

PALLIATIVE CARE

NEEDS ASSESSMENT

EXECUTIVE SUMMARY

A Needs Assessment is a systematic method of identifying the health needs of a population. The focus of this Assessment are the people and services located in the Northern Sydney Primary Health Network region and what their needs are in relation to palliative care. This work has been undertaken through the Greater Choice for At Home Palliative Care project funded by the Australian Government Department of Health and Aged Care.

The information provided in this document takes a broader look than the requirements of the project to better inform Sydney North Health Network and our members and ensure adequate consideration of the palliative care needs of the community in our region.

National and state health data was utilised and added to a rich collection of quantitative and qualitative data collected through consultations from a broad cross-section of local health and community services sector. Over sixty stakeholders took part in small group workshops, including specific engagement with the community. Methodological triangulation was then performed to identify fifteen key recommendations for the Northern Sydney region. The whole process to develop this document followed the guiding principles of the Primary Health Network needs assessment policy guide, published in 2016 by the Department of Health and Aged Care.

Fifteen key findings and recommendations are made in this document. Northern Sydney has the third highest number of residential aged care facilities, by aged care planning regions, and increasing rates of dementia. Northern Sydney is also very diverse with a high proportion of culturally and linguistically diverse people compared to NSW totals, and within those groups is an under reporting of Aboriginal or Torres Strait Islander identities, and a need for culturally appropriate information on palliative care. In our region there are pockets of disadvantage which highlight financial barriers in accessing primary care. Other findings include the educational needs for General Practice, aged care and the community around death and dying. As well as a need to build clearer care pathways and an inter-connecting tree of all the services that constitute palliative care.

Most importantly we have found that a compassionate communities model calls for a whole-of-community approach in providing individualised care. This model supports an approach to step away from the traditional medicalised model of end of life and builds supportive networks of care in the community to enable people to die at home.



FOREWORD FROM THE CEO

We are extraordinarily privileged in Northern Sydney by having some of the best palliative care services in Australia. It was these people and the community who have helped inform our Palliative Care 2023 Needs Assessment. We offer the knowledge and findings in this document to our region, to help inform and guide the best possible palliative care through an interconnected tree of services and community supports.

Death and dying can be a challenging topic to initiate, yet it is one of the most important conversations you will ever have with your loved ones, or your patients. At Sydney North Health Network, we know there are only three unescapable facts in life, we are born, we will die, and in between change will be constant. We value every person and every phase of life, we know that death and dying can be a beautiful experience and a profound way to celebrate a life.

The community plays a significant role in the additional supports a person with a life-limiting illness needs. Whether that be a friendly ear over a cup of tea, bringing over a meal, walking the dog, or mowing the lawns. There is a variety of things we can do as neighbours, friends, family, and colleagues. Most people, where possible, will choose to die at home (Swerissen & Duckett 2014). Our palliative care projects, like all our work, are person-centred. As well as addressing the other findings in this document, our aim over the coming years is to better enable the community to be more involved with end-of-life care and supporting people to remain at home in the community.

We hope you will join us in reaching for this goal, a more connected and compassionate community will organically enhance wellbeing, health outcomes and is the essences of holistic care.

Kind regards,

Kevin Barrow

A handwritten signature in black ink, appearing to be 'KB' followed by a stylized flourish.

Acknowledgements

Thank you to all those that contributed to the Sydney North Health Network Palliative Care Needs Assessment for their input and participation in the consultations.

Suggested citation

Palliative Care Needs Assessment – Northern Sydney Primary Health Network (2023), Sydney North Health Network, NSW Australia

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BACKGROUND

Palliative care is a vital part of integrated and person-centred health services. It can improve the quality of life for a person and that of their families and carers, who are facing challenges associated with life-threatening illness, whether physical, psychological, social, or spiritual.

Palliative care can be delivered in a variety of settings, including residential hospices, residential aged care facilities, public and private hospitals, community health centres, outpatient clinics, and at home.

“A basic human right, palliative care is vital to health and human dignity.”

This report aims to identify and highlight the palliative care needs and service landscape of the Northern Sydney Primary Health Network (Northern Sydney PHN) geographical region through the systematic process of a needs assessment. Northern Sydney PHN is operated by Sydney North Health Network (SNHN). The purpose of the needs assessment is to identify and consolidate existing sources of data and build on this information through further consultations to form an adequate understanding of the palliative care landscape in the region.

The Sydney North Health Network Palliative Care Needs Assessment was funded under the **Greater choice for at Home Palliative Care** (GCfAHPC) initiative by the Australian Government Department of Health and Aged care.

PROJECT PLAN

The palliative care needs assessment planning process involved identifying information and knowledge gaps on local data, development of a consultation and stakeholder engagement plan, and drawing on state and national data sources.

This document was developed utilising the principles of the **Primary Health Network (PHN) needs assessment policy guide (2016)**, published by the Department of Health and Aged Care.



NEEDS ASSESSMENT ANALYSIS

The Sydney North Health Network **Palliative Care Needs Assessment** is informed by both qualitative and quantitative data from local, state, and national data sources.

This data has been used to evaluate key considerations in palliative care and end of life care and the potential impact on the Northern Sydney population. This analysis has been presented in a readily accessible format so that Sydney North Health Network can continue to update and build upon, as an iterative process for future needs assessments.

The information gained from the Palliative Care Needs Assessment will inform the development and delivery of the program of work for Palliative Care at Sydney North Health Network.

Methodology

Quantitative and qualitative data were primarily sourced through consultations from a broad cross-section of the local health and community service sector, the Northern Sydney community, along with evaluation reports, frameworks, and data from local, state, and national palliative and end of life care sources and research articles.

Methodological triangulation was used to gather data through individual and small group consultation workshops and interviews, questionnaires, research articles, and reports to support a deep and wider understanding of the conceptual framing in the analysis.

As qualitative research methods are oriented toward understanding meanings and experiences, they can provide new insights and knowledge in poorly understood and complex areas. Thematic Analysis and Content Analysis was carried out on qualitative data, to bring together the commonalities and differences in participant descriptions of their subjective experiences.

A grounded theory methodology approach was utilised using selective coding to identify themes through Content Analysis, followed by Thematic Analysis to further examine the relationship and meanings of these themes.

Limitations

Qualitative research has a strong emphasis on written and spoken word as the mode by which a 'reality' can be captured. An awareness of this limitation is important for both Thematic Analysis and Content Analysis. The same questions may elicit different responses at different points in time and when asked by different people, but this does not mean they produce low-quality results.

While this might be considered a limitation of Thematic Analysis and Content Analysis, these methods do provide opportunity to take an analytic position that is broader and more open to a range of theoretical interpretations.

Consultation Process

Sydney North Health Network has taken a consultative approach to develop an informed and comprehensive understanding of the palliative care landscape in the Northern Sydney Primary Health Network (Northern Sydney PHN) geographical catchment, as part of an ongoing commitment to engage and consult with key stakeholders.

Consultation with the interconnected network of health sector professionals and the community extended to primary care, specialist palliative care services, community services, residential aged care facilities, Northern Sydney Local Health District (NSLHD), and the community, including the SNHN Community Council.

The consultations build upon findings of previous Sydney North Health Network needs assessments and findings from earlier consultations.

In 2022 over 60 stakeholders were engaged through the consultation process across 10 consultation workshop sessions and included representation from a broad cross-section of the local community and service sector, including the following:

- General Practice
- Sydney North Health Network (SNHN) Community Council
- Sydney North Health Network Healthy Ageing and Palliative Care Advisory Committee
- Community of the Northern Sydney Region
- Northern Sydney Local Health District (NSLHD)
- Residential Aged Care Facilities
- Allied Health – public and private
- Ambulance NSW
- Non-Government Organisations and Not for profit organisations



KEY FINDINGS & RECOMMENDATIONS

- 1** Northern Sydney has the third highest number of residential aged care facilities in Australia by aged care planning region, and an ageing population. The complex needs of an ageing population, with a rise in chronic disease and comorbidities, will impose an increasing demand on healthcare services within the region, including the need for appropriate palliative care services.
- 2** Dementia including Alzheimer's disease are the leading cause of death of women, and the second leading cause of death of men, following coronary heart disease. It is predicted that the number of Australians with dementia will more than double by 2058. Further understanding on what palliative and end of life care looks like for Australians living with dementia and building dementia friendly (dementia inclusive) communities will be crucial for the Northern Sydney region.
- 3** Financial barriers to accessing primary health services, due to a low number of bulk-billing GPs, are present, with pockets of disadvantage concentrated in the Ryde, Northern Beaches, and Hornsby Local Government Areas. Additionally, Dural-Wisemans Ferry and Warringah indicate a shortage of general practitioners.
- 4** Higher proportion of Culturally and Linguistically Diverse population in Northern Sydney compared to NSW, indicating a need to develop culturally appropriate interventions to cater for the diverse health needs of all our communities within the region.
- 5** Underreporting of Aboriginal or Torres Strait Islander identity leads to a lack of specific health and community services for Aboriginal or Torres Strait Islander people living in the region. There is currently one Aboriginal-specific GP clinic in the region, which is operating one day per week. Developing culturally appropriate care models and aged care pathways for Aboriginal and Torres Strait Islander people ensures we are working alongside the **National Palliative Care Roadmap** (2022-2027) to address key issues.
- 6** Currently service delivery across the Northern Sydney region is not clearly defined on what palliative care services are provided and by whom. There is a wider palliative team made up of a broad range of individuals who each play a unique role in supporting people with a life limiting illness, and are part of the 'interconnected tree' of services. An understanding of the work each of these individuals and organisations do, will assist in identifying current needs gaps and aid in future planning of effective service delivery and community support.



- 7 Workforce planning is highlighted in the **National Palliative Care Strategy (2018)** as an essential element in achieving functional and sustainable healthcare across the palliative care sector. Once we have a better understanding of the landscape in Northern Sydney, a usable tool that is accessible by all in our community, including the person needing care, their family and carer, the community, and the workforce (paid and unpaid), would be valuable. These initiatives can also lead to good advance care planning discussions which are determined by having an understanding around what can be done, or what is possible, for the individual in hospital or at home.
- 8 There are numerous systemic barriers to communication between services that inherently reduce cooperation and understanding around the sector, including funded programs delivered by different organisations, public and private service, various terms of communication and ways of working, as well as geographical barriers. This can cause barriers to information being shared about the patient. The person needing care is moving between services, as opposed to services moving around them. Guided by the **NSW Health End of Life and Palliative Care Framework** (2019-2024) key priorities, care should be delivered in an integrated and well-coordinated manner with seamless transitions between services and settings.
- 9 Northern Sydney has multiple palliative care and end of life care sector network groups across the region. There is opportunity to develop more connectedness across the wider palliative care team in Northern Sydney, through shared knowledge and collaboration, so that all parts of the 'interconnected tree' supporting the person are acknowledged and communicate effectively to one another.
- 10 How people approach the end of their life is highly individual and a deeply personal experience, and service engagement and communication plans should correspond with this need. Care should be person centred, based on the unique, holistic needs and preferences of the person receiving care, and developing resources inclusive of diversity is critical to this approach.
- 11 In a changing world of primary care, there is a need to better understand what the capacity and willingness of general practice is to provide palliative care and end of life care services. General practices have a considerable workload in managing the palliative care of their patients. There is still an opportunity to have a shared relationship with general practice on their patient's palliative care journey, although we need to better understand what this will look like as service demand continues to increase into the future.



- 12 A compassionate community approach calls for a move away from an individualised model of caregiving to a whole community approach, and while caring networks are essential, they are not widely supported across health networks. The Northern Sydney region holds micro-communities that are engaged in supporting the cause for quality and connected care in their palliative care journey through volunteers, carers, professionals, and other community members. The term **Compassionate Communities** is used world-wide to describe localities that encourage and develop a whole-of-community culture focused on caring networks and the social and emotional support of dying people and their families, reducing the load on individuals and the health system, and contributing to a sense of wellbeing at the end of life.
- 13 Unpaid carers are central to the palliative care team and play a role that can be physically and emotionally demanding. Carers need to be equipped with the right knowledge and feel that they are supported in caring for their loved one, with a care network around them. Carer stress can be a significant detriment that prevents people from continuing to care for someone who wishes to die at home. Carer burden will increase over the years as expectations on community carers rises in tandem with the increase of diseases such as dementia, or as the new public health palliative care approach moves toward a whole of community approach.
- 14 Psychosocial health is a major palliative care concern globally. In Northern Sydney there is a need across the wider palliative care team for better understanding what mental health services are available for people with a life limiting illness, their family, loved ones, and carers. More services are needed in family and bereavement support than are currently on offer. Additionally, the lack of knowledge around death and dying can produce feelings of fear and isolation. Equipping on death and dying across the whole community can reduce anxiety by empowering people with knowledge about end of life and palliative care.
- 15 Education around death and dying plays a part in changing the approach to care across the wider 'interconnected tree' of palliative and end of life care. There are, however, unique challenges in providing education to so many different groups.

**Early recognition is proactive rather than reactive palliative care.**

Health professionals confidence plays a crucial part in patient experiences. By recognising deterioration in the acute sector, and not being afraid to use the words 'dying', or 'palliative' or 'end of life', we can give staff more confidence and understanding of what to expect and what to do next.

Education for families, loved ones, and carers can provide better understanding on providing palliative care at home. Families can benefit from education around death and dying, but it is more effective if it is at a time that suits them and in a place that they prefer, for example, out of business hours and in a non-clinical environment.

There is some reluctance in discussing palliative care earlier on in primary care. This may be around confusion between palliative care or end of life care, or how and when to start the conversation.

Empower (non-clinical) community workers and volunteers with knowledge, to give them more confidence in matters of end of life, which in turn enhances quality in the delivery of care for patients and supports positive interactions with the family and loved ones.

Quality education and training are available in the aged care sector, but staff have limited time available to access them. There is a skill and chronic staff shortage in aged care, and the workload creates a barrier to the quality of care delivered. Training and education need to be meaningful and impactful for aged care sector staff, if it can be delivered at all.

Language plays an important part in changing the dialogue and societal views on death. Supporting our community to relearn the knowledge that death and dying are a part of the human journey, and nurturing community conversation around this, can enhance palliative care services, networks, and care environments.

HEALTH NEEDS ANALYSIS

SERVICE ACCESS & DEMAND

Northern Sydney Primary Health Network Population

The Sydney North Health Network Palliative Care Needs Assessment draws upon the Northern Sydney PHN 2022 - 2025 Needs Assessment to highlight key indicators of service demand.

Northern Sydney PHN region covers an area of around

900km²

Including nine local government areas (LGAs)

H

H

• Hornsby

HH

• Hunters Hill

K

• Ku-ring-gai

LC

• Lane Cove

NB

M

• Mosman

NS

• North Sydney

NB

• Northern Beaches

R

R

• Ryde

W

W

• Willoughby

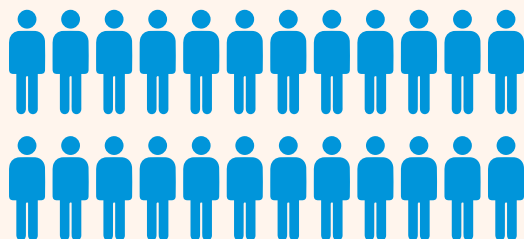
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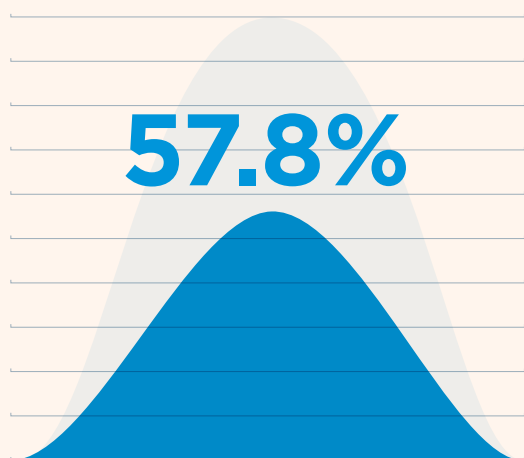
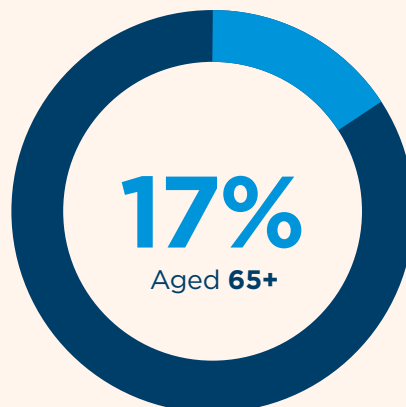
NS

M



Total population in 2022

914,298



The **65+** years population in this region is projected to increase by **57.8%** between **2021 - 2041**



85,003

Increase of 85,003 people aged **65+** years by **2041**

This indicates an increase of

4,000

older people each year, for the next 20 years



SERVICE ACCESS & DEMAND



296

General Practices



76.2%

Bulk-billed

Northern Sydney (2016-2017)



85.7%

Bulk-billed

Nationally (2016-2017)



There are financial barriers to accessing primary health services due to low number of bulk-billing GPs.

Areas around Dural-Wisemans Ferry and Warringah are considered distribution priority areas, indicating a shortage of general practitioners. Distribution priority areas are defined as catchments with low levels of provision of GP services compared to a benchmark calculated based on demographic and socio-economic status.

Patients accessing GP services after hours decreased from

23.6%



in 2016-17 to

15.8%

Similar to the national trend of decreasing proportion of people accessing after hours services over the past four years.

Whilst there is a high availability of after-hours providers within the Northern Sydney region (**124 per 100,000**) compared to NSW (**101 per 100,000**) and Australia (**107 per 100,000**); there are hotspots within the region with lower availability of after-hours providers concentrated in Dural-Wisemans Ferry, and Northern Beaches.

Health of older people



100

Aged Care Facilities



Third highest number of residential aged care facilities in Australia by Aged Care Planning Region

Geographic Hotspots: Ryde and Willoughby with high population growth in those aged 65 years and over



65+ 

Earlier Sydney North Health Network consultations with stakeholders identified declining physical function, associated frailty, and high falls risk as key emerging needs for older people across the region, requiring additional access to allied health supports.

Dementia hospitalisation rates within the Northern Sydney region increase with age. A similar trend is evident for NSW, and there is a lack of awareness or recognition of dementia as a life-limiting illness.

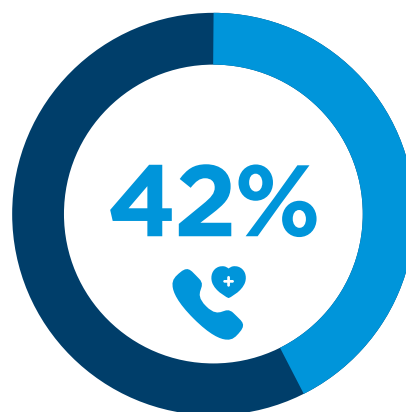
The complex needs of an ageing population, with a rise in chronic disease and comorbidities, are already imposing increasing demand on healthcare services, including the need for appropriate palliative care services.

This need for palliative care resources in Northern Sydney aligns with the global need for palliative care because of the ageing of populations and the rising burden of noncommunicable diseases and some communicable diseases.

Telehealth

Analysis of local data from the **45 and Up study**

42% of respondents indicated that they used telehealth services since **January 2021**

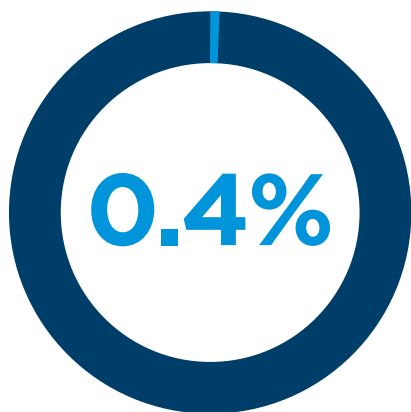


Earlier Sydney North Health Network consultation with stakeholders highlighted access to information and treatments were impacted by disparities in digital literacy across cohorts, with a greater need of increasing awareness of utilising digital services effectively across the population. Population cohorts disproportionately impacted by the disparities include older people and people living with an intellectual disability.

Whilst telehealth generally provided greater flexibility with accessing services across cohorts, a mixed based approach to service delivery combining face to face and telehealth service delivery was identified as being prudent to address any adverse outcomes and health inequalities.



Aboriginal and Torres Strait Islander People



of the population identify as Aboriginal and Torres Strait Islander

Nationally, there is a higher prevalence of chronic disease in Aboriginal and Torres Strait Islander People.

Earlier Sydney North Health Network stakeholder consultation identified underreporting of Aboriginal and Torres Strait Islander identity by health care professionals in the region, highlighting that the questions about identity are not always asked, and when they are, there is a need to ask in a respectful and culturally appropriate manner. Underreporting of Aboriginal and Torres Strait Islander identity leads to lack of cultural specific health and community services for residents in the region.



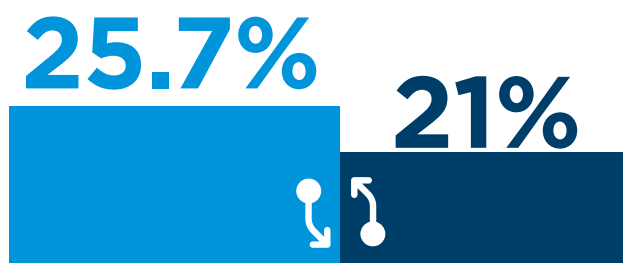
In the Northern Sydney region there is only one Aboriginal-specific GP clinic. It operates one day per week.

There are also significant issues relating to a hidden population and the Stolen Generation, with people who do not always self-identify as a consequence of historical oppressive government and systematic policies, with the effects still being experienced today, such as an inability to access culturally appropriate and available health care provision.



Culturally and Linguistically Diverse (CaLD) People:

Higher proportion of Culturally and Linguistically Diverse people compared to NSW



A growing population of people concentrated in specific geographic areas, experiencing additional language and cultural barriers to accessing aged care and other types of services, including palliative care.

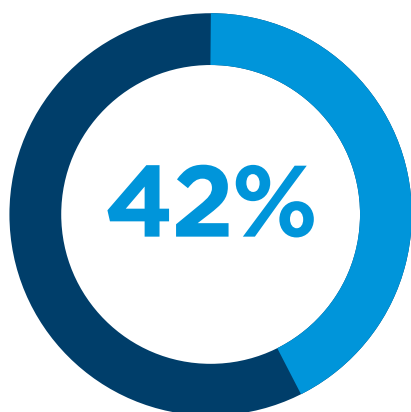


47.7%

of people in the **Ryde LGA** speak a language other than English



The **Ryde LGA** has the highest proportion of people from culturally and linguistically diverse backgrounds



Cultural beliefs, customs, and expectations influence how people define health and illness, in turn impacting their decision making in how and when to access healthcare.

There are specific barriers to accessing health services which subsequently impact the health status of culturally and linguistically diverse people and communities. There is a subsequent need to develop culturally appropriate and bi-lingual interventions to cater for the diverse health needs of growing communities. There is limited availability of national and local data to understand the complexities of the multiple culturally and linguistically diverse groups within the region and their differing health needs.

Lesbian, Gay, Bisexual, Trans and Intersex People

Diverse needs of the LGBTI population are under-represented in aged care planning

The **National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy** (DoHA 2012), the **Aged Care Diversity Framework** (DoHA 2017), and the **Aged Care Diversity Framework Action Plans** (DoHA 2017) are designed to ensure the aged care sector can deliver the appropriate care and inform the way the Government responds to the needs of older LGBTI people, as they:

Recognise

The rights and needs of older LGBTI people.

Empower

Older LGBTI people to access high-quality services.

Encourage

LGBTI individuals and communities to be involved in the development of aged care services.

It is difficult to perform any analysis of the local health needs of LGBTI populations due to a lack of available data, specifically notably absent from the Australian Bureau of Statistics Census datasets.

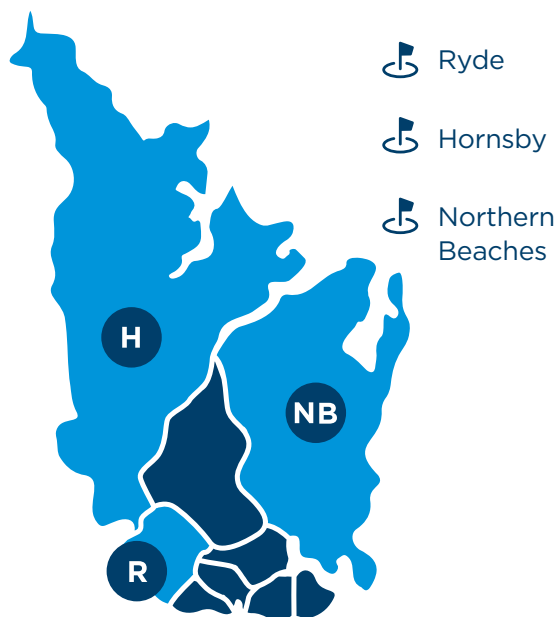
Due to previous experiences in healthcare and other settings, LGBTI people are less likely to seek support, or more likely to delay seeking treatment. This can lead to an increase in poorer outcomes for physical and mental health. Services need to be actively inclusive and continue to create safe and supportive environments in order to deliver effective care.

Note

We have used the term **LGBTI** when referring to older people in respect to LGBTI elders who have experienced the term queer as derogatory. We recognise that language changes over time and that today the term queer has a different and empowering meaning to many in the community.

Socio-economic disadvantage

Pockets of disadvantage within the region



There is also a small number of people residing in the natural landscape, across the rock caves of the Hawkesbury River and Ku-ring-gai National Park.

A scoping study by Palliative Care NSW states that 'The age limits currently enforced within some services can result in patients who do not meet these specific requirements being refused the care they seek'.

Palliative Care services are often targeted towards older patients, although terminal illnesses can occur at any stage of life. Due to the unique challenges of service provision for a person who is homeless, flexible and holistic care is needed to ensure that the care is person-centred with meaningful impact.

Homelessness

For a person who is homeless, having their daily needs met is a challenge. This creates immense barriers to other needs such as health, and consequently palliative care services if needed.

Leading causes of death in Northern Sydney

Indicated through the **Mortality Over Regions and Time (MORT)** books,

27,349

total deaths from 2016 to 2020

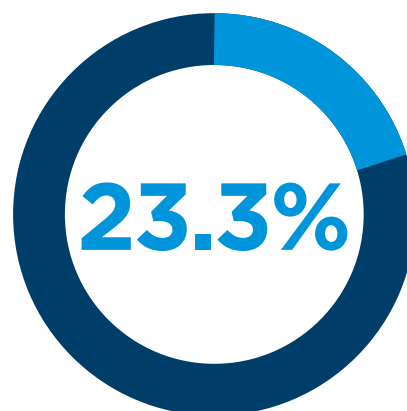
Median Age



83.8



88.1



are of a premature death (aged under 75)

Premature mortality is defined as the average annual aged-standardised rates of death from all causes, **per 100,000 population aged 0-74** years. Cancer is the main cause of premature mortality in the Northern Sydney region, followed by circulatory system diseases, and Dementia and Alzheimer's disease.

Twenty leading causes of death for the Northern Sydney Primary Health Network region
2012 to 2016

Rank	Cause of death - Females	Deaths	% of all causes
1	Dementia including Alzheimer's disease	1,987	13.8
2	Coronary heart disease	1,472	10.2
3	Cerebrovascular disease	1,363	9.4
4	Breast cancer	587	4.1
5	Colorectal cancer	494	3.4
6	Lung cancer	469	3.2
7	Influenza and pneumonia	454	3.1
8	Chronic obstructive pulmonary disease	427	3.0
9	Heart failure, complications and ill-defined heart disease	390	2.7
10	Cardiac arrhythmias	334	2.3
11	Hypertensive disease	289	2.0
12	Pancreatic cancer	285	2.0
13	Diabetes	258	1.8
14	Cancer of unknown or ill-defined primary site	252	1.7
15	Kidney failure	230	1.6
16	Accidental falls	212	1.5
17	Other ill-defined causes	212	1.5
18	Ovarian cancer	211	1.5
19	Parkinsons disease	177	1.2
20	Exposure to unspecified factor	162	1.1

Twenty leading causes of death for the Northern Sydney Primary Health Network region
2012 to 2016

Rank	Cause of death - Males	Deaths	% of all causes
1	Coronary heart disease	1,563	12.1
2	Dementia including Alzheimer's disease	1,021	7.9
3	Cerebrovascular disease	799	6.2
4	Prostate cancer	565	4.4
5	Lung cancer	542	4.2
6	Colorectal cancer	439	3.4
7	Chronic obstructive pulmonary disease	346	2.7
8	Heart failure and complications and ill-defined heart disease	311	2.4
9	Parkinsons disease	310	2.4
10	Diabetes	306	2.4
11	Influenza and pneumonia	280	2.2
12	Suicide	255	2.0
13	Pancreatic cancer	251	1.9
14	Kidney failure	229	1.8
15	Cancer of unknown or ill-defined primary site	228	1.8
16	Liver cancer	225	1.7
17	Leukaemia	205	1.6
18	Accidental falls	177	1.4
19	Lymphomas	167	1.3

Given many of the deaths recorded within the region are related to a chronic cause, many of these deaths are likely to have a distinguishable phase where there was an opportunity for the provision of appropriate and effective palliative care.

It is important to highlight the need for early recognition of palliative care needs for diseases that are non-malignant. Whilst a diagnosis of stage 4 cancer has a more clearly defined pathway, pathways for people with non-malignant diseases are less defined, and more awareness and appropriate timing of palliative care is needed.

Cancer Screening rates:

Bowel cancer screening participation rate
among people aged

50-74
years

Slightly lower than the NSW rate

36.3% **34.8%**

Cervical cancer screening participation rate
among people aged

20-69
years

Higher than the NSW rate

55.9% **48.5%**

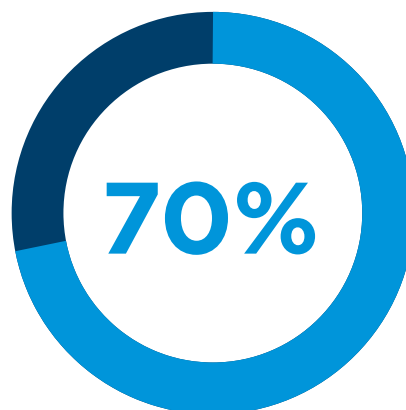
Breast cancer screening participation rate
among people aged

50-74
years

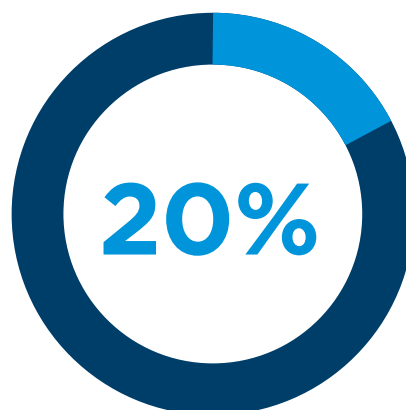
Slightly lower than the NSW rate

49.4% **48.5%**

Dementia



7 out of 10 dementia hospitalisations were of the highest clinical complexity



compared with close to 2 out 10 hospitalisations without a routine diagnosis of dementia

People with dementia may have more than one health condition

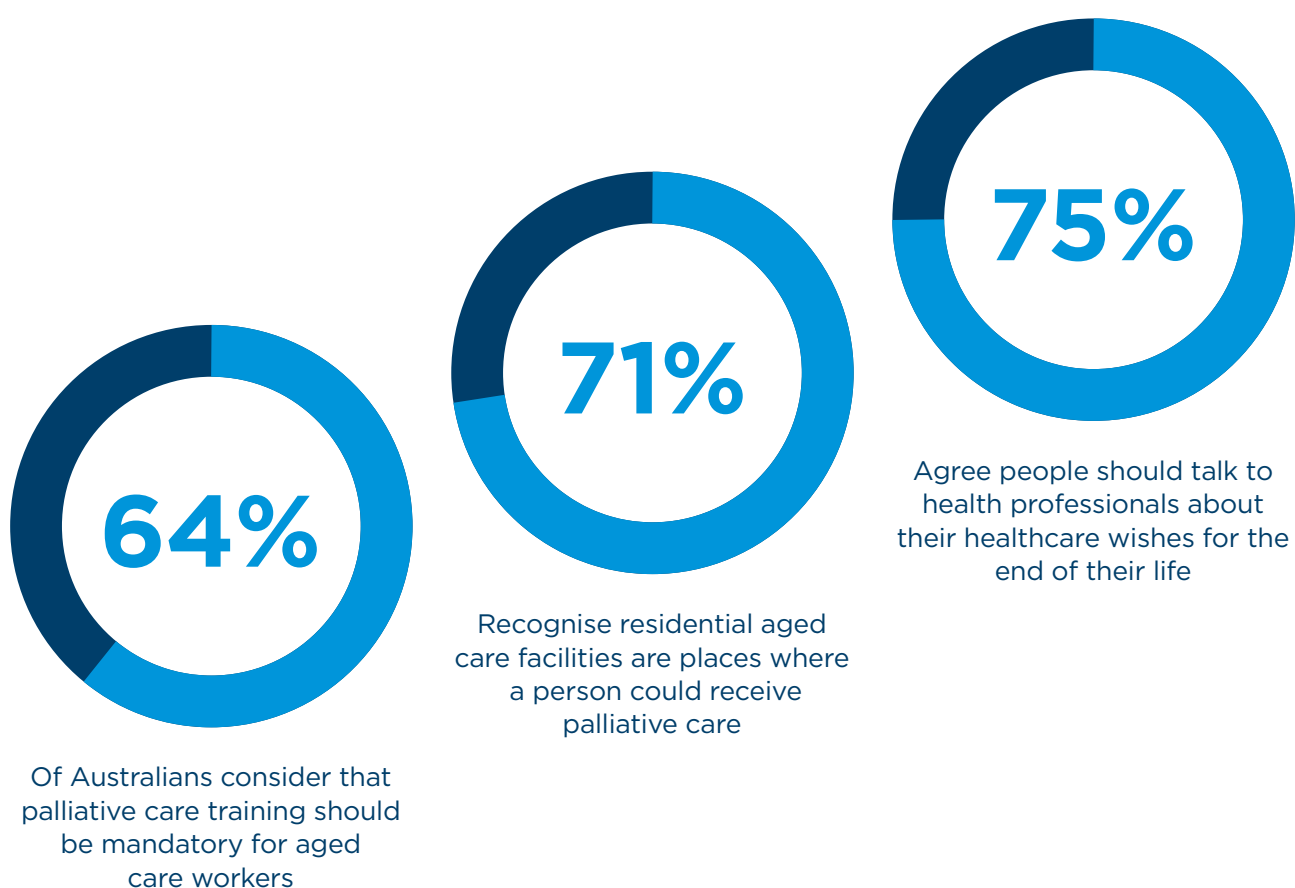
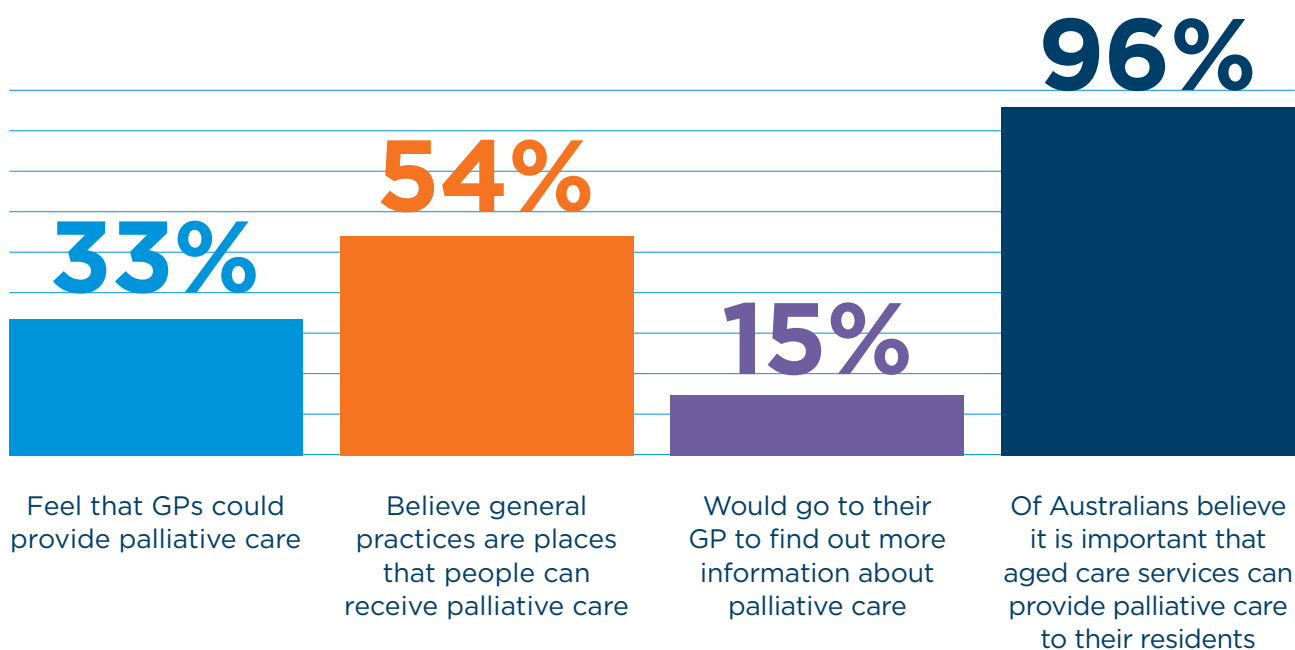




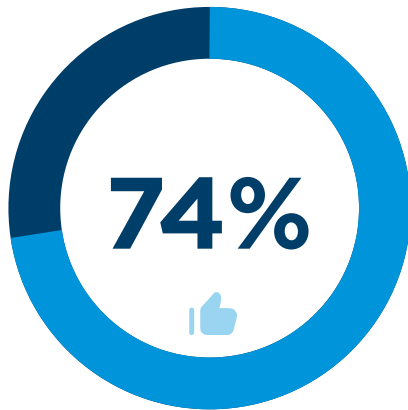
PALLIATIVE CARE SERVICES IN AUSTRALIA

Australians understand the importance of talking about end of life wishes and preferences, but many are not prepared to have the conversations or put plans in place.

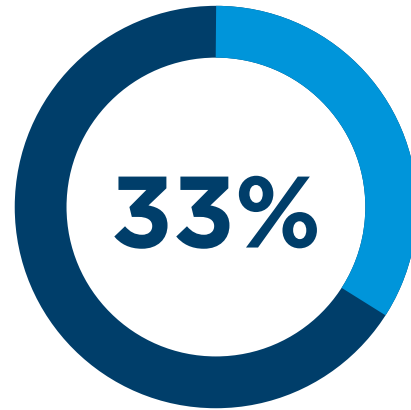
National Palliative Care Survey in 2022



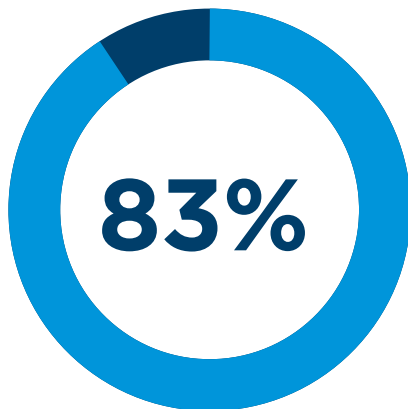
“Health professionals should ask people about their healthcare wishes at the end of their life”



Agree with this statement



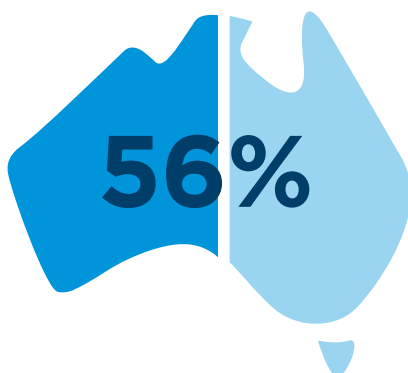
Do not have any plans in place.



of Australians believe that planning ahead for end of life:

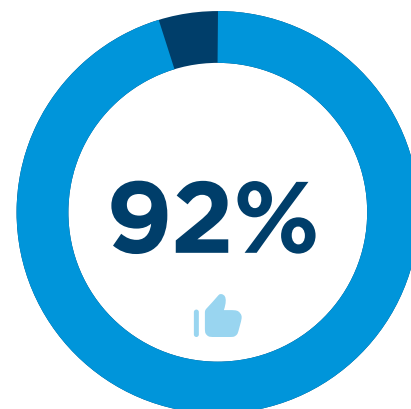
- Reduces the burden and stress on family
- Gives you control over the care you receive at the end of life
- Gives you control over where you spend your final days

Despite these understandings, well over half of Australians have not taken any action regarding talking about or recording their end of life wishes.

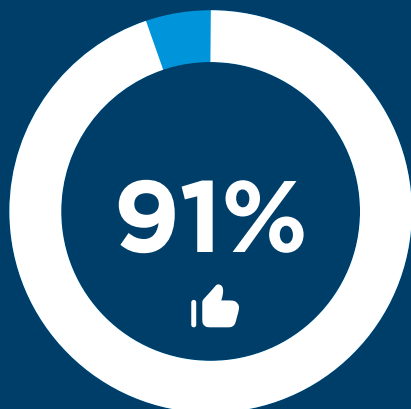


The World Health Organization (WHO) acknowledges palliative care as a universal human right, stating:

Palliative care is explicitly recognized under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.



Agree with this statement by the World Health Organisation



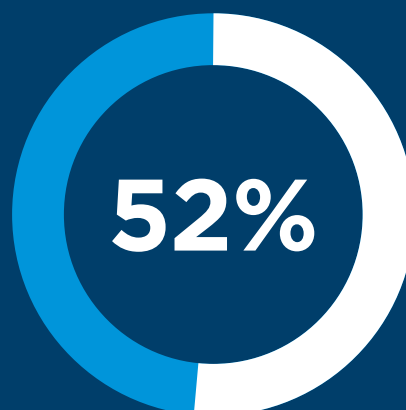
Agree that palliative care services must be strengthened to achieve universal health coverage

Palliative care involves a range of services delivered by a range of professionals that all have equally important roles to play, including physicians, nurses, support workers, paramedics, pharmacists, allied health, carers, and volunteers in support of the patient and their family.

Early delivery of palliative care reduces unnecessary hospital admissions and the use of health services.



3 in 5 patients who died in hospital received palliative related care during their final hospitalisation



1 in 2 palliative care hospitalisations recorded a principal diagnosis of cancer



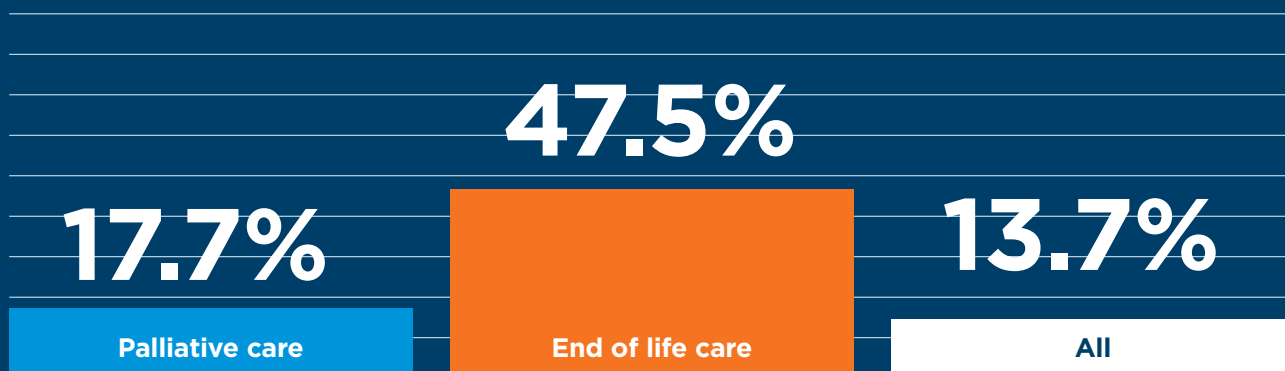
In 2019 to 2020

87,000

palliative care-related hospitalisations (49,200 for palliative care and 37,700 for other end of life care).



Increase in hospitalisations over the period 2014/2015 to 2018/2019





The National Palliative Care Roadmap of 2022 to 2027 highlights key issues to address in palliative care in Australia and ways to address them;

- Investment is required in palliative care service delivery, workforce development and research and data.
- Making palliative care core business in aged care.
- Investment is required in palliative care medicine schedule, training, and communication.
- Investment is needed in grief and bereavement standards, research, and services.
- It is vital to develop culturally appropriate care models and aged care pathways for Aboriginal and Torres Strait Islander people.

Palliative Care Workforce

According to the **National Palliative Care Strategy** 2018, workforce planning is an essential element in achieving functional and sustainable healthcare across the palliative care sector. Palliative care faces a range of challenges, including an increase in demand for services due to an ageing population and a decrease in ability to meet service demand due to the size of and changes in the palliative care workforce. An understanding of the characteristics of the workforce will assist in identifying current needs gaps and aid future planning.

The palliative care workforce is made up of a broad range of professional groups, including specialist palliative medicine physicians, palliative care nurses, general practitioners, pharmacists, allied health professionals, other medical specialists (such as oncologists and geriatricians), as well as other health and community workers, support staff, domestic assistance, and volunteers. Each of these play a unique role in supporting people with a life limiting illness to receive comprehensive, patient-centred care. However, existing national data sources only capture information on physicians with a primary specialty of palliative medicine (palliative medicine physicians) and nurses working in palliative care (palliative care nurses).

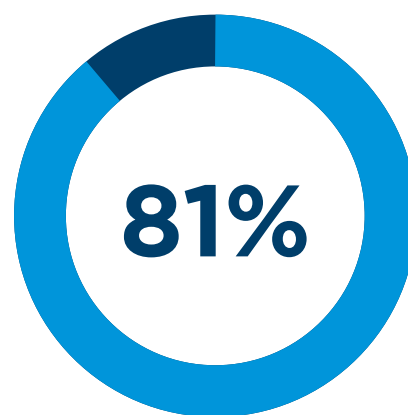
Measurement of Service

Palliative Care Outcomes Collaboration (PCOC) and Palliative Aged Care Outcomes Program (PACOP)

A national palliative care programme funded by the Australian Department of Health, PCOC data collection supports a common clinical language in palliative care, and data are obtained from clinical assessments where this clinical language is used as part of routine clinical practice. Data is captured at three levels: the patient level, episode level and phase level.

Services in our region utilising PCOC (January 2023)

- HammondCare Nerigah Hospital
- HammondCare Greenwich Hospital
- Hornsby Hospital
- Mona Vale Palliative Care Unit
- Northern Beaches Palliative Care Consult
- Royal North Shore Hospital
- Ryde Hospital Palliative Care Consult Service
- Sydney Adventist Hospital (SAN)



Died in their preferred place

Indicated in PCOC study that examined two community palliative care providers in Australia, The Sydney Adventist Hospital, or 'The SAN' in the Ku-ring-gai local government area, and another based in Victoria, which analysed the relationship between a person's preferred place of death and other individual variables that might influence their actual place of death with a cross-sectional study of 2353 people who died between August 2016 to August 2018.

In light of the Royal Commission into Aged Care Quality & Safety identifying the need for immediate action to improve the quality of care for residents who are dying in aged care homes, it is essential that we help aged care homes and aged care organisations identify, understand and address the palliative care needs of their residents. PACOP does this by helping aged care homes to embed the use of standardised outcomes assessments and tools, and to use the information gathered to respond in a timely way.



PALLIATIVE CARE SERVICES IN NSW

NSW End of life Framework

How people approach the end of their life is highly individual and a deeply personal experience. As people enter this phase of their life, they, their families, loved ones and carers should be able to make decisions about the care they want, how it is delivered, and the places and circumstances it is provided.

Indicated in the **NSW Health End of Life and Palliative Care Framework** 2019 – 2023, are five key priorities, informed by the **NSW Palliative Care Survey** (2018).

1. Care is person centred, and should be based on the unique, holistic needs and preferences of the person receiving care.
2. Families and carers play a pivotal role in the end of life and palliative care service system. It is essential their role is recognised, valued, and supported.
3. Access to care providers across all settings who are skilled and competent in end of life and palliative care is crucial. End of life and palliative care can be delivered in multiple settings.
4. People needing end of life and palliative care may receive care from multiple services across a number of settings. Care should be delivered in an integrated and well-coordinated manner with seamless transitions between services and settings.
5. Access to quality care should be equitable. There can be significant variation in access to end of life and palliative care services across NSW. There are groups across NSW who need greater support to access end of life and palliative care services.

Highlights in findings of the survey

Nearly **50% of deaths** occur in the acute setting

Over **1600** palliative care volunteers in Australia

Volunteers are a strong force in supporting palliative care services

36.8% of older Australians accessing health services had at least 1 Advance Care Directive documented in their health record. Higher than the national result of **30%**

11,400 End of Life home care packages delivered to **7,983 people** in the last 5 years

End of Life (EoL) Packages

End of Life (EoL) packages are non-clinical packages of case management and home care services delivered through the **NSW Health Out of Hospital Care (OHC) Program**, that provide low to medium levels of home care services for patients who are in the deteriorating or terminal phase of a life limiting illness or condition.

Packages are available for up to six weeks at a time and referrals can be made from NSW public hospitals or Local Health District community teams including.

- Specialist Palliative Care
- Community Nursing
- Chronic Care
- Aged Care

Each patient is allocated a Case Manager who becomes their main contact throughout the term of the EoL package. The Case Manager will either visit the person in hospital, at home or if urgent speak with the family, carer, or loved one via phone to assess their needs.

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Cicely Saunders



PALLIATIVE CARE SERVICES IN THE NORTHERN SYDNEY REGION

In the Northern Sydney region there are several service providers, care pathways, and funding organisations within palliative care, and varying eligibility criteria. Good practice across the region exists but also a desire to further improve service delivery and interaction between service providers and care settings.

The patient journey is not a linear process and can be realised by the determinants of their individual circumstances, access and availability of services, and medical acuity.

Palliative care services can be provided in the home, in community-based settings, for example a residential aged care facility, palliative care units, and in hospitals across multiple providers.

- Public hospitals (inpatient & outpatient)
- Private Hospitals
- Non-government organisations
- Home nursing services
- Residential aged care facilities
- General Practice
- At a person's own home

A person with palliative care needs will need to be able to move freely between these places in response to their medical care and support requirements. The pattern of care will be different for every individual and may depend on factors like geography, services in an area and the needs and desires of the person, their family members, and friends.

The following information provides an overview of the landscape of palliative care in the Northern Sydney region; however, it is crucial to point out that it is not an exhaustive list and a clearer picture of the network of services and support across the wider palliative care team is needed.

Northern Sydney Service Mapping

Northern Sydney Local Health District (NSLHD) Palliative Care Network consists of specialist palliative care clinicians, nurses, and allied health providers.

Most inpatient palliative care provided in Northern Sydney Local Health District hospitals are through request for palliative care consult by other Local Health District specialities and services, or referred via cancer care providers.

Other departments requesting palliative care include Haematology, Rheumatology, Cardiology, Gastroenterology, ICU, Geriatrics, Emergency, and surgical specialties.

Palliative care consultative services are available through Ryde Hospital, Royal North Shore Hospital, Hornsby Hospital, and the Northern Beaches Hospital.



Northern Sydney Home Nursing Service (NSHNS)

NSW Health

Provides community-based nursing care to people both within their homes and in clinic environments throughout Northern Sydney. They offer counselling, support, and palliative care to terminally ill people, their families, and carers. NSHNS operates 7 days a week from 8.00am to 8.00pm, there are seven community nursing centres throughout Northern Sydney based at Mona Vale, Brookvale, Hornsby, Royal North Shore and Macquarie Hospitals, and Hillview Community Health Centre.

They provide an initial in-person assessment for patients and then depending on the referral arrangements, the patient can be followed and monitored by HammondCare and/or NSHNS.

Mona Vale Palliative Care Unit (MVPCU)

NSW Health

Located in the Northern Beaches local government area, 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.

600 admissions
since opening in 2021

47% of admissions
direct from community compared to
28% of admissions to PCUs across Australia.

Strong collaborative through senior medical input consistent across both services, shared senior clinicians in multidisciplinary teams, joint teaching structures, and combined mortality and morbidity (MnM) meetings.

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:

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



Palliative Aged Care Supportive Service (PACSS)

NSW Health

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 will endeavour to strengthen this collaborative approach to meet the challenges of providing palliative care in aged care.

A nurse practitioner led model of care by Northern Sydney local Health District (NSLHD) 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 (RACFs) with supportive and palliative care needs with services that include:

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

587
referrals

204
collaborations
with outreach geriatric services

Hospital avoidance

Timely prescribing of symptoms management medication and
deprescribing for people approaching the end of life

Support RACF residents to receive treatment for
reversible causes in place of choice

(July 2022 to June 2023)

Collaborative Outreach Geriatric Services of NSLHD

NSW Health

Aged Care Rapid Response Team (ARRT), a home-visiting hospital outreach service who assess and treat older people experiencing a new decline in their health and are at risk of needing hospital. **Beaches Rapid Access Care for the Elderly (BRACE)**, on the Northern Beaches, and **Geriatric Rapid Access Care for the Elderly (GRACE)** at Hornsby Ku-ring-gai hospital are a hospital avoidance Service for older people. These services aim to reduce avoidable emergency department presentation and hospital admissions, by providing rapid assessment for older patients in their own homes, including residential aged care homes, who are experiencing new medical and/or functional decline.



Adolescent and Young Adult Hospice (AYAH)

NSW Health

Located in the Northern Beaches local government area, the Manly Adolescent and Young Adult Hospice (AYAH), which opened in February 2023, is Australia's first dedicated service for young people with life limiting illness. The 8 bed facility offers services to patients 15 to 24 years old across respite care, symptom management, end of life care, and care coordination to support in the transition from children 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, psychology, art therapy, dieticians, speech pathology, pharmacy, and pastoral care.

Referrals can be made at any time by contacting admissions, and there is no cost for a child or family to stay at AYAH.

Bear Cottage

NSW Health

Also located at Manly, in the Northern Beaches local government area, 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.

The team include Staff Specialists, Visiting Medical Officer's, 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 programs provide opportunities for those in like circumstances to connect and alleviate feelings of isolation family members may have in a supportive therapeutic environment.

Ongoing bereavement support is provided through [Footprints in the Sand](#), a bereavement program for families provided for as long as the family needs.

Referrals can be made at any time by contacting the Clinical Nurse Specialist and emergency admissions through the Nursing Unit Manager, and there is no cost for a child or family to stay at Bear Cottage.



HammondCare

Contracted by Northern Sydney Local Health District (NSLHD) to provide palliative care services to NSLHD patients on behalf of the district. A recent Service Level Agreement (SLA) was established to support the monitoring of services provided to include:

- Palliative care inpatient units at Greenwich and Neringah Hospitals
- Palliative care outpatient clinics and community services
- Consult services provided to Royal North Shore Hospital (RNSH)
- Palliative Care Medical Specialists and Nurses provide consultation and in-reach at Hornsby from **Neringah**, Manly, and Mona Vale hospitals from **Mona Vale**, and Ryde from **Greenwich**.

Greenwich Hospital

A 25-bed inpatient unit in Greenwich, the Palliative and Supportive Care Service within Greenwich Hospital provides a day hospital, outpatient clinics, lymphedema in, and outpatient service, community outreach, bereavement counselling and telephone advice 24/7. A multidisciplinary team (medical, nursing, social work, physio, occupational, art therapy, massage, pastoral care, and bereavement counsellors) provide end-of-life care, symptom control and rehabilitation to patients and their families affected by a life limiting illness. The hospital cares for approximately 500 inpatients a year with up to 200 patients on the community list at any given time.

Neringah Hospital

An inpatient unit of 19 beds that provides short-term acute care to patients for managing a life limiting illness. The unit provides palliative care for short-term admission to alleviate symptoms and the distress they cause, and holistic care to meet the special needs of patients in the final stages of their illness.

Northern Beaches Palliative Care Service

The Northern Beaches Palliative Care Service (NBPCS) offers community palliative care service through a multidisciplinary team to palliative care patients in their own homes in the Manly, Warringah and Pittwater Shires to assist with control of pain and symptoms, hospital or hospice admission when required, equipment, social support and counselling, and volunteer support. Palliative Care Clinics provide service to support patients who are registered with the Northern Beaches Community Palliative Care Service (NBCPCS).

Mater Hospital, St Vincents Health Australia

A multidisciplinary team comprising of specialists, registrar, consultant nurse, social worker, physiotherapist, occupational therapist, and pastoral care that offers advice, support, and care regarding symptom management and end of life care. Construction has begun on a new 12 bed palliative care facility and modernised day surgery unit for the Mater Hospital in Northern Sydney. The new facility will also become a research and teaching centre for advancing and improving practices in palliative care.

The SAN

Sydney Adventist Hospital, known as 'The SAN', provide integrative and palliative care through a multidisciplinary team of oncologists, surgeons, physicians, and allied health, with facilities equipped to alleviate through therapies available both in facility and community setting through the palliative care clinic and inpatient care and community services.

Residential Aged Care Facilities (RACFs)

It's important older people are supported to receive palliative care in their place of choice, and this includes their residency within an aged care facility. Residential aged care services face unique difficulties in providing palliative care.

Palliative care services are provided in these settings through partnerships in delivery of care with other services. Local consultation with these stakeholders and continued analysis of palliative care through service measurement data, such as the Palliative Care Outcomes Collaboration (PCOC) and the Palliative Aged Care Outcomes Program (PACOP), are supportive in understanding the landscape of these services.

General Practices

General Practices (GPs) may provide palliative care services to patients and refer them to other services as needed. GPs can use Advanced Care Directives & Palliative Care HealthPathways as decision support and reference materials. A small number of GPs see a high proportion of palliative care patients and therefore provide in-home care and care to patients in residential aged care facilities. Consultations in the region by the Northern Sydney Local Health District identified a large variability in palliative care commitment, knowledge, and skill.

Nearly two thirds of GPs are interested in providing palliative care. However, a personalised approach to engagement of the GP is needed to cater for various outlooks and behavioural patterns. It is important to note that providing palliative care can mean a large amount of work in primary practice not all of which can be billed for under Medicare. Statistical analysis revealed four different segments of GPs with respect to palliative care. Palliative Care Experts (25%) are comfortable, knowledgeable, interested and engaged. Palliative Care Aspirers (39%) are interested in doing more palliative care, but current skill/knowledge levels and lower exposure to palliative patients hold them back. Palliative Care Indifferent (23%) will do palliative care if required, but do not seek it out. Palliative Care Avoiders (14%) actively avoid palliative care, and dislike many of the tasks associated with it.



Palliative and End of Life Care collaborative networks

Northern Sydney has **multiple palliative care and end of life care network groups** to support collaborative work and shared communication and understanding around services in the region, however there is capacity to expand the network to include the wider palliative care team, across the health and community services sector, allied health, and other providers pertinent to the care provided in our region across a person's palliative care journey.

In the Northern Beaches there is **engagement in the community** around end of life and palliative care, where everyday people can play a stronger role in the care and support of people as they age and at the end of life. There is further opportunity to develop the compassionate communities model in this local government area and across the whole of the Northern Sydney region.

The **Northern Beaches Dementia Alliance** has key stakeholders across aged care, dementia, healthcare professionals, community members, people living with dementia and their carers, with the aim to create a Dementia-Friendly Community:

- A place where people living with dementia are supported to live a high quality of life with meaning and purpose.
- A place where people living with dementia are understood, included, and accepted without the stigma associated with dementia.
- A place that provides opportunities for social participation for people living with dementia and their carers to reduce social isolation.
- A safe physical and social environment for people living with dementia.

Along with the Northern Beaches Dementia Alliance, promoting a Dementia Friendly community has started to activate across local councils in the region.

SERVICE NEEDS ANALYSIS

Local consultations: Northern Sydney Region

Earlier consultations

In 2017 Sydney North Health Network conducted a market analysis capturing the data from stakeholder consultations and interviews to better understand both the size and nature of service gaps, why they exist, and the barriers to improving services or providing new services. The work aimed to support planning for specific end of life care initiatives and services to meet areas of growing demand and service gaps for the region.

Three stories of change were revealed through consultation:

1. Supporting primary care to provide quality end of life care by addressing the limitation of what can be done by primary care practices in the afterhours period.
2. The significance of the integrated role of primary and community care to help people who want to die at home, to do so, through understanding, cooperation, and improved relationships across the sector, with the need to see the upskilling of primary and community healthcare professionals as a major priority.
3. Limited resources allocated to end of life care in residential aged care facilities can lead to poorer patient outcomes and increased hospitalisations reinforcing a hospital focus for end of life care provision.

Recent consultations

In 2022 Sydney North Health Network conducted further consultations through workshops and interviews of over 60 stakeholders to capture local knowledge and data of the palliative care landscape in the region.

The information gained from the consultations highlighted six key stories:

Story 1: Education around death and dying

Story 2: Communication and information sharing

Story 3: The wider palliative care team

Story 4: Carers central role in determining outcomes

Story 5: Mental Health in palliative care

Story 6: The patient journey



STORY

one

EDUCATION AROUND DEATH
AND DYING

Death is a part of the human journey, and in this country, as a predominantly western society, we have moved away from talking about death and what dying looks like.

The word 'palliative' can be feared sometimes, causing a reluctance to engage in palliative care services, affecting referrals or the acceptance of referrals. Palliative care can be easily confused with end of life care.

Language plays an important part in changing the dialogue, and societal views on death.

Educating everyone in the 'interconnected tree' or service and support networks involved with looking after an individual can support a palliative approach to care for them. There is however a challenge in providing education to so many different groups.

In the community

Talking about death has almost become taboo and we need to think about how to normalise it.

What does this look like in the community so we can talk about it without becoming frightened?

Sometimes it takes just one member of the family willing to discuss death and dying to encourage conversation within their own family and network.

“We keep coming back to death as this physiological event, and it's so much more than a physiological event. It's actually a societal issue, but we make it this single physiological event that is predictable ... the complexity is so much greater than that. It's around changing the whole dialogue.”

Consultation participant

In Primary Care

“You have to use the words death and dying. Don't be afraid of those hard but worthwhile conversations.”

Consultation participant

Some reluctance in discussing palliative care earlier on by the GP with their patient may be caused by confusion of the difference between palliative care and end of life care, or how and when to bring up the conversation. There is education around this for GPs which many GPs are participating in, but there is a hidden group of GPs not accessing this knowledge.



Some GPs are more comfortable in providing palliative care. Palliative care, however, may not occur very often in some practices, so it is important to provide education and support to these GPs and help them feel better equipped to have timely conversations about palliative care and end of life care with patients and their families, and to better manage people who are palliating.

In the health sector

Education around recognition in the disease trajectory can trigger conversations about care and end of life options, especially for non-malignant illnesses.

The health professional's confidence plays a crucial part in patient experiences. By recognising deterioration in the hospital or acute sector and being encouraged to be courageous and use the words 'dying', or 'palliative' or 'end of life', staff have greater confidence in understanding what to expect and what to do next.

Early recognition is proactive rather than reactive palliative care.



“If our colleagues don’t know what to do, how are our patients supposed to? People (in our sector) want the words to use, they want information and knowledge to share.”

Consultation participant

In the community services sector

Giving community workers an opportunity in understanding the palliative approach to care.

When provided with the same encouragement and language, community sector professionals can approach death and dying with more confidence when working in supportive wrap around services. The community sector can include services such as, but not limited to, patient transport, delivery of meals, personal care, companionship, and domestic services.

There is an opportunity here to educate and provide these workers with knowledge and understanding around death and dying, so they feel more equipped and confident when supporting their client. In turn this enables workers to provide a service that enhances the quality of care for the clients, and builds supportive, positive interactions with the family.

In aged care

We have numerous quality educational and evidence-based resources through initiatives such as **End of Life Direction in Aged Care (ELDAC)**, **palliAGED**, and **CareSearch**, although due to chronic under staffing in aged care, workers have limited time to access them.

Residential aged care facility educators are limited in their capacity to teach staff comprehensively on the floor. It was acknowledged that there is education and training available, but the current workload of a reduced pool of aged care staff creates a barrier to the quality of care delivered, as identified in the Royal Commission into Aged Care Quality and Safety. Education programmes like **Program of Experience in the Palliative Approach (PEPA)** are effective but unfortunately residential aged care facilities are time limited for staff to participate in the program. This is further exasperated by the casual and transient nature of the workforce. If staff could participate properly, this could lead to better outcomes for residents.

When staff are participating in education around deterioration, for example, they are upskilled to be able to keep the resident in the facility as the training assists staff to understand what to look out for in a resident, what to expect, and how to recognise and respond to deterioration.

Programs where staff can participate in experiential learning in acute care have been suggested as a supportive form of learning, providing an opportunity to observe, experience, then practice and share this knowledge within their own facility.





For the person, their families, loved ones and carers

Consultations highlighted that at times there has been confusion for patients and families around the differences between palliative and end of life care, which has resulted in a patient or family not considering palliative care service support.

“A patient might say, I don’t need that because I’m not actually dying.”

Consultation participant

“GPs need a quick guide to be able to explain to patients what end of life care is. Just in simple words that can be communicated to patients.”

Consultation participant

Education for families, loved ones, and carers can provide better understanding on what palliative care at home can look like, by transferring knowledge to families and carers around death and dying, and providing those practical skills of caring for someone.

Timing of education for the person, their families and carers

Travelling at the pace of the recipient is critical.

Education around death and dying is effective, but it needs to be delivered at a time and place that the person, their family and loved ones prefer. It needs to be in a familiar setting, a human experience, and preferably in a non-clinical environment or approach to education.

Too much education at once can be overwhelming, making it difficult to retain information. Reiterating the key things throughout the education session can support people to process more of the information.

Ongoing open dialogue can be utilised as a form of education, and providing the right information at a given time, rather than all the information at once, is more effective in passing information and knowledge.

“We don’t want to just give education, but model and mentor, these are the sorts of things that really make a difference, rather than printed bits of information.”

Consultation participant



STORY

two

COMMUNICATION AND INFORMATION SHARING

Information is continually shared about the patient to the wider palliative care team across multiple places of care and support services to provide the best possible care for the patient or resident.

How do we have more meaningful conversations with families, carers, and between services, so that we are all on the same page about the individuals' goals, or preferences of care?

Communication and knowledge sharing comes in many forms, it can be a simple conversation between colleagues, a residential aged care facility providing information to a family, or from one health and community sector professional to another across multidisciplinary teams. Where, when, and how this communication happens can have very different outcomes, and so we need to consider how to have more meaningful exchanges, and processes that support the patient's preferences of care.

Conversations for planning ahead

“There needs to be ongoing training for healthcare professionals to be able to have these conversations and to not see them as “difficult” conversations but rather as a kindness to someone that enables them to have control of their own health.”

Consultation participant

Meaningful conversations that explore what matters to each individual are central to advance care planning. Advance care planning provides opportunity to talk openly about palliative care and end of life choices, guided by the thoughts and conversations that determine the wishes of the person with a life limiting illness.

The sooner we start the conversation, the sooner we can understand the wishes of the individual so that we can provide care throughout the journey, and all be on the same page. By starting the conversation earlier, we are avoiding a rushed conversation at a point of crisis.

Good advance care planning discussions involve having an open conversation in more detail when documenting their wishes, rather than ‘ticking through the boxes’.

“Sometimes all it takes is sitting and listening to someone, not to just solve problems, but actually listening to what they want to say and what they’ve got to talk about.”

Consultation participant

The Buddy Program, an initiative of one aged care organisation, where residents are ‘buddied’ up with a staff to provide companionship and conversation has been noted as an approach to care with more outcomes. Conversations in the buddy program are generally not about clinical activity but about the resident's life, and so meaningful relationships are developed.

How can we support health and aged care staff to communicate well with families? To feel equipped and confident to share knowledge with the family of death and dying throughout each phase of the process, so that it reduces the stress as much as is possible.

Providing written information around planning ahead to families is useful, but only if we can schedule some time to sit down and have a conversation, essentially giving time to professionals to have those meaningful conversations.

A discharge letter is also one form of conversation between one health professional to another. Being as clear as possible in the discharge letter for end of life care, for example by really documenting the family conversations well so that it reflects what was said in the room, can really support the future quality of care for that person.



Case conferences

Case conferences have been highlighted as a positive learning experience and an effective communication tool with the wider team around the resident's needs in a residential aged care facility. It helps staff to understand what to look out for in the resident.

Barriers to case conference attendance can include staff shortages in the residential aged care facility, and difficulties accessing the GP and families at the same time. Virtual conferencing has helped reduce the severity of some of these barriers, for example geographical barriers, as families are able to engage from different locations around Australia and the world.

A recent pilot program launched in early 2022 across the NSLHD was highlighted as a program gaining a positive response. It involves Palliative Care Needs Rounds by hospital palliative care staff in residential aged care facilities. The Needs Rounds provide the space for case conferencing and having meaningful conversations earlier, rather than closer toward the end of life.

When a person needs palliative care, it is a difficult time for their family and carers, it can be overwhelming to acknowledge and comprehend, and difficult making crucial decisions, especially at a time of crisis. The quality of information and support provided at the right time can enhance family's knowledge and understanding of what to expect and what help is available.





Systems

“If you look at all the things and break it down, it gives you a reasonable picture of what actions require investing in. We’ve got a superb system in this country, but I think we could probably do a lot better.

We really need to pause, stand back, and break it down, to work out what changes would need to happen.”

Consultation participant

There are numerous systemic barriers to communication between services, which inherently reduce cooperation and understating around the sector. Some of these include multiple silo funded programs delivered by different organisations, public service and private service, various terms of communication and ways of working, and geographical barriers to name a few. These systematic barriers due to a range of determinants can affect what information is shared about the patient.

In an ideal scenario, the wider team would collaborate with each other without systematic barriers that exist between different services. Instead of physically moving the patient between each service, services would be moving around them.

“It would be nice if it was just the patient in the centre and services all providing care collaboratively around them, to allow those transitions to happen really easily.”

Consultation participant

Good communication about what is happening for the patient is important, so that the next person they’re seeing knows exactly what has been going on and can see the full picture. For example, when the patient moves outside the Local Health District, information may not always transfer across with them, and having a good hospital discharge letter can help communicate the plan to other service providers and ensures the patient’s GP is also kept updated.

It was highlighted in Sydney North Health Network consultations that at times the patient’s GP may have not been informed about the patient’s current circumstance. By keeping the patient’s GP updated, better yet, regarded as a crucial member of the wider palliative care team, a more united vision and higher quality of care can be achieved.



STORY

three

THE WIDER PALLIATIVE CARE TEAM

We need to recognise the distinctive yet interconnected role that the wider palliative care team and the community play in providing holistic care.



Palliative care can be provided where the person or their family want, which may include at home, in hospital, a hospice, or residential aged care facility. In fact, many people indicate a preference to die at home and making this possible depends on several factors.

Contributing factors, such as the nature of the illness, how much support is available to the person from family and community, and if the person has someone at home who can provide physical care and support, all affect the outcome of how and where care is received.

The wider palliative care team can include the palliative care physician and other specialist medical staff, palliative care nurses, aged care staff, allied health, GP and practice staff, health and community sector support workers, the family, the carer, and the broader community that acts compassionately to people in need.

Dying is everybody's business.

“We have that one chance to get it right, and everybody has a role in that. It's not just the nurses. It's not just the care workers. It's everybody around the person that participates in that process.”

Consultation participant

How do we bring everybody together to have shared understanding of the current situation for the palliative person and what their preferences are?

“We've taken death away from community and said it's the remit of a medical subspecialty, so we've actually said now dying is the responsibility of a specialist group of people.”

Consultation participant

The community has lost the skills to care for dying people and we need to share knowledge and re-learn how to be a compassionate community once again.

There are several organisations and personnel working around the person to deliver services. When all sectors work together around the person, the quality of care delivered increases. There is opportunity for better understanding and cooperation within the wider palliative care team through shared knowledge and more opportunity for connection.

A compassionate community

Adopting the evidence based International Compassionate Community model can be a catalyst for social change, alongside and integrated into all the services that Sydney North Health Network commissions, from birth to death. It can become part of our language and actions that connect us, our organisation and the streets and communities that we live in.

“We can be a geographical region that helps to end loneliness and isolation and promote good health within our community. Perhaps the way will be messier than structured programs and services, but the outcomes may be defined by inspirational narratives within our communities.”

Consultation participant

The term Compassionate Communities is used world-wide to describe localities that encourage and develop a whole-of-community culture focused on caring networks and the social and emotional support of dying people and their families, reducing the load on individuals and the health system and contributing to a sense of wellbeing at the end of life.

Surveys in Australia show that over 70 per cent of people would rather die at home, but most die in hospital instead. The increasing focus on the role of primary care, and community health and other services, is consistent with an increasing preference of people to die in their own homes, whenever possible.

Compassionate communities are most effective when they are part of broader public health approaches to palliative care, end of life care and bereavement. Currently there is an engaged community in the Northern Beaches, where everyday people can play a stronger role in the care and support of people as they age and at the end of life, and there is further opportunity to develop the compassionate communities model in the whole of the Northern Sydney region.

The **Hornsby Village Hub**, a collaborative initiative at Sydney North Health Network is an example of a connected and compassionate community in action with an overarching focus on connecting people in the community beyond end of life.

“There really has to be a group supporting that person, time and energy is needed to mobilise the group together. It’s certainly do-able when we look at compassionate communities.”

Consultation participant

Connectedness to General Practitioner

Proactive palliative care involves keeping the GP informed of the patient journey through meaningful communication and information sharing via case conferences, palliative care needs rounds, and discharge letters. This supports a GP to manage symptoms earlier and put anticipatory medication in place. In the residential aged care facility connectedness to and limited availability of a GP can be a barrier to communication and information sharing on resident's needs.

GPs are pivotal in being able to keep a person at home. What is the capacity of the general practitioner to provide care in a changing world of general practice? In the northern beaches, for example, there are several larger medical practices and less independent GPs, which can pose a challenge in direct communication for care of the patient.

Consultations reiterated that GPs would prefer a shared relationship of care for the patient when going through their palliative care journey, and initiatives such as case conferencing are valuable in realising this, however often the request may come in late from the residential aged care facility, and at a time that the GP is unable to attend.

Matters around communication were discussed in consultations and, for example, having a more thorough discharge letter for the GP that could provide a comprehensive picture of the patient's journey, and empower a GP needs to practice with the right knowledge about the patient.

Consultations highlighted the necessity to work around the dying person, their family and loved ones as a wider connected palliative care team, engaging and empowering the General Practitioner as a fundamental member of the patient's journey of care.



There is interest in gaining more in-depth knowledge and information around support and services available, as well capacity building around a palliative approach to care, for example education on bereavement for family, friends, and loved ones, and range of services available.

“Having someone to call, who can just refer us onto the right services, a concierge service for palliative care.”

Consultation participant

The Nurse Practitioner’s role

The valuable role of the nurse practitioner was emphasised in the consultations as an underutilised resource and indicated as immensely beneficial in providing palliative care in general practice through a nurse practitioner model.

The Registered Nurse role in aged care

The role of the Registered Nurses (RNs) in an aged care facility, specifically managing residents in the afterhours periods, can be a significant factor in reducing hospital admittance.

RNs spend a lot of time coordinating care for residents, and just having an operational support person can reduce overburden of paperwork and operational tasks, allowing the RN to spend more time delivering care on the floor. Skill and staff shortages have been a significant factor in the delivery of care within the residential aged care facility.





STORY

four

CARER'S CENTRAL ROLE IN DETERMINING OUTCOMES

Unpaid carers are central to the palliative care team and play a role that can be physically and emotionally demanding.



Carers need to be equipped with information and resources to make informed decisions.

Carers can feel overburdened in providing and making decisions and need support to maintain a sense of wellbeing.

Caring for someone in the home can be a 24 hour role, and for a carer to have access to practical support and the opportunity for respite can mean the difference between going to hospital or not, for the person needing care. Funded carer support packages need to provide support equivalent to the needs of the dying person. There are packages available such as the End of Life (EoL) package, but they are limited in the number of hours that are supplied.

The burden of responsibility can produce feelings of exhaustion, guilt, and anxiety. Carer stress can be a significant detriment that prevents people from continuing to care for someone to die at home. Knowing what services are available can help a carer to know they are not alone. It is also valuable for the carer to access quality information from one source, and not have to go through multiple teams, assessments, and sources of information, to reduce the burden in coordinating care.

It's important that the carer understands what caring for someone in the home entails. Education and information sharing is essential, so carers understand what to expect and have a clearer understanding of their own capacity to deliver that care. The social determinants of the carer will influence the level of care they are able to give. For example, the physical ability of an older carer can determine their ability to provide physical care.

Dementia

People living with dementia, their family and carers can experience tremendous levels of stress, especially around making decisions for the person's care. Delirium and Behavioural and psychological symptoms of dementia (BPSD) can become significant issues in some types of dementia as it worsens. This has quite an impact on care, and occasionally special units and staffing are needed.

Carer support is vital to reducing the emotional strain and burden of caring for someone with Dementia. Often the demand can be high due to them being the only familiar face for the person with dementia. Grief can also look different, as they have lost the person repeatedly over time.



STORY

five

MENTAL HEALTH IN PALLIATIVE CARE

Psychosocial health is a major palliative care concern globally. Patients and caregivers engaged in palliative care may experience challenges with their mental and social health.



Across these consultations there was strong agreement and acceptance of the importance of psychosocial, psychotherapeutic, and creative psychotherapeutic services in palliative care. The consultations also revealed a lack of understanding in what mental health support services are available and how to connect with these services. Incorporating the needs of the dying person, their family and caregivers can further enhance mental health services.

The lack of knowledge and understanding around death and dying can produce feelings of fear. Education on, talking about, and normalising death and dying can reduce fear and anxiety by empowering people with knowledge, providing them with emotional support, and helping people prepare with coping with the natural process of dying.

Feelings of fear around death and dying are not exclusive to patients and caregivers, but also health and community sector staff, which can negatively affect the communication and information shared with families and between services. It is critical that we don't use avoidance language, and instead be transparent about death and dying.

Being able to provide comfort for families and carers, notably families of residents in aged care facilities who are nearing end of life, is an area of need in Northern Sydney. Support programs can occur at different phases such as early education on death and dying, mental health support for families, and grief and bereavement support. Timely mental health support can be supportive of meaningful conversations that support the care preferences for the patient.



STORY

six

THE PATIENT JOURNEY

We can learn about the palliative care landscape in our region and the unique needs of individuals by better understanding the patient's perspective, looking at their journey and the touch points to health services, and what their experience was with these health services at different times and stages of their palliative care journey.

“It is a privilege being with someone who’s dying and celebrating their life. It’s not just somebody lying in bed waiting for the next medication. We need to personalise it.”

Consultation participant

How do you we know what services are available and how to connect to them?

Providing a picture of what resources, services, and supports are available can enhance the quality of care and reduce stress. There is a need in Northern Sydney to map out those supports from both the professional care team and the community. Service mapping can equip primary care and aged care with knowledge to coordinate and lead care for the patient and enable them to make informed decisions.

“Sometimes we can have the best laid plans and it just becomes scary for that person, with breathlessness for example, and they end up in the Palliative Care Unit or call an ambulance.”

Consultation participant

There are several educational and support resources available online, although technical knowledge is most beneficial when it has a human element behind it. Having a 24-hour phone support service (help in the after-hours period), for example, was emphasised several times in these consultations as a useful supportive resource, not only for families and carers, but for aged care and community staff as well. This can possibly mean the difference between staying at home or an ambulance being called.

“How we can reshape the whole health system to make sure that the resources that we have available to us in hospital, in 24-hour care are actually relocated to the community so people can reliably plan? There’s a pretty good case to shift an awful lot of what happens in the acute hospitals back out into the community, but then we need to make sure it’s resourced properly.”

Consultation participant

The unique needs of all people must be included, for example, a younger person living with a disability who resides in a group home funded by the National Disability Insurance Scheme (NDIS). Think about the difficulties experienced by carers in that setting when coordinating care, navigating through different funding models, and their inexperience of death and dying, and continuing to support others also living in the home.

Sometimes the barrier to be able to keep someone in the home is the level of support available. It’s reassuring for a person to learn about services early and to know that someone is going to come and help them in the home, enabling them to plan ahead.

Having flexible support to accommodate the changing needs of the person and their carer is going to support the patient in their journey as best as possible. The support packages, knowledge and understanding around services available to them, and a support network is going to support that flexible delivery of care.

Accessing Services

Access to general practice, for multiple systematic reasons, can be a barrier to communication with GPs. This includes GP rostered schedules, the traction of larger medical centres and less independent GPs, reduced home visiting services, and a change of GP when a person transfers into a residential aged care facility.

There are tools to support referral in palliative care, for example **HealthPathways** and the **Palliative Care NSW GP Referral Guide**, but there is capacity for better utilisation in primary care and in aged care.

What's the capacity of general practice to provide palliative and end of life care in a changing world of general practice?

Timely access to GPs can help with prescription of end of life medication. Planning ahead can aid in timely anticipatory prescription, through case conferencing and palliative care needs rounds, for example, to facilitate discussion early and put a management plan in place. Telehealth and virtual conferencing have been supportive in strengthening connection to general practice. GPs have a considerable workload in managing care of their patients, but there is still an opportunity to have a shared relationship with general practice on their patient's palliative care journey, and a disposition of willingness, co-operation, and shared understanding in primary care on their patients' journey. GPs in the Northern Sydney region have indicated that they would like to be better informed, and part of their patient's palliative care journey. Having another health professional to speak with about palliative care services is a useful tool in navigating care pathways.

“It would be beneficial to have someone to just call and refer us onto the right service. A central point of service information we can access”

Consultation participant

Allied health is an essential component in palliative care, and access to these services, such as physiotherapy, psychology, creative psychotherapeutic services, and podiatry, for example, are limited and can be improved in residential aged care facilities.



They can also be cost prohibitive to patients in the community, especially for people who are unable to access allied health through aged care packages.

“If we had the resources, allied health services are, highly beneficial for a resident.”

Consultation participant

“There is a need for multilingual psychotherapeutic services.”

Consultation participant

“Creative psychotherapeutic services are quite effective in the Palliative Care Unit.”

Consultation participant

Planning ahead

Being proactive can help to recognise what is happening to the patient sooner and start responsive action rather than reactive at a time of crisis. Proactive planning provides confidence to staff on what to expect and what to do next. Proactive planning includes good discussions on what matters most and individualising the services through holistic care.

Starting the conversation early also helps people to be more engaged in planning their own healthcare. This conversation can take place in primary care if GPs are supported with the right tools, language, and knowledge of the palliative care service landscape, or through upskilling aged care staff both in residential and home care.



Palliative Care improvement initiatives such as **Palliative Care Outcomes Collaboration (PCOC)** and the **Palliative Aged Care Outcomes Program (PACOP)** have helped in starting the conversations earlier. Early recognition is important to trigger conversations about care and end of life options. This can also support the family by preparing them to plan ahead of time.

Aged care staff place a lot of time into family meetings that involve the Registered Nurse, GP, and other people who know the resident well. There is an immense amount of value in bringing everyone together, having a united plan and shared understanding about what the needs are. This supports both the family and staff to feel empowered and proactive.

Timing

The timely responsiveness of support packages can be a determinant on keeping someone at home. Previously trained carers were able to go to a person's home to stay overnight for an 8-hour shift, being available almost immediately when the patient arrived at home. The current End of Life packages are supported by a great team, but the limits of the package on how many hours are offered, for example, are not quite servicing the need.

Early identification of changes in a person's wellbeing is a key factor in quality of care. Deterioration needs to be identified earlier so that plans can be put in place.

Sometimes it's the care workers in the residential aged care facility that might recognise it earlier, but due to systemic issues, they may be unable to communicate this effectively to other staff. Training care workers in communication around deterioration has been effective in residential aged care facilities in the region. Early identification supports timely medication management and allows time for reviews. Syringe Drivers in residential aged care facilities and education around how to use them were also identified across the consultations as an area of need.

The **Amber Care Bundle** and **Surprise Question Tool** are initiatives that help to trigger conversations in acute care. Amber care triggers clinicians to flag a patient who is at risk of dying, and it's an action that is promoted by palliative care staff and prompts earlier discussions.

GPs are often operating on the scale of a small to medium sized business, and don't have the operational and specialist support services of the acute sector. Nurse Practitioners can also be a point of referral and care delivery, which enables less reliance on the General Practitioner. Similarly, the Practice Manager is a valuable support in assisting with appropriate timing and information sharing. Education around palliative and end of life care services and understanding the service landscape in the region can equip the Nurse Practitioner and Practice Manager in advancing primary care.

Dementia

There is a consideration and awareness to be raised about integrating palliative care with the life-limiting illness of diseases such as dementia. Early recognition and referral can be supportive of relationship building with the person and their family.

Questions such as timing of referrals will need further attention. For example, people who have moderate to severe dementia, who might be okay now, but might deteriorate quite quickly. Advance Care Planning is very important across all settings. A person with dementia cannot communicate their wishes as the disease progresses.

APPENDICES



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