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An Australian Government Initiative

Sydney North Health Network

Palliative Care Needs Assessment

2025 Update

Executive Summary

The 2025 Palliative Care Needs Assessment updates the 2022 assessment and provides a renewed evidence base for planning and improving palliative and end-of-life care across Northern Sydney. It draws on local, state and national data, alongside consultation with more than 100 stakeholders, including community members, General Practitioners, residential aged care homes, palliative and end-of-life care services, allied health, community services and funeral service providers.

The assessment reflects a diverse and evolving region, with an ageing population, growing cultural diversity, a substantial unpaid carer population, significant residential aged care presence, and ongoing access and coordination challenges across care settings. People aged over 75 make up 17.4% of residents, and Northern Sydney has 103 residential aged care homes supporting 7,514 residents.

The region also has the third highest number of people living with dementia in NSW, reinforcing the importance of palliative care capability across community, primary care and aged care settings.

Northern Sydney's diversity reinforces the need for culturally safe and inclusive palliative care. Among people aged over 65, 44.7% were born overseas and 23.8% speak a language other than English at home. There are also groups with specific needs, including Aboriginal and Torres Strait Islander peoples, LGBTQIA+ communities, people with disability, people living with dementia, carers, children and young people, and people experiencing social isolation.

Lived experience was central to the assessment. Community members described palliative care as a deeply personal journey shaped by relationships, communication, family, trust, culture, grief, community supports and the need to feel seen, heard and respected. Carers described caring as both a privilege and an exhausting responsibility, often carrying significant emotional, physical and practical responsibility while navigating complex systems.

The findings are organised into six key stories: **Education and Dialogue; Communication and Information Sharing; The Wider Palliative Care Community; Carers' Central Role in Outcomes; Living Well; and The Patient Journey.** Across these stories, palliative care is understood not as a single service, but as an ecosystem of care around the person, where families, carers, communities, General Practice, aged care, specialist services, allied health, volunteers and informal supports all contribute to living well and dying well.

A clear shift has emerged since 2022. While the need to normalise conversations about death and dying remains, consultations now point to education as relational, cultural and experiential. People want timely, plain-language and culturally responsive information, introduced before crisis points, supported by human guidance. The findings also highlight grief and bereavement as part of the whole palliative care journey, with people, families and carers needing support before, during and after death.

Sector feedback highlighted the need for clearer service visibility, stronger referral and escalation pathways, improved information sharing, consistent documentation and better coordination across public, private, primary care, aged care and community services.

The recommendations aim to build on existing strengths across Northern Sydney, foster local innovation, and support care that is compassionate, connected, inclusive and responsive to what matters most to people, families, carers and communities.

Jacqui Emery, CEO
Sydney North Health Network

CEO Foreword

Palliative care is not simply about the care we provide. It is about the community we build around people when they need it most, and the strengths we nurture together so no one faces the end of life alone. Every person deserves to live well, be cared for with dignity, and feel supported by those around them throughout every stage of life.

This Palliative Care Needs Assessment provides an updated picture of the experiences, needs and aspirations of people, families, carers and service providers across Northern Sydney. Most importantly, it reflects the voices of those with lived experience and the many individuals who generously shared their stories and insights.

What stands out most is not only the challenges ahead, but the incredible strengths that already exist across our region. We have dedicated carers, skilled clinicians, committed service providers, compassionate volunteers and strong partnerships that support people to live well and die well. This assessment recognises those strengths and identifies opportunities to build on them.

The findings reinforce that palliative care is not delivered by a single service. It is experienced through a network of relationships involving families, carers, General Practitioners, aged care providers, hospitals, community organisations and volunteers. Together, we play a role in creating care that is compassionate, connected and centred on what matters most to people and their loved ones.

At Sydney North Health Network, we see our role as bringing people together, strengthening partnerships and supporting more coordinated, equitable and person-centred care. The recommendations in this report provide a foundation for continued collaboration, innovation and improvement across Northern Sydney.

I would like to sincerely thank everyone who contributed to this assessment, especially the community members, carers and people with lived experience whose voices have shaped its direction.

By building on the strengths that already exist within our community, we can continue working together to ensure every person is supported to live well, right through to life's final chapter.

Jacqui Emery

Acknowledgments

Sydney North Health Network acknowledges and sincerely thanks all individuals, families, carers, community members, health and community sector professionals, general practitioners, residential aged care staff, palliative care services, allied health providers, community organisations and funeral service providers who contributed to the 2025 Palliative Care Needs Assessment.

We are especially grateful to those in our community who shared personal stories, professional insights, lived experiences and reflections on what matters most in palliative and end-of-life care. These contributions have helped deepen understanding of the palliative care landscape across Northern Sydney and have informed the priorities and recommendations outlined in this assessment.

We also acknowledge the ongoing work of the wider palliative care community across Northern Sydney, including those supporting people, families and carers across homes, hospitals, residential aged care homes, community settings and specialist services.

Suggested citation

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Contents

Informing the Assessment	5
Recommendations	8
Regional Profile: Northern Sydney	12
Overview of Palliative Care: Australia & NSW	17
Overview of Palliative Care Services: Northern Sydney	21
Insights & Key Stories: Community & Sector Perspectives	26
Citations	49

1. Informing the Assessment

Background

This Palliative Care Needs Assessment is a foundational tool for planning and improving care, ensuring that decisions are informed by evidence and aligned with the real needs of people in Northern Sydney. It builds on the 2022 Sydney North Health Network (SNHN) Palliative Care Needs Assessment and is an initiative of Greater Choice for At Home Palliative Care (GCfAHPC), funded by the Australian Government Department of Health, Disability and Ageing (DHDA).

By updating the 2022 assessment, this work aims to deepen understanding of the palliative care landscape across Northern Sydney, build a clearer picture of current service delivery and inform future planning and service development to deliver compassionate, accessible, and high-quality care.

Methodology

A mixture of qualitative and quantitative data was sourced from a range of local, state, and national resources. A review of the previous Palliative Care Needs Assessment was undertaken to locate the latest data which was then updated to incorporate new insights.

Sydney North Health Network continues to take a consultative approach to building a comprehensive understanding of the palliative care landscape across the Northern Sydney Primary Health Network (PHN) catchment. In-person and online consultation sessions were held with community members, health and community sector stakeholders, and service providers, contributing qualitative data that offered meaningful insights to inform this needs assessment. Thematic analysis was undertaken to interpret the data gathered through these consultations. By gathering and analysing local data from health and community stakeholders, engaging with community voices, and mapping service gaps, this assessment supports evidence-informed planning and delivery of quality palliative care.

Stakeholders engaged:

General Practice | Palliative Care Services | Community Health
Northern Sydney Local Health District | The Community | Residential Aged Care
Allied Health | Community Services | Funeral Service Providers

The consultation process was designed to capture diverse perspectives and lived experiences across the Northern Sydney PHN catchment. For community engagement, in-person sessions were held, and structured to encourage open dialogue. These sessions incorporated interactive activities such as small group discussions, individual storytelling, and feedback tools. This approach allowed for nuanced understanding of community priorities, barriers to care, and expectations for quality palliative care. Participants were invited to a follow-up session to review the thematic analysis and provide feedback, ensuring the validity and accuracy of the findings.

For health and sector stakeholders, consultations were delivered online to enable flexible participation and reduce barriers related to time and location. Two virtual sessions were conducted, following a similar interactive format to the community consultations, ensuring that sector voices were also represented. In addition to these sessions, targeted surveys were distributed to general practitioners (GPs) and residential aged care staff across the catchment to capture quantitative and qualitative data on service gaps and workforce challenges.

All qualitative and quantitative inputs were synthesised through thematic analysis to provide a more robust evidence base to inform planning and service improvement.

Over 100 stakeholders were engaged

Community	19%
Sector	26%
General practitioners	26%
Aged Care Homes	29%

Limitations

Quantitative data in palliative and end-of-life care is often limited, and to address these limitations, a consultative approach was undertaken. While the experiences captured through consultation are context-dependent and represent a small proportion of the palliative care experiences within our region, they remain valid and meaningful, reflecting the diverse realities of those receiving and providing palliative care across a range of settings within the region.

2. Recommendations

The recommendations in this assessment are grounded in the diversity of people, families, carers, loved ones and care settings across Northern Sydney.

Across education, navigation, communication, care planning, support services and workforce practice, implementation is strengthened when it is culturally responsive, trauma-informed, accessible and respectful of identity, language, family structures, spiritual beliefs, rituals and preferences for care. This means building on the strengths, knowledge and preferences of different communities and care settings, and shaping engagement, communication and support in ways that feel meaningful, safe and relevant.

Implementation should also remain flexible enough to support local innovation, community-led approaches and emerging opportunities that strengthen connection, trust, meaning, care and responsiveness as they arise.

These recommendations aim to build on the strengths already present across Northern Sydney, foster local innovation and support care that is compassionate, connected, inclusive and responsive to what matters most to people, families, carers and communities.

1. Adopt a whole-of-life approach to education that builds openness and care around death, dying & grief

Develop a coordinated, whole-of-life approach to education and dialogue in the community, delivered through flexible channels that meet people where they are; practically, emotionally and culturally.

Education should begin early with age-appropriate resources and continue across life stages to normalise conversations about death, dying, grief and bereavement.

This approach should support dialogue across families, schools, community settings, General Practice and health care services, helping people understand what lies ahead, strengthen family-inclusive conversations and prepare before crisis points. It should also increase visibility and use of high-quality resources already available for families and carers, while developing additional resources where gaps exist and ensuring information is easy to understand, access and share.

2. Embed practical, human-centred education into routine care & workforce practice

Consistently and proactively introduce plain-language, culturally responsive information about palliative care, place-of-care and care planning at trusted touchpoints in the delivery of care services. Education should be embedded where care happens, using practice-based approaches such as bedside coaching, case discussions, joint visits, needs rounds and micro-learning in residential aged care.

Existing tools, including checklists, conversation guides, translated resources, and after-death guidance, are most valuable when embedded into everyday workflows and handovers. Uptake can be sustained through local clinical leadership, protected learning time, consistent terminology, and palliative care champions, particularly in residential aged care homes and at key service transition points.

3. Improving visibility & navigation of the palliative care service landscape across Northern Sydney

Building on the strong palliative care services already available across Northern Sydney, visibility and navigation of the full-service landscape including public, private, primary care, community-based and residential aged care services should be strengthened. This would help people, families, carers and providers better understand what services are available, who is eligible, and where to seek help at different points in the journey.

Foster stronger connection between families, general practice, and care providers, and empower families through proactive sharing of vital service information, alongside provision of clear, plain-language resources with human-guided support.

4. Enabling connected care through strengthened communication & information sharing

Communication and information sharing across the wider palliative care system in Northern Sydney can be strengthened to enable connected care across public, private, primary care, community-based and residential aged care services. This is particularly important at transitions of care.

This includes addressing fragmentation arising from siloed systems, inconsistent contact pathways and limited interoperability (for example, the absence of simple, reliable sector-wide contact mechanisms such as a single, recognisable 'health email' contact for professional-to-professional communication).

Enhancing communication through improved system connectivity, standardised language and documentation, and clearer visibility of service roles and capabilities, including: greater consistency and completeness in key documentation such as goals of care, discharge handover and Advance Care Planning, alongside shared understanding of service scope, acuity and referral thresholds. The initiatives above should be pursued with recognition of existing workforce constraints in general practice and aged care, and with consideration of emerging or expanded models of care that may help mitigate communication and continuity gaps.

5. Strengthening and empowering the wider palliative care team

The story of the Wider Palliative Care Team highlights that palliative care is not experienced as a single service, but as an interconnected web of relationships and supports that together enable people to live and die well.

Continue to strengthen, expand, and embed integrated palliative care models across Northern Sydney that recognise the wider palliative care team, including families, carers, aged care, general practice, community services, health services, pharmacies, volunteers and informal networks.

Integrated models are strengthened by clear roles, trusted handovers, proactive GP communication, responsive escalation pathways and timely specialist advice. Family and carer support, after-hours responsiveness, aged care capability and community-based care are key enablers of helping people remain in their preferred setting where possible.

6. Create space for carers and strengthen support during escalating care needs

Consultation findings indicate that carers often carry significant responsibility for maintaining care at home, and this becomes increasingly difficult when needs escalate, information is unclear, or support is limited after hours.

Supporting safe, compassionate and sustainable care at home can reduce avoidable burden on carers at critical points.

This includes ensuring responses are attuned not only to practical and clinical pressures, but also to carers' wellbeing and mental health. Carers need timely, compassionate spaces to process fear, grief and exhaustion as they arise, alongside practical relief, clear guidance and responsive clinical support.

7. Enable whole-person wellbeing across the palliative care journey

Living well is as important as dying well. Enhance delivery of innovative community-based bereavement, grief and wellbeing supports across Northern Sydney, including building on the district-wide public health approach to bereavement, to strengthen whole-person support from diagnosis through bereavement.

Enable early access to psychosocial and spiritual support, proactive grief education, trauma-informed and culturally safe care, and flexible pathways to mental health, peer, family, community and bereavement supports. Services should recognise that peace of mind comes from many sources, including connection, meaning, feeling prepared, spiritual care, creative expression, nature, movement and practical support. Help to normalise grief without over-medicalising it while ensuring people can access more specialised support when needed.

8. Map and support a clearer palliative care journey across Northern Sydney

Building on visibility of services (recommendation three), a clear regional palliative care journey map that identifies existing supports, who to contact, when to refer, and what steps to take at key points in the journey can enhance the patient journey.

This should build on the strong services and resources already available, while making local pathways easier to understand across public, private, primary care, aged care, community, disability, and non-government services. The journey map should clarify referral options, provider roles, eligibility, service capacity considerations, and points where pathways may differ across settings.

The journey map is most effective when supported by relational navigation or advocacy support for people, families and carers who are isolated, overwhelmed or moving between services. Priority should be given to transition points where confusion, delay or distress are most likely, including hospital discharge, entry into residential aged care or group homes, escalation of dementia-related behaviours, home-based end-of-life care and after-death processes.

This process would also help identify gaps, duplication and opportunities to improve consistency across the region.

9. Strengthen GP involvement across the palliative care journey

Better enable GPs as trusted gateways within the palliative and end-of-life care system, particularly for people receiving care at home or in residential aged care.

Across the wider palliative care team, the GP remains a key point of contact for patients, carers, and families. Empowering GPs requires consistent, visible referral, escalation, and specialist advice pathways, such as local HealthPathways tools, while actively recognising time, workforce, and funding constraints. Additionally, strengthening the interface between general practice, hospitals, community care, and aged care facilitates earlier engagement, seamless continuity, and highly coordinated care.

Strengthening collaboration with nurse practitioners and other multidisciplinary partners can further support access, escalation, and responsiveness, particularly in community, residential aged care, and after-hours contexts.

10. Support regional coordination and shared learning across the palliative care network

Build on existing committees, partnerships and communities of practice by supporting a local Northern Sydney palliative care community of practice.

This would bring together providers from public, private, primary care, residential aged care, community, disability, non-government and specialist palliative care services, alongside lived experience perspectives, to share local updates, strengthen relationships, identify pathway issues and support practical problem-solving.

This should complement, rather than duplicate, state and national forums by focusing on the local relationships, referral pathways and coordination challenges that directly affect people, families, carers and providers in Northern Sydney.

3. Regional Profile:
Northern Sydney

Hornsby | Hunters Hill | Ku-ring-gai
Lane Cove | Mosman | North Sydney
Northern Beaches | Ryde | Willoughby

900 km²

across 9 Local Government Areas

963,869

Total population (2024)

The projected increase of people aged 65 years of **57.8%** remains true within the region with **17.4%** of the population over 75 years of age (Torrens University 2025).

Health equity

Health equity is an ongoing challenge within the region as large pockets of disadvantage continue to grow in Ryde, Hornsby and the Northern Beaches (SNHN, 2023; SNHN, 2024). While the Northern Sydney region is generally considered socioeconomically advantaged compared to other PHN regions, it continues to face complex challenges, including mental health needs, housing insecurity, and service access inequities. The region's growing cultural diversity also brings important considerations for inclusive and responsive palliative care delivery (SNHN, 2024).

There is currently a low percentage of patients over the age of 75 years who receive annual health checks (SNHN, 2024), alluding to further difficulties in accessing services for older people.

Aboriginal & Torres Strait Islander People

In 2021 **0.3%** of people over the age of 50 in Northern Sydney identify as First Nations (Australian Institute of Health and Welfare [AIHW], 2025).

In 2021 **0.5%** of the general population identified as First Nations (PHIDU, 2025).

This comparison demonstrates the need for culturally sensitive palliative care services within the region. Bungee Bidgel Aboriginal Health Clinic, located in Hornsby, is the only clinic in Northern Sydney that offers Aboriginal General Practice services within the region (Northern Sydney Local Health District [NSLHD], 2025), while additional Aboriginal health services are provided by Northern Sydney Local Health District based out of Royal North Shore Hospital (RNSH). Of these services, none provide specialised palliative care services to First Nations populations. There are also ongoing barriers to culturally safe care that persist for hidden populations, including Stolen Generations members, who may not self-identify due to the enduring impacts of past government policies.

Culturally and linguistically diverse populations

44.7% of people in the region over the age of 65 were born outside of Australia, which is greater than both the state and national average (AIHW, 2025).

23.8% of people over the age of 65 used a language other than English at home, which is higher than the state and national average (AIHW, 2025).

The growth of culturally and linguistically diverse populations, particularly in the Ryde Local Government Area, highlights the need for culturally sensitive services and accessible language support to ensure informed care for patients and families.

Cultural identity is nuanced – language data alone may not capture it, as community affiliation is not always tied to birthplace, and under-reporting of additional languages can create gaps in representation. Furthermore, understanding cultural beliefs, values, and practices is essential to delivering person-centred and culturally safe palliative care.

Lesbian, Gay, Bisexual, Transgender and Intersex people

Reliable local prevalence data for LGBTQIA+ populations in Northern Sydney is limited; most estimates are drawn from state or national sources.

A NSW survey of 419 LGBTQIA+ community members found **24%** had direct or indirect experience with palliative care, yet many reported barriers such as fear of discrimination, mis-gendering, and lack of recognition of chosen family.

While most participants who accessed palliative care described respectful interactions, **78%** identified staff knowledge and attitudes as a major barrier, and **54%** highlighted the need for inclusive, non-discriminatory service delivery and staff training.

Carers

In 2021, more than 56,000 people in Northern Sydney were providing unpaid care to a person with disability, chronic illness or age-related frailty, representing **10.8%** of the population aged 15 years and over. This highlights the substantial contribution of informal carers and the importance of ensuring carers are recognised, supported and included in service planning.

Residential Aged Care Homes

The region has:

- 103 Aged Care Homes, giving Northern Sydney the third highest number of aged care homes by Aged Care Planning Region (AIHW, 2025).
- 7,514 residents, meaning Northern Sydney has the third highest number of residents serviced by residential aged care homes (AIHW, 2025).
- 1,903 out of 2,275 residents (**83.6%**) exit residential aged care due to death (2023/2024 financial year - AIHW, 2025).

General Practitioners

Northern Sydney has 296 General Practices (SNHN, 2025) and a bulk billing rate of **71.3%** compared with the national average of **77.8%** in the 2024-2025 financial year (Department of Health, Disability and Ageing [DHDA] 2025).

The trend of available after-hours services continues to decline, which matches the national trend of after-hours service utilisation (DHDA, 2025). Timely access to GPs and after-hours care is essential in palliative care to ensure effective symptom management, reduce hospital admissions, and uphold patient comfort and dignity in their preferred setting.

GPs surveyed as part of the consultation informing this needs assessment reported varying levels of involvement in palliative care:

- **33%** frequently involved (around monthly)
- **52%** provide palliative care occasionally (a few times a year)
- **15%** rarely (only a few times over the past three years).

All respondents indicated some level of palliative care provision, with none reporting that they never offer these services. However, GPs highlighted that current funding models and recognition structures do not adequately reflect the workload and complexity, particularly the work across residential aged care homes.

Leading causes of death in Northern Sydney

Rank	Leading causes of death Males in Northern Sydney	Deaths	% of all causes
1	Coronary heart disease (I20–I25)	1,492	10.9
2	Dementia including Alzheimer's disease (F01, F03, G30)	1,176	8.6
3	Cerebrovascular disease (I60–I69)	786	5.7
4	Prostate cancer (C61)	549	4.0
5	Lung cancer (C33, C34)	526	3.8
6	Colorectal cancer (C18–C20, C26.0)	407	3.0
7	Parkinson disease (G20)	345	2.5
8	Diabetes (E10–E14)	342	2.5
9	Chronic obstructive pulmonary disease (COPD) (J40–J44)	331	2.4
10	Heart failure and complications and ill-defined heart disease (I50–I51)	321	2.3
11	Coronavirus disease 2019 (COVID-19) (U07.1, U07.2, U10.9)	316	2.3
12	Pancreatic cancer (C25)	266	1.9
13	Suicide (X60–X84, Y87.0)	251	1.8
14	Kidney failure (N17–N19)	249	1.8
15	Cancer of unknown or ill-defined primary site (C26, C39, C76–C80 excl. C26.0)	235	1.7
16	Liver cancer (C22)	232	1.7
17	Influenza and pneumonia (J09–J18)	230	1.7
18	Leukaemia (C91–C95)	215	1.6
19	Accidental falls (W00–W19)	215	1.6
20	Other ill-defined causes (R00–R94, R96–R99, I46.9, I95.9, I99, J96.0, J96.9, P28.5)	206	1.5
	Top 20 leading causes	**8,687**	**63.3**
	All causes	**13,717**	**100.0**

Rank	Leading causes of death Females in Northern Sydney	Deaths	% of all causes
1	Dementia including Alzheimer's disease (F01, F03, G30)	2,242	15.3
2	Cerebrovascular disease (I60–I69)	1,186	8.1
3	Coronary heart disease (I20–I25)	1,163	7.9
4	Breast cancer (C50)	584	4.0
5	Lung cancer (C33, C34)	485	3.3
6	Colorectal cancer (C18–C20, C26.0)	430	2.9
7	Chronic obstructive pulmonary disease (COPD) (J40–J44)	378	2.6
8	Heart failure and complications and ill-defined heart disease (I50–I51)	368	2.5
9	Pancreatic cancer (C25)	321	2.2
10	Influenza and pneumonia (J09–J18)	307	2.1
11	Diabetes (E10–E14)	305	2.1
12	Cardiac arrhythmias (I47–I49)	301	2.1
13	Hypertensive disease (I10–I15)	296	2.0
14	Other ill-defined causes (R00–R94, R96–R99, I46.9, I95.9, I99, J96.0, J96.9, P28.5)	282	1.9
15	Kidney failure (N17–N19)	269	1.8
16	Coronavirus disease 2019 (COVID-19) (U07.1, U07.2, U10.9)	244	1.7
17	Accidental falls (W00–W19)	239	1.6
18	Cancer of unknown or ill-defined primary site (C26, C39, C76–C80 excl. C26.0)	221	1.5
19	Parkinson disease (G20)	209	1.4
20	Ovarian cancer (C56)	201	1.4
	Top 20 leading causes	**10,032**	**68.4**
	All causes	**14,666**	**100.0**

Mortality Over Regions and Time (MORT) books categorised by Primary Health Network regions with updated data released in 2025, captures deaths within the region between 2019 and 2023.

- 28,382 total deaths between (2019 and 2023).
- Median age of death for Males 84.0 years
- Median age of death for Females was 88.3 years.

of all deaths in the region, **22.1%** were considered premature (aged under 75).

Cancer Screening Rates

National bowel cancer screening rates in 2020-2021 showed **40.9%** of people aged 50-74 who were invited to participate in screening were screened. Northern Sydney's screening rates were **2.2%** above the national rate in the same year. Between 2014 and 2021, the rate within Northern Sydney has continueto improve with screening rates now above the national average (AIHW, 2023).

49.9% of women between the ages of 50 to 74 who were eligible for screening mammograms participated in the BreastScreen program, across Australia (2019-2020), Northern Sydney screening rates are **1.4%** lower in the same year at **48.5%** (AIHW, 2023).

National Cervical Screening Program saw **62.4%** of the population between the ages of 25 and 74 participated in Cervical Screening (2018 and 2021). Northern Sydney's cervical screening rate was **6.9%** higher than the national rate (**69.3%**) (AIHW, 2023).

Over 41,000 prostate cancer cases were diagnosed in NSW between 2019 and 2023, with 4881 diagnosed in Northern Sydney (Cancer Institute NSW, 2025)

Dementia

Northern Sydney has the 3rd highest number of people living with dementia in New South Wales (AIHW, 2025).

- **35.8%** male
- **64.2%** female

In Northern Sydney **41%** of GPs report feeling well equipped and another **41%** feel somewhat equipped to support patients living with dementia in a palliative context.

However, **11%** do not feel adequately prepared, pointing to targeted dementia specific palliative care training needs.

4. Overview of Palliative Care:

Australia & New South Wales

This section provides a snapshot of recent developments and initiatives in palliative care, it is not an exhaustive list but highlights selected examples of activities shaping the sector. For a more comprehensive understanding of palliative care service development nationally, refer to Palliative Care Australia, the peak body advocating for quality end-of-life care across the country. To understand the palliative care landscape in NSW, refer to Palliative Care NSW, the state peak body, providing resources, education, and sector support.

Palliative Care Australia
Matters of life and death

Palliative Care New South Wales

The National Palliative Care Workforce Survey highlights (PCA, 2024)

- Only **16%** working in the specialist palliative care setting agreed funding for their service was sufficient to provide out-of-hours care.
- Only **18%** of primary care workers said that the boundaries between their role and the role of specialist palliative care services was clear.
- **39%** of aged care workers agreed that the service where they work was adequately funded to provide palliative care in the last year.
- In specialist palliative care, **73%** of respondents said they were comfortable discussing voluntary assisted dying (VAD) with patients, families and carers while **82%** were comfortable directing patients and carers to VAD information and supporting their decisions.
- **75%** of specialist palliative care and **54%** of primary care respondents agreed that more patients, families and carers want to discuss VAD.

Palliative Care Volunteers

There are 1,049 active volunteers in NSW working across 38 palliative care volunteer services, with **80%** of services planning to recruit more volunteers.

Since 2022, active volunteer numbers have increased by **40%**. The total volunteer hours worked in 2024 was 66,495. Additionally, 11 services across NSW plan to launch a new biography program, a service that helps patients create a life story or legacy document or further develop an existing one.

Palliative Care New South Wales (PCNSW) is a member-based organisation and state peak body that promotes access to equitable and quality palliative care and leads advocacy for quality palliative care across New South Wales. The Volunteer Services Support Program (VSSP) is funded by the NSW Ministry of Health. As a part of Palliative Care NSW, it champions palliative care volunteering across the state.

Allied Health

The general allied health workforce increased by **67%** (from 2013 to 2022), indicating it is the fastest-growing clinician group in Australia (AIHW, 2024).

Allied health professionals play a critical role in symptom management and quality of life for palliative care patients and caregivers. They provide non-pharmacological interventions alongside medical care, focusing on optimising function and independence for as long as possible, managing symptoms like dyspnoea, fatigue, communication and swallowing difficulties, and addressing psychosocial needs such as grief, loss, and bereavement.

Advance Care Planning

Only **33%** of Australian adults have undertaken any form of advance care planning. [health.gov.au], [dcj.nsw.gov.au]

Only **6%** of Australian adults have completed a formal Advance Care Directive. [health.gov.au], [dcj.nsw.gov.au]

In the 2024 National Carer Survey, almost one in four carers (approximately **25%**) reported that the person they cared for had an Advance Care Plan in place.

Palliative Care for Children & Young People

Palliative care provided to children and young people makes up a small proportion of total palliative care services provided to the population nationally. Although there has been a strong focus on the delivery of adult palliative care services, there is a great need for the provision of care to children and young people (AIHW, 2024).

Those children who died with a life-limiting condition in 2021, **46%** received specialist paediatric palliative care from a children's hospital (AIHW, 2024). It is estimated that in 2021, less than **1%** of total deaths nationally were children who died with a life-limiting condition. This has been calculated based on deaths reported in the MORT (2025) and the estimated total paediatric deaths as reported by the AIHW (2024). The lower rates of children living with a life-limiting illness compared to adult population with life-limiting illness has resulted in a knowledge gap for management of child palliative care needs (AIHW, 2024).

In fact, non-specialist healthcare providers are less familiar with management of palliative care for children and young people due to the lower rates of dying children compared to adult palliative care (Palliative Care Australia, 2024)

A statewide paediatric palliative care service provides specialist care and support for children and young people and their families in NSW. Led by:

- The Children's Hospital at Westmead
- Sydney Children's Hospital, Randwick
- John Hunter Children's Hospital, Newcastle

The teams at these children's hospitals connect with local hospital, paediatric and community health teams to support patients and families to be cared for at home or in their local hospital. Northern Sydney is home to Bear Cottage, NSW's only children's hospice, and the Adolescent and Young Adult Hospice (AYAH), Australia's first youth-focused hospice, ensuring age-appropriate palliative care for children, adolescents, and young adults. These services not only meet critical state needs but also provide models and knowledge that can be shared across other health sectors to strengthen holistic, inclusive care.

Voluntary Assisted Dying (VAD)

Since the previous Palliative Needs Care Assessment, New South Wales introduced the Voluntary Assisted Dying Act 2022. Across New South Wales, there are a total of 272 Medical Practitioners and 24 Nurse practitioners who are authorised to provide voluntary assisted dying services. (New South Wales Government, 2024).

Between 28 November 2023 and 30 June 2024, 1,141 people requested voluntary assisted dying, with a total of 398 patients who died as a result (New South Wales Government, 2024). **85%** of people requesting voluntary assisted dying services in New South Wales were receiving palliative care at their initial assessment. (New South Wales Government, 2024). Within Northern Sydney, the following number of requests for voluntary assisted dying were made within each local government area:

Local Gov. Area	Number of First Assessments for VAD
Hornsby	13
Hunters Hill	0
Ku-Ring-Gai	15
Lane Cove	<5
Mosman	<5
North Sydney	11
Northern Beaches	36
Ryde	8
Willoughby	8

> “Approaches to death and dying reveal much of the attitude of society as a whole to the individuals who compose it.”
>
> Dame Cicely Saunders, founder of the modern hospice movement, Oxford Textbook of Palliative Medicine (1993).

End-of-Life Care – Individual Funded Support

There are both state and national pathways for accessing funding for end-of-life care, since the previous Palliative Care Needs Assessment (2022). Several reforms within the Aged Care sector have influenced funding of at-home palliative care services. The Support at Home (SaH) program replaced the Home Care Packages (HCP) program on July 2025 and the Short-Term Restorative Care Programme in November 2025.

End of Life Pathway (Department of Health, Disability, and Ageing)

The End-of-Life Care Package commenced on the 1 November 2025 and can now be accessed through the Support at Home (SaH) program if patients have been diagnosed with 3 months or less to live and have a desire to receive care in the comfort of their own home (DHDA, 2025). Patient’s eligibility for the program is dependent on a combination of their estimated life expectancy and their Australian-modified Karnofsky Performance Status (AKPS) score (DHDA, 2025).

End of Life Packages (NSW Health)

NSW Health provides End-of-Life packages for six weeks, extendable based on patient needs. These packages support people in the deteriorating or terminal phase who wish to remain at home, offering assistance with daily living and carer support. Referrals can come from inpatient, outpatient, or community teams, including Specialist Palliative Care, Community Nursing, Chronic Disease, and Aged Care Assessment.

5. Overview of Palliative Care Services:

Northern Sydney

Palliative care in Northern Sydney is delivered across a range of settings including public and private hospitals, residential aged care, general practice, community services, and in people's homes. While good practice exists, service access and coordination can vary depending on individual needs, geography, and provider availability. This list offers a snapshot of available services, but it is not exhaustive.

A locally maintained service directory across public, primary, private and community services would support clearer navigation and more integrated care across the region.

NSHNS Oncology and Palliative Care: Northern Sydney Home Nursing Service (NSHNS) - Northern Sydney Local Health District (NSLHD)

Community nursing centres located in: Northern Beaches LGA (Brookvale, Mona Vale), Hornsby LGA, Ku-ring-Gai LGA, North Sydney LGA, and Ryde LGA.

They support people to remain at home in the community, operating 7 days a week. NSHNS includes the Oncology and Palliative Care nursing team who deliver care in the community to people in the end-of-life stage. This includes:

- symptom management and regular nursing assessments
- counselling and emotional support for people with terminal illness, their families, and carers
- end of life care

NSHNS work collaboratively with NSLHD inpatient teams and the HammondCare Palliative Care team to ensure multidisciplinary and coordinated care that supports patients, their families, and carers.

Safer@Home (Safer at Home) team, a Nurse Practitioner-led after-hours palliative care service operating from Friday to Monday, including:

- rapid response for patients with complex care needs
- a focus on symptom management and deterioration support.

Mona Vale Palliative Care Unit (MVPCU) - NSW Health

Located in: Northern Beaches LGA (Mona Vale)

MVPCU opened in February 2021 with 10 beds and is run by the Northern Sydney Local Health District (NSLHD). MVPCU collaboratively engages with community palliative care to ensure access for patients to MVPCU directly from home, aiming to avoid unnecessary acute hospital admissions. The local community service is the Northern Beaches Community Palliative Care Service (NBCPCS) run by HammondCare.

- Over 1000 admissions since opening in 2021
- Up to **50%** of admissions direct from community

The partnership demonstrates strong collaboration through senior medical input, consistent across both services, shared senior clinicians in multidisciplinary teams, joint teaching structures, and combined mortality and morbidity (MnM) meetings. This contributes to:

- Value to patient
- Avoiding unnecessary acute hospital admissions and multiple transfers
- Utilising Palliative Care Outcomes Collaboration (PCOC) to develop quality processes for benchmarking patient care, which has provided:

1. Capability in tracking patient flow
2. Comparing MVPCU independent data collection markers, for example, patient admission source with other like services.
3. Benchmarking symptoms and responsiveness.

Adolescent and Young Adult Hospice (AYAH) - Northern Sydney Local Health District (NSLHD)

Located in: Northern Beaches LGA (Manly)

The Manly Adolescent and Young Adult Hospice (AYAH), opened February 2023, and is Australia's first dedicated service for young people with a life limiting illness.

The 8-bed facility offers services to patients 16 to 30 years old across elective and emergency respite care, complex symptom management and end of life care, and is one of the pathways in place to support in the transition from paediatric to adult services.

It is run by Northern Sydney Local Health District with a multidisciplinary team of specialist medical staff, nursing staff, social work, physiotherapy, occupational therapy, clinical psychology, art therapy, dietitians, music therapy, speech pathology, pharmacy, and pastoral care. Referrals can be made at any time by contacting admissions, and there is no cost for a patient or family to stay at AYAH.

Bear Cottage - Sydney Children's Hospital Network (SCHN)

Located in: Northern Beaches LGA (Manly)

Bear Cottage Children's Hospice is a warm and home-like environment providing respite, symptom management and end-of-life care for children with life-limiting conditions along with support for their families. The 8-bed facility is a statewide service and the only children's hospice in NSW. It is governed by The Sydney Children's Hospital Network (SCHN). The dedicated team includes Staff Specialist, Visiting Medical Officers (VMOs), paediatric palliative care Registered Nurses, Social Workers, Child Life Therapists, Art Therapist, Music Therapist, Physiotherapist, Chefs and Housekeeping staff. Bear Cottage provides an extensive Family Support Program which includes programs for siblings, parents and grandparents.

These innovative programs provide opportunities for those in like circumstances to connect and alleviate feelings of isolation in a supportive therapeutic environment. Ongoing bereavement support is provided through the 'Footprints in the Sand' bereavement program for as long as a family needs. There is no cost for a child or family to stay at Bear Cottage.

HammondCare

NSLHD and HammondCare have established a partnership to deliver a comprehensive range of supportive and palliative care services for residents of NSLHD.
Services include:

Palliative care inpatient units at Greenwich and Neringah Hospitals

- **Specialist palliative care community services and outpatient clinics**
- **Bereavement Support**

Specialist community palliative care

Specialist community palliative care services are provided by HammondCare through a multidisciplinary team to NSLHD patients in their own homes.

The team operate out of three hubs; Neringah Community Team (covering Upper North Shore), Greenwich Community Team (covering the Lower North Shore) and the Northern Beaches Team).

Greenwich and Neringah Hospital

Greenwich Hospital and Neringah Hospital are Schedule 3 Affiliated Health Organisations (AHO) situated in the suburbs of Greenwich and Wahroonga. They are owned and operated by HammondCare and contracted by NSLHD to provide public palliative care services, with Greenwich Hospital including a 22-bed subacute palliative care unit and Neringah Hospital including a 19-bed subacute palliative care unit.

The palliative care units are able to accommodate public, private, Department Veteran Affairs (DVA) and self-funded patients. Both units provide short-term needs-based care for patients with life-limiting illnesses at various times in their illness journey. This care is provided by comprehensive multidisciplinary teams which include medical, nursing, allied health, and pastoral care support to meet the unique needs of the patients, carer, and family.

This includes symptom management (physical, psychosocial, and spiritual), high quality end-of-life care and discharge planning.

Palliative Aged Care Supportive Service (PACSS) Northern Sydney Local Health District (NSLHD)

As palliative care becomes an essential component of aged care services in Australia, partnerships ensure that care is responsive to the needs of older Australians. PACSS strengthens this collaborative approach to enhance provision of palliative care in aged care. PACSS is a nurse practitioner led model of care that enables people to live and die in their place of choice. It is a streamlined approach to patient discharges from hospital to residential aged care facilities with supportive and palliative care needs with services that include:

- Comprehensive assessment
- Family case conference
- Advance Care Planning
- Ongoing review and support as required

Hospital avoidance:

- Urgent clarification of advance care planning which prevented transfer to hospital
- Urgent family conference which prevented transfer to hospital
- GP not available to review, or unable to prescribe S/C End of life care medications.
- Palliative Care Outcomes Collaboration (PCOC) phase measured unstable due to distress from uncontrolled symptom: moderate to severe.
- Contact from ambulance, geriatric outreach team, emergency department, residential aged care home (RACH), family, and Virtual Palliative Care Navigator for urgent review.

6. Insights & Key Stories:

Community & Sector Perspectives

The insights presented below are drawn directly from engagement with the wider palliative care community, including community consultations, further separate consultations with health and community sector professionals, and targeted engagement across aged care and primary care settings. These insights reflect participant experiences, perspectives, and priorities, highlighting changes over time, what is working well, and where gaps and challenges remain. The information is presented separately as community and sector insights to preserve the integrity and distinct context of each consultation process.

The six key stories presented in this assessment reflect an evolving understanding of palliative care needs across Northern Sydney. While the number of thematic areas remains consistent with the 2022 needs assessment, the stories themselves have deepened and shifted in response to new conversations and perspectives. As with previous assessments, this process remains iterative, shaped by continuous engagement with the wider palliative care team.

- **Story 1: Education and Dialogue: Death and Dying**
- **Story 2: Communication and Information Sharing: Connected Care**
- **Story 3: The Wider Palliative Care Community**
- **Story 4: Carers Central role in Outcomes**
- **Story 5: Living Well: Emotional, Physical, Social and Spiritual**
- **Story 6: The Patient Journey**

Story 1

Education & Dialogue: *Death & Dying*

Education as relational, cultural & experiential

While the need to normalise conversations about death and dying and clarify palliative care remains, consultations point to a growing emphasis on education as relational, cultural and experiential. Education is increasingly seen as a lifelong process, beginning early through age-appropriate resources and school programs, and continuing through family-inclusive approaches, community education, workforce training and companionship initiatives.

Key themes include flexible learning in familiar spaces, plain-language and culturally responsive resources, interactive formats such as storytelling and peer learning, and practical workforce approaches including micro-learning, bedside coaching and palliative care champions. Spiritual care, culture and language were also highlighted as integral to meaningful conversations, regardless of religious affiliation. This shift recognises that preparation for death and dying requires more than information. It requires ongoing dialogue that supports shared learning, lived experience, cultural understanding, practical confidence and meaning-making across families, services and communities.

Insights: Community

1. Community readiness & relational support

Education and dialogue about death and dying can begin early in life and continue across the life course. Age-appropriate education in schools, community-based learning and calendar events can help normalise conversations about death, dying, grief and bereavement, reduce stigma and build a more death-literate community.

Within families and relationships, open dialogue should be encouraged and supported through family-inclusive approaches, practical conversation guides and community companion programs. This includes strengthening connections between General Practice and families, linking education with will-making and planning, and providing companionship initiatives that reduce isolation and recognise that no one should face end of life alone.

2. Accessible, trusted, and human-centred approaches to education

The What: Community consultations highlighted the need for greater awareness of what to expect, what palliative care is, who is involved, how to care at home, and what services and supports are available. Practical resources already exist, including the Palliative Care NSW Palliative Caring booklet, which can help build understanding, confidence and readiness for individuals and families.

However, availability does not always translate to awareness, access or timely use. Opportunities remain to strengthen how information is introduced and shared so that it is timely, relevant and easy to use.

The Where: Education about death and dying can be offered where people are already comfortable and connected, for example, in community halls, libraries, training facilities, retirement villages, cultural centres, and spiritual or faith-based settings, making conversations more accessible, relevant and meaningful.

The How: Different people learn in different ways, so flexibility in approach and accessibility matters.

An omnichannel approach of print, web, in-person, with partnerships and primary care integration;

- community groups
- seniors groups
- retirement villages
- faith spaces
- home visits where possible for those unable to travel.

The Who else: Participants value choice and flexibility.

- informal, interactive, and supportive delivery
- group sessions for shared comfort and guided discussion
- peer learning and personal storytelling
- 1:1 consults for privacy
- self-learning resources.

3. Emerging themes: Language, Culture & Spiritual Care

Language: Use of simple terminology and in-language where possible.

Culture: When engaging communities in education about death and dying, it is important to recognise that cultural beliefs, practices and traditions shape how people understand, discuss and respond to death. While loss is universal, the language used to describe it and the rituals surrounding it vary across communities.

Spiritual Care: Be ready for spiritual and existential conversations that support meaning, connection and peace. Spiritual needs can extend beyond religion and may be expressed through relationships, nature, creativity or personal values. Language should be flexible, allowing people to define spirituality on their own terms.

Insights: Sector

1. Community readiness & relational support

- Consistent terminology and family education support earlier access to palliative care and shared decision-making.
- Education initiatives, including family webinars in aged care have proven valuable and provide opportunities for questions, setting expectations, and planning. Helping to reduce uncertainty and prevent unnecessary emergency department presentations.
- Plain language translated resources and culturally responsive approaches are important for meaningful engagement of diverse communities, and support inclusivity and understanding.
- Misconceptions about palliative care and palliative care units can affect decision-making; clear and compassionate information can improve understanding and confidence in care choices.
- When care needs can no longer be supported at home, people and families may be hesitant to consider a palliative care unit. Clear, compassionate information about what to expect can address misconceptions, build confidence and support informed decisions about place of care.

2. Conversations with younger members of families about death, dying, and grief

- Children and young people benefit from age-appropriate, honest information and opportunities to ask questions about illness, dying and grief in ways that feel safe and comfortable for them.
- Discussions are often delayed or avoided, which can leave children feeling excluded, confused or unprepared during significant family moments.
- Open, truthful conversations can foster emotional safety, trust and resilience, while gentle involvement in care and family rituals can help children feel connected and included.
- Education about death and dying can begin early through schools, community programs and age-appropriate resources, helping build confidence, healthy grieving and lifelong death literacy.
- Partnerships with paediatric, adolescent and young adult organisations can support the development and delivery of tailored resources and education.

3. Workforce capacity and structures shaping learning and practice

- Workforce turnover, time pressures, and burnout can undermine continuity of palliative care education and capability development across aged care.
- Palliative care champions, particularly Registered Nurses in aged care settings, can play an important role in building workforce capability, modelling best practice and supporting the use of assessment tools.
- Across health and aged care services, workforce constraints, variable confidence and limited access to specialist expertise can make conversations about death, dying, goals of care and what matters most to the person more challenging.
- Additionally concerns about diminishing hope, cultural sensitivities and uncertainty about timing can contribute to delayed conversations, leaving people and families less prepared for changes in condition and care needs.
- Knowledge and confidence can be lost when people move between services, highlighting the importance of consistent communication, education and care coordination.
- The disability sector faces additional challenges, with support workers often having limited access to timely clinical oversight and support for managing complex or deteriorating conditions, particularly in group home settings where support workers reported feeling underprepared for end-of-life care.

4. Effective education approaches in aged and home care settings

- Practice-based learning, such as joint visits, case-based discussions and Needs Rounds, was valued for building confidence and practical skills across aged care, with relevance for home care settings.
- Online training alone was seen as less effective unless supported by action-oriented learning, micro-learning and ongoing reinforcement to help staff apply and maintain skills.
- Placement-based learning opportunities, including PEPA (program of experience in the palliative approach), were identified as valuable for strengthening engagement, confidence and hands-on experience in the palliative approach.
- Practical tools, such as flip charts, printed and digital resources, end-of-life care guides and bereavement packs, can support staff and families, particularly where time pressures or language barriers exist. These are most useful when they provide clear guidance across palliative care, end-of-life care and after-death processes and are easy to access at the point of care. For example, those available through palliAGED and End of Life Directions in Aged Care (ELDAC).

Insights: Residential aged care homes & General Practice

Aged care homes surveyed identified preferred education formats as:

51% in person workshops

34% online modules

8% experiential learning

Aged care home staff report that families' limited understanding or acceptance of palliative care can potentially obstruct care plans, highlighting that facilities want family education and culturally responsive support.

General Practitioners surveyed identified preferred education formats as:

44% online modules

30% in-person workshops

11% peer mentoring or case conferencing

15% Not currently interested in engaging in further training and support

Blue Sky Thinking

Aged care homes aspired to practical, ongoing capability building at the point of care, including:

- Monthly refreshers and micro-training
- Bedside coaching to support staff in real-time care situations
- Supernumerary rounding with a palliative care specialist to strengthen learning on the floor.
- Confidence building for junior staff
- Palliative care champions to guide teams and embed the palliative approach in everyday practice.

Story 2

Communication & Information Sharing: Connected care

A stronger focus on accessibility, navigation, interoperability and relational continuity for families.

> **The 2025 findings reinforce a clear message:** information must be easy to find, easy to understand, easy to share and supported by human guidance.

While early discussions about goals of care remain central, consultations point to the need for locally relevant information about services, eligibility, referral pathways and practical next steps. Families need support to navigate systems before crisis points, while services need better interoperability, secure messaging, reliable contact directories and standardised templates to reduce fragmentation, administrative burden across organisations, and repeated storytelling.

Connected care also depends on role clarity, visibility of service capacity and relational communication, including repeated family conversations, culturally responsive information, and emotional and spiritual support alongside clinical care.

This recognises that connected care depends not only on better systems, but also on timely, human and culturally responsive communication.

Insights: Community

Community consultations emphasised the need for clear, accessible and reliable information about local palliative care, aged care, end-of-life care and support services. Participants wanted simple, locally relevant guides that explain available services, eligibility, where to seek help and when to act before issues escalate. They also highlighted the need for human-guided support to navigate complex systems and practical tasks, such as uploading Advance Care Plans to My Health Record or accessing My Aged Care. Navigating care can feel overwhelming, with no "rehearsal" for these stages of life. Stronger communication between General Practice, families and services could help ensure information reaches the right people at the right time, rather than relying on family members to pass it on.

Insights: Sector Services

1. Fragmented systems undermining connected care

- Siloed IT systems, limited interoperability, inconsistent use of My Health Record and outdated contact details continue to undermine communication across services.
- These gaps create administrative burden, delays, data loss and repeated storytelling for patients, carers and families.
- Day-to-day care coordination is affected by unclear contact points, at times difficulty reaching General Practitioners, particularly in large bulk billing practices, and delays in receiving key documentation.
- Transitions between hospital, home, residential aged care, subacute care, respite and Emergency Department settings remain vulnerable, particularly when discharge information is missing, unread or not shared with families. Transitions improve where a clear single point of contact exists.
- The sector called for whole-of-system communication infrastructure across public, private, primary care, aged care, community and non-government services, including reliable contact directories, secure messaging pathways, interoperable data sets and consistent access to relevant clinical information.

2. The role of standardised language & documentation as an enabler of connected care

- Consistent language, standardised forms and complete documentation were seen as key enablers of connected care, particularly for goals of care, discharge handover and escalation planning.
- Checklists, templates and outcome programs, such as the Palliative Aged Care Outcomes Program (PACOP) and the Palliative Care Outcomes Collaboration (PCOC), are valued for supporting shared language, clearer communication and greater consistency across services.
- Discharge communication can be variable, particularly in relation to goals of care, escalation plans and information needed to support continuity after discharge. Proactive GP contact, early follow-up with community and residential aged care services, and the development of a NSLHD palliative care specific discharge template were identified as ways to address this gap.
- Multiple, non-aligned Advance Care Planning forms across state, national and organisational settings can create confusion, inconsistent terminology and duplication. Participants support Advance Care Planning as relational work, recognising that meaningful conversations require time, skill and confidence.

3. Service awareness, role clarity & workforce constraints

- Limited visibility of available services, provider roles and service capabilities can contribute to missed or inappropriate referrals and misaligned expectations.
- Clearer information about service capacity, scope and acuity requirements is needed to support appropriate referrals and coordinated care pathways.
- Workforce and funding pressures, including limited GP availability for home visits and follow-up can make communication and planning more difficult.
- Nurse Practitioners were identified as a potential role to help address some of these gaps in future service models.

Insights: Residential aged care homes & General Practice

Aged care homes surveyed reported that families are typically involved in case conferencing, a major enabling factor for goal concordant care. GP participation was also reported as strong, with palliative care specialist teams and allied health involved for a sizeable subset.

Aged care homes reported that while early, proactive referral is desired, it is not always enabled where referral criteria feel unclear or thresholds appear high. Navigation was also described as challenging, with inconsistent advice, unclear costs and processes, and variation depending on location.

General Practitioners surveyed reported varying levels of confidence in initiating palliative and end-of-life care conversations:

- **44%** felt very confident
- **56%** felt somewhat confident

GPs identified coordination and navigation as key pain points, particularly the need for clear referral pathways and emergency contacts. Concerns were also raised about access, continuity and the risk of delayed engagement or fragmented care within public palliative care services.

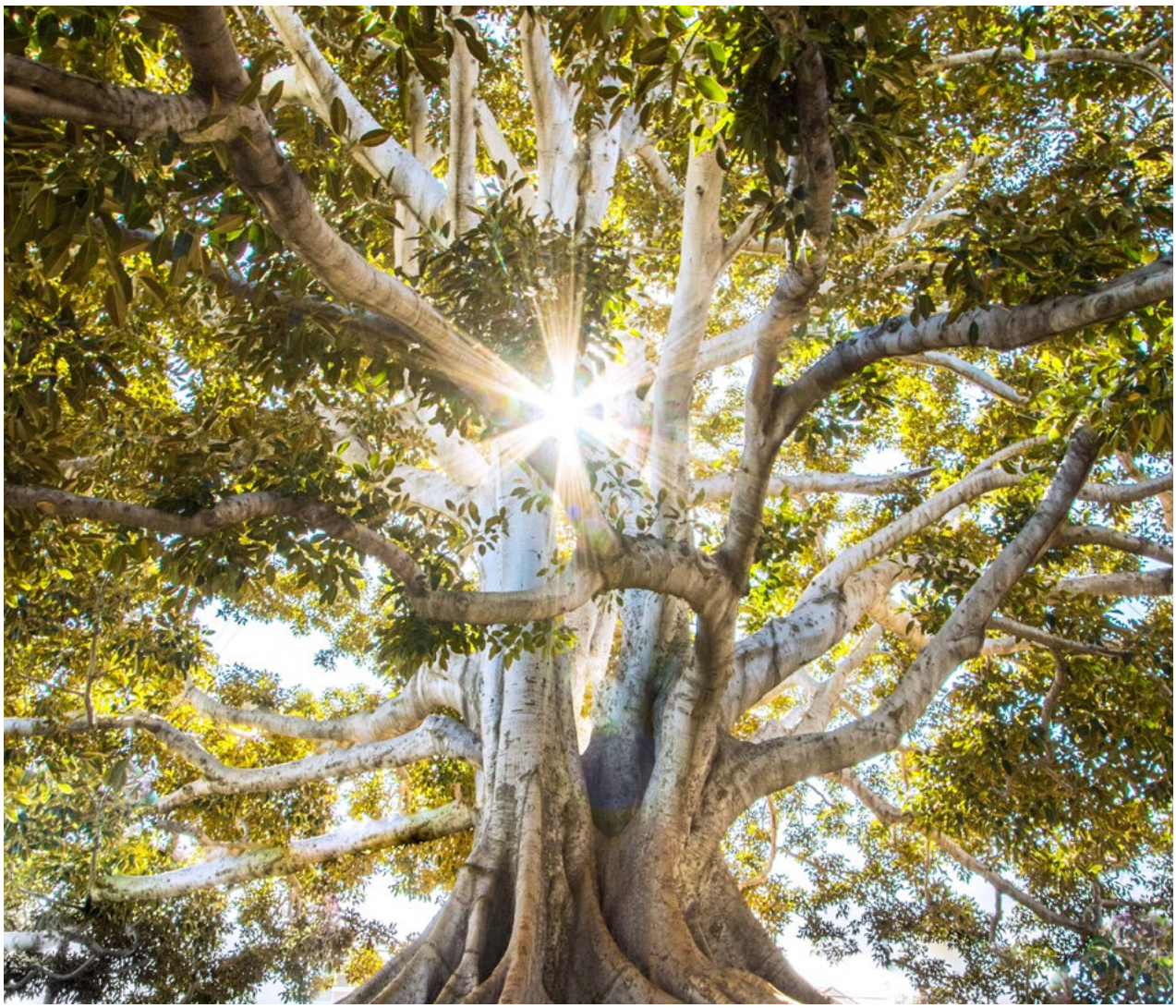
Advance Care Directives were reported as widely implemented by GPs. However, use of available digital clinical tools for palliative care was inconsistent, with HealthPathways and palliMEDS emerging as the most commonly used resources. This suggests an opportunity to increase awareness and consistent use of existing digital tools, including HealthPathways, to support clearer referral, escalation and care planning

Blue Sky Thinking

Aged care homes aspired to communication and information sharing anchored in relational care, including: (1) Early and repeated family conversations, (2) Clear, practical information for residents & families, (3) Emotional and spiritual support alongside clinical care.

Story 3

The Wider Palliative Care Community



Palliative care is delivered through a wider circle of care that extends beyond specialist services to include families, carers, General Practice, aged care, community providers, pharmacies, volunteers and local networks. All part of the interconnected tree of the wider palliative care community.

Since the 2022 Needs Assessment, this approach has been strengthened by Sydney North Health Network through regional education, forums and compassionate community initiatives that bring different parts of the palliative care ecosystem together. The 2025 findings show that the focus is now shifting from recognising the wider palliative care team to better enabling it's interconnected community. While home remains a preferred setting for many, this depends on timely, flexible, coordinated, and relationship-based support. This includes practical help for carers, responsive outreach, strong GP and service connections, and community capacity that connects people to the right support as needs change, helping ensure no one faces end of life in isolation.

Insights: Community

Community stories highlight that palliative care extends far beyond clinical treatment. It involves a network of people, families, carers, services, and values that support living well and dying well. Services play an important role in recognising and supporting the whole circle of care, fostering collaboration and communication across everyone involved.

The description of living well: simplicity, comfort, connection, and thoughtful environments, reflects values that the wider palliative care team can uphold collectively. These elements aren't just about clinical care, they involve collaboration between clinicians, families, carers, personal networks, and community support services.

For some, the care journey begins suddenly, often triggered by a diagnosis or a significant change in health, requiring urgent decisions and practical steps such as treatment planning, arranging care, or preparing for funeral arrangements. These moments highlight the challenges families face in providing support under difficult circumstances.

Participants discussed aged care services as integral to the wider palliative care team for older people, enabling people to remain at home longer, but raised concerns about inconsistent quality by service providers as service environments change rapidly.

Insights: Palliative and End of Life Care Services

1. Home as the preferred setting: preferences and constraints

- Stakeholders emphasised the importance of starting conversations early and revisiting them over time, including one-to-one Advance Care Planning consultations, to help preserve choice and prepare people and families for what end-of-life care at home may involve.
- While many people prefer to remain at home, this depends on practical factors such as carer capacity, 24/7 support, home layout, clinical complexity, medication access, overnight care and responsive care packages.
- Carer exhaustion, fear of unmanaged symptoms and limited respite can make home care difficult to sustain, particularly for single carers, leading to late-stage transitions to hospital or inpatient palliative care.
- Confidence to support care at home can grow through education, trusted relationships and practical support from GPs, community pharmacies, volunteer groups and other local assets.
- Timely, flexible and quality-assured support, including evening and overnight care, is critical to sustaining home-based end-of-life care. Delays or inflexibility in care packages can leave families unsupported during critical moments. The introduction of End-of-Life Care Packages provides relevant policy context for these findings through the Support at Home Program.

2. Community capacity and informal supports

- A strong community around the person, including family, neighbours, schools, sporting groups and social networks, can help sustain care, reduce isolation and provide practical support.
- Contemporary living patterns, such as smaller families, geographic distance and high-density living, can limit the availability of informal and organic support, and increase reliance on formal services. Strengthening compassionate communities and local networks can help build confidence, reduce isolation and support practical wraparound care.
- Planning ahead can help build death literacy and normalise future-focused conversations that identify small, practical supports, such as help with shopping, bins, school pick-ups or transport, to reduce stigma, prevent overwhelm, and distribute care more sustainably across networks.
- Building community capacity requires deliberate investment in local networks, compassionate community approaches and culturally inclusive models of support, so that no person faces end of life in isolation.

3. Trusted gateways and integrated care: coordinating teams around the person

- Families consistently identify GPs as a trusted first point of contact. GPs play an important role in early identification, reframing palliative care and signposting to community and specialist supports.
- Effective care depends on coordination across acute services, community providers, general practice, pharmacy, aged care and private carers, supported by clear roles and trusted handover arrangements.
- Outreach and nurse-led models, community pharmacy involvement and specialist support to residential aged care homes are valued, although access and consistency vary.
- Rapid response and aged care outreach models, such as Palliative Aged Care Supportive Services (PACSS), geriatric outreach teams such as ARRT, BRACE and GRACE, and HammondCare in-reach palliative models, were identified as effective in supporting care in community and residential aged care settings. These models can strengthen timely access to care, support any unecessary hospital admission, where appropriate, and generate sustained system benefit when embedded and supported over time.
- Flexible movement between home and inpatient palliative care units can reduce fear, preserve therapeutic relationships and support "try home" periods with clear safety nets when care needs escalate. They are particularly important when care needs escalate rapidly, providing reassurance and responsive support to families.

Insights: Residential aged care homes & General Practice

Aged care homes surveyed

- Aged care homes value palliative care services, with several reporting strong support from community palliative care teams and **75%** indicating adequate access to external palliative care services.
- Opportunities identified to strengthen timely specialist palliative care responses, proactive GP liaison, and clearer pathways to help residents remain in their care setting.
- Clear response categories, such as urgent versus routine, simple referral and triage pathways, and explicit GP liaison expectations were highlighted as important.
- Workforce shortages, including limited Registered Nurse availability on shift, can affect confidence and capacity to provide complex end-of-life care.
- Recent investments, such as dedicated palliative care practitioners, were noted as important supports for building capability in aged care homes.

General Practitioners surveyed

- Among GPs surveyed, **52%** felt somewhat connected and **20%** felt very connected to the wider palliative care team, while one in four reported no connection, suggesting an opportunity to strengthen integration.
- GPs reported the need for fast, dependable co-management, particularly for residential aged care and acute symptom escalation.
- Timely access to specialist palliative care and nursing support was identified as important.
- GPs valued collegial support, shared decision-making, case collaboration and peer mentoring, particularly for managing people receiving palliative care at home.
- Open-ended responses suggested that face-to-face interaction and opportunities to meet the palliative care team may help build stronger working relationships.

Blue Sky Thinking

Aged care homes aspired to more responsive and embedded palliative care support, including:

- 24/7 palliative medical and nursing advice
- Rapid "flying squad" activation when complexity escalates.
- An escalation pathway beyond the GP when urgent specialist input is needed.
- Dedicated in-house palliative care champions to support family conversations, coach staff and coordinate pathways.

Story 4

Carers' Central Role in Outcomes

The carer role remains central to determining palliative and end-of-life outcomes, but the 2025 findings highlight a deeper understanding of how carer wellbeing, confidence and capacity shape outcomes.

Carers are not only providing care, but they are also often coordinating 24/7 support, navigating uncertainty in complex systems, financial pressures, cultural and language barriers, and carrying significant emotional, physical and practical responsibility.

Comfort, peace and family harmony are now recognised as core outcomes, making timely respite, overnight support, practical guidance and proactive clinical response essential to sustaining care at home and supporting compassionate end-of-life experiences.

Insights: From the community

Carers describe caring as both a privilege and an exhausting responsibility, highlighting the need for rest, sleep, respite, emotional support and practical assistance to manage the physical and emotional strain of caregiving.

Comfort was described as central to quality care, understood as peace, dignity and freedom from suffering. Families valued comfort not only for the person receiving care, but also for easing the emotional burden of witnessing distress. Comfort, peace and family harmony were therefore seen as important outcomes for both the person and those around them.

1. Carer wellbeing & mental health

- Carers need space and support to process the emotional impact of caring, including grief, isolation, regret, anger, sadness and powerlessness, both during and after the caring role.
- Short, flexible breaks can help carers maintain capacity and create a rhythm of recovery, supporting rest, sleep and emotional resilience.
- Access to empathetic, supportive and practical respite and relief, including overnight support, was described as difficult to obtain through both services and personal networks.
- The caring role can reshape relationships, as partners or family members shift into full-time caring roles. This can affect work, autonomy, identity, social connection, and physical and emotional wellbeing.

2. Carers' role in shaping care experiences and outcomes

- Carers play a central role in shaping end-of-life outcomes, with their capacity strongly influenced by how clearly, consistently and responsively they are supported.
- Uncertainty about what to expect, what to do next or who to contact increases distress and reduces confidence, particularly during periods of rapid change or crisis, with carers describing past experiences as overwhelming, fearful, and emotionally demanding.
- Carers value proactive outreach, real-time clinical response and in-person support during critical moments, especially for symptom management and decision-making.
- Positive care experiences were linked with proficiency, continuity, compassion and relational warmth. Familiar workers who understand the person's story were seen as vital for recognising changing needs early.
- Flexible, coordinated and holistic support helps sustain care at home, particularly when carers, families and knowledgeable staff are brought together. By contrast, limited after-hours or weekend access can leave carers feeling abandoned during periods of acute distress.
- Financial strain, access to practical aids and availability of reliable local services also affect whether home-based care can be sustained.

Insights: Palliative and End of Life Care Services

1. Carers as de facto coordinators of 24/7 care

- Carers often become de facto coordinators of home-based care, organising continuous, shift-like support that can fall heavily on one person.
- The number, reliability and stamina of available helpers are key factors in whether care at home can be sustained.
- Nights and weekends are critical pressure points, when carer confidence can falter and distress can escalate.
- Clear, responsive after-hours options, including non-transport ambulance assistance where appropriate, can help reduce distress and avoid potentially preventable hospital presentations.
- Home and community nursing are trusted sources of hands-on care, training and reassurance. Ongoing in-person education and “feet on the ground” support can build carer confidence and safety at home.

2. Intersecting system and social pressures on carer capacity

Continuous caring demands, particularly for people who are bed-bound or have complex needs, can rapidly exhaust carers and contribute to hospital transfers.

Carers often navigate complex and fragmented service systems while fatigued and emotionally strained, increasing confusion, decision pressure and reliance on crisis responses.

Limited after-hours support, trusted respite or practical relief can further reduce the sustainability of home-based care.

Carer capacity is also shaped by social context, including dispersed families, housing pressures, reduced local supports and the absence of a “village” to share the practical and emotional load.

Strong family responsibility norms can sometimes limit acceptance of external support, concentrating care demands on one person.

Language, culture, residency status, digital literacy and financial capacity can affect access to services and delay engagement.

Language barriers, particularly when combined with dementia, can make assessment, counselling and expression of distress more difficult. Language-specific counsellors, translated resources, culturally matched volunteers and clearer navigation support were identified as enablers of earlier and more equitable care.

Story 5

Living Well: Emotional, Physical, Social and Spiritual

Living well was described as foundational to physical, emotional, social and spiritual wellbeing. Participants linked wellbeing to everyday practices and meaningful experiences, including sleep, balanced diet, movement, fresh air, gardening, music, creativity, spirituality, shared meals, time for self and connection with others.

Mental health was seen as central to palliative care for the person, families and carers. Peace of mind was supported by dignity, choice, attentive care, meaningful activity, and clear early information about services, eligibility and finances, particularly exasperated when pain, physical limitation or uncertainty were present.

Music was identified as playing a key role in daily wellbeing. Engagement in the arts, including music, visual arts, dance, movement, craft and literature, can act as a language beyond words for emotional regulation, identity and connection.

Nature was identified as restorative for mind and body, easing stress and supporting mental health. Participants valued access to green spaces, gardens, natural light, plants, shared meals and creative activities that support connection, preserve personhood and celebrate life stories.

Participants emphasised that support should begin early and continue across the palliative care journey, recognising that grief, uncertainty, family distress and spiritual needs may arise well before end of life. Living well therefore requires whole-person, trauma-informed and culturally responsive approaches that support the person, their carers and family before, during and after death.

Insights: From the Community

1. Access and modalities

- Psychosocial, spiritual and practical support should be available early in the palliative care journey, ideally at or soon after diagnosis, to reduce fear, open conversations and provide clarity about prognosis, expectations and roles.
- Mental health support is seen as most effective when it allows time, continuity and trusting relationships, with flexible access through face-to-face, phone and clear referral pathways via aged care, allied health and community services.
- Grief was described as present across the whole palliative care journey, with participants valuing proactive grief education and ongoing support for patients, carers and families.
- Participants were interested in dedicated spaces within health and community settings for reflection, remembrance and emotional support.
- Spiritual care was identified as central to wellbeing, offering comfort, meaning and peace. It should be guided by individual preference and recognise that spirituality may include, but is not limited to, religious or faith-based beliefs. It may also be expressed through culture, relationships, nature, values, meaning and connection, alongside emotional and mental health support.

2. Family, carer and peer support

- Families and carers play a pivotal role in mental health and wellbeing outcomes, and require practical, emotional and relational support.
- Participants valued structured peer support opportunities, including groups that enable sharing of lived experience, alongside practical respite and home-based support.
- Facilitated family meetings was seen to support communication, ease tensions and reduce distress, particularly when the wishes of the person and their family differ.
- Participants described fear, protectiveness and uncertainty as emotional barriers that can make end-of-life conversations difficult. They felt these could be supported through openness, reassurance and relational support.
- The need for "permission to die" was discussed, reflecting the need for acceptance, reassurance and emotional safety from loved ones, helping individuals and families feel connected and at peace as end of life approaches.

3. Approach to care, connection and bereavement support

- Trauma-informed approaches were valued, including staff capacity to recognise trauma responses, respond safely in emotionally charged or time-pressured situations, and support emotional regulation. Responsive communication skills were seen as particularly important as communication needs change with cognitive decline.
- Pain was understood holistically, with physical, emotional and existential pain recognised as integral to mental wellbeing in palliative care.
- Cultural safety was identified as central to quality care, including explanations that make sense to the person, care options that reflect cultural background, and respectful acknowledgement of beliefs, practices and rituals.
- Trusting relationships, individualised support and continuity of care were described as essential foundations of wellbeing.
- People under 65 reported greater difficulty accessing care that meets emotional, physical and spiritual needs through a whole-person lens, highlighting the need for flexible and inclusive responses across the lifespan.
- Participants wanted practical "how to" resources, language for difficult conversations, anticipatory grief education, culturally appropriate explanations and age-appropriate information for children and young people. There was a clear call for broader community education to normalise conversations about death and dying and build confidence in navigating end-of-life experiences together.

Insights: Palliative and End of Life Care Services

1. Normalising grief without over-medicalising

- Grief is understood as a natural response to illness, dying and loss, but stigma and over-medicalisation can make people feel their experience needs to be fixed rather than supported.
- Services emphasised the importance of normalising grief while ensuring timely access to additional support where needed, including counselling, group support and specialist mental health or psychiatry referral when appropriate.
- Informal, low-barrier supports such as morning teas, walking groups and peer connection were valued when they are safe, structured and supported by trained facilitators, with optional access to mental health professionals ensures support, without making the space feel clinical.

2. Access and Equity Challenges

- After-hours gaps, limited psychiatry access, digital exclusion and variable follow-up can leave families unsupported during critical periods, particularly in community settings.
- Tailored approaches are needed for older adults, people with disability, culturally and linguistically diverse communities, people living with dementia, and those experiencing anticipatory grief or the “long goodbye”.
- Culturally responsive grief and bereavement support through the value of culturally congruent environments, in-language resources, music, spirituality, food, language, and community-based counselling, can help people engage with support in ways that feel safe and meaningful.
- Inpatient services may have more visible supports, while community-based bereavement support can be harder to identify or access. Better integration, mapping and referral pathways can reduce duplication and improve equitable access.

- Families may only feel ready for support months or years after a death, highlighting the need for ongoing check-ins, memorial spaces and clear referral points across the bereavement journey.
- Bereavement support can be missed or inconsistently offered, particularly in community settings. Families may only feel ready months or years after a death, highlighting the need for ongoing check-ins, memorial spaces and clear referral pathways over time.
- A district-wide public health approach to bereavement is delivered in response to this, across the NSLHD through HammondCare Community Palliative Care Services. This stepped model provides grief education, community-based and group supports, and targeted individual support, recognising that grief experiences vary and change over time.

4. Family Wellbeing as a Patient Priority

- Patients may experience greater peace when they know their family is supported, making family wellbeing an important part of person-centred palliative care.
- Pre-bereavement conversations and personalised follow-up plans can help families prepare emotionally and practically, while ensuring support continues in ways that suits each family's needs and preferences.
- Children connected to a person with palliative care needs can feel confused or isolated when excluded from conversations about illness, death and grief. Honest, age-appropriate communication, compassionate support from adults and professionals, and inclusion in family experiences can build emotional safety, trust and understanding, while easing distress for both children and parents approaching end of life.

Insights: From aged care homes

Blue Sky Thinking

Aged care homes aspired to environments that support quality of life and a dignified death in place, including:

- Calm, private and culturally attuned spaces with soft lighting, music, personal or cultural items, and room for family to gather.
- Larger rooms or dedicated palliative care rooms that allow families to stay overnight and remain close during end-of-life care.
- On-site counselling, spiritual care, clear grief pathways and team debriefing to support residents, families and staff wellbeing, and help prevent workforce burnout.

Story 6

The Patient Journey

The palliative care journey is deeply individual, shaped by personal preferences, family context, culture, trauma, frailty, changing needs and readiness for information. The 2025 findings highlight that people want to feel seen, heard, and respected through care that is flexible, compassionate and responsive rather than process-driven.

While strong services and resources exist across Northern Sydney, the journey can still feel difficult when pathways are unclear, services are disconnected, or people are left repeating their story. A clearer, more coordinated journey requires an inclusive service directory, practical guidance, timely referral, relational first contact, and advocacy or navigation support that helps reduce complexity as needs change.

The patient journey also requires accessible, culturally safe information and emotional and psychosocial support before, during and after death, including anticipatory grief guidance and aftercare. Overall, this story is about seeing the person, not just the system, highlighting the need for pathways that prioritise comfort, dignity, respect and peace throughout the journey.

Insights: From the community

1. A personal and evolving journey

- Participants emphasised that the palliative care journey is deeply individual. What is right for one person may not be right for another, and care needs to respond to personal preferences, family context, culture, past trauma, changing needs and readiness for information.
- Good care was described as feeling seen, heard and respected. Participants valued clear explanations, dignity, shared decision-making and communication that involves talking with people, not at them. Flexibility in services, practitioners and communication was seen as essential, with people wanting to feel understood, not just informed.
- Emotional and psychosocial support were also viewed as part of the journey, not separate from it. Participants wanted early guidance on grief, loss and anticipatory grief, as well as compassionate aftercare for carers and families once the caring role ends.

2. A journey that needs timely coordination and clear next steps

- Participants described the journey as difficult when services feel disconnected, information has to be repeated, or the next step is unclear. This was particularly challenging for people who are isolated, overwhelmed, or without family and community support.
- There was a strong call for a designated navigator or a qualified person who can advocate with the person, carer, and family when they are struggling to communicate their needs, understand options or move between services.
- Participants noted that General Practitioners are under significant pressure, and their heavy workloads can affect communication and collaboration. They called for a more holistic and coordinated approach to communication across the wider care team.
- Timely referral to palliative care, early involvement of social work, community nursing and other supports, and clear care plans were viewed as important to continuity. Participants also emphasised the need for services to check capacity before referrals are made, so people and families are not left chasing unavailable supports.
- Participants wanted practical guidance that explains what to do, when to act and who to contact, including clear and accessible information about Advance Care Planning.
- Care responses should be supported by coordinated communication across the wider care team, including General Practice, and reflect age, frailty, cumulative health impacts and personal circumstances, with comfort, peace, dignity and continuity prioritised throughout the journey.

Insights: Palliative and End of Life Care Services

1. Making the journey simpler, clearer and easier to navigate

- Sector participants identified the need to make the palliative care journey easier to understand and navigate for patients, carers, families, GPs and clinicians. A clearly visible navigation pathway, supported by local service information and plain-language guidance, was seen as important so people can understand what help is available, where to seek support and what to expect at different points in the journey. Existing pathway tools, including HealthPathways, can support clearer referral decisions and more consistent provider navigation, but their visibility and uptake remain important.
- While a single “concierge” access point was seen as desirable, sector feedback also highlighted the complexity of coordinating access across multiple providers, teams and referral processes. Residential aged care was identified as an example where pathways may differ depending on whether referral occurs through hospital discharge or via a GP from within the aged care home. This reinforces the need for clearer pathway mapping, shared referral guidance and visibility of provider roles.

- Consistent language, timely information and practical guidance were seen as important to reducing confusion, repeated storytelling and misdirection. Participants also highlighted that first contact should be relational, with phone, face-to-face or video options helping identify uncertainty, reluctance or confusion in ways that apps or brochures alone may not.
- The NSW Health Single Digital Patient Record (SDPR) provides important policy and system context for improving continuity across NSW Health services. As it is progressively implemented, SDPR may help reduce repeated storytelling and improve access to relevant clinical information within public health settings. However, consultation feedback highlights that the palliative care journey also spans primary care, aged care, private providers, community organisations and non-government services, meaning local pathway mapping, referral guidance and communication across sectors will remain essential.

2. Designing the journey for equity, diversity and different care settings

- Sector participants emphasised that the patient journey needs to be designed for diverse needs, including people with disability, Aboriginal and Torres Strait Islander peoples, LGBTQIA+ communities, culturally and linguistically diverse communities, people living with dementia, and people supported in group homes or residential aged care.
- In-language resources, culturally safe communication, community spaces and links with cultural organisations were identified as important to improving understanding and access. While many high-quality resources are already available, participants highlighted the need to increase their visibility, timely use and connection to trusted local pathways.
- Dementia-related behaviours, terminal agitation and myths about reversibility were also noted as areas where families, carers and staff may need clearer information and more responsive support. Integrated behaviour management and rapid-response counselling can ease distress and prevent breakdowns in care.
- Participants highlighted that some carers may minimise their own needs, saying “I’m fine” despite significant strain, and may require proactive follow-up.
- In group homes and residential aged care, scope-of-practice limitations, medication administration issues, staffing pressures and variable access to services can affect whether people are able to remain in their preferred setting. Dedicated pathways and anticipatory planning for these settings were seen as important to reducing crisis transfers and improving end-of-life experiences.

3. After-death practical guidance

Sector participants highlighted the importance of clear, practical guidance for families and providers about what to expect before and after death, including who to call, what forms are needed, and what steps occur when someone dies at home.

This has been strengthened through the development of practical resources within Northern Sydney Local Health District (NSLHD) and Northern Sydney Home Nursing Service (NSHNS), including a brochure outlining what to do when someone dies at home, alongside an existing inpatient resource, When a Friend or Relative Dies in Hospital, delivered as part of the bereavement program. Funeral providers were also noted as contributing to workforce capability through in-person education for aged care services on after-death practices, post-death processes and basic mortuary care.

Participants also noted that expected home death planning, medications in the home, verification of death processes and GP involvement are important parts of supporting end-of-life care at home. For people linked with community palliative care services and planning end-of-life care at home, expected home death planning is routinely supported through relevant forms, explanation of verification of death processes, and appropriate medications in the home. Challenges arise when GP involvement is limited, particularly in relation to death certification, timely support for home-based end-of-life care, and the availability or adequacy of MBS items to support this work.

Insights: Residential aged care homes & general practice

Aged care homes surveyed

Aged care homes reported a need for greater GP availability after hours, alongside education and support with opioid prescribing to reduce hesitancy and support comfort-focused care.

Earlier identification of the palliative phase and recognition of deterioration were highlighted as ongoing needs. Among aged care homes surveyed, **53%** felt somewhat confident, **31%** confident and **16%** not yet confident in recognising deterioration in a resident.

Confidence was slightly stronger in recognising when a resident may be entering an end-of-life phase. Overall, most staff felt at least somewhat confident, but confidence appears to reduce as acuity and complexity increase.

- **56%** confident
- **25%** somewhat confident
- **19%** not confident.

- Gaps were identified in culturally appropriate palliative care, including access to practical resources, guidance and documented processes for diverse residents.
- **47%** of aged care homes reported having systems in place to support culturally appropriate palliative care for diverse residents
- **31%** partially, **13%** not in place, and **9%** unsure.
- Use of Advance Care Directives was reported as near universal, representing a strength. Structured quality improvement and education tools such as PACOP and ELDAC were also noted, while clinical resources such as palliAGED and palliMEDS are available but not yet consistently embedded in practice.

General Practitioners surveyed

- GPs identified time pressure and funding mechanisms as key barriers to supporting patients with palliative care needs, noting that current funding and recognition structures may not reflect the workload and complexity involved.
- Navigation and access issues were also reported as barriers, highlighting the need for clearer pathways, practical support and better alignment between General Practice and palliative care services.

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