Palliative and End-of-life Care

Needs Assessment
February 2023

Healthy North Coast is an independent, not-for-profit organisation proudly delivering the PHN Program in North Coast NSW. We are committed to improving the health of our communities through quality primary health care. The PHN program is an Australian Government initiative.

www.hnc.org.au

Acknowledgement of Country

In the spirit of reconciliation, we would like to acknowledge the traditional owners of the lands throughout Australia on which we live and work.

We acknowledge the traditional custodians of the lands across our region, which includes the Githabul, Bundjalung, Yaegl, Gumbayngirr, Dunghutti and Birpai nations. We pay respect to the Elders past, present and on their journey.

We recognise these lands were never ceded and acknowledge the continuation of culture and connection to land, sky and sea. We acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First Peoples and honour the rich diversity of the world's oldest living culture.

About this report

This report was commissioned by Healthy North Coast and funded together with partners, the Department of Health and Ageing. We would like to acknowledge the people and organisations who contributed to the development of this needs assessment. Without their contribution, we would not be able to reflect the experiences of consumers, their family and carers and service providers across the North Coast.

While the Australian Government helped fund this document, it has not reviewed the content and is not responsible for any injury, loss or damage arising from the use of or reliance on the information provided herein.

If you have any feedback on this needs assessment, please email us at contact@hnc.org.au.

Warning

Aboriginal and Torres Strait Islander people should be warned that this document refers to the sensitive issue of death and dying.

Table of contents

Palliative and end-of-life care snapshot

Build Community Capacity

Death literacy is being able to talk about death and dying to support people to make informed choices about their end-of-life care and supports their ability to care for others.

Advance Care Planning gives people choice and control. It is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions.

Building Compassionate Communities where everybody recognises that we all have a role to play in supporting each other in times of loss, ageing, dying and grief. Everyone is ready, willing, and confident to have respectful discussions to support each other in emotional and practical ways.

Support service capacity and capability

Support service providers with the resources, information, and systems to deliver safe, high-quality palliative and end-of-life care.

Advanced Care Planning is a priority for quality person-centred, palliative, and end-of-life care. It ensures people receive the care and treatment of their choice and can reduce hospitalisations.

Greater investment in technology will complement service delivery and enable increased access to palliative care services at home or close to home, particularly for people living away from larger towns in our region.

Connect Systems

Primary health care can be supported through the development of local palliative care directories and referral pathways, the use of common language and tools, greater integration with other areas of the health care system, and a better understanding of the clinical triggers for commencing palliative care.

Navigation of services can be complex. General practice plays a central role in the integration and coordination of services and support on the continuum of care.

Introduction

Across Healthy North Coast (HNC) and Australia, the demand for palliative care and end-of-life-services is increasing due to an ageing population, an increasing number of people with multimorbidity and an increasing prevalence of cancer. Existing services across the HNC region are disjointed, the palliative care system is not easy to navigate or transition through as support needs change. There are gaps with accessibility and availability of services and supports, especially acute in inner and outer regional areas such as HNC, where local services are limited or unavailable. Limiting people's choices means that their preferences for care and place of death are not met.

Death and dying are something many people are uncomfortable with, as individuals and as a community. Low death literacy and high levels of stigma around ageing and dying impact on our ability to engage in end-of life-discussions, access palliative care services, and support people after loss.

Early engagement in end-of-life discussions and advanced care planning affords people the opportunity to understand, prepare for, and be in control of the care they receive. Discussing advance care planning with anyone, including health professionals, made a person three times more likely to document an advance care directive.[1]

Healthy North Coast has received funding as part of the Greater Choice at Home Palliative Care measure. The objectives of this program are to:

- Improve access to palliative care at home and support end-of-life care systems and services (in primary health care and community care)
- To enable the right care at the right time and in the right place (to reduce unnecessary hospitalisation)
- Generate and use data to support continuous improvement of services across sectors
- Use available technologies to support flexible and responsive palliative care at home, including in the afterhours.

The needs assessment is a deliverable of the Greater Choice program and has been developed through the cumulation of sociodemographic information for the region overlayed with information derived through a series of consultations that occurred across the region from May to November 2022 and included 181 people comprising health providers, community members, volunteer organisations, peak bodies, and representatives of National Palliative Care projects.

Thematic analysis to identify opportunities to support palliative and end-of-life access and services across HNC relied on the project team's understanding and experience of the subject area. To strengthen this approach, the qualitative data has been used to support the quantitative data to gain deeper insights into the health needs in relation to palliative and end-of-life care.

Key Concepts

Palliative Care

"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families facing the problems associated with a life-threatening illness. The approach is based on prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual." (WHO 2020) [2]

Palliative care is explicitly recognised under the human right to health.[3] It neither hastens nor postpones death. Palliative care is for any person, regardless of age, who has been told they have a life-limiting illness that cannot be cured. There are benefits to providing palliative care in association with active treatment for symptom control and pain management.

Where feasible, palliative care is delivered where the person and their family want, including in their home, in a hospital, in a hospice, or in a residential aged care facility. It is provided by a wide range of providers including people working in health, community, disability, aged and social services. Palliative care is a crucial part of integrated healthcare services.

The National Palliative Care Strategy 2018 affirms that palliative care is a person-centred approach with those affected by life-limiting illnesses at the heart of their care, surrounded by their community and supported by services (Figure 1).[4]

The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include personal care, bereavement support for families and carers, equipment, and management of pain and other symptoms.

Figure 1: The person is at the centre of palliative care.

Source: Department of Health (2018)

End-of-life Care

"End-of-life care includes physical, spiritual, and psychosocial assessment, care and treatment delivered by health professionals and ancillary staff. It includes support for families and carers, and care for the patient's body after their death. People are considered to be 'approaching the end-of-life' when they are likely to die within the next 12 months." (AIHW 2016)[5].

End-of-life care and palliative care are often used interchangeably; however, they refer to different services targeted towards different stages of people's life-limiting illnesses. Palliative care can begin as soon as a person is diagnosed with a life-limiting condition, and in some instances continues for years. End-of-life care represents a specific time frame, usually the last 12 months of life but may be only the last few days of life.

Demand for palliative and end-of-life services across HNC

The demand for palliative care services is increasing across the HNC region with one in three people projected to be 65 years and over by 2041. This is further impacted by an increasing prevalence of chronic disease and cancer.[6]

End-of-life care is provided in a range of settings, and whilst 7 in 10 Australians want to die at home, 5 in 10 of all deaths occur in a hospital.[78] There were 5,114 deaths recorded across the HNC region in 2020.[9] Although the HNC region has only 6.7% of the NSW population, we had 9.8% of all deaths in NSW in 2020. The median age at death in HNC was 79 years for males and 85 years for females.[10]

The ten leading causes of death across the region from 2016-2020 are outlined below, accounting for one in every two deaths (Table 1). One in three deaths across the region were classified as premature as the person was aged under 75.[11]

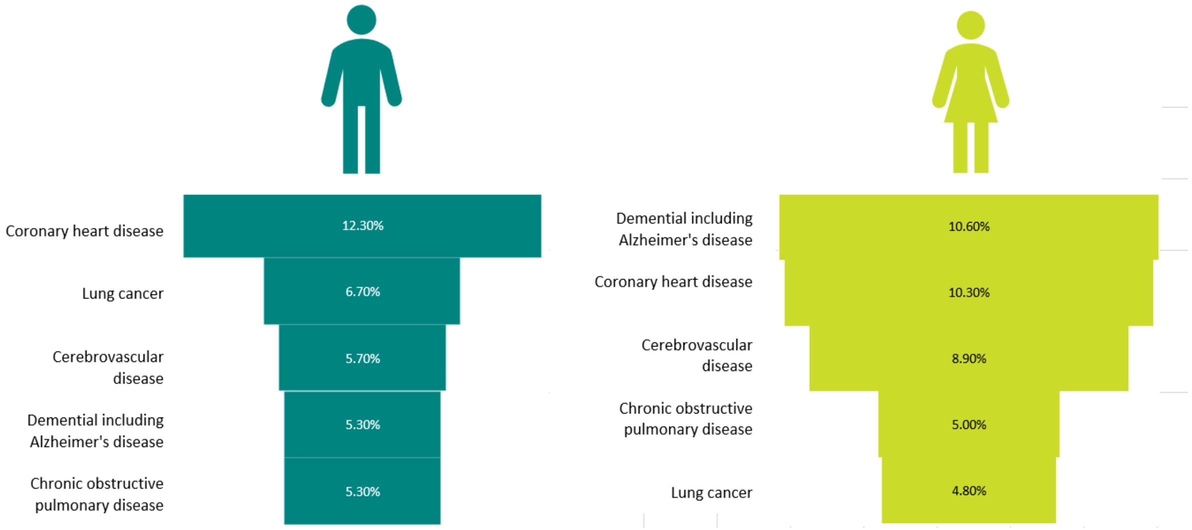
Table 1: Top ten leading causes of death in HNC region 2016-2020.

Cause of death (ICD classification)	Deaths	Proportion of all causes
Coronary heart disease (I20-I25)	3,000	11.4%
Dementia including Alzheimer's disease (F01, F03, G30)	2,065	7.8%
Cerebrovascular disease (I60-I69)	1,888	7.2%
Lung Cancer (C33, C34)	1,521	5.8%
Chronic obstructive pulmonary disease (J40-J44)	1,353	5.1%
Colorectal cancer (C18-20, C26.0)	870	3.3%
Diabetes (E10-E14)	768	2.39%
Prostate cancer (C61)	632	2.4%
Cancer of unknown or ill-defined primary site (C26, C39, C76-80 excl. C26.0)	598	2.3%
Heart failure and complications and ill-defined heart disease (I50-I51)	557	2.1%

Source: AIHW 2021

For every one death for males caused by dementia including Alzheimer's, there were two deaths for females caused by dementia including Alzheimer's across the region. Whereas for coronary heart disease for every four deaths in males there were three deaths in females. Due to limitations in data collection, it is unknown how many of these people may have received and/or benefited from palliative and end-of-life care over the course of their illness.

Figure 2: The top five causes of death for all people are ongoing and progressive conditions.



Source: AIHW 2021

Key population statistics for our region

HNC has a population of **541,046** in 2021 forecast to increase by 10% by 2041

HNC has **12** local government areas and **2** local health districts

Only 3

rental properties in the HNC region were affordable and appropriate for a couple on the aged pension with no children (on 19 March 2022)

6 in 100

people identify as Aboriginal and/or Torres Strait Islander

1 in 4

are aged 65 years and over. This is predicted to grow to 1 in 3 by 2041

3 in 4

households are in the most disadvantaged two quartiles for the experimental index of household advantage and disadvantage

increasing frequency and impact of natural disasters

people are living regionally

highest rate of GP chronic disease management plans services in Australia

Consultation Process

Consultation for the Greater Choices project occurred with various stakeholders across the region from May to November 2022. This process included:

- Two palliative and end-of-life care workshops exploring patient journeys, in Coffs Harbour and Ballina. The 40 participants were comprised of health professionals and community members. The feedback provided insights into priority areas of need, improvements, barriers, and gaps across the region in the areas of palliative and end-of-life care
- Onsite visits to five Residential Aged Care services with 11 staff interviews
- 24 online questionnaire responses (17 health care professionals, 7 community members). The questionnaire was focused on enablers and barriers to accessing palliative care in the region
- Two online forums, *"What is a good death?"* with 25 participants (LHD staff, primary care providers)
- Face-to-face consultation with 14 carers of people living with dementia and service providers. 16 responses to a questionnaire disseminated through Dementia Alliances in Port Macquarie and Ballina and through the Dementia Outreach Service
- Interviews with key stakeholders - 43 health professionals, 3 volunteer organisations, 2 Peak bodies, and with project leads from 3 National Palliative Care projects.

HNC acknowledges that engagement and consultation is an ongoing process and looks forward to the opportunity to meet with, and learn from, future participants in the project.

Opportunities

To assist with palliative and end-of-life care across the region and afford people the greatest opportunity to have a good death, the following opportunities have been identified.

1. Build community capacity

Regional areas benefit from building compassionate communities where members of the community play a stronger role in the care and support of people as they age and reach the end of life. Normalising death and dying as part of the life continuum builds individual and community capacity to understand options and make informed health care and end-of-life decisions.

2. Support service capacity and capability

Increasing demand for palliative care services will exacerbate workforce issues across the region. Opportunities identified include supporting and connecting service providers to information, tools, and resources to improve their knowledge and confidence to enable the delivery of consistently safe high-quality palliative and end-of-life care (Advance Care Planning, telehealth, cultural awareness, assessment, early referral to palliative care, anticipatory planning). Improved systems, planning and skills will support service capacity.

Greater investment in technology and the use of virtual care will complement service delivery and enable increased access to palliative care services at home or close to home, particularly for people living away from coastal areas in our region.

The availability of data is an important infrastructure for both the delivery and promotion of palliative and end-of-life care. There is limited consistent data, particularly of care delivered by GPs, allied health, non-palliative medical specialists, and other health professionals.

3. Connect systems

Improved integration and coordination of services and support on the continuum of care with GPs playing a central role.

1. Build Community Capacity

Key Points:

- Normalising death and dying can reduce stigma and fear and supports end-of-life planning conversations. This allows people the opportunity to share what matters most to them.
- Raising community death literacy empowers people to be more involved in their own care planning, including end-of-life planning.
- Increasing the capacity of community to support people and their families living with a life limiting illness can result in people being cared for closer to home.
- Advance Care Planning enables individuals to identify the kinds and types of support they would like at end-of-life, reducing inappropriate treatment and care, and improving the quality of end-of -life.
- There is a lack of knowledge and awareness around the purpose and role of palliative care that can be improved through effective campaigns.
- The important role of carers and the need to ensure they are appropriately supported is required.
- Palliative care doesn't end when the person with the life limiting illness dies. It continues to support family and carers through loss, grief, and bereavement.

Overview

There is a general lack of individual and community awareness, education and understanding of what palliative care is, how it can improve quality of life, which health and social care providers are involved and what services are available. Specific areas that have been identified through the consultations include advance care planning, service awareness, death literacy and palliative care. Community engagement, awareness and support are important to improve health and death literacy and reduce stigmas around ageing, death and dying. Normalising death and dying is a part of life and a human experience, not just a biological or medical event.

Death Anxiety

How we die has changed significantly over the last century, from death being largely a family and community affair to becoming highly medicalised with most people dying in hospital. We are losing the *'language, knowledge and confidence to support and manage dying'* (Sallnow et al 2022) resulting in our increased reliance on health care.[12] Death anxiety refers to a person's fear of death and the process of dying.

We are living longer, and with advancing medical treatments available, dying is often more prolonged than generations ago. At times, this can be at the expense of quality of life. In Australia, males live 71.5 years (89%) and females 74.1 years (87%) of their lives in full health.[13]

Over the last two years during the Covid-19 pandemic, the media reported death daily. Images of medicalised death were everywhere, including masked staff and people dying alone in intensive care beds, cementing the idea of health care services at the centre of death and dying.[14] Covid restrictions impacted people's grief and loss experience, limiting their ability to follow their traditions, their cultural practices, and to gather with family and friends.

A negative impact on people's finances can increase anxiety, with a recent AIHW report finding that nearly all Australians use health services in their last year of life, with 8% of all health service costs spent on people during this time.[15] Males have a higher average annual cost than females ($26,300 and $21,600 per person, respectively).[16] Health service costs were highest for people dying from cancer, with bowel cancer average costs being $40,700, breast cancer $35,500 and prostate cancer $34,500.[17]

Death has been devalued, rather than considered as a normal part of life. The Australian Commission on Safety and Quality in Health Care characterised Australia as a death-denying culture, reluctant to engage in conversations about death and dying, or their wishes for end-of-life.[18] This can lead to people receiving inappropriate, unnecessary, or unwanted treatment and an over-medicalised death.

To support someone to have a good death, a recent literature review found the following is needed:

Core themes to support a good death

Preferences for dying process i.e. how, who when, where and preparations for death

Pain free

Emotional wellbeing

Family support, acceptance, and preparation

Dignity

Other, such as recognition of culture and financial assistance

Life completion, saying goodbye, a life lived well, acceptance of death

Spirituality

Treatment preferences

Quality of life

Relationship with health care provider

Source: adapted from Meier et al. (2016)[19]

In modern times, death has moved from being part of life to an enemy of life.[20] To create a new vision of death and dying, the Lancet Commission on the Value of Death sets out five-principles of how death and dying could be:

- tackle the social determinants of death, dying and grieving
- death is seen not just as a physiological event but rather as a relational and spiritual process
- networks of care lead support
- sharing stories about death and dying becomes common
- death is recognised as having value.[21]

> ***"We are a death-denying society, thinking of death as a failure rather than as a natural process, there is a lack of discussion in the community regarding death and dying."***
>
> **Clinician, Coffs Harbour Workshop**

Death Literacy

Death literacy is defined as a set of skills and knowledge that make it possible to learn about, understand, and act on end-of-life and death-care options.[22] This includes the legal process; what happens when someone dies; who needs to be notified and involved; what support is available; and what good end-of-life care looks like.

Figure 3: Key components to promoting death literacy

Source: adapted from Leonard et al. (2020)

Recent death literacy research found that of every three Australians, two have sat with someone dying and are comfortable talking about these issues given the right conditions and one will avoid talking about death and dying.[23]

People and communities with high levels of death literacy have the knowledge of, and the ability to put that knowledge into practice.[24] There is emerging evidence that increasing the death literacy of individuals and communities strengthens the capacity for future caregiving.[25] High death literacy in a community may also reduce death anxiety.[26]

Death literacy in a population can be measured using the Death Literacy Index.[27] This index can be used to determine current levels of death literacy at both whole-of-population and local levels and measure the impact of local and widescale initiatives. Two national surveys undertaken in Australia suggest that Australians report comparatively higher levels of their ability to talk about issues relating to death and dying. However, people are less confident in the ability to provide hands-on care and even less confident with factual knowledge about legal and administrative processes. The main findings were that death literacy is developed through experience.[28]

Grieving usually accompanies loss, and is often tied to death, though not always. Grief literacy is defined as values, knowledge and skills that promote compassion for self and others in the face of loss.

Normalising death and dying supports end-of-life planning conversations, allowing people to share what matters most to them and identify their values, wishes and care preferences. Understanding death and dying as part of the life continuum reduces associated stigma and fear.

> ***"People can feel isolated when they feel they can't talk about it. Especially after someone close to them has died."***
>
> **Consumer, workshop Coffs Harbour**

Opportunities identified to build death and grief literacy include:

- Sharing strength-based stories of grief, loss, hope, healing, and recovery through regular community newsletter articles
- Facilitating access to community education. Suggested topics include: What is palliative care? Discussion starters - What matters most? Advance Care Planning, how to speak to children about death and dying, the role of the carer and self-care, grief and bereavement, and building compassionate communities
- Collaborating and connecting with school communities to develop resources to support social and emotional well-being in relation to death, grief and dying
- Supporting health and social services to understand different nuances of grief, to support early identification and referral to psychosocial support through connecting to established resources
- Supporting awareness of existing locally available services and supports.

According to Death Literacy Index surveys and highlighted throughout our consultation, the weakest aspect of death literacy in Australia is in both the legal and administrative processes, particularly Advance Care Planning.[29]

Advance Care Planning

Advance Care Planning (ACP) is a voluntary process where individuals make plans for their future health care. It enables people to make decisions about the healthcare they would or would not like to receive if they were to become seriously ill and unable to communicate their preference for making decisions.

It is not only for people who are older or have a life-limiting illness. Everyone should think about, discuss, and record their preferences for the type of care they would like to receive and the outcomes they would consider acceptable.

ACP is not a single event, but rather an ongoing process and conversations that should be undertaken early and revisited regularly.

An ACP can be created on behalf of someone with diminished or no capacity to make decisions themselves. The aim is that people create ACP before being unable to communicate their preferences or make decisions. This involves documenting their preferences for future care. It can include their values, life goals and preferred outcomes and directions about care and treatments.[30]

As part of ACP, it is recommended that people with decision-making capacity complete an Advance Care Directive (ACD) which may contain:

- Instructional directives: specific directions about treatment that they would consent to, refuse and/or withdraw for a time
- Values directives: general views regarding their values and/or preferences for care[31]
- An ACD guides medical decisions when a person no longer has decision-making capacity. In cases where the ACD specifies a directive refusing medical intervention, a health practitioner cannot provide treatment, and this cannot be overridden by the enduring guardian.32 If there is no ACD, an enduring guardian is required to provide informed consent before the provision of treatment, where a person lacks decision-making capacity. In NSW, decisions made by a person in their ACD can be spoken or written.33

Discussing ACP with anyone, including a health professional, made a person three times more likely to document an ACD.[34]

It was highlighted during the consultations that:

- ACP discussions need to happen early – planning for end-of-life early allows people time to consider their needs and their options for services and supports the person and family-centred care
- There is a lack of awareness in the community about the importance of ACP and ACDs, including when and how to complete the documentation
- ACP and ACDs can reduce inappropriate treatment and potentially transfer to a hospital
- ACP is not always routinely undertaken prior to admission to a Residential Aged Care (RAC), even though completed ACP and ACDs can reduce unnecessary transfer to hospital emergency departments.

The importance of uploading completed ACDs to My Health Record to ensure that they are accessible by health care providers. This is especially important when a person is unable to speak for themselves. It reduces unnecessary treatment being provided, including transfer to acute care and reduces distress for loved ones.

Paramedics don’t have access to a person’s medical records or know their background before meeting them. Therefore, ACP and ACDs are fundamental documents that give vital information, especially in an acute situation.

Opportunities to promote ACP and ACDs include:

- Linking and supporting health professionals, especially General Practice staff, to resources and education on how/when to commence ACP to enable increased completion of ACDs. This includes supporting practice nurses to act as advocates/case managers for ACP
- Supporting community education on the importance of completing ACP and ACDs. Linking to discussion starter resources and ACP resources
- Highlighting and sharing discussion starter resources with general practice staff
- Supporting residential aged care homes to implement ACP systems and processes to ensure ACDs are completed on entry and updated regularly
- ACP part of discussions at 50 plus and 75 plus health checks with GPs
- Encouraging people to upload their completed ACD to My Health Record, ensuring they are accessible by health care providers
- Supporting consistent approaches for advance care planning, for example with LHDs, community providers and aged care.

> ***"It'll happen we just have to. Something will trigger it and we'll get it done because my wife and I have to do it together pretty much and it is a bit of work but it's important especially when you have a house, and you have four children, and you have a house basically. Like what happens if something happens to me tomorrow and someone needs to get into my computer or my phone."***
>
> **Consumer, aged 59, Coffs Harbour**

Building Compassionate Communities

Compassionate communities are a key ingredient of public health approaches to palliative care.[35] This occurs when everyday people play a stronger role in end-of-life care for people in their community. Compassionate communities are built around the idea that a person dying spends 5% of their last year of life face-to-face with health professionals, and the remaining 95% of their time with family, friends, and community, alone or online.[36] It is a way of taking a step back from the medicalisation of death.

Compassionate communities are usually made up of existing networks or people within the same geographic location but also involve family, friends, faith and community groups, workplaces, and people with similar shared experiences.[37]

Building community capacity to support people and their families living with a life-limiting illness, particularly in outer regional settings, can offset the lack of available formal services and supports.

The potential benefits of compassionate communities when combined with other approaches to improving palliative and end-of-life care have been well documented in published research and case studies for the person at end-of-life, their families and carers, health and social care professionals and communities.[38 39]

> ***"Death and dying needs to go back into the hands of the community to support people to stay close to home."***
>
> **Health professional, Coffs Harbour workshop**

Opportunities identified to support the people and their community include:

- Developing public health campaigns to raise community capacity and death literacy through education and shared experience
- Utilising existing resources such as The Ground Swell Project's tools for a community-led approach to end-of-life care, and the Death Literacy Index Community User Guide
- Identifying and supporting people who are without informal carers
- Recognising the value in building community capability, capacity and resources through volunteers, support groups, equipment pools, transport, social connections, shared knowledge, and experience.

Service Awareness

Low knowledge and misconceptions of palliative care exist in both the community and within health and caring professionals. Low knowledge of palliative care may impact on future access in the event of a life-limiting illness.

Common misconceptions include the idea that palliative care is only for people at the very end-of-life, and societal taboos include talking about death and dying. People are afraid of the stigma of being linked to palliative care services which can lead to late uptake of referrals.

Opportunities to support people to locate and connect to services and supports include:

- Sharing information and positive stories on the role of palliative care and the benefits of early referral
- Conducting public education programs that raise awareness and use public health approaches to shift attitudes to palliative care.

Supporting Carers

Caring for someone when they have a life-limiting illness or at end-of-life can be difficult, challenging and demanding, though people who have done it, say it is both the hardest and most rewarding thing they have done. [40,41] Carers may be family, a friend, or a neighbour and while some may take caring on willingly, for others it is more of an obligation.[42]

Some of the challenges include meeting the needs of the person requiring care, advocating on their behalf, whilst managing daily life including finances, young children, family conflict in caring, and the carer's own needs. Caring can be physically and emotionally challenging, raising feelings about their death and dying and their own mortality.[43] Support needs can be unpredictable or deteriorate rapidly and the carer may need to decide if they can continue in the caring role.

It is essential that carers are recognised, valued, and supported. It is important they are involved in the planning for and provision of care, and that they receive the services and support to continue or stop caring. This includes:

- Personal and home care, counselling, and respite
- Access to targeted resources, information, and advice to help navigate the palliative care system – particularly regarding accessing services, as well as encouraging access to local support networks
- Support for carers includes access to trained palliative care staff, 24-hour phone support, overnight care and access to medication and equipment
- Access to respite care that is flexible (e.g., in-home, day care, clinics, short-and long-term respite) and available to carers when they need it to help support care at home and prevent unnecessary hospitalisations
- Manual handling and medication management training where required
- Support through the bereavement and grieving journey, particularly support that normalises the grief process.[44]

> ***"We need to have some kind of hospice care option in this region. Dad didn't want to die in a hospital, and he didn't want to be cared for in a hospital. We were lucky that we were able to take care of him, but there must be so many people who don't have that option.***
>
> ***It takes such a massive toll on the family, there should be other options. We could have really used some respite for a day or two. It would have been hard to hand over to someone else, but we needed a break, and we couldn't get it.***
>
> ***Also, it was just so overwhelming and confusing – who we needed to talk to about what thing. I think that was part of it too – it was so hard to try and find help, it was actually easier for us to do it ourselves."***
>
> **Consumer, Coffs Harbour workshop. November 2022**

Opportunities to support carers include:

- Identifying and/or establishing local support networks for the family/carers
- Directing carers to local, state, and national resources and services
- Building community capacity to activate support for carers in local communities
- Increasing awareness and understanding by service providers on the role of the carer as an integrated care team member.

Grief, Loss, and Bereavement

Palliative care extends after death, to support carers and family members with grief, loss, and bereavement. After loss, support can be emotional, financial, practical challenges, spiritual beliefs, and specific cultural needs.

All palliative care providers should be able to assess where carers and family members are on a continuum of need for bereavement support and offer referrals and care planning where appropriate. Approximately 7% of grieving people experience prolonged grief disorder and may require targeted specialist services.[45]

We all respond to grief and bereavement differently. How individuals respond can depend on different factors such as age and spiritual views of life and death. Children for example, may feel a loss of safety and control. The impact of grief can be compounded by earlier experiences, such as health services policies that may limit people's ability to follow traditional practices around death, such as smoking ceremonies or the need to have family always surrounding the person.

Aboriginal and Torres Strait Islander people express their grief in a variety of ways. Many Aboriginal and Torres Strait Islander people, communities and organisations are working to heal from the grief caused by current and ancestral losses and historical trauma.[46] Grief can be multilayered, with people experiencing multiple losses at the same time due to premature passing and increased incidence of chronic disease.

People with a life-limiting illness and their carers may experience anticipatory grief. Grieving the loss of experiences, possibilities and an imagined shared future before the person dies. Feelings of grief and loss are normal before death but are rarely talked about. Services are available for people seeking support for grief both before and after death, such as through the Australian Centre for Grief and Bereavement online resources for grief or Griefline.

With 50% of deaths occurring in hospitals and 35% in residential aged care homes (RACHs),[47] need support staff, including non-clinical staff, with grief and bereavement, particularly RACH staff, who may have formed long-term relationships with residents and their families. Grief support for all health professionals and RACH staff should be a key component of self-care. Workplaces could make mentoring, professional supervision, care reviews and access to confidential support programs such as Employee Assistance Programs available to staff.[48]

Opportunities include:

- Providing grief and bereavement information to families, carers, and significant others as part of all palliative and end-of-life support
- Resourcing appropriate bereavement services as a part of palliative and end-of-life care
- Sharing stories about people's experiences concerning serious illness, dying, death and grief to normalise death and dying and highlight available services and support
- Highlighting and sharing existing resources such as the NNSW LHD Bereavement guide and the Australian Centre for Grief and Bereavement online resources on HealthPathways and social media and promote during Palliative Care week.

Voluntary Assisted Dying

The Parliament of New South Wales passed the Voluntary Assisted Dying Act 2022 (the Act) on 19 May 2022. The Act will allow eligible people the choice to access voluntary assisted dying in NSW from 28 November 2023.

During stakeholder engagement, concerns were raised by health professionals and community members about the confusion between quality palliative care and VAD.

Opportunities identified to clarify VAD for health professionals and community members include:

- Developing a HealthPathway to give clinicians information relating to a VAD pathway
- Connecting health professionals to education and training around the laws and process of VAD
- Promoting education around VAD to people and communities.

2. Support Service Capacity and Capability

Key Points:

- Palliative and end-of -life care is delivered across a range of care settings and delivered by a multitude of service providers. Developing an integrated and coordinated system of care can support and strengthen service capacity and capability.
- Reduced access to, and availability of palliative care in some areas means that some people do not receive the care they want or die in their preferred place of death.
- Timely referral to palliative care and Identifying people nearing end-of -life including tools, assessment, acknowledgement, and communication is vital.
- Supporting primary care providers with access to education, resources and information will support the provision of care to people in our community as they approach and reach end-of-life.
- Investment in technology will complement service delivery and enable increased access to palliative care services at home or close to home, particularly for people living away from larger towns in the region.
- Highlighting the importance of ACP and supporting the completion of Advanced Care Directives will ensure people receive treatment of their choice and reduce unnecessary hospitalisations and medical intervention.
- Linking RACHs to education and information, including specialist palliative care services will enhance staff and facility knowledge, skills and confidence and the implementation of systems to support the provision of consistent, safe, high-quality palliative and end-of - life care.
- Providing support for RACHs with afterhours triaging of palliative and end of life care issues will reduce unnecessary hospital admissions and alignment with care choices documented in ACD's.
- The identification of palliative care and end-of-life care assets within the community can support access to services especially in regional and remote areas.

Overview

Palliative care services are provided in a range of settings, including hospitals, residential aged care services, primary care services, hospices, community settings and people's homes. An individual's preference for where to receive palliative care or end-of-life services and where they would prefer to die can change over time as their support needs change.

Almost 70% of palliative care is delivered by primary care professionals, aged care services and community and volunteer organisations.[49] Specialist palliative care services are delivered by multidisciplinary teams with specialised skills, competencies, experience, and training. Services are delivered to people with palliative needs that are complex and persistent and are available in specialist inpatient settings, hospices, and community-based specialist services.[50]

Several specific considerations impacting palliative care delivery across the HNC region include distance to travel for services, regional service delivery including workforce capacity and capability, especially to areas classified as outer regional, lack of hospices, a smaller number of service providers, GP access and availability and underserved and priority target population groups.

Policy Supporting Practice

Palliative care is an integral part of a person-centred health system and is a recognised component of the right to the highest attainable standard of health.[51] Recognising this right, the Australian Government first published a National Palliative Care Strategy in 2000. We now have the third version of this strategy which builds on previous work. From the 2018 strategy comes a range of National Palliative Care Projects, including Greater Choices for At Home Palliative Care and National Palliative Care Guidance including Care Standards, Service Delivery Guidelines, and a Framework for Advance Care Directives.

The National Palliative Care Standards (the Standards) articulate the vision for compassionate and appropriate specialist palliative care in Australia:

Care	Governance
Assessment of needs	Service culture
Developing the care plan	Quality improvement
Caring for carers	Staff qualifications and training
Providing care	
Transitions between services	
Grief support	

In Australia, we have seen increased recognition and investment in the palliative care system over the last five years, including $294.1million over eight years from 2017-18 to strengthen the system including workforce education, career support, quality improvement, advanced care planning and national communications and research activities.[52]

The Royal Commission in Aged Care Quality and Safety made some key recommendations for palliative care including: [53]

Recommendations	
70 and 78	Compulsory palliative care training for aged care workers. The reviewed Certificate III in Individual Support (Ageing) will require units of study on dementia and palliative care.
35	Comprehensive sector funding specifically including palliative care and end-of-life care for care at home. The Government is developing a Home Care – Future design and funding. The Government continues to invest in the expansion of Greater Choice for at Home Palliative Care measures, which saw HNC included in this program. Staff qualifications and training.
58	Access to multidisciplinary outreach services. The Government is responding to this recommendation through the Residential Aged Care Quality and Safety – improving access to primary care and other health services.
2	A new Aged Care Act that includes the right to access palliative care and end-of-life care. The new Act is intended to commence from 1 July 2023.

At a state level, NSW End-of-life and Palliative Care Framework 2019-2024 identifies five priority areas to improve the delivery of palliative care services and guide service improvement:

- Care is person-centred
- There is recognition and support for families and carers
- There is access to care providers across all settings who are skilled and competent in caring for people requiring palliative and end-of-life care
- Care is well-coordinated and integrated
- Access to quality care is equitable.[54]

The NSW Government has committed an additional $743 million over five years (2022-23 to 2026-27) to enhance palliative and end-of-life care. This funding aims to improve both hospital and community health services for people with a life-limiting illness and to strengthen equity and access across regional, rural, and remote NSW.[55]

Service Access and Availability

One of the World Health Organisation's guiding principles of palliative care is accessibility.[56] Palliative care is explicitly recognised under the human right to health. Every Australian living with a life-limiting illness should have equitable access to quality needs-based palliative care at any point in their illness journey, with timely referral to specialist palliative care if required.[57]

> ***The postcode you live in-in Northern NSW there is a huge disparity between services provided to people in the coastal areas versus people that live in the west of the district."***
>
> **Health professional, HNC survey**

Equitable access and availability of resources, palliative care services and support are not afforded to all people across the HNC region, with people living in rural areas being especially affected. Reduced access to and availability of palliative care services and supports means that some people do not receive the care they want or die in their preferred place of death.

There are several gaps in the current capability and capacity of the palliative care workforce in meeting the needs of people experiencing serious illness, dying, death and grief. The issues will only be exacerbated as demand increases given the region's ageing population and increased prevalence of chronic illnesses. Some of the gaps include physical resources, transitions of care, insufficient experience, knowledge, and training of the workforce in palliative care and lack of cultural awareness. These issues have a negative impact on patient outcomes in meeting and supporting their palliative care needs.

The following barriers were identified in accessing palliative and end-of-life care during our stakeholder consultation:

- Recruitment and retention of appropriately trained staff, especially in rural and remote areas
- The capacity and capability of existing services and supports, and the need for additional services (hospices, respite care, community-based supports, volunteers, support for carers, access to 24/7 care, education, bereavement and counselling services, equipment)
- People living in regional and outer regional areas can have difficulty accessing care at home
- Siloed nature of government services such as MyAgedCare, NDIS, and Services Australia, with insufficient and inflexible funding
- Aboriginal and Torres Strait Islander people are impacted by unique factors such as intergenerational trauma, cultural dislocation, oppression, and systemic racism that influence their decision-making around end-of-life considerations
- Care coordination and integration
- Lack of consistency - assessment tools and language
- Lack of data on regional service delivery.

Opportunities to improve access and availability of services include:

- Mapping patient palliative and end-of-life care journeys through the system will help to Identify and highlight gaps and opportunities to improve people's journeys
- Building localised data on palliative care services and access – asset mapping to support referral pathways
- Investigating the role of virtual technologies to enable increased access to services for people living remotely or who are unable to travel
- Scoping integrated models of care to guide service delivery, support care coordination, and transition between services
- Maintaining currency of HealthPathways for palliative and end-of-life care and VAD.

Workforce Capacity and Capability

A strong workforce is essential to providing high-quality care. We know the palliative care workforce is made up of a broad range of professionals such as social workers, occupational therapists, physiotherapists, nurses and general practitioners, and physicians.

There are often heavy workloads, with a lack of staffing adding to the burden of care. Higher levels of burnout are reported by the health professionals providing palliative and end-of-life care.[58]

NSW Health has made the following changes to support the palliative care workforce:

- More allied health positions
- Palliative care nurses with a focus on outer regional and rural NSW
- Aboriginal health workers in every district and network in NSW
- Palliative care specialists and relief specials for rural and regional NSW
- Palliative care education and training for the health workforce
- Opportunities to support workforce capability and capacity are identified below in Primary Health Care, Home Care Providers and Residential Aged Care.

Primary Health Care

Primary health care is often the entry into the health system, where a person first meets with a health professional. General Practitioners (GPs), nurses, Aboriginal health practitioners, pharmacists, social workers, allied health professionals, and local pharmacists deliver palliative care services in the primary health care setting. Services are delivered in settings such as general practices, community health centres, Aboriginal Community Controlled Health Services, allied health practices and via digital technologies such as telehealth and video consultations.[59]

The proportion of people in Australia receiving palliative care in the community increased by 65% between 2016-2020, compared to a 31% increase in inpatient care.[60] Both settings now deliver 34,000-35,000 palliative care episodes per annum.

General Practice

GPs are increasingly expected to provide palliative and end-of-life care. GPs are essential due to their long-term relationships with many of their patients, placing them in a position to identify changing care needs and goals of care for people living with a life-limiting illness. The extent of palliative care and ACP services delivered by GPs across the North Coast and Australia cannot be established at this stage as there is no specific Medicare Benefits Schedule (MBS) item number for GPs delivering palliative and end-of-life care.

The AIHW is working with stakeholders to establish consistent data collection on palliative care activity in general practice that will better inform both the community and decision-makers about the levels and quality of GP provision of palliative care.[61]

The availability of community palliative care services influences the ability of GPs to provide home-based palliative care. GPs in rural areas experience a greater impact due to longer travel times for home visits. The MBS payment model does not compensate GPs for time spent travelling to home visits, family meetings, or organising case conferences.

"There is a reluctance to take on the care of people requiring end-of-life care as it requires a large commitment, emotionally with high rates of burnout caring for people who are dying."

GP, North Coast

GPs are well positioned to support ACP and end-of-life discussions. However, there needs to be more time allowed for these complex discussions or is not the primary reason for the visit. Advance Care Planning Australia provides guidance on ACP in general practice, including the use of MBS items.62

The barriers to GPs providing palliative and end-of-life care can be grouped into three categories:

- Personal: skills, competence, time, interest
- Relational: lack of integration of services, communication, and collaboration
- Organisational: compartmentalisation of health services, remuneration.[63]

Opportunities identified to support general practice:

- Improving integration with other areas of the health care system, and how a better understanding of the clinical triggers for commencing palliative care would support practice across the region
- Developing improved communication/access between community nurses, specialist palliative care teams and General Practice. i.e. facilitate medication orders/respond to changing care needs of patients in the community
- Utilising available local health district virtual health opportunities to review/participate in case conferencing with community/specialist pall care teams to support patients in the community
- Supporting General Practice staff with increasing the uptake and completion of ACP/ACDs. General Practice staff are well positioned to support and engage in ACP discussions with patients, their families, significant others, and carers
- Identify GPs with an interest and specialised skillset in palliative and end-of-life care and are willing to accept referrals from GPs not positioned to provide end-of-life care at home and residents of RACHs
- Facilitating local education opportunities for General Practice staff with specialist palliative care providers
- Providing information on supporting an expected death at home. The process is smoother and a better experience for the family members when there is documentation of a person's comorbidities or life-limiting illness
- Supporting primary care providers with access to education, resources, and information to support the provision of care to people in our community as they approach and reach end-of-life. i.e. National palliative care projects and localised referral information.

Community Pharmacies

Pharmacists often work in isolation from the healthcare team, making it difficult to anticipate changes in care needs and which medicines to stock.[64] NSW has a core palliative care medicine list which was developed in 2018 with community pharmacists, GPs and palliative care teams. This allows community pharmacies to anticipate the medicines most likely to be prescribed.

Community pharmacists can play an important role in palliative care by identifying people with palliative care needs; understanding people's journeys, for example, physical deterioration can result in the ability to swallow and the need to switch to liquid or subcutaneous injections; increase the capacity of caregivers through education, providing opportunities to ask questions, support to keep medicine lists up to date; having standard palliative care medicines in stock.

> ***"Access to medications, especially on weekends - can take 24 hrs to have GP prescribe and have pharmacy deliver."***
>
> **RACH staff member**

Palliative care medicines are one component of holistic palliative care. Treating and/or preventing symptoms associated with the palliative care diagnosis is one of the critical tenants of palliative care.

In 2020-21, GPs prescribed 91.4% of all palliative care schedule items, palliative medicine specialists 0.5% and other clinicians 87.7%. For all three prescribers, the most common medication group was pain relief. The most common forms of pain relief were anti-inflammatory and antirheumatic products, non-steroids 58.1%, opioids 17.8% and other analgesics and antipyretics.[65]

Australian Government expenditure by palliative care schedule items in NSW in 2020-21 was:

Medication group	Expenditure in NSW	Percentage expenditure in NSW	Percentage of national expenditure
Pain relief	$5,858,555	85.9%	28.9%
Gastrointestinal symptoms	$793,288	11.6%	31%
Neurological symptoms	$52,630	0.8%	26.4%
Respiratory symptoms	$84,193	1.2%	19.4%
Psychological symptoms	$29,198	0.4%	29.5%

Source: AIHW 2021

Those people living in inner and outer regional areas, such as across HNC are more likely to be dispensed with palliative care-related prescriptions (2.5 per 1,000) compared to people in major cities (1.8 per 1,000). There is no region-specific or SA3 data available.

Access to palliative and end-of-life medications is essential to the provision of quality palliative and end-of-life care. By 2027, without intervention, it is estimated that there will be as few as 52 pharmacists per 100,000 people in regional and remote areas, compared to 113 pharmacists per 100,000 people in major cities.[66]

Barriers to accessing palliative and end-of-life medications in the community include:

- Rural and remote access to pharmacists
- The ability to access all relevant medicines from one pharmacy at short notice as needs change
- GP reluctance or knowledge to prescribe some scheduled medications
- Cost: In the community, medications are self-funded, whereas inpatient medications are free.

Opportunities to support access to palliative medicines include:

- Recognition of the important role of community pharmacists in the provision of palliative care medications for symptom relief and quality of life
- Enhanced planning and access to essential medicines in aid of people who wish to die at home
- Development of a core medicines list through consultation with local palliative care providers
- Increasing awareness of anticipatory prescribing
- Involving Pharmacists in codesign to support resource development for the community
- Building the capacity of caregivers through education, providing opportunities to ask questions, support to keep medicine lists up to date, and having standard palliative care medicines in stock.

Aboriginal Community Controlled Health Services

Aboriginal Community Controlled Health Services (ACCHS) provide culturally appropriate health and wellbeing services to Aboriginal and Torres Strait Islander people across the HNC region. Each ACCHS offers different services and programs.

Opportunities include:

- Collaborating with the ACCHS in each area, to identify the localised need and key people within the communities to work with, when planning palliative care education and training
- Working with ACCHS to host palliative care travelling road shows, inviting key people identified by local ACCHS and health professionals such as GPs and pharmacists in the local area, to foster connections and provide education
- Collaborating with ACCHS staff to develop patient journeys, informing patients and health professionals about what steps to take along the palliative care pathway.

Allied Health Professionals

Allied health professionals can play an important role in palliative and end-of-life care. Assisting people and their carers, with physical, psychological, social, and spiritual needs.[67] Access to subsided allied health services for people with palliative and end-of-life care needs is often limited to GP referral via a Chronic Disease Management Plan or while admitted to hospital.

Allied health professionals support people with life-limiting illnesses, their families, and carers, through:

- Assisting people to maintain function and independence
- Providing psychological and social support, pastoral care, and bereavement support
- Therapies and interventions focused on improving quality of life
- Education and information about disease progression
- Supporting people to manage physical symptoms, including nutrition, mobility, and communication
- Manual handling training for carers.

In 2020, 408 occupational therapists, 615 physiotherapists, 674 psychologists and 439 pharmacists were working across the region.[68] National registration information is not available on other allied health professionals that are routinely involved in palliative care, such as social workers and pastoral care. From the numbers above, we cannot tell how many are delivering palliative care services in our region.

Opportunities to support Allied Health Professionals and improve access for people with life-limiting illness include:

- Promoting the role of allied health professionals in supporting people living with a life-limiting illness, their families, and carers
- Ensuring referral pathways and assets are updated and available on HealthPathways
- Supporting education and training on palliative and end-of-life care for allied health professionals by sharing and linking service providers with training, resources, and education opportunities
- Support for improved integration of allied health professionals into palliative care teams and earlier referral for services.

Home Care Providers

Home care services can provide non-clinical end-of-life care for people of all ages with a life-limiting illness, their families, and carers to support them to remain at home. Services include domestic assistance, personal care, meal preparation and transport. Staff may require additional training and support to assist someone with a life-limiting illness and for their emotional support. Home care services can work with community services and specialist palliative care services to support people with life-limiting illnesses, their families, and significant others to remain at home if that is their preference.

Standard 3 of the Aged Care Quality Standards applies to all services delivering personal and clinical care. Requirement (3)(c) - The needs, goals and preferences of consumers nearing the end-of-life are recognised and addressed, their comfort maximised, and their dignity preserved.

Timely access to in-home support services can enhance someone with a life-limiting illness's ability to die at home. Providers' knowledge and skill levels vary, leading to inconsistent care delivery.

Opportunities identified to improve the service delivered by home care providers include:

- Connecting services with palliative and end-of-life care education and resources to ensure workers are appropriately skilled, trained, equipped, and supported to deliver quality palliative and end-of-life care and services
- Improving pathways and care planning between service providers
- Supporting the community with information on funding and access to home care providers.

Residential Aged Care Home

Residential aged care homes (RACHs) are a common place of death, with 30% of deaths occurring each year in NSW, and a significant provider of palliative care and end-of-life care for people aged 65 years and over.[69] Over eight in ten exits from RACHs are due to death, with the median stay being 23.9 months.[70]

The Royal Commission into Aged Care Quality and Safety called for greater investment in palliative care. The recommendations included providers' requirement to demonstrate their capacity to provide high-quality palliative care, including staff capacity (number, skill, and type), processes and clinical governance, for recognising deterioration and dying.

In NSW in 2020-21, 2.2% of people in RACHs had an Aged Care Funding Instrument Appraisal indicating the need for palliative care.[71] This number underestimates the number of residents receiving palliative and end-of-life care as it only reflects those appraised and with claims submitted. Nearly one in three of these people required hospital leave in 2020-21.

Lung, prostate, and other malignant tumours were the most common medical diagnosis for RACH residents on a palliative care plan. Circulatory system and musculoskeletal were the next most common diseases. One in two patients with a palliative care plan exited the RACH in less than eight weeks.[72]

Across HNC, there is a variation in the needs of RACHs regarding palliative and end-of-life care. While some RACHs have key staff driving palliative and end-of-life care systems, some facilities have difficulties in the delivery of day-to-day care with little scope or capacity for implementing system reviews. For example, one facility in Coffs Harbour identified seven staff to drive palliative and end-of-life care improvement activities and to be the facility's palliative care champions. The facility has organised for the champions to attend Palliative Aged Care Outcomes Program (PACOP) training which will support the implementation of PACOP assessment and review of residents to support care planning and identification of changing needs to support anticipatory planning.

In general, the provision of palliative care in a RACH can be challenging for several reasons, including:

- High number of residents to support with multi-morbidities including dementia and frailty
- Workforce capacity combined with varying levels of knowledge, skills, experience and/or confidence in providing palliative and end-of-life care
- Lack of awareness about National Palliative Care projects designed to support RACHs with palliative and end-of-life education
- Access to specialist palliative care services for advice and guidance due to lack of specialist palliative care team capacity to respond to requests
- Ensuring there are systems in place to update management plans regularly - identifying residents with changing care needs and goals of care. Lack of anticipatory planning
- ACP and ACDs are not routinely completed on admission to a RACH or regularly updated
- GP coverage - difficulty accessing a GP due to the reluctance of many GPs to provide services at RACHs
- The need for grief, loss and bereavement support for residents, staff, carers, and families. Particularly needed whilst facilities are experiencing multiple resident COVID 19 related deaths
- After-hours support – managing/triaging residents' palliative and end-of-life care needs after hours without support/resources can result in potentially unnecessary transfers to hospital emergency departments that may not align with care preferences as outlined in ACDs.

These challenges can be exacerbated in rural locations due to a need for more equity in service provision.[73]

“The system is just stretched. There is a high turnover of staff in RACHs.”

Health professional, Ballina workshop

The Pharmaceutical Society of Australia found that 95% of residents in RACHs have at least one medicine-related problem, over 50% of residents are exposed to at least one potentially inappropriate medicine and 20% of hospital admissions from RACHs are due to improper medicine use.[74] In response to the Royal Commission into Aged Care Quality and Safety, the Australian Government is investing in on-site pharmacists and community pharmacy services in government-funded RACHs. This will provide a new approach to improve medicine used in aged RACHs and support palliative and end-of-life care.

GP visits to RACHs frequently occur after hours, resulting in delays before a pharmacy can deliver the appropriate medication and the patient experiencing unnecessary discomfort or condition worsening. HNC heard firsthand from GPs who will no longer take on care of residents in a RACH as they were concerned about the quality of care being delivered and the need for more experienced staff.

Opportunities identified to improve access to quality palliative and end-of-life care for residents in RACHs include:

- Connecting RACH staff to training, resources and support ensures they are confident and have the skills required to deliver quality palliative and end-of-life care. This includes medication management, symptom management, training on talking to residents and family members about end-of-life care, managing family conflict and the cultural, religious, and spiritual aspects of palliative care. This includes supporting evidence-based systems that enhance care culture and anticipatory planning
- Supporting and linking RACHs with National Palliative Care Projects providing training and mentoring opportunities i.e., ELDAC, PEPA, PACOP
- Having an onsite ‘imprest’ medication system would mean GPs and other health professionals can prescribe from the list of medications available in the RACH
- Having After Hours support – triaging resources and access to specialist advice
- Utilising digital technologies to support virtual health consultations with GPs and specialist providers and to support family and case conferences
- Promoting the practice of self-care including physical, mental, and emotional health
- Scoping the development of an integrated model of care to guide service delivery, support care coordination and transition between services.

“Palliative care and end-of-life planning like dementia care should be the core business of residential aged care facilities.”

Palliative Care Australia 2020 [75]

NSW Ambulance

Ambulance NSW encourages people to complete an ACP with their GP or treating clinician, so paramedics can support them to remain at home, or in a facility of choice. As paramedics arrive on the scene with no prior information about the person's health, a completed ACP assists them to make decisions about the person's care. The treating medical clinician can provide authorisation for care outside of normal Ambulance practice including pre-authorised medications and procedures.

Opportunities to improve interaction with NSW Ambulance services and decrease hospital admissions for people with a life limiting illness, include:

- Encouraging the completion of an ACD with a person's GP or practice nurse and having it available for paramedics on arrival
- Educating RACH staff and GPs on the benefit of anticipatory management plans such as plans used in the Last Days of Life toolkit by the Clinical Excellence Commission would decrease transfer and hospital admissions.

Specialist Palliative Care

Specialist palliative care services are multidisciplinary teams with specialised skills, competencies, experience, and training to deliver care to people with complex and persistent palliative needs.[76] At this time, we can only provide information on the number and characteristics of the employed nurses working in palliative care and physicians with a primary speciality in palliative medicine as these can be identified explicitly as palliative care providers using the Health Workforce Data Tool. However, we need to accurately capture the extent of palliative care services delivered by these health professionals using existing national data sources.

In 2020 there were three FTE palliative care specialists in HNC, equating to 0.6 FTE per 100,000 people (Table 2.). This is lower than for NSW at 1.3 or Australia at 1.1. Palliative care specialists in HNC work on average 44.7 hours a week, with 91% being clinical hours compared to 36.9 hours/week and 78% clinical hours in Australia. This may be due to the lower ratio per 100,000 population and the ageing population in our region.

Table 2:

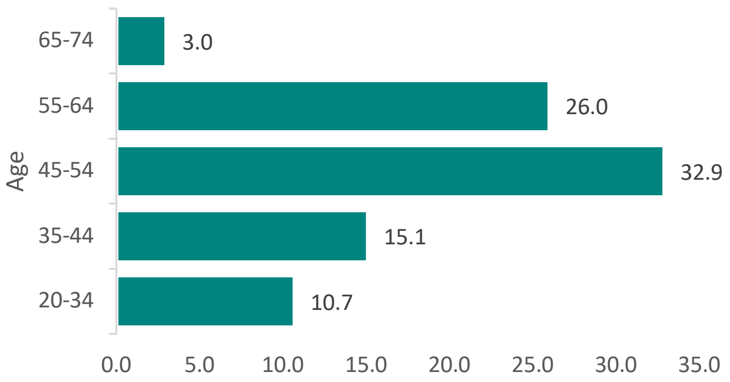
	HNC	NSW	Australia
Number of palliative medicine physicians	3	107	302
Average total hours worked per week	44.7	38.7	36.9
Average clinical hours worked per week	40.5	29.2	28.9
FTE number	3	103.5	278.6
Clinical FTE	3	78.2	21.3
FTE per 100,000 population	0.6	1.3	1.1

Source: AIHW 2022

There are 87.7 FTE equivalent palliative care nurses across the HNC region, representing only 1.2% of the nursing workforce in 2021 (Figure 4).[77] This is higher than Australia with only 0.9% of all nurses working in palliative care. Nine in ten palliative care nurses in Australia are women.[78]

Figure 4:

One in every three palliative care nurses are aged **45-54 years.**



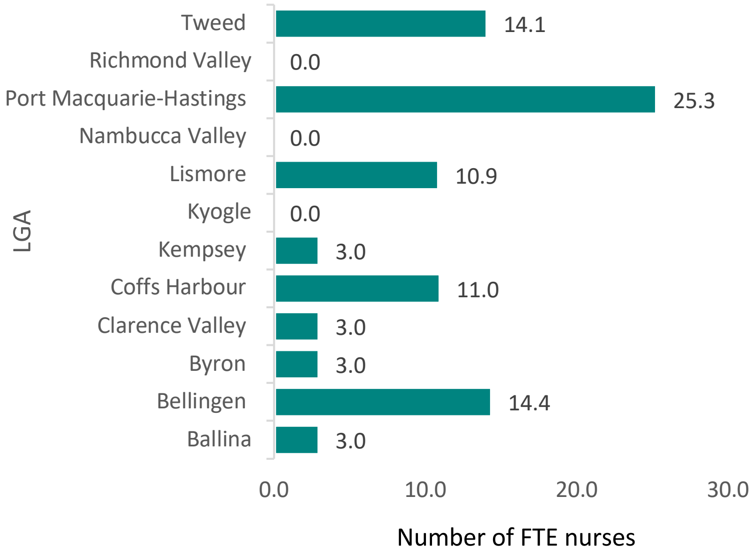
Source: NHWDS (2022)

None of the palliative care nurses in HNC identified as Aboriginal and/or Torres Strait Islander, whereas 1.2% identify as Aboriginal and/or Torres Strait Islander across Australia.[79]

Seven in every ten palliative care nurses work in the four LGAs with the largest hospitals and population base, Port Macquarie, Tweed, Coffs Harbour, and Lismore (Figure 5). Of note, Bellingen has 1.6 of every ten palliative care nurses. Kyogle, Nambucca Valley, and Richmond Valley do not have any palliative care nurses.

Figure 5:

7 in 10 palliative care nurses work in the four LGAs with the largest hospitals.



Source: NHWDS 2022

Communicating with and caring for people with a life-limiting condition can be confronting and stressful, particularly as it forces people to face their own mortality and personal experiences of death and loss. [80]

Priority Target Populations

HNC has priority populations with specific needs relating to palliative and end-of-life care. These people may be vulnerable and have an increased susceptibility to adverse health outcomes resulting from not having equal access, or access to quality health care, when and where they need it. This may include identifying when palliative care is necessary, who receives palliative care and where, and what is necessary to complement palliative care and end-of-life care.[81]

> ***"What enables access to quality palliative and end-of-life care at home for people with a life-limiting condition on the North Coast?...... Sensitive information inclusive of cultural considerations for community members. Opportunities to raise the topic of comfort care for those living with a life-limiting illness in a manner that is respectful and in line with the wishes of the person".***
>
> **Health professional, survey response**

Awareness and understanding of priority target populations and their needs, ultimately improve the health outcomes for the people requiring palliative and end-of-life care.[82]

Opportunities to better support our underserviced populations include:

- Ensuring cultural safety across services
- Encouraging awareness, understanding and education for all health professionals around the specific needs of priority target populations relating to palliative and end-of-life care
- Developing physical spaces in hospitals, palliative care units, hospices and RACHs where cultural practices can be carried out at end-of-life, such as smoking ceremonies
- Developing clinical pathways and patient journeys, so that health service staff, people with a life-limiting illness and their carers know whom to contact and what is required at each stage of their illness
- Promoting inclusivity accreditation to health professionals and services.

Aboriginal and Torres Strait Islander people

Many Aboriginal people and Torres Strait Islander peoples have a strong relationship-based kinship system that provides the social structuring of family and the community (language group, nation, or clan). Cultural and traditional beliefs are entrenched with spirituality that supports the cyclic belief of life-death-life. This ongoing journey is necessary for the next part to occur. For many Aboriginal people and Torres Strait Islander people, their life experiences may have provided a mix of beliefs and practices.[83]

Continued consultation with Aboriginal and Torres Strait Islander consumers and health professionals have provided valuable insight into the unique needs of Aboriginal and Torres Strait Islander people within HNC including:

- Grief and bereavement become complex because people aren't just dealing with their own grieving but the communities.
- ACP is difficult because of this fear of death and the belief that talking about it will bring it closer
- Importance of caring for people with a psychological, physical, social, and spiritual model of care
- People are sometimes scared to approach health professionals due to past negative life events, for example, family members who have had traumatic experiences such as being a member of the stolen generation
- People don't know how to deal with their grief and psychological pain
- Accounts of multiple family members dying from chronic diseases in a relatively short period of time, as well as untimely deaths within the communities, mean that people don't have time to process one death before the next one occurs.

Culturally and Linguistically Diverse

At end-of-life, differences in beliefs, values, and traditional healthcare practices shape attitudes about death, dying and palliative care preference.

Coffs Harbour and Port Macquarie LGAs are Refugee Welcome Zones and have welcomed over 2,000 people since 2006 from nations such as Sudan, Myanmar, Ethiopia, and Afghanistan.

> ***"Some of these individuals (refugees) have arrived in a poor state of health, suffering both chronic and infectious diseases and may well be suffering trauma because of their experiences.***
>
> ***Very few refugees have health records with previous medical history or immunisation status, many may also have chronic and complex illnesses which have largely been untreated or self-treated for a long period of time leading to long-standing poor health and disability."***
>
> **MNC LHD Multicultural Unit clinical nurse consultant**[84]

People Experiencing Homelessness

Many homeless people tend to present to emergency departments as their entry point to health services because they are not under the regular care of a GP. Even outside of emergency presentations, it is often only once a crisis point has been reached when homeless people do present to health services. As a result, care providers must be reactive, which is a situation that hampers the provision of holistic palliative care. [85]

Palliative care must be flexible, holistic, and person-centred, in an environment that is familiar to the person. Some of the challenges faced by health professionals providing palliative care to people experiencing homelessness include:

- reaching people where they are situated
- no medical knowledge or history of the person requiring care
- lack of privacy
- if in a hostel, lack of safe storage of medications, and staff experience and skills.

Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and Intersex (LGBTQI)

People identifying as LGBTQI experience additional barriers to accessing healthcare services, including stereotypes, discrimination and stigma, anticipatory fear and distrust of health providers, lack of access to ACP, mixed recognition of partners and chosen families, and social isolation. [86]

From stakeholder engagement, there has been positive feedback about the inclusivity and acceptance provided to LGBTQI people at end-of-life by the staff and volunteers at Wedgetail Retreat community hospice. ACON has an office in Lismore and outreach from Coffs Harbour delivering a voice to the LGBTQI community and strengthening inclusion.

Disaster Management

The HNC region has experienced an increase in natural disasters such as pandemics, bushfires, and floods causing people to be displaced from their homes and communities. People die during natural disasters and during pandemics of non-related causes and studies show that natural disasters impact greatly on end-of-life care.[87] Palliative and end-of-life care must be considered in disaster preparedness planning, ensuring that people and their carers have access to care and supports during these times and that care is not compromised.

> ***"With lots of natural disasters e.g. flooding, we need a plan for at-home palliative care when there is no power and limited access. Drones to bring in medications are one approach. Source of power when mains is out. Palliative care needs to be embedded in emergency planning".***
>
> **Health professional, Coffs Harbour**

Opportunities to connect systems in disaster management include:

- Embedding palliative care and end-of-life care in emergency and disaster planning
- Collaborating with health professionals, council, and government to find solutions for staffing, housing, and providing care needs during disaster responses.

Digital Health Innovation

Digital health technology and innovation in palliative care can range from SMS text messaging, mobile devices, telehealth, and electronic prescribing to connected wearable devices, robotics, big data analytics and artificial intelligence.

Access to digital technology can improve health for people with a life-limiting illness and their carers, by increasing access, decreasing travel costs, and reducing waiting time. Health technologies can also increase the quality and efficiency of information shared and communication between health professionals and health care services, improving continuity of care.[88]

During disasters and pandemics, technology has played an important role in palliative care, allowing communication between families and facilitating spiritual and social support to people and their carers.[89]

A recent survey of 170 health professionals working in palliative care in Australia found few reported electronic access to patients' ACP documents.[90] The survey found that palliative care health professionals would like to see more digital innovations in client health records, telehealth, and personal health tracking.

Consultation with consumers and health professionals in the region supports national findings relating to barriers to using digital technologies. These include:

- Limited NBN service in some inner and outer regional areas, suggesting a poor level of digital health infrastructure[91]
- Lack of knowledge about and access to technology, particularly for people with lower socio-economic status and disabilities.

Opportunities to increase the uptake of digital health, include:

- Encouraging digital health and technology literacy in the community
- Supporting clinicians to provide palliative and end-of-life care for people in their home, RACH or inpatient setting using telehealth technology
- Establishing greater e-health and telehealth services to support people with access to services as they approach and reach end-of-life.

Data Collection

The 2018 National Palliative Care Strategy recognises the importance of data and evidence in strengthening the delivery of palliative care. It recognises the importance of collecting consistent and strong data and a strong research agenda to strengthen and improve palliative care.

The data priorities of Goal Six include:

- Nationally consistent data collection is used to monitor, evaluate, and report on access to and outcomes of palliative care
- Palliative care providers contribute to data collection, monitoring and reporting activities
- Data collection and reporting inform continuous quality improvement of palliative care.[92]

The Palliative Care Outcomes Collaboration (PCOC) aims to improve outcomes for both palliative care patients and their carers. It utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in services is voluntary. National data shows that in 2021:[93]

1. 58,7000 people received 77,500 palliative care episodes from 177 palliative care services participating in the PCOC program. Or 1.3 palliative care episodes per person
2. Palliative care episodes occurred in similar numbers in the community and inpatient settings. Inpatient episodes were generally shorter, 5 days compared with 20 days in the community setting
3. Over 4 in 5 episodes commenced the day the patient was ready for palliative care, or the day after
4. The average age at the start of an episode of care was 76 years which increased from 72.8 in 2017
5. 3 in 4 palliative care closed episodes ended within 30 days, with most ending within 2 weeks. Episodes end when the settling of palliative care changes, the principal clinical intent of the care changes, or the patient is no longer receiving palliative care due to formal separation from the service or death.

PCOC is a positive step towards collecting data and evidence to inform delivery of palliative care.

Opportunities to improve regional data collection include:

- Promoting PCOC tools to measure and benchmark patient outcomes in palliative care.
- DOHA have engaged Price Waterhouse Coopers to develop an evaluation framework for the GCfAHPC measure which should support improvements in regional data collection.

3. Connect Systems

Key points:

- The palliative care system is not easy to navigate or transition through as support needs change.
- General practice plays a central role in the integration and coordination of palliative and end-of-life services and support on the continuum of care.
- Primary health care could be better supported through the development of local palliative care directories and referral pathways, use of common language and tools, greater integration with other areas of the health care system, and a better understanding of the clinical triggers for commencing palliative care.
- People living in both inner and outer regional areas are hospitalised for palliative care at a higher rate than their city counterparts.
- There are opportunities to connect the different parts of the system to deliver coordinated/integrated palliative care services.

Overview

Palliative and end-of-life care are delivered in almost all settings where health care is provided, including RACHs, and community services. However, existing services are disjointed, and the care system is not easy to navigate or transition through as support needs change. Improved integration and coordination of services and support on the continuum of care with GPs playing a central role is needed.

Practice across our region could be better supported through connected systems. The development of local palliative care directories and referral pathways, common assessment tools and language, greater integration with other areas of the health care system, and a better understanding of the clinical triggers for commencing palliative care.

System navigation and integration

Early referral and acknowledgement that a patient is dying, support opportunities for planning or provision of palliative care. Late occurrence of referrals to the palliative team limits the opportunity for palliative care patients to benefit from palliative care provision and end-of-life discussions.[94]

Problems with the integration and coordination of care result in difficulties for patients navigating between services, with gaps in services, time lost, resources and duplication.

> ***What enables access to quality palliative and end-of-life care at home, " The presence of high-quality community palliative care services throughout our region with good collaboration and links between GPs, specialists, and cancer centres."***
>
> **Health professional, HNC survey response**

Barriers to system navigation and integration:

- Late occurrence of referrals to the palliative team limits the opportunity for palliative care patients to benefit from palliative care provision and end-of-life discussions
- Siloed service provision - Palliative and end-of-life care and support are delivered across a range of settings and by multiple service providers across the continuum of care. Lack of integration and communication between service providers can negatively affect service provision. I.e., people can miss out on care or services at home
- Not recording or uploading information to My Health Record
- No referral pathway for paramedics to speak directly with GP or palliative care team about the person's care makes decision-making difficult. Without information or conversation, paramedics may take the person to ED if they require further care, particularly when care is required out of hours or require ongoing needs of care.

Opportunities to improve transitions between services, service integration and navigation:

- Ensuring early referral and acknowledgement that a patient is dying, supports opportunities for planning or palliative care provisions
- Improving collaboration across care providers to improve communication, referral pathways, interservice awareness and avoid duplication. Developing and facilitating NNSW and a MNC palliative and end-of-life networks for service providers
- Encouraging the use of My Health Record would ensure that patient information is available across all care settings and supports continuity of care (including access to ACDs)
- Improving referral pathways between service providers with clear communication and clarity of roles
- Using digital health technology which can connect the patient, carers, and healthcare providers to support palliative and end-of-life care service delivery across different specialities and care settings
- Supporting the community with information to assist with navigating services and supports. Local community directories
- Supporting the currency of HealthPathways and promoting as the single source of truth to support and guide service providers
- Scoping the role of local community care coordinators (PalliNavigators) to support people to navigate services and connect with local community supports
- Developing a steering committee of key stakeholders to provide expert input to guide project delivery
- Scoping the development and coordination of integrated models and systems of service provision.

Service Mapping

Across HNC there are 10 hospitals, 26 community health or nursing services, 79 RACHs, 41 home-based services or assistance and specialised palliative care services, delivered to people as inpatients or in the community.

Figure 6: Palliative care services across HNC

Services	No.	Areas serviced	Capacity
Specialist palliative care services			
Bellingen hospital	1	Bellingen, Coffs Harbour, Nambucca, Kempsey	6-bed specialist palliative care unit staffed by a clinical nurse specialist and allied health professionals
Coffs Harbour Base Hospital	1	Coffs Harbour and surrounds	Palliative care unit available 5 days a week
Macksville hospital	1	Macksville	Small palliative care service, available 7 days a week with clinical nurse coordinator, registered nurses, and social workers. Offers both in-reach into the hospital and local RACHs.
Kempsey Hospital	1	Kempsey	Two designated palliative care beds
Wauchope Hospital	1	Port Macquarie	8 bed palliative care unit staffed by nurse practitioners and bereavement counsellors.
Clarence Palliative Care Service	1	Clarence Valley	Nurse-led clinic, available 7 days/week. Access to specialist doctor (via GP referral). Clients have access to equipment, volunteers, and specialist staff.
Richmond Specialist Community Palliative Care Service	1	Lismore	Consultancy /Liaison service including assessment and referral, symptom and pain management, and support for end-of-life care. Eligible clients may receive social support from trained volunteers as well as have access to the equipment loan pool. Bereavement support is also available. After-hours telephone support is available to clients registered with the service.
Tweed Heads Community Health Palliative Community Service	1	Tweed Heads	Community RNs and multi-disciplinary teams monitor pain symptoms and offer support in collaboration with the patient's GP and treating specialists. Inpatients care is available at Tweed and Murwillumbah Hospitals. Assistance from trained volunteers for in-home respite, equipment loan and transport. Information and assistance regarding prostheses, wigs. Transport to Brisbane radiation. Clinical and financial support. Bereavement support.
Mid North Coast Community Health Service	9	Bellingen, Camden Haven, Coffs Harbour, Dorrigo, Kempsey, Macksville, Port Macquarie, Southwest Rocks, Wauchope	Palliative Generalist Nursing Service into homes, in hospital and RACHs. Care includes assessment and maintenance of symptoms, nursing in palliative care social worker, shared care, equipment, bereavement support.
Tweed outpatient clinic	1	Tweed, Byron	Palliative care specialist and palliative care team. Available Monday-Friday from 8am-4:30pm.

Private hospitals that provide palliative care services			
Baringa Private Hospital	1	Coffs Harbour	
St Vincents – Lismore	1	Lismore, Ballina, Byron	9-bed unit for both private and public patients.
Port Macquarie Private Hospital	1	Port Macquarie	
Hospices			
Wedgetail Retreat Hospice	1	Tweed	a purpose-built, four-bedroom Hospice based just outside Murwillumbah. Provides respite or end-of-life care for people with a life-limiting illness.
Other support services			
Tweed Palliative Support	1	Tweed	Volunteer lead, hospice at home service
Northern Rivers Supportive and Palliative Care	1	Byron, Ballina, Lismore	Private palliative care specialist – assessment and symptom management, navigation support
Nambucca Valley Cancer Support Group	1	Nambucca Valley	A volunteer organisation that provides services to cancer sufferers and their families. Including equipment, social support and information.
Amitayus - Home Hospice Service	1	Byron Shire	A volunteer service that provides support and care for those with a life-threatening illness and who wish to be cared for at home. They provide training courses for volunteer carers and run ‘Last Aid – Care for the Dying’ course through Byron Community College.
Hasting’s Cancer Trust	1	Hastings, Macleay, and Camden Haven areas	The Friends of the Hastings Cancer Trust are a group of volunteers who support the Trust and its vision, using their free time, talents, and ideas to help raise funds for the local Hastings Macleay Regions.
Lotus Palliative Care	1	Northern NSW	Private palliative care service. Providing clinical and non-clinical services. Services and support 7 days a week. Overnight phone support.
Home-based services or assistance	41	HNC wide	This includes domestic and personal care, equipment, respites, counselling, home maintenance, home modifications and social support. Providing general palliative services, not specialist palliative care support.
Residential Aged Care	79	HNC wide	Different palliative care service offerings and models across the RACHs
General Practitioners	758 FTE	HNC wide	
Aboriginal Community Controlled Health Services	8	Port Macquarie, Kempsey, Nambucca, Coffs Harbour, Grafton, Maclean, Casino, Tweed Head, Lismore, Ballina	Provide a range of culturally appropriate health and wellbeing services to Aboriginal and Torres Strait Islander people. Eight services, across eleven locations with outreach clinics to four other locations.

Palliative care and end-of-life hospitalisations

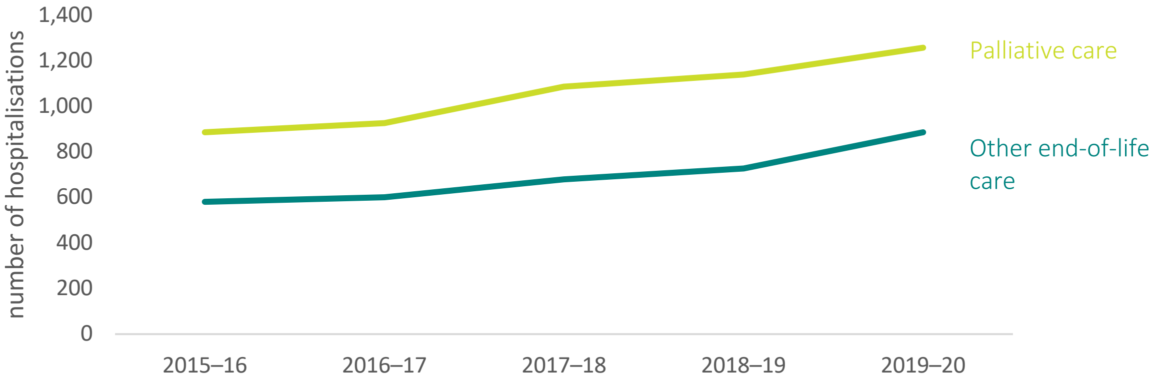
If the person's care needs become more complex, secondary care may be required by specialist providers such as oncologists or cardiologists. Coordination of care by a GP or palliative care team is beneficial, but access to these services may be limited to people living in outer regional areas in HNC.

86,700 palliative care-related hospitalisations were reported in Australia in 2021-21 from both public and private hospitals. 56.5% of these were for palliative care and involved specialist palliative care, and 43.5 were for other end-of-life care hospitalisations where a diagnosis of palliative care was provided but care was not necessarily delivered by a palliative care specialist.[95] Of these:

- nearly 9 in 10 hospitalisations occurred in public hospitals
- 1 in 2 had a cancer-related principal diagnosis
- most non-cancer-related principal diagnoses were other sepsis, heart failure and pneumonitis due to solids and liquids
- In Australia, people living in both inner and outer regional areas are hospitalised for palliative care at a higher rate than their city counterparts, 25.4 per 10,000 people compared to 17.3.[96]
- Data from the Australian Institute of Health and Welfare show that palliative care-related hospitalisations increased by 18% in the five years to 2020. Rates of hospitalisation for all causes rose by just 6% in the same period. Length-of-stay for palliative care was also roughly twice as long as that of other conditions.[97]
- Palliative care and other end-of-life care hospitalisations are increasing for Aboriginal and Torres Strait Islanders at a higher rate than for non-Aboriginal people, 10.1% between 2015-16 and 2019-20 compared to 4.2% respectively (Figure 7).[98] This is consistent with increased rate of hospitalisations for Aboriginal and Torres Strait Islanders compared to non-Aboriginal people.[99]

Figure 7:

Increasing palliative care and end of life hospitalisations for Aboriginal and Torres Strait Islanders.

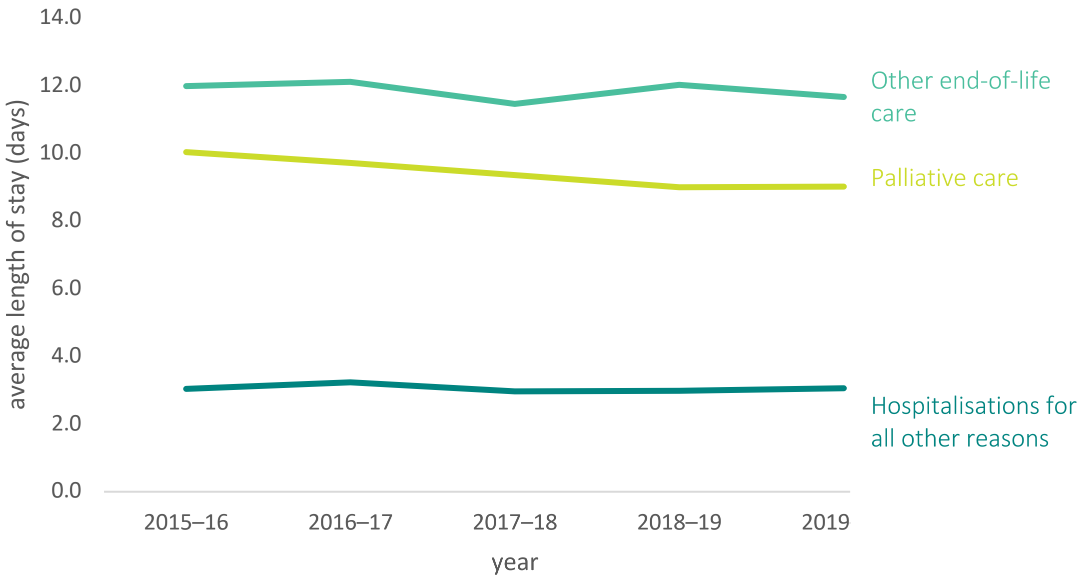


Source: AIHW 2022

In NSW, the average length of stay for palliative care hospitalisations was 9 days, end-of-life care 11.7 days and hospitalisations for all other reasons 3.1 days in 2019/20 (Figure 8). Of the palliative care hospitalisations 61.3% died, 23.4% returned to their usual residence, 4.5% entered a residential aged care facility (not their usual residence) and 7.3% were transferred to another hospital.

Figure 8:

Palliative and end of life care hospitalisations are on average **longer** hospitalisations for all other reasons in NSW.

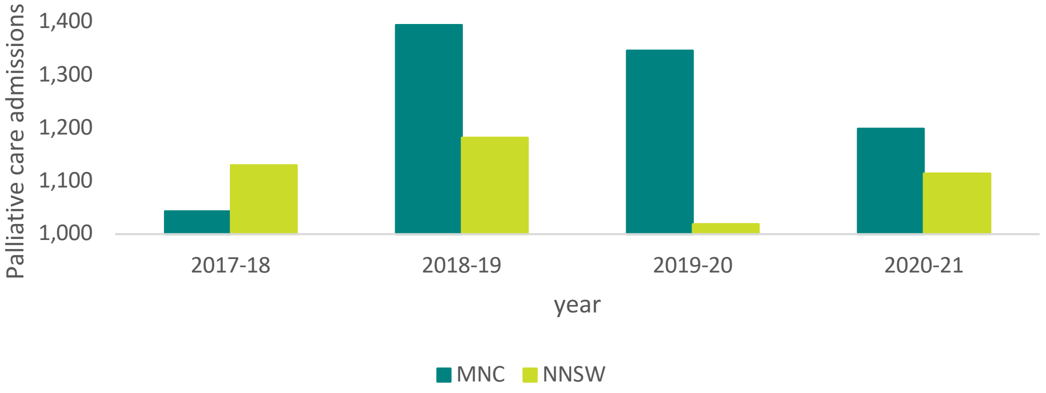


Source: AIHW (2022)

Across HNC, there were 2,313 palliative admissions to hospitals in 2020-21, with 52% of these being in the MNC LHD (Figure 9).[100]

Figure 9:

There are **more** palliative admissions in the MNC LHD.



Source: AIHW 2022 My hospital data

Local Health District services

Mid North Coast Local Health District

Mid North Coast Local Health District (MNCLHD) Palliative Care services are widely available across all areas of MNCLHD from Coffs Harbour area in the north to Port Macquarie area in the south.

Palliative care is provided at all MNCLHD services at all sites. MNCLHD Hospitals include:

- Bellinger River District Hospital
- Coffs Harbour Health Campus
- Dorrigo Health Campus
- Kempsey District Hospital
- Port Macquarie Base Hospital
- Wauchope District Memorial Hospital

There are 12 community health centers including:

- Bellingen Community Health
- Bowraville HealthOne
- Camden Haven HealthOne
- Coffs Harbour Community Health
- Dorrigo Community Health
- Kempsey Community Health
- Macksville Community Health
- Nambucca HealthOne
- Port Macquarie Community Health
- South West Rocks Community Health
- Wauchope Community Health
- Woolgoolga Community Health

Figure 10: Map of HNC, showing two LHDs and 12 LGAs

Multi-Disciplinary (MD) Specialist Palliative Care (SPC) teams focused on complex palliative care symptom management and End of Life Care are mostly based in community in-reaching into hospitals to consult with complex cases. In addition, there are two dedicated specialist palliative care inpatient units based in Bellinger River District Hospital and Wauchope District Memorial Hospital, both with 8 beds.

SPC staff are available seven days per week. Hours of operation are currently being expanded to improve End of Life care support.

MD SPC staff include:

- Palliative Care Staff Specialists
- Registrars & Advanced Trainee positions
- Nurse Practitioners
- Clinical Nurse Consultants
- SPC Clinical Nurse Educator
- Clinical Nurse Specialists & Registered Nurses
- Social workers
- Chaplains

- Bereavement counsellors
- Occupational therapists
- Physiotherapists
- Senior Aboriginal Health Workers
- Volunteer Coordinator

Northern NSW Local Health District

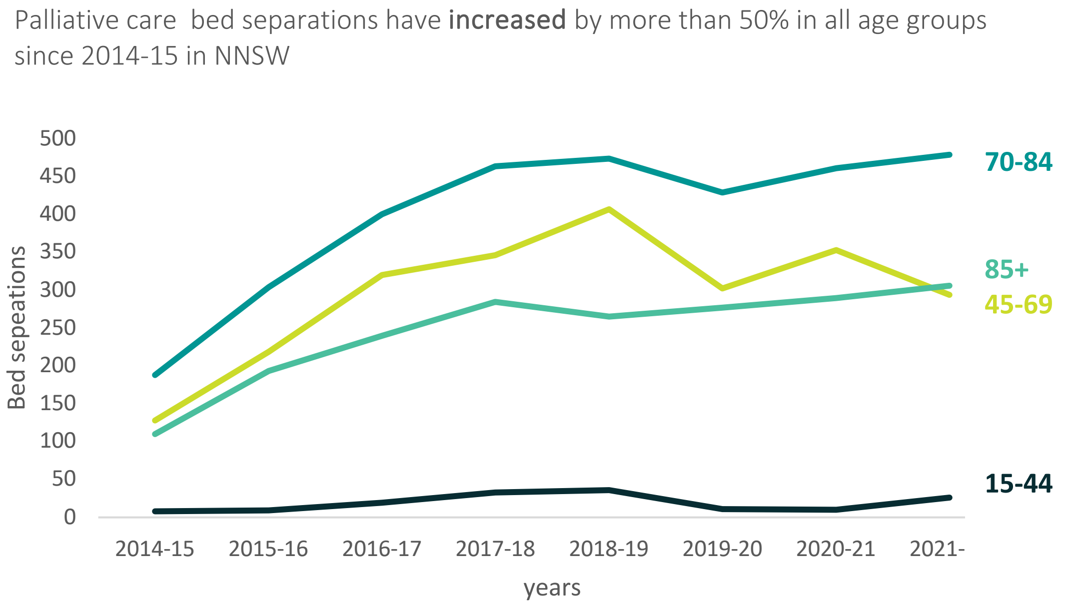
NNSW LHD consists of eight hospitals and four multi-purpose services. Inpatient palliative care is provided at Lismore, Tweed, Murwillumbah, Grafton, and Maclean hospitals.

There are three palliative care specialists in the NNSW LHD. Community Patients registered with the palliative care team have access to an after-hours 24/7 telephone support phone number. In-reach into local RACHs occurs on a consultative basis. The community-based service operates 7 days a week.

The specialist team consists of medical specialists, and nursing and allied health staff, including occupational therapists and social workers, with a bereavement coordinator joining the team in 2023.

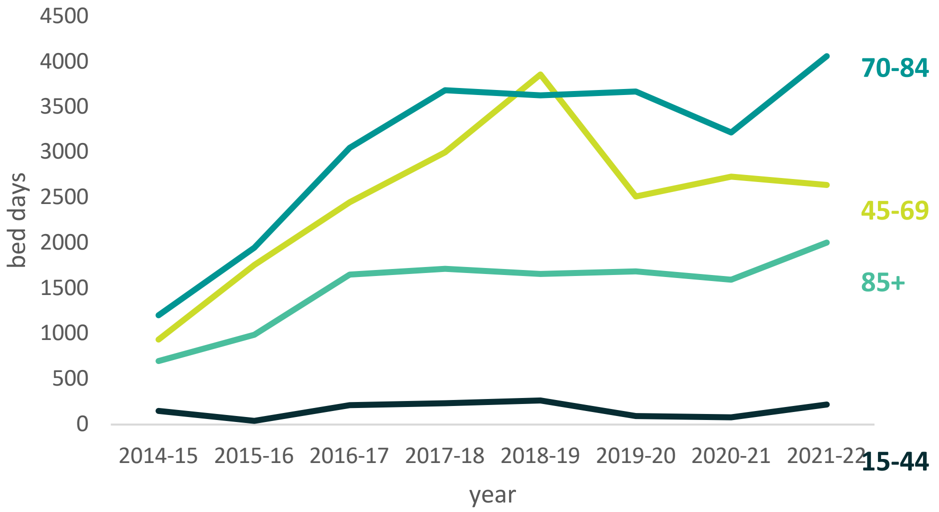
Figures 12 and 13 show the change in NNSW LHD palliative care-related hospital separations and associated bed days from 2014-15 to 2021-22.

Figure 11:



Source: supplied by NNSW LHD, Palliative Care Services 2022

Figure 12:



Palliative care bed days have increased sharply for both **70-84** and **85+** age groups from 2020-21 to 2021-22 in NNSW.

Source: supplied by NNSW LHD, Palliative Care Services 2022

Opportunities

With an ageing population and an increasing prevalence of chronic diseases, the demand for palliative care and end-of-life services across HNC will continue to increase, and this should be considered a high priority. Many people with a life-limiting condition would like to be cared for and die at home, where it is possible to do so. To support the delivery of the right care at the right time and in the right place for people living with a life-limiting condition and their families and carers the following enablers, align with the NSW End of Life and Palliative Care Blueprint.[101]

- A common language of palliative and end-of-life care between health professionals and across the community. This will lead to greater service awareness, earlier referral and access to palliative care and end-of-life services and raise people's death literacy
- Local ownership and engagement will support the development of Compassionate Communities across our footprint, which will increase community capacity and capability and improve the ability of people to remain in their own homes if they choose
- Access to specialist palliative care knowledge and expertise to support general practice, RACHs, home care services and other community organisations, carers, and other significant family members
- Linkages between primary care and aged care to education, practice training and professional development, including grief and bereavement support and self-care
- Collaborative governance arrangements and shared responsibility of all stakeholders to support the development of an integrated system of care.

Other opportunities identified in this needs assessment require further exploration, prioritisation, and resourcing. HNC will work with our existing Ageing Strategy Reference Group, consumers, service providers and palliative care experts to prioritise needs/areas of action and co-design initiatives.

Acronyms

ACCHS	Aboriginal Community Controlled Health Services
ACD	Advance Care Directive
ACP	Advance Care Planning
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
ELDAC	End of Life Direction for Aged Care
EoL	End-of-life
ePAF	Electronic Palliative Care Approach Framework
GCfAHPC	Greater Choices for At Home Palliative Care
GP	General Practitioner
LGA	Local government area
LHD	Local Health District
MBS	Medicare Benefits Schedule
MNC LHD	Mid North Coast Local Health District
NNSW LHD	Northern New South Wales Local Health District
PACOP	Palliative Aged Care Outcomes Program
PCOP	Palliative Care Outcomes Collaboration
PHN	Primary Health Network
RACH	Residential Aged Care Home
RACGP	Royal Australian College of General Practitioners
SPCP	Specialist Palliative Care Physician
VAD	Voluntary Assisted Dying

Appendix

Consultation and Engagement Summary May – November 2022

Consultation & Engagement	Date	Attendees
HNC Ballina Byron Clinical Society - Palliative Care	17/5/22	48 Healthcare and service providers
HNC Coffs Harbour & Bellingen Clinical Society – Palliative Care	24/5/22	25 Healthcare and service providers
HNC Nambucca & Macksville Clinical Society – Palliative care	25/5/22	18 Healthcare and service providers
Online forum – What is a good death? Mid North Coast	6/9/22	10 Healthcare providers
Online forum – What is a good death? Northern NSW	13/9/2022	15 Healthcare providers
Online focus group	20/10/23	11 Commonwealth Home Support Program providers
Online survey	30/8/22 – 19/9/22	21 responses – Healthcare providers and community members
ELDAC Linkages programme -	15/9/23	6 Healthcare providers and National palliative care project lead
Two Healthy Ageing and end-of-life Journey workshops – Ballina and Coffs Harbour	Ballina - 12/10/22 Coffs Harbour – 3/11/22	40 Healthcare providers and community members
ChiLL Community awareness raising event - end-of-life planning	20/10/22	40 Community members (retirement village)
HNC Back to Health Conference – break out room, Barriers to End-Of-Life Care at Home	22/10/22	12 Healthcare providers
ELDAC Linkages programme - RACH	2/11/2022	5 Healthcare providers and National palliative care project lead
HNC Dementia Resource -consumer pathway consultation activities. Responses included feedback on palliative care (FTF meetings and a survey)	Oct and Nov 2022	14 face-to-face consultations with carers of people living with dementia and service providers. 16 responses to the survey.
Residential Aged Care Homes (RACHs)	Oct 2022	5 x RACHs, 11 RACH staff interviewed
Key Stakeholder Interviews	May – November 2022	43 health professionals, 3 volunteer organisations, 2 Peak bodies, and with project leads from 3 National Palliative Care projects.

References

[1] Advance Care Planning Improvement Toolkit: New South Wales. 2022. Advance Care Planning Australia, Austin Health, Melbourne

[2] World Health Organisation (WHO)(2020). Palliative Care. Retrieved from https://www.who.int/news-room/fact-sheets/detail/palliative-care

[3] WHO (2020) Palliative Care, available at Palliative care (who.int), accessed October 2022.

[4] Department of Health. (2018). *National Palliative Care Strategy 2018*. Retrieved from https://www.safetyandquality.gov.au/sites/default/files/2019-06/national_palliative_care_strategy_2018.pdf

[5] Australian Institute of Health and Welfare. (2016). 6.18 End-of-life care. In AIHW (Ed.), *Australia's health 2016*.

[6] Department of Planning and Environment (DPE) (2021) Population Projections accessed July 2022

[7] AIHW (2017) Deaths in Australian hospitals 2014-15, available at https://www.aihw.gov.au/reports/hospitals/deaths-in-australian-hospitals-2014-15/contents/summary/how-many-deaths-occur-in-hospital, accessed November 2022

[8] Swerissen, H and Duckett, S., 2014, Dying Well. Grattan Institute, available at https://grattan.edu.au/report/dying-well/, accessed November 2022

[9] ABS (2020), Table 5: Deaths, Summary, Local Government Areas - 2011 to 2020 Australia 2020

[10] AIHW (2021) Mortality Over Regions and Time books, Primary Health Network, 2016-2020

[11] ibid

[12] Sallnow, L., Smith, R., Ahmedzai, S., Bhadelia, A., Chamberlain, C., (2022) Report of the Lancet Commission on the Value of Death: bringing death back into life, The Lancet Commissions, Vol 399 (10327) p937-884

[13] AIHW (2022) Deaths in Australia, available at https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/life-expectancy, accessed November 2022.

[14] Sallnow, L., Smith, R., Ahmedzai, S., Bhadelia, A., Chamberlain, C., (2022) Report of the Lancet Commission on the Value of Death: bringing death back into life, The Lancet Commissions, Vol 399 (10327) p937-884

[15] AIHW (2021) The last year of life: patterns in health service use and expenditure, available at https://www.aihw.gov.au/reports/life-expectancy-deaths/the-last-year-of-life-health-service-use-patterns/contents/key-findings, accessed November 2022

[16] ibid

[17] ibid

[18] Australian Commission on Safety and Quality in Health Care (2013). Safety and Quality of End-of-life Care in Acute Hospitals: A Background Paper. https://www.safetyandquality.gov.au/sites/default/files/migrated/SAQ083_End_of_life_care_V15_FILM_REVISED_TAGGED.pdf, accessed January 2023

---

[19] Meier, E.A., Gallegos, M.A., Montross-Thomas, L.P., Depp C.A, Irwin, S.A, and Jeste D.V., (2016) Defining a Good Death (successful Dying): Literature Review and a call for Research and Public Dialogue, Am J Geriatr Psychiatry. 2016 April ; 24(4): 261–271

[20] Arora,V., (2021) The Changing Paradigm of Death and Dying, Social Change, Vole 51(3)

[21] Sallnow, L., Smith, R., Ahmedzai, S., Bhadelia, A., Chamberlain, C., (2022) Report of the Lancet Commission on the Value of Death: bringing death back into life, The Lancet Commissions, Vol 399 (10327) p937-884

[22] Noonan, K., Horsfall, D., Leonard, R., and Rosenberg, J., (2016) Developing death literacy. Progress In Palliative Care, Science and the Art of Caring, 24(1)

[23] Noonan, K, Horsfall, D and Kelly, M (2018). Beyond Taboos? Australians' capacity to care for each other through death, dying and loss. Research report. The GroundSwell Project. Sydney.

[24] Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., and Rahn, A. (2020). Death Literacy Index: A Report on its Development and Implementation. Sydney: Western Sydney University. https://doi. org/10.26183/5eb8d3adb20b0

[25] The Groundswell Project Australia (2022), Death Literacy Index, https://www.thegroundswellproject.com/death-literacy-index, accessed December 2022

[26] McClatchey I. and King S . (2015). The impact of death education on fear of death and death anxiety among human services students. *Omega* 71, 343–361. 10.1177/0030222815572606

[27] https://www.thegroundswellproject.com/death-literacy-index

[28] Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., and Rahn, A. (2020). Death Literacy Index: A Report on its Development and Implementation. Sydney: Western Sydney University. https://doi. org/10.26183/5eb8d3adb20b0

[29] ibid

[30] Advance Care Planning Australia. (2022). Advance care planning explained. Retrieved from https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-explained

[31] Advance Care Planning Australia. (2022). Advance care planning laws in New South Wales Retrieved from https://www.advancecareplanning.org.au/law-and-ethics/state-and-territory-laws/advance-care-planning-laws-in-nsw

[32] ibid

[33] NSW Health. (2022). *Making an Advance Care Directive*. Retrieved from https://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf

[34] Advance Care Planning Australia (2002) Advance Care Planning Improvement Toolkit: New South Wales. Austin Health, Melbourne

[35] Rankin Smith, H., and Read, N., (2020) Building Compassionate Communities In Australia: Tools for a community-led approach to end-of-life-care, https://static1.squarespace.com/static/5f27363644ecfc2277942c88/t/5fe260a17b20a60e9ff6fbea/1608671461774/Building+Compassionate+Communities_the+GroundSwell+Project+2020.pdf, accessed December 2022

[36] Ibid

[37] Nouse (2018) Compassionate communities: An Implementation guide for community approaches to end of life care, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/09/An-implementation-guide-for-community.pdf, accessed December 2022

[38] Aoun SM, Abel J, Rumbold B, Cross K, Moore J, Skeers P, Deliens L. The Compassionate Communities Connectors model for end-of-life care: a community and health service partnership in Western Australia. Palliat Care Soc Pract. 2020 Jul 2;14: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7333490/, accessed December 2022.

[39] 4. Sallnow L, Richardson H, Murray SA, et al. The impact of a new public health approach to end-of-life care: a systematic review. *Palliat Med* 2016; 30: 200–211. https://journals.sagepub.com/doi/abs/10.1177/0269216315599869?journalCode=pmja, accessed December 2022

[40] Palliative Care NSW. (2020). *Palliative Caring: Information for families and carers who are caring for a person with a life-limiting illness or condition*. Retrieved from https://palliativecarensw.org.au/new-carer-booklet-resource-available/

[41] Carers Australia. (2022). Caring to the end. *Palliative and End-of-life Care.* Retrieved from https://www.carersaustralia.com.au/information-for-carers/palliative-care-and-end-of-life-care/

[42] CareSearch. (2018). Caring for Someone with a Life-limiting Illness. Retrieved from https://www.caresearch.com.au/Portals/20/Documents/CareSearch_FactSheet_Caring-for-Someone-with-Life-limiting-Illness.pdf

[43] ibid

[44] NSW Health. (2019). *End of Life and Palliative Care Framework 2019-2024*. Retrieved from https://www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf

[45] Palliative Care Australia and Australian Centre for Grief and Bereavement (2018) Policy Statement, available at https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/08/Grief-and-Bereavement-Policy-Statement-FINAL.pdf, accessed January 2023

[46] Australian Indigenous Health InfoNet, available at https://healthinfonet.ecu.edu.au/learn/health-topics/social-and-emotional-wellbeing/grief-loss-trauma/, accessed January 2023.

[47] AIHW (2021) Interfaces between the aged care and health systems In Australia - where do older Australian's die? https://www.aihw.gov.au/getmedia/56c1f616-8b2c-493e-8e1c-2db5083ad59d/aihw-age-106.pdf, accessed 19 January 2023

[48] Palliative Care Australia and Australian Centre for Grief and Bereavement (2018) Policy Statement, available at https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/08/Grief-and-Bereavement-Policy-Statement-FINAL.pdf, accessed January 2023

[49] Swerissen. H., and Duckett, S., (2014) Dying Well, Gratton Institute: https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf, accessed October 2022

[50] Palliative Care Australia (2018) Palliative Care Service Development Guidelines, https://palliativecare.org.au//wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf, accessed October 2022

[51] United Nations (1966) International Covenant on Economic, Social and Cultural Rights, Article 12:

[52] Hunt, G, Former Minister for Health and Aged Care, 2021, "$56 million to improve end-of-life care for Australians", released 2 December 2021

[53] Commonwealth of Australia (2021) Royal Commission into Aged Care Quality and Safety: Final Report, Care, Dignity and Respect, https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf, accessed November 2022

[54] NSW Health. (2019). *End of Life and Palliative Care Framework 2019-2024*. Retrieved from https://www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf

[55] Perrottet, D. Premier of NSW, 2022 "$743 million to enhance end-of-life care in NSW" released 9 June 2022

[56] Who Health Organisation. (2020). Palliative Care. Retrieved from https://www.who.int/news-room/fact-sheets/detail/palliative-care

[57] Palliative Care Australia. (2019). *Palliative Care and Voluntary Assisted Dying*. Retrieved from https://palliativecareqld.org.au/wp-content/uploads/2021/06/2019-VAD-position-statement-Final.pdf

[58] Peters L, Cant R, Sellick K, O'Connor M, Lee S, Burney S, et al. Is work stress in palliative care nurses a cause for concern? A literature review. Int J Palliat Nurs. 2012 Nov;18(11):561-7.

[59] Australian Institute of Health and Welfare. (2016). Primary health care in Australia. *Primary Health Care.* Retrieved from https://www.aihw.gov.au/reports/primary-health-care/primary-health-care-in-australia/contents/about-primary-health-care

[60] AIHW (2021) Palliative care services in Australia, Palliative Care outcomes, https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-outcomes, accessed November 2022

[61] AIWH (2002) Palliative care services in Australia, available at https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-general-practice, accessed November 2022

[62] Advance Care Planning Australia. (2018). Advance care planning in general practice: Guidance on the use of Medicare Benefits Schedule Items. Retrieved from https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-fact-sheets/acpa_mbs-factsheet_2018_online.pdf?sfvrsn=67cae33c_37

[63] Groot MM, Vernooij-Dassen MJ, Crul BJ, Grol RP. (2005) General practitioners (GPs) and palliative care: Perceived tasks and barriers in daily practice. Palliat Med 2005;19(2):111–18.

[64] Tait, P., Chakroaborty, A., Jones., K., and Tieman, J., (2021) What is the community pharmacist' role in supporting older Australians with Palliative Care Needs, Healthcare (Basel) Vol 9(5)

[65] AIHW Data Tables 2020-21 Medicare-subsidised-palliative-medicine-services

[66] Pharmaceutical Society of Australia (2021), Working with PSA and pharmacists. An information guide for PHNs. Accessed January 2023.

[67] Gravier S, Erny-Albrecht K. Allied health in Australia and its role in palliative care. Adelaide: CareSearch; 2020. https://www.caresearch.com.au/Portals/20/Documents/Allied-health-in-Australia-and-its-role-in-palliative-care.pdf, accessed January 2023.

[68] National Health Workforce Dataset (NHWDS) (2022), https://hwd.health.gov.au/resources/information/nhwds.html, accessed November 2022

[69] Buck K, Detering KM, Sellars M, Sinclair C, White B, Kelly H and Nolte L. (2019) Prevalence of Advance Care Planning documentation in Australian health and residential aged care services. Advance Care Planning Australia, Austin Health, Melbourne.

[70] AUHU (2022) Gen Aged Care Data, People leaving aged care, available at https://gen-agedcaredata.gov.au/Topics/People-leaving-aged-care, accessed November 2022

[71] AIHW (2022) Palliative care for people living In residential aged care, https://www.aihw.gov.au/getmedia/8511d62a-f272-4ea4-b9d6-858482c3e98d/Palliative-care-in-residential-aged-care-2020-21.pdf.aspx, accessed November 2022.

[72] AIHIW (2022) Palliative care services in Australia, https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary, accessed November 2022

[73] Rainsford S, Liu W-M, Johnston N, Glasgow N. The impact of introducing Palliative Care Needs Rounds into rural residential aged care: A quasi-experimental study. The Australian Journal of Rural Health, Vol 28, Issue 5. Oct 2020, p 480-489. https://onlinelibrary.wiley.com/doi/full/10.1111/ajr.12654

[74] Pharmaceutical Society of Australia (2020) Medicine Safety: Aged Care, accessed https://www.psa.org.au/wp-content/uploads/2020/02/Medicine-Safety-Aged-Care-WEB-RES1.pdf, November 2022

[75] Palliative Care Australia. (2020). *Palliative Care is Core Business for Aged Care*. Retrieved from https://palliativecarewa.asn.au/wp-content/uploads/Palliative-Care-is-Core-Business-for-Aged-Care-April-2021.pdf

[76] AIHW (2022) Palliative care services in Australia, https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/overview#references, accessed January 2023.

[77] National Health Workforce Dataset (NHWDS) (2022), https://hwd.health.gov.au/resources/information/nhwds.html, accessed November 2022

[78] AIHW (2022) Palliative care services In Australia, Palliative care workforce, https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce, access January 2023

[79] Department of Health and Aged Care (2022) National Health Workforce Data Set, https://hwd.health.gov.au/datatool/ accessed December 2022

[80] Palliative Care Curriculum for Undergraduates (PCC4U) Project Team. (2018). *Communication: Self-care for healthcare professionals. Impact of caring.*

[81] Stienstra, D., & Chochinov, H. M. (2012). Palliative care for vulnerable populations. *Palliat Support Care, 10*(1), 37-42. doi:10.1017/s1478951511000563

[82] Palliative Care Australia. (2012). *Palliative care and culturally and linguistically diverse communities*. Retrieved from https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Culturally-and-Linguistically-Diverse-Communities-and-Palliative-Care-Position-Statement.pdf

[83] iPEPA Project team. (2020). *IPEPA Cultural Considerations Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples.* Retrieved from https://pepaeducation.com/wp-content/uploads/2020/12/PEPA_CulturalConsiderationsFlipbook_Web.pdf

[84] Andrea Ferrari. (2022). Healing Work Recognised in Coffs Harbour During Refugee Week. *News of the Area*. Retrieved from https://www.newsofthearea.com.au/healing-work-recognised-in-coffs-harbour-during-refugee-week-95931

[85] Australian Healthcare Associates. (2019). *Exploratory Analysis of Barriers to Palliative Care: Issues Report on People Experiencing Homelessness*.

[86] LGBTIQ+ Health Australia. (2021). *LGBTIQ+ Health Australia Annual Report 2020-2021*. Retrieved from Sydney: www.lgbtiqhealth.org.au

[87] Kelly, M., Mitchell, I., Walker, I., Mears, J., & Scholz, B. (2021). End-of-life care in natural disasters including epidemics and pandemics: a systematic review. *BMJ Support Palliat Care*. doi:10.1136/bmjspcare-2021-002973

[88] Australian Institute of Health and Welfare. (2022). Digital Health. Health System. Retrieved from https://www.aihw.gov.au/reports/australias-health/digital-health

[89] Mills, J., Fox, J., Damarell, R. *et al.* (2021) Palliative care providers' use of digital health and perspectives on technological innovation: a national study. *BMC Palliat Care* **20**, 124. https://doi.org/10.1186/s12904-021-00822-2

[90] ibid

[91] ibid

[92] Palliative Care Australia (2022) Mind the data Gap: Media Release, https://palliativecare.org.au/mediarelease/mind-the-data-gap-we-cant-improve-what-we-dont-measure/ accessed December 2022.

[93] AIHW (2022) Palliative Care Services in Australia, https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-outcomes

[94] Handley T., End of Life Care in a sample of Regional and Rural NSW – what is the current situation and what are the problems? A white paper developed to support the work of NSW Regional Health Partners; 2019.

[95] AIHW (2022) Reports and data: hospitals, admitted patient activity, accessed November 2022

[96] AIHW (2022)Data Table: Admitted Patient Care Palliative care 2019-20, accessed November 2022

[97] AIHW (2022) Palliative Care Services web report; https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary-of-palliative-care-services-in-australia. Accessed 6 Dec 2022.

[98] AIHW (2022) Palliative Care Services in Australia – Admitted patient palliative care and other end-of-life care and hospital facilities. https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/admitted-patient-palliative-care, Accessed November 2022

[99] AIHW (2015) The health and welfare of Australia's Aboriginal and Torres Strait Islander people: 2015 , https://www.aihw.gov.au/reports/indigenous-health-welfare/indigenous-health-welfare-2015/contents/health-welfare-services-key-points, accessed January 2023.

[100] AIHW (2021) My hospital data, Admitted Patient Care Palliative care 2019-20, https://www.aihw.gov.au/reports-data/myhospitals/sectors/admitted-patients, accessed January 2023.

[101] NSW End of Life and Palliative Care Blue Print (2022), https://aci.health.nsw.gov.au/palliative-care/blueprint, accessed January 2023