and/or accessible such as nursing, equipment and after-hours care.
- Geographic inequity: remote areas particularly throughout the Blue Mountains and Hawkesbury face long travel times and fewer services are available.
- Bed shortages in hospitals and hospices (none in the NBM region).
- Funding gaps to access timely allied health services (occupational therapy, physiotherapy, speech pathology, dietetics and social work) delayed or unavailable.
- Medication access issues: pharmacies not stocking palliative medications and delays experienced on weekends.

Continuity of Care – After Hours:

- Lack of after-hours symptom management for medical reviews, medications and specialist advice.
- Poor continuity of care between GPs, specialists and palliative teams.
- Carers confused about processes, especially outside business hours.
- Limited face-to-face after-hours support.

Knowledge and awareness:

- Stigma around discussing end-of-life wishes.
- Families and patients unaware of available services or how to access them.
- GPs and nurses could benefit from more training on early palliative discussions and referral pathways.
- Poor communication between providers such as GPs, pharmacists and LHD teams.
- Pharmacists sometimes unaware of urgent medication pathways.

Cultural and social needs:

- Need for culturally safe palliative care for Aboriginal and Torres Strait Islander peoples.
- Lack of recognition of non-malignant conditions requiring palliative support.
- Carer burden with limited respite options, high costs and transport challenges.
- Desire for places where people can die with dignity.

System-level challenges:

- Rising demand for support with an ageing population and insufficient resources.
- Unequal distribution of services across the region leads to inequitable access.
- Bed block in hospitals affecting timely care.
- Confusion about pathways as patients and families do not know who to contact or how to navigate services.

Suggested areas for improvement or **further development** include:

- Integrated care pathways to strengthen links between GPs, LHD palliative care teams and community providers.
- Timely home-based support to expand community nursing and allied health services, including after-hours coverage.
- Improved education and awareness for both health professionals and community by providing training in early palliative discussions and public campaigns to normalise conversations about dying and raise awareness of services.
- Improved communication channels with clearer pathways between GPs, pharmacists and palliative teams for urgent medication and care coordination.
- A single point of contact/referral for all palliative care services.
- Enhanced infrastructure and resources with an increase in the number of palliative care beds and establish dedicated hospice facilities in the region, as well as ensuring equitable distribution of services across the region.
- Develop models of care that respect Aboriginal and Torres Strait Islander peoples perspectives and diverse cultural needs for culturally appropriate care.[23]

EVALUATION

NBMPHN is committed to continuing to deliver the Greater Choice for At Home Palliative Care Program to improve awareness of local palliative care options and to coordinate and facilitate access to palliative care services at home. It will be important to:

- Continue to distribute and capture results from the death literacy surveys to assess any changes in the communities' level of death literacy in our region.
- Review and update the My Health Connector directory to ensure it meets the communities' needs for people accessing services and support for end-of-life care.
- Generate HealthPathways data to review the most popular clinical pathways related to palliative care and ensure clear referral pathways are accessible to health professionals in our region.
- Support the ongoing engagement with the Palliative Care Advisory Committee as an important connection between primary care providers, the local health district, and community.
- Provide education and training for health professionals on a range of palliative care topics including medication management.
- Deliver awareness and information to the community on palliative care and advance care planning focusing on the diverse needs of vulnerable population groups.

CONCLUSION

The 2025 Palliative Care Needs Assessment highlights the growing demand for palliative and supportive care services across the Nepean Blue Mountains region, driven largely by an ageing population and longstanding access inequities in rural areas. Despite recent enhancements in after-hours and residential aged care support, significant gaps remain in service availability, continuity of care, cultural responsiveness, and system-level coordination. Strengthening integration across providers, improving communication pathways, building workforce capability, and expanding homebased and community centred supports will be essential to achieving more equitable and connected palliative care. The findings of this needs assessment will guide NBMPHN in prioritising activities under the Greater Choice for At Home Palliative Care program to ensure people in our region can access safe, culturally appropriate, and high quality palliative care when and where they need it.

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