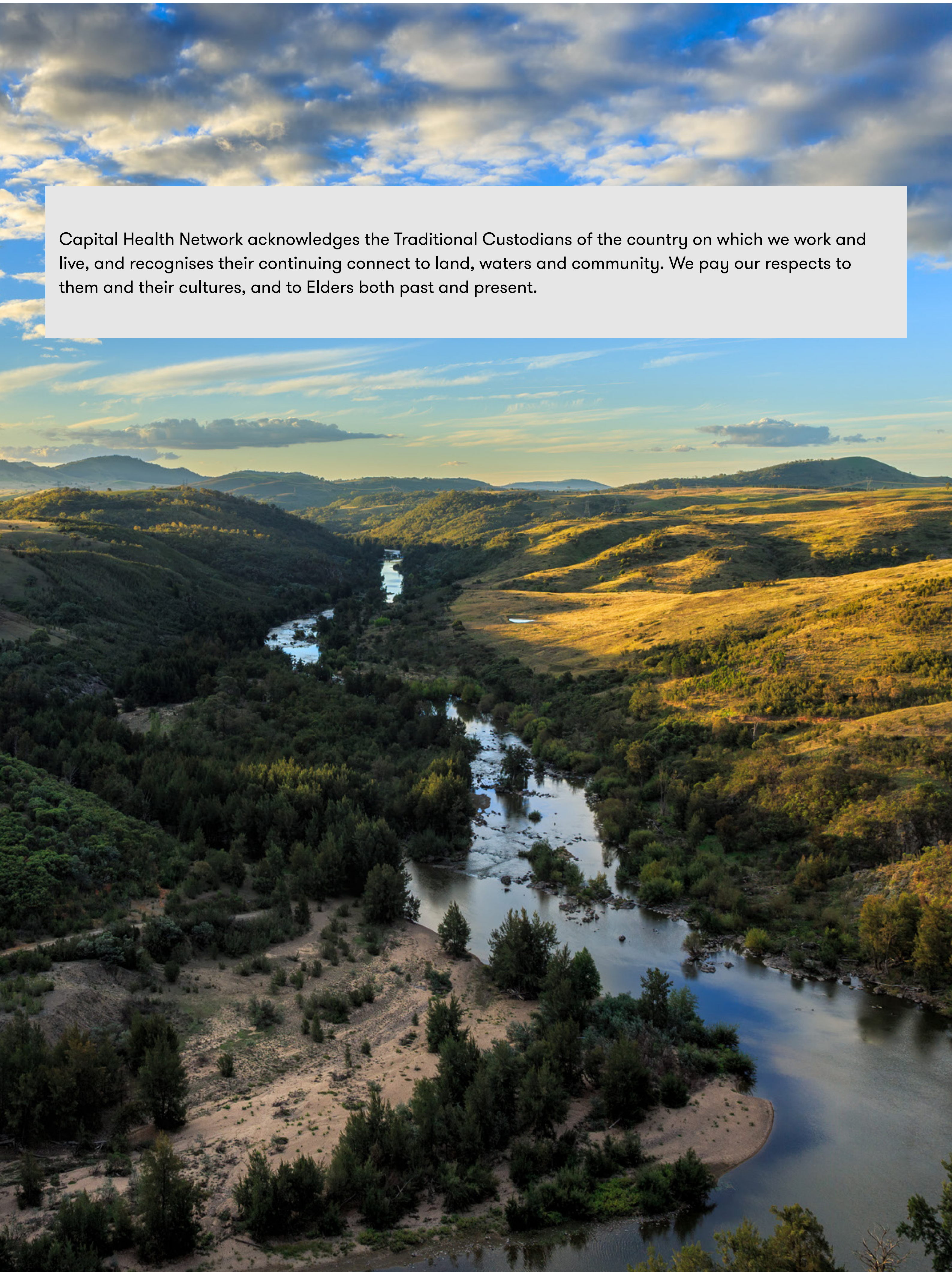
CAPITAL HEALTH NETWORK

PALLIATIVE CARE TARGETED NEEDS ASSESSMENT

An Australian Government Initiative

Partnering for better health

Contents



Capital Health Network acknowledges the Traditional Custodians of the country on which we work and live, and recognises their continuing connect to land, waters and community. We pay our respects to them and their cultures, and to Elders both past and present.

Executive Summary

Purpose

This Palliative Care Targeted Needs Assessment (the assessment) has been developed as part of the Greater Choice for At Home Palliative Care (GCfAHPC) program funded by the Australian Department of Health, Disability and Ageing (DHDA). Its purpose is to inform service planning, commissioning, and delivery of palliative care initiatives in the Australian Capital Territory (ACT).

By examining current gaps and challenges within the ACT palliative care system, the assessment identifies priority needs that can be addressed through targeted GCfAHPC initiatives aligned with the DHDA GCfAHPC guidelines, role and scope of Primary Health Networks (PHNs), the Capital Health Network (CHN) Strategic Plan, and national reform policies.

In line with the DHDA GCfAHPC guidelines, this document provides a strategic foundation to identify local needs, guide Activity Work Plans, measure program impact, support local services, providers, and the community. The assessment will be used to monitor and evaluate program outcomes and inform responsive, locally tailored initiatives.

The GCfAHPC Program, funded nationally across all PHNs, aims to improve awareness of and access to safe, high-quality palliative and end-of-life care at home, support better coordination by strengthening primary and community care systems, reduce avoidable hospitalisations, enhance data-driven improvement, and utilise technology to support timely and responsive care, including after-hours services.

Priority Needs

The CHN Needs Assessment (2024-2027) identifies several high-level priorities to strengthen palliative care across the ACT. These priorities focus on improving system navigation, building workforce capability, enhancing equity, and supporting coordinated, home-based care.

System navigation and stronger referral pathways

Clear, consistent referral processes, improved information sharing, and better coordination for people with complex needs.

Enhanced primary and community care capability

Targeted education, strengthened roles and shared care models for GPs and primary care nurses, improved after-hours support, and expanded community-based clinical care.

Improved access to essential supports at home

Reliable access to palliative medicines, strengthened allied health and nursing capacity, and embedding evidence-based models of care as appropriate.

Greater equity for priority populations

Culturally safe care for First Nations people, improved support for multicultural communities, people with disability, people who use drugs, and children requiring palliative care.

Stronger data and system stewardship

Improved data collection, reporting, and use of the Palliative Care Reporting Framework to guide planning and quality improvement.

Better support across all sectors

Earlier identification of end-of-life needs, stronger multidisciplinary care, and improved access to specialist palliative care for people with non-cancer conditions.

Improved community awareness and access to information

Increased public understanding of palliative care and advance care planning (ACP), and development of a single, trusted information hub.

Support for home-based palliative care

Monitoring impacts of reduced home-care availability and increasing awareness of pathways such as the 65+ Support at Home End-of-Life Pathway.

This assessment provides a clear and evidence-informed foundation for strengthening palliative care across the ACT. By identifying the most pressing system gaps and priority needs, it supports CHN's GCfAHPC team and stakeholders to plan and deliver initiatives that are targeted, equitable, and responsive to the growing need and complexity of palliative care. The findings reinforce the importance of coordinated action across primary, community, aged care, specialist services, and the broader population to ensure people can access high-quality palliative care at home. Guided by national GCfAHPC objectives, local stakeholder insights, and alignment with broader health system reforms, this assessment positions the ACT to advance a more connected, capable, and person-centred palliative care system over the 2025–2029 period.

Overview

Purpose

This Palliative Care Targeted Needs Assessment has been developed as part of the Greater Choice for At Home Palliative Care (GCfAHPC) Program for the 2025–2029 funding period. Its purpose is to inform the planning and delivery of palliative care initiatives in the Australian Capital Territory (ACT) by CHN's GCfAHPC team. This work responds to the growing complexity of palliative care needs in the ACT. By examining existing gaps and challenges within the ACT palliative care system, it identifies priority needs that can be addressed through targeted GCfAHPC initiatives to support meaningful system improvement aligned with national reform priorities.

In alignment with DHDA's GCfAHPC guidelines, this document will serve as a strategic tool to:

- Identify local gaps and issues in palliative care.
- Provide a data-driven foundation for aligning Activity Work Plans with GCfAHPC objectives.
- Measure the impact of GCfAHPC on palliative care systems in the ACT.
- Justify flexibility and resourcing of specific activities within the program.
- Support local services, providers, and the community.

Greater Choice for At Home Palliative Care

The GCfAHPC program is funded by the DHDA across 31 Primary Health Networks (PHNs) over four years from 2025-26 to 2028-29. It was first established in 2017-18 and expanded nationally to include all PHNs from 2021-22 to 2024-25 (1).

The core objectives of the GCfAHPC Program are to:

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

Scope

This targeted Needs Assessment focuses on the factors influencing the delivery of palliative care services across the ACT.

- Identify available services and accessibility of these services.
- Understand workforce distribution, capacity, and capability.
- Determine the level of community awareness and understanding of palliative care services.
- Discuss factors and barriers that affect the palliative care system in the ACT.
- Identify underserviced populations and understand unique barriers and challenges facing these populations.

This targeted Needs Assessment will inform current and future palliative care needs in the ACT.

Methodology

A mixed methods approach was utilised including:

- Review of literature: An environmental scan was completed to identify trends, ongoing needs, and barriers. Including, CHN's previous needs assessments, service function review commissioned by the ACT Health and Community Services Directorate as well as relevant local and national data.
- Quantitative analysis: Data from sources such as DHDA, Australian Institute of Health and Welfare (AIHW) and ACT Health was collected and utilised to determine needs and priorities.
- Qualitative analysis – Stakeholder consultations were undertaken with GPs, practice nurses, non-clinical and clinical inpatient and community health care providers, palliative care specialists, multicultural communities, carers, disability and ageing representatives, and people with lived experience of drug use. Extensive consultation with First Nations people was completed through the ACT Service Function Review and was therefore not repeated for this assessment. These perspectives provided essential depth, context, and nuance, ensuring that real-world experiences and unmet needs were accurately reflected in the development of priorities.

What is Palliative care?

Palliative care, as defined by the World Health Organisation (WHO), is an approach that improves the quality of life of patients and families facing life-threatening illness. It prevents and relieves suffering through early identification, accurate assessment, and treatment of pain and other physical, psychosocial, or spiritual issues (2).
A palliative approach focuses on optimising comfort, improving function, and supporting physical, social, emotional, and spiritual wellbeing.

Around 80% of expected deaths in Australia each year—about 110,000 people—are estimated to require palliative care (3). Palliative care can be delivered across most health care settings by a wide range of health professionals. Primary care plays a key role as the usual first point of contact, making the integration of palliative care principles essential for holistic, patient-centred care.

End-of-life care is a subset of palliative care for people likely to die within the next 12 months. Palliative care is broader, supporting anyone with a life-limiting illness and often provided over a longer period, with early intervention and ACP central to high-quality care (4).

Primary palliative care is for people with life-limiting illness, delivered by primary health care professionals such as GPs, practice nurses, community nurses, and allied health professionals. It focuses on relieving suffering to improve quality of life, alongside curative treatments. It includes identifying needs, assessing, and triaging patients, and referring to specialist palliative care when required (5,6,22).

Other considerations related to context in ACT

Voluntary Assisted Dying

Voluntary assisted dying commenced in the ACT on Monday, 3 November 2025. A Voluntary Assisted Dying Care Navigator Service has been established to support access to the scheme.

As the scheme has only recently been implemented, no observations, commentary, or identification of emerging needs are included in this report, however, it is noted that the voluntary assisted dying legislation, eligibility requirements, care pathway, and navigation service have been informed by learnings from other Australian states (15).

Aged Care Reform

The new Aged Care Act (2024) commenced on 1 November 2025 (16). The Act strengthens the Aged Care Quality Standards, including requirements relating to palliative and end-of-life care. Within Standard 5: Clinical Care, Outcome 5.7: Palliative and End-of-Life Care outlines aged care provider responsibilities for the delivery of high-quality care (17).

As a result, the Support at Home program (18) has been established to support older people to maintain independence and remain living in their own homes for as long as possible, including at end-of-life.
The End-of-Life Pathway (19) is designed to complement, and work in partnership with, existing States and Territory palliative care services, to ensure continuity of care and access to specialist palliative care. As the Support at Home program has only recently been implemented, no observations, commentary, or identification of emerging needs are included in this report.

Key findings

This section outlines the key findings from the analysis completed for the targeted Needs Assessment. As the palliative care system is diverse and complex, these findings have been grouped into themes to provide clarity and allow for identification of needs.

Service availability and accessibility

In 2023, ACT Health's Palliative Care Service Function Review (7) reported 63 organisations which were identified as providing clinical or non-clinical palliative care services. These services ranged from specialist palliative care services (SPC), primary care services, community clinical services, community based non-clinical palliative care services, grief and bereavement services and other services which are relevant for those with palliative care needs. Some organisations provide multiple services across a variety of settings, for example Clare Holland House provides a hospice service, an outpatient clinic, a home-based palliative care program and the Palliative Aged Care Specialists service (PEACE) for residential aged care homes (RACHs).

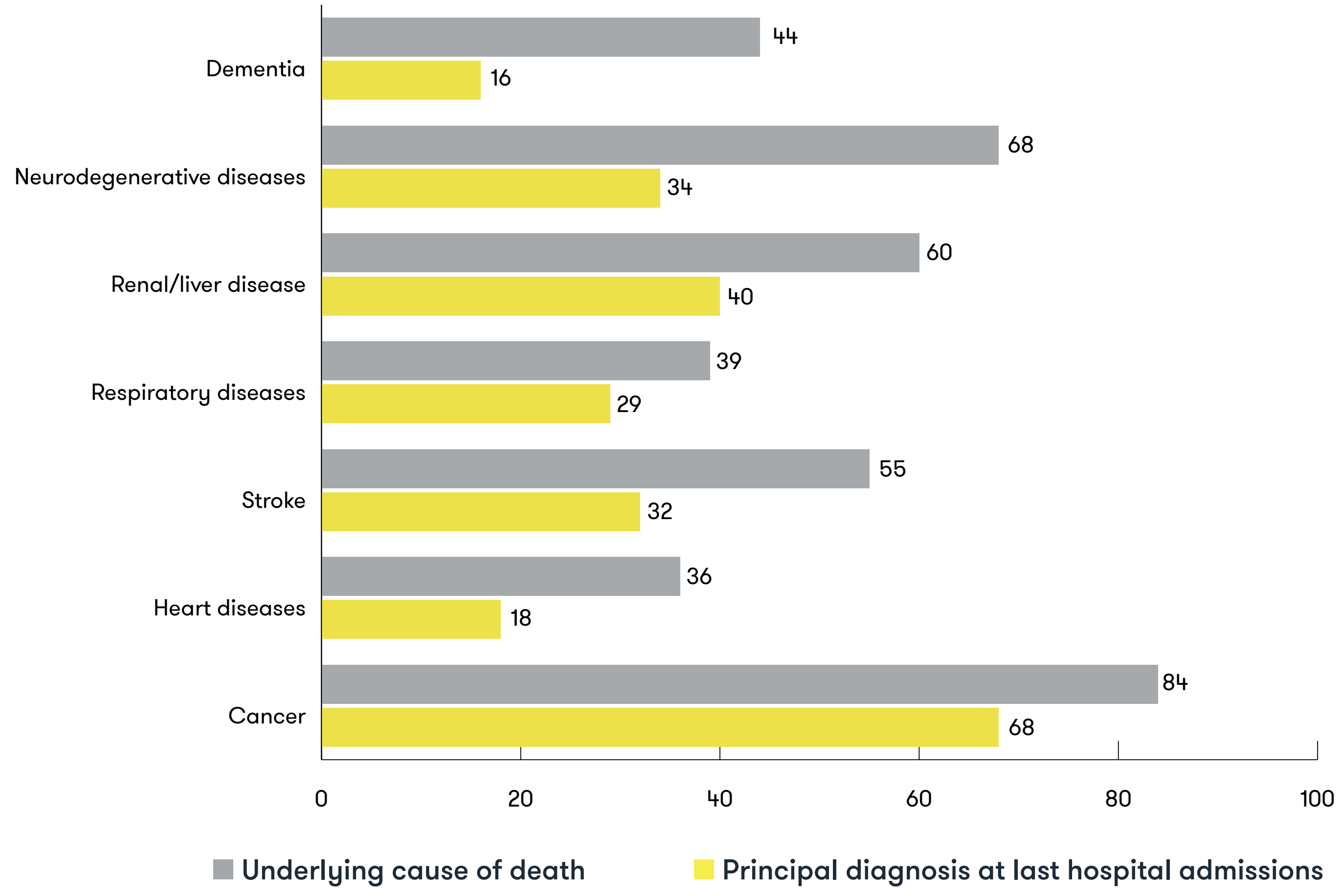
Specialist palliative care services

There are two organisations providing specialist palliative care services for ACT residents:

- **Canberra Health Services (CHS)**
  - North Canberra Hospital and Clare Holland House
    - Hospice
    - Outpatient clinic
    - Home based palliative care program
    - PEACE
    - Hospital Specialist Palliative Care Consult Team
  - The Canberra Hospital
    - Hospital Specialist Palliative Care Consult Team
    - Advance Care Planning Program Team
    - Renal Supportive Care Clinic
  - Centenary Hospital for Women and Children
    - Paediatric Palliative Care Service
- **Queanbeyan Hospital and Health Service - Queanbeyan Palliative Care Services**

Specialist palliative care is well embedded for cancer but remains significantly under-utilised for non-cancer predictable deaths, particularly when patients present with acute hospital admissions, highlighting a major equity, quality, and efficiency gap in end-of-life care. In 2024, the proportion of people with predictable deaths who received specialist palliative care, grouped by diagnosis and underlying cause of death at last hospital admission (graph below).

Proportion of people with predictable deaths who received specialist palliative care, within each diagnosis group , by underlying cause of death and principal diagnosis at last hospital admission, 2024



Primary care (General Practice)

In 2024, 646 GPs working solely in the ACT accounted for 422.4 fulltime equivalent (FTE) GP positions. In 2023–24, these GPs provided 2,234,801 Medicare subsidised GP services in the ACT (20).

National research indicates that approximately 1% of GP consultations involve a palliative care component (14). Applying this proportion to ACT activity suggests that palliative care represents approximately 22,348 GP attendances each year, and approximately 4.2 FTE worth of GP time.

While this is a small proportion of total GP activity, it nonetheless reflects a significant volume of palliative care delivered in primary care settings and reinforces the need for ongoing support, education and training to strengthen GP confidence and capability in managing palliative care patients and validates the notion that 'palliative care is an essential element of primary health care' (22).

In the ACT there are a small number of general practices that focus on supporting people with a life-limiting illness throughout the stages of the end-of-life journey including care in the home and RACHs. The role of primary care practitioners in the ACT palliative care system will be further explored in this document.

Community based care

The ACT Health Service Function Review identified 22 providers of community based clinical and non-clinical palliative care services (7). These services cover a breadth of service types, ranging from services based out of the hospital to those which are delivered by peak bodies, or which provide specific end-of-life support services in the community.

Despite the number of providers identified, stakeholders consistently report that there is lack of in-home clinical and non-clinical palliative care support in the ACT. ACT HCSD's service mapping found limited evidence of in-home services focused specifically on palliative and end-of-life services (7).

Short term funding cycles and associated limitations to funding have significantly impacted capacity to meet in-home service needs. A number of pilot projects have been implemented successfully and independently evaluated demonstrating their impact as in-home services.

During 2022 - 2024 CHN funded the ACT Breathlessness Intervention Service (ABIS) (23) pilot to deliver patient-centred, coordinated care through community health care providers to people with palliative care needs at home. The pilot demonstrated significant reduction in ambulance callouts and likely ED presentations related to breathlessness. This service was able to offer vulnerable patients access to timely, in-home management for breathlessness, in turn decreasing the risk of distress and avoiding hospital admissions.

Home Care

In 2013, after a successful pilot responding to service gaps and rising demand for in-home palliative care, ACT HCSD funded Community Options to deliver practical, home-based palliative support. This included case management and a range of non-clinical services. This was not funded by CHN.

Most non-clinical support involved domestic assistance, personal care, and social support, with additional services such as respite, home modifications, and equipment. These supports were designed to assist both people receiving palliative care and their carers. Younger clients generally required more hours of overall support.

A recent report and stakeholder roundtable (24) found that the home care program enabled safe, sustainable discharge home for most referred clients. More than 70 people were supported to die at home, their preferred place of care. Clients and families reported improved quality of life, reduced carer stress, and consistently high satisfaction with services.

Referring agencies noted that the program:

- Reduced “social admissions” to hospital by providing practical in-home support.
- Enabled safe, timely transitions from hospital to home for clients with complex needs.
- Supported carers through flexible services such as domestic assistance, meal preparation, and respite.
- Provided a reliable point of coordination within a fragmented service system.

Changes to funding models now limit Community Options to case management only. Although the organisation continues to self-fund some in-home support to address critical gaps, this approach is not sustainable. Without renewed investment, the service gaps first identified in the 2012 pilot are likely to re-emerge, further reducing access to non-clinical, in-home palliative care also highlighted in the Service Function Review (2023) (7).

After-hours

The 2023 Service Function Review (7) reported 14 services were identified in the ACT that provided after-hours palliative care services, however, half of these services provided either respite care or telehealth/ online support only.

Access to after-hours palliative care services has been consistently raised as one of the highest priorities for the ACT palliative care system. Service Function Review (2023) (7) and CHN’s stakeholder engagement activities suggest the current level of service provision in the after-hours is not sufficient to meet the demand of those requiring care, particularly for at home services (8,12).

Palliative Care Australia’s 2024 After-Hours Primary Care Review (25) found that many after-hours’ needs for people with life-limiting illness, such as symptom management, urgent medical advice and reassurance for carers, can typically be managed by a GP or primary care nurse. If patients cannot access these services and health professionals in the after-hours period, it may trigger presentation to the ED for care. Data from the AIHW suggests that around 1 in 9 people (11.9%) who are in their last 3 months of life will have a potentially preventable hospital admission (26).

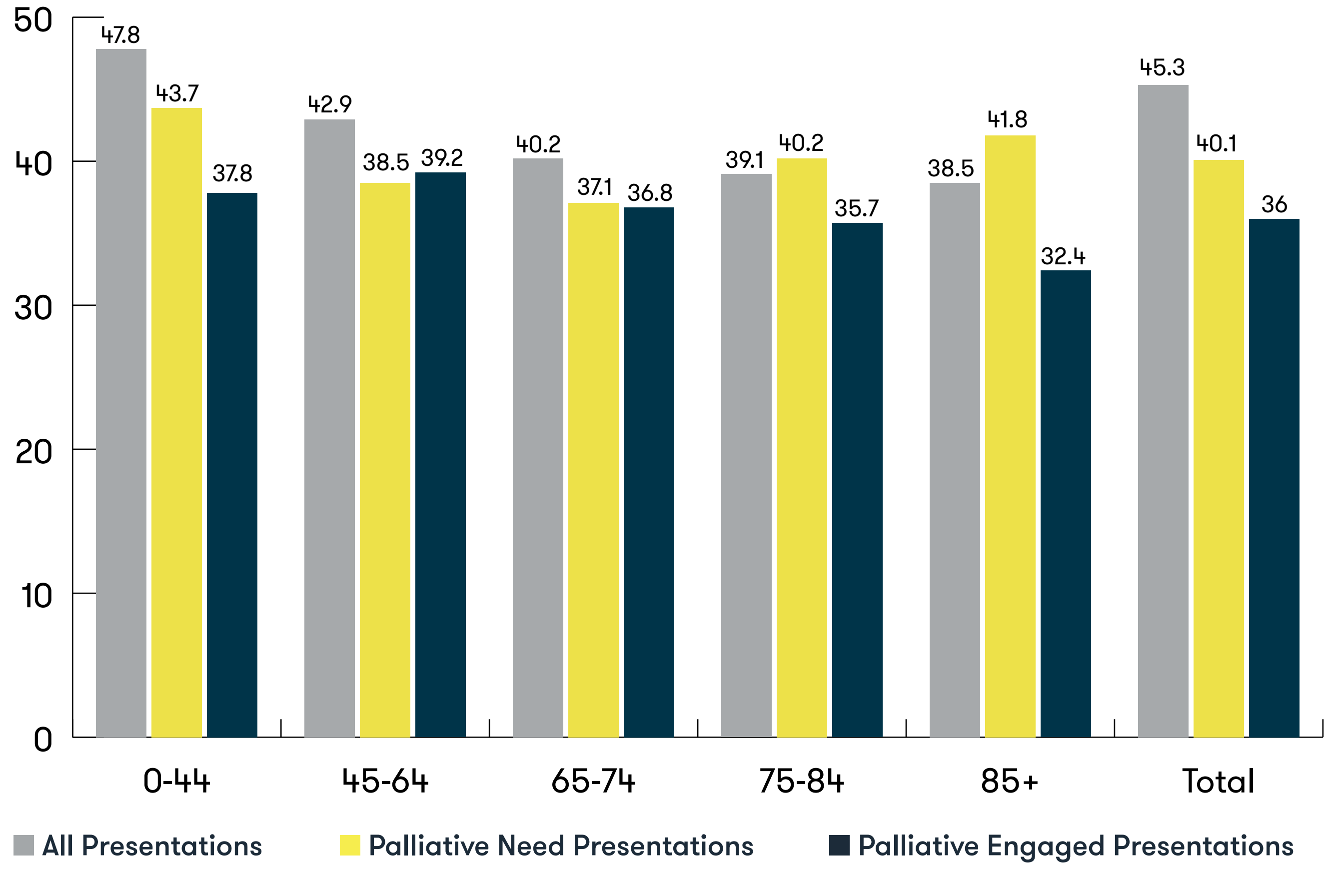
To better understand the after-hours use of specific palliative care services within the Emergency Department (ED), the ACT HCSD Epidemiology team applied a palliative care–focused Natural Language Processing (NLP) program to ED data from 2015-2022 (9). Although early results are encouraging, there remains scope to further enhance program performance. Consequently, analyses generated using these methods may contain some inaccuracies, and the findings presented here should be interpreted as one component within a broader evidence base.

Key findings include:

- High after-hours ED use among palliative care patients: A notably high proportion (41.8%) of after-hours presentations occurred among people aged 85+ with palliative care needs, compared with 32.4% among those engaged with palliative care services. Individuals engaged with services were more likely to present during weekday business hours. Weston Creek recorded a disproportionately high rate of palliative presentations compared with other SA3s (ABS Statistical Area) (9).
- High hospital admission rates for palliative presentations: Most ED presentations by people with palliative care needs (77.0%) and those engaged with palliative care services (79.2%) resulted in hospital admission. The difference between the two groups was minimal. By comparison, the admission rate for all ED presentations was 31.8% (9).

The high rate of after-hours ED presentations among people aged 85+ years with palliative care needs (41.8%) suggests significant challenges in accessing timely support outside standard business hours. For palliative patients, after-hours presentations may often be driven by symptom escalation, caregiver distress, or limited in-home clinical support.

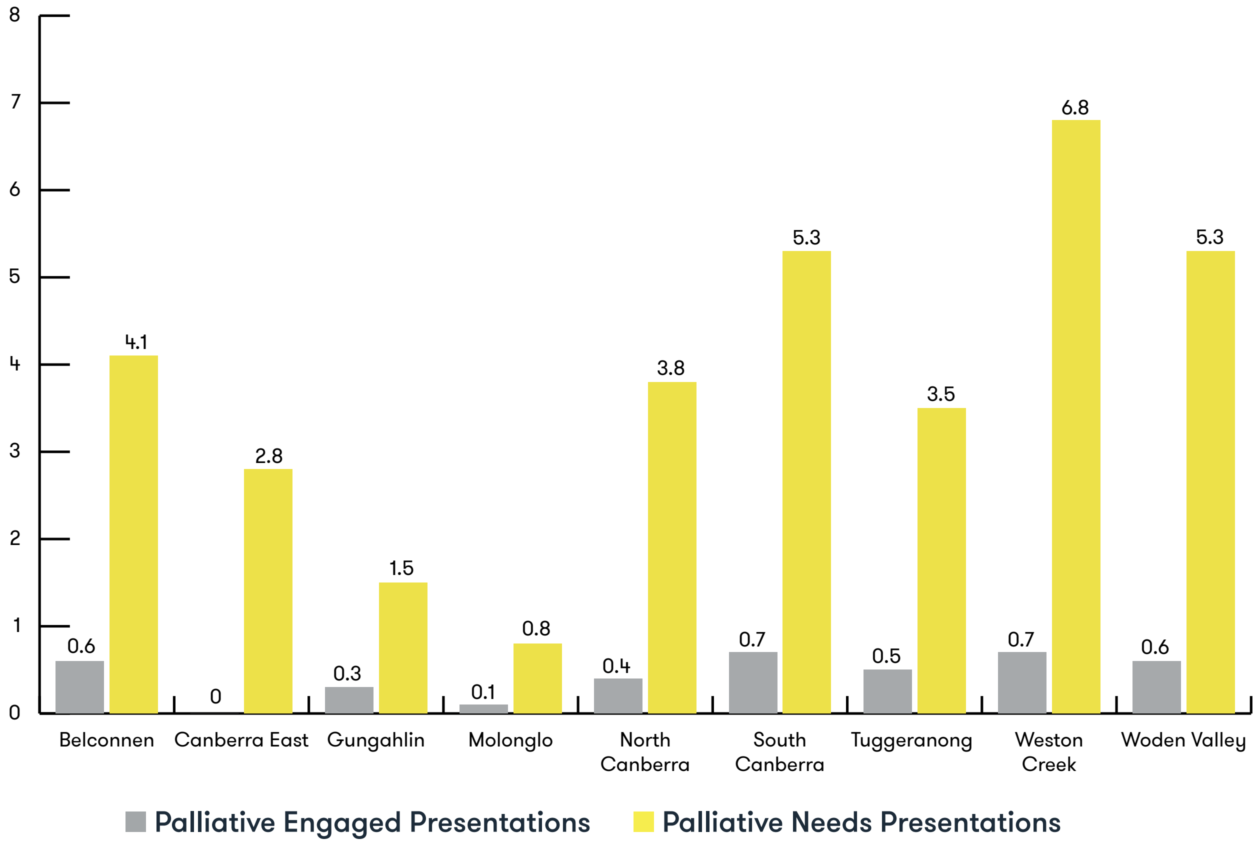
Proportion of ED Presentations occuring after-hours by age, ACT Public ED's, 2015/16 - 2021/22



In contrast, individuals actively engaged with palliative care services demonstrated a lower rate of after-hours presentations (32.4%) and were more likely to present during weekday business hours. This pattern suggests that implementing a palliative approach—which includes care coordination, proactive symptom monitoring, and timely intervention before symptoms escalate—can help prevent unexpected deterioration after-hours and reduce unplanned emergency department (ED) presentations.

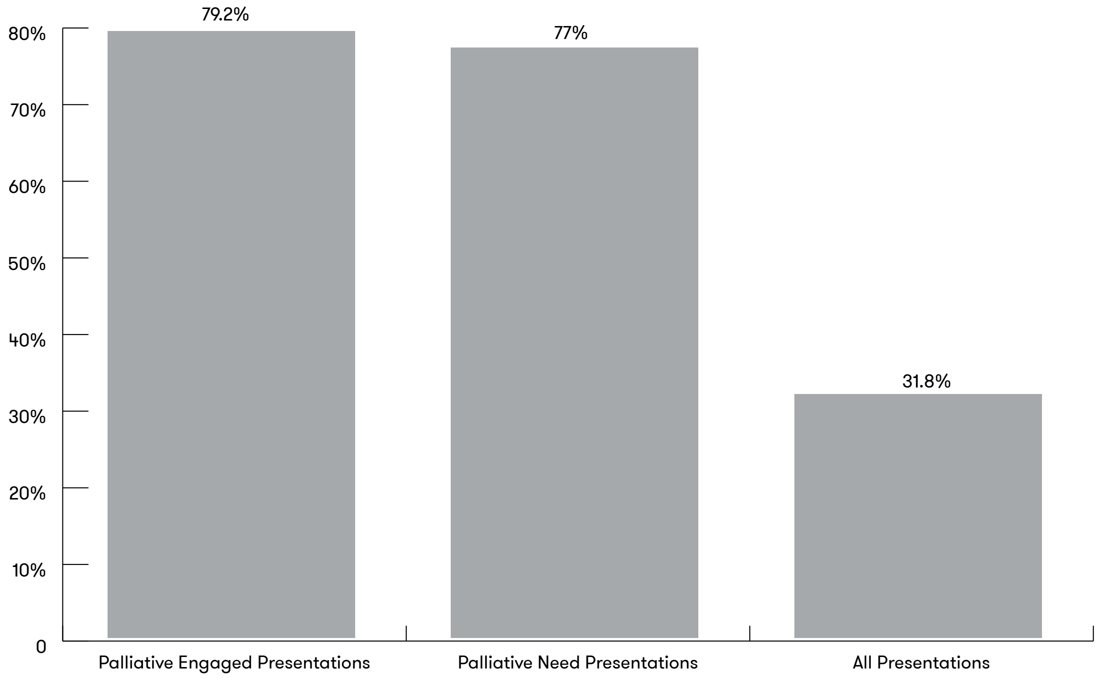
The finding that Weston Creek has a disproportionately high rate of palliative presentations compared with other SA3 areas raises questions about local service availability, population characteristics, or unmet need within this region. This area may benefit from targeted investment in community-based palliative supports or after-hours services although needs further investigation.

Rate (per 1000 residents per year) of ED presentations Type by SA3, ACT Public EDs, 2015/16-2021/22

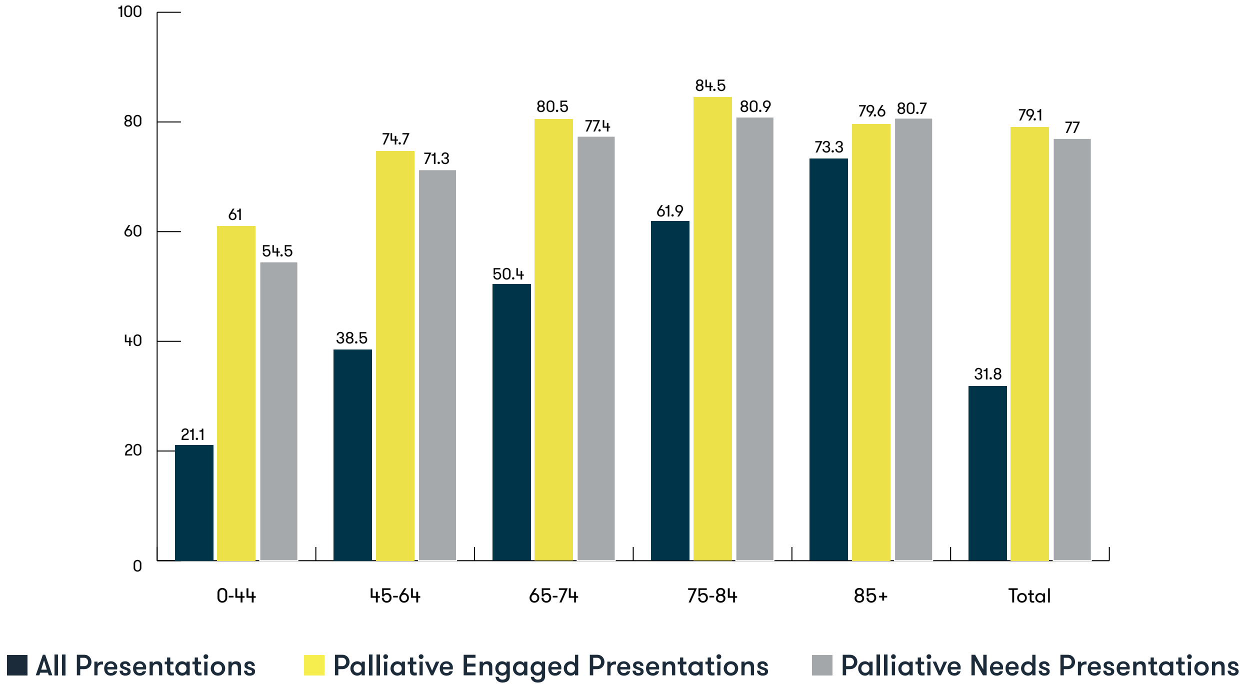


The very high hospital admission rates for both groups—77.0% for those with palliative care needs and 79.2% for those engaged with services—suggest that once palliative patients reach the ED, their level of clinical acuity or care complexity is similar regardless of service engagement. ED presentations in this population may typically reflect acute deterioration or symptoms that cannot be managed in the community. The limited clarity provided by ICD coding restricts understanding of the specific reasons for presentation and whether earlier clinical or nonclinical interventions could have prevented ED attendance.

Proportion of ED presentations resulting in Admission, ACT Public EDs, 2015/16-2021/22



Proportion of ED Presentations resulting in admission by Age Groups, ACT Public EDs, 2015/16-2021/22



ACT Ambulance Service

The ACT Extended Care Paramedic (ECP) program enhances pre-hospital care by deploying paramedics trained to deliver a broader range of clinical services than standard paramedics. By assessing and treating patients onsite when hospital-level care is unnecessary, the program reduces avoidable ambulance transports and ED presentations.

ECPs receive additional training in advanced life support and can provide more complex treatments in the community, including for palliative and terminal patients who wish to remain at home. In the ACT, they also complete targeted palliative care training to strengthen skills in symptom management, end-of-life support, and collaboration with palliative care services.

Following an initial trial in 2012-2013, the program now operates 8:00 am to 8:00 pm, seven days a week, to address the high number of ambulance callouts that did not require ED intervention, including for palliative patients preferring to stay at home

ECPs provide palliative care in private homes and RACHs, managing common symptoms and supporting patients, carers, and other health professionals. Standard paramedics often lack equivalent palliative training and confidence, and in the face of complex symptoms or limited system supports may default to hospital transfer. This can conflict with patient and carer preferences, diminish care experience, and contribute to paramedic moral distress.

To address this, ACT Ambulance Service endorsed the ACT's first Paramedic Palliative Care and Voluntary Assisted Dying Clinical Management Guidelines in November 2025. The guidelines offer clear direction for managing palliative and terminal patients according to their goals of care, aiming to increase paramedics' confidence, support safe care at home and reduce potentially unwanted ED transfers. As they are newly implemented, outcomes are not yet known.

Community Palliative Care Medicines

From 2017 to 2022, CHN funded an after-hours, home-based palliative medicines service pilot program to address a significant gap in timely access to palliative medications for patients at home, particularly after-hours. GCfAHPC program funding was not used for the pilot. The service enabled timely access of essential medications to palliative care clients at home, helping alleviate symptoms, enhance comfort, and reduce the stress and burden for carers associated with medication administration. As a result, patients were often able to spend more meaningful time with family, remain at home, avoid ED presentations or hospital admissions, and die in their preferred place of care—benefiting both patients and their families (23). The Service Function Review highlighted that since the service ended in 2022 the gap in community access to palliative medicines has re-emerged (7).

Residential Aged Care Homes

CHN's 2022 Needs Assessment (11) found that after-hours support was particularly challenging for RACHs in the ACT. Contributing barriers included out-of-date ACPs, limited end-of-life planning, medicine availability issues, family misunderstanding, and gaps in staff skills and confidence. Stakeholders reported that these factors often led to inefficient, reactive use of after-hours palliative care services, with facilities engaging the most available rather than the most appropriate service. In addition to improving planning and earlier identification of residents approaching end-of-life, increasing the capacity of RACHs to use digital health to connect with service providers could support more timely and efficient responses.

In 2023–24, the Digital Health in Residential Aged Care Homes (RACHs) initiative, funded by DHDA (27) aimed to strengthen digital health capability and support the introduction of digital health for residents. Financial assistance, equipment grants and ongoing training were offered to all RACHs in the ACT. 24 RACHs purchased digital health tools to enable telehealth assessments for timely access to care, recording, and communication.

The initiative achieved strong sector engagement and RACHs adopted digital health equipment, attended workshops, and received one-on-one coaching, hands-on implementation support. The program supported development of telehealth policies and procedures, helped aged care homes set digital health priorities, and produced induction checklists and policy templates. Overall, it improved staff confidence, foundational telehealth knowledge, and digital capability (28).

Despite this progress, several challenges and barriers remain including digital readiness of other stakeholders, in particular general practices, high staff turnover within RACHs, emergencies and addressing changing priorities, internet connectivity, compatibility with other systems outside of RACH environment.

In 2026 CHN will continue building digital health capability within RACHs while exploring ways to increase readiness and engagement among affiliated health care providers. This includes improving support for residents, including those approaching end-of-life, by ensuring seamless, digitally enabled care, and collaboration across care teams.

Telehealth and phone services

Palliative care telephone support services have been implemented in some states and territories and provide after-hours support to primary care professionals from specialist palliative care services. In the ACT, there is a 24/7 phone service available for clinicians to access clinical support in managing symptoms for their palliative patients who are known to specialist palliative care services. Feedback from GPs has highlighted that primary care clinicians have not been effectively utilising this service, and specialist availability has been inconsistent. This issue may hinder patients in the community from accessing timely and appropriate care and advice, especially after-hours.

Patients who are not engaged with SPC services do not have access to a telephone support service. A territory-wide palliative care phone support service has been raised as a need in the Service Function Review (7), however as identified in CHN's 2022 Palliative Care Scoping Review (12), feedback from stakeholders and consumers has been mixed. Some concerns have been raised about the utility of such a service, with worries that many will be unnecessarily directed to present to the ED.

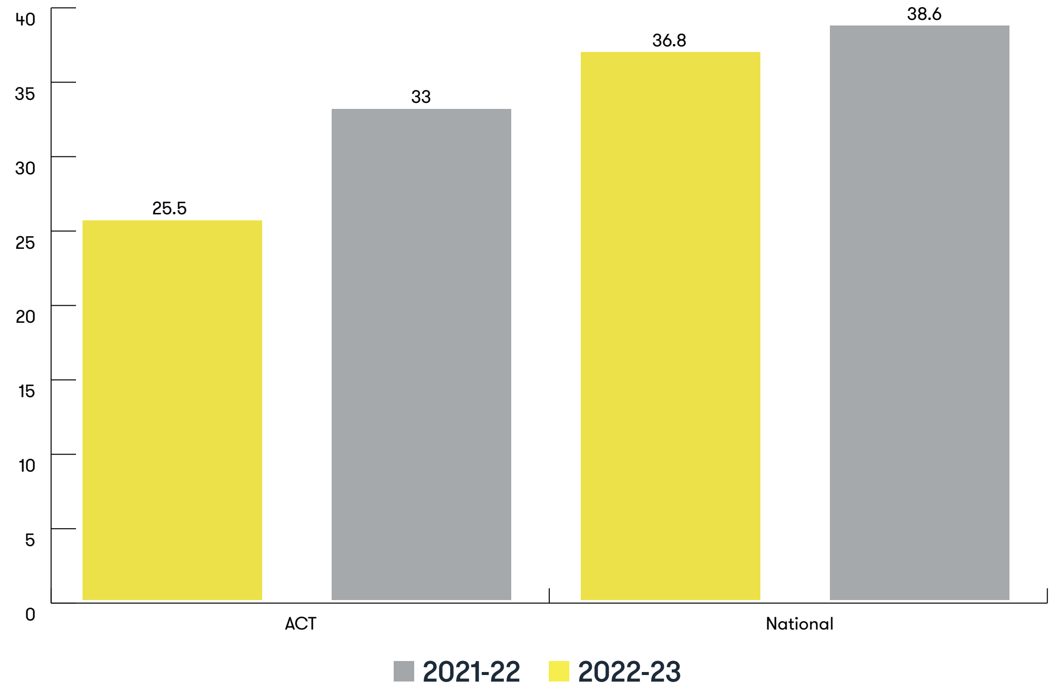
Stakeholders noted the need for a palliative care navigator service, similar to the care finder model in aged care or the South Australian Navigator Pilot (report pending). A single point of contact would help people navigate multiple complex systems during their palliative journey (8).

Hospitalisations and medication use

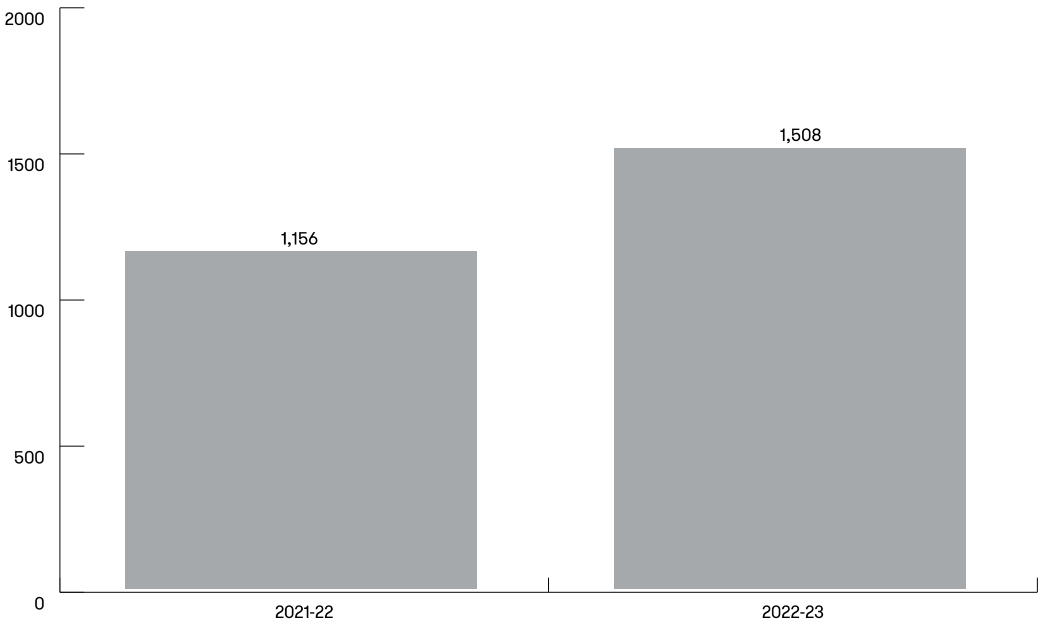
Palliative care is also delivered through hospital-based palliative care services within the public and private health system.

In 2022-23, there were 1,508 hospitalisations for palliative care in the ACT (26). The rate of palliative care related patients was slightly lower in the ACT (33.0 per 10,000) when compared to national rates (38.6 per 10,000). The number and rate of hospitalisations have risen from the previous year, when there were 1,156 hospitalisations at a rate of 25.5 per 10,000. Two in 5 (40%) hospitalisations for palliative care were due to a cancer diagnosis, while hospitalisation rates were highest in the 75+ age group, with 335.6 hospitalisations per 10,000 population.

Palliative Care-Related Hospitalisations Rate (per 10,000 population), ACT and Australia, 2021/22-2023/24

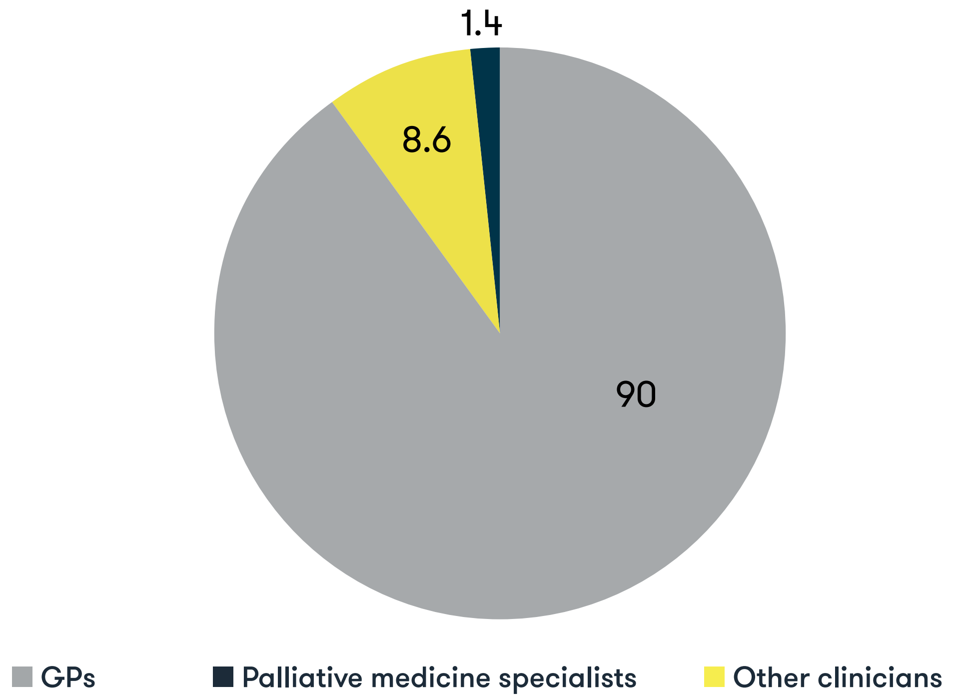


ACT Palliative Care-Related Hospitalisations Number, 2021/22 - 2022/23

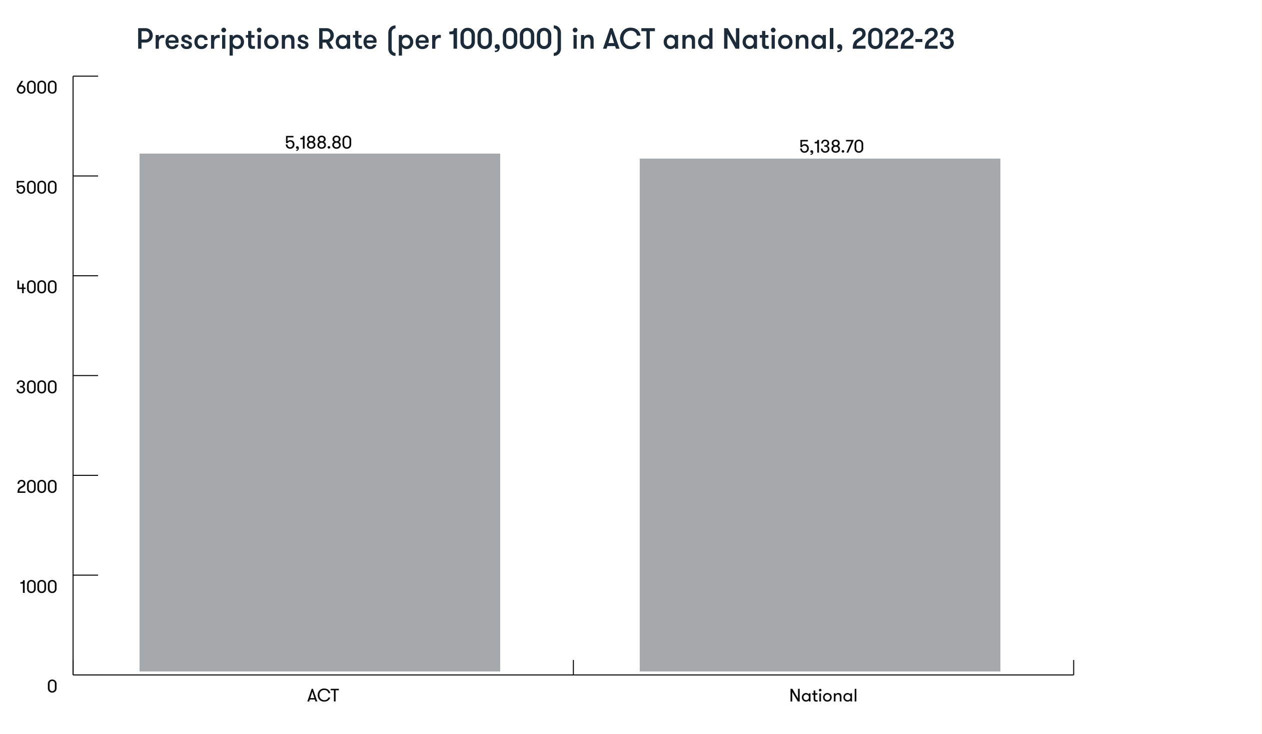


Prescription of medication to address symptoms such as pain and maintain comfort and function is an important aspect of palliative care. Nationally in 2022-23, 90% of palliative care related prescriptions were prescribed by GPs, highlighting the role of primary care practitioners and the importance of their knowledge of palliative care (26).

Prescriber Type Proportion (%) in Palliative ccare-related medication from PBS Palliative Care Schedule, National, 2022-23



In 2022-23, there were 7,550 people in the ACT who received PBS palliative care-related medications, with 23,709 total prescriptions provided. The rate of prescriptions in the ACT (5,188.8 per 100,000) was similar to the national rate (5,138.7 per 100,000). Approximately, 20,410 (86.1%) of these prescriptions were pain relief medications, with opioids the most common type of medication.



Grief and bereavement services

The Service Function Review (7) identified 24 ACT organisations providing carer focused support, including grief, bereavement, and psychosocial services. However, stakeholders reported that carers and providers still struggle to connect with these supports. A key finding was the need to increase awareness of available emotional, spiritual, and psychological services and strengthen linkages across the sector. Ensuring primary care practitioners, palliative care clinicians and the broader community have up-to-date knowledge of these supports is critical to holistic, patient and carer-centred palliative care.

CHN's GCfAHPC Scoping Report found these challenges are most pronounced for people not referred to SPC services—predominantly those with chronic illnesses, as cancer patients are more likely to access SPC. Patients and carers linked to SPC have easier, cost-free access to grief and bereavement support, unlike those outside SPC pathways.

Although the ACT Palliative Care Daisy Directory (29) and HealthPathways Bereavement, Loss and Grief Support Services pathway (30) page lists available services, stakeholders noted the information may not be widely known among health care providers or nonclinical palliative care services. Additionally, regularly updating available services list is highly resource intensive to ensure accuracy with current service availability.

Carers ACT provides counselling and coaching through the Carer Gateway (31), offering free support for up to six months after the caring role ends, typically 6–8 sessions. Carers ACT has advocated for extending this period, noting that grief often emerges over longer time frames and that carers face unique post caring challenges, including loss of identity.

Stakeholders also highlighted limited confidence and skills among frontline health care professionals to provide informal emotional support (12). In response, CHN delivers an annual face-to-face Grief and Bereavement Workshop for primary and community health care providers. These full-day sessions are consistently oversubscribed, with low GP attendance due to the format. To improve accessibility, CHN and the Australian College of Rural and Remote Medicine (ACRRM) have introduced free online grief and bereavement learning modules.

Data

Data availability in palliative care has long been a major challenge, limiting the ability to understand, plan and deliver effective services. While some specialist data exist, information about palliative care delivered through primary and community settings is often incomplete or absent. Nationally, identifying palliative care within existing data collections and establishing dedicated data sets has proven difficult. Recent work by the AIHW, funded by the DHDA aims to address these gaps, including the first release of linked datasets in 2024. The Palliative Care Outcomes Collaborative (PCOC) also supports quality improvement through specialist palliative care data.

Locally, limited data restricts understanding of the full palliative care system. ACT PCOC data have not been available since 2019 (32). In addition to the absence of PCOC data, there is insufficient information about the palliative care workforce, community need and services delivered across the Territory. National reporting captures only specialist palliative medicine physicians and palliative care nurses, and ACT physician numbers are not reported due to the small workforce.

Despite multiple services contributing to palliative care delivery, significant data gaps persist. The ACT Palliative Care Reporting Framework was designed to address several of these gaps and was endorsed in 2024 by the ACT HCSD Palliative Care Governance Committee, but implementation has been delayed and the framework was not operational as of January 2026.

The Palliative Care–related ED Presentation NLP project represents the first local attempt to identify ED presentations by people with palliative care needs or those already engaged with services. While early results are promising, further refinement is required, and analyses generated using these tools may contain inaccuracies. Findings should therefore be interpreted as one component of a broader evidence base.

Overall, richer and more comprehensive data would strengthen the ability to identify need, support continuous quality improvement, and inform planning, policy, and funding for palliative care in the ACT. Establishing consistent processes to collect, analyse and use palliative care data should be a priority for all current and future initiatives.

Priorities

Primary Care:

Strengthen primary care capability in palliative care by ensuring GPs and practice teams are equipped, trained, and supported to manage the significant volume of palliative care needs presenting in general practice across the ACT.

Community-based Care:

Expand community-based and in-home palliative care options in the ACT by strengthening service availability and ensuring dedicated, accessible end-of-life support beyond hospital-based models.

Breathlessness Intervention Support:

Highlight the needs of this at-risk group and explore options to provide breathlessness management education or training to in-home allied health staff.

Home Care:

Monitor the impact of emerging reduction in-home care and explore strengthening alternative pathways, including the new End-of-Life Pathway under the Support at Home program for aged care.

After-hours access challenges:

Strengthening after hours care pathways is a priority to ensure timely symptom management and reduce avoidable hospital use.

Ambulance Service Role:

Embed and strengthen the Extended Care Paramedic model within palliative care by partnering with the ambulance service to monitor and support paramedic responses to palliative patients at home, with a particular focus on after-hours care to reduce avoidable hospital transfers.

Community Palliative Medicines:

Re-establishing of a sustainable after-hours, home-based palliative medicines service to ensure timely access to essential medications, reduce avoidable hospital presentations and support patients to remain at home in their preferred place of care.

Residential Aged Care Homes:

Increase timely ACP completion, support early identification of end end-of-life patients, and strengthen palliative care capability through targeted education and training.

Telephone support:

Improve the accessibility, consistency, and effectiveness of after-hours palliative care telephone support by strengthening specialist responsiveness, increasing GP awareness, and evaluating options for a consumer-focused territory-wide service that provides timely guidance without defaulting to unnecessary ED referrals.

Grief and bereavement support gaps:

Improve access to grief, bereavement, and psychosocial support for carers by increasing awareness of available services, strengthening sector linkages, ensuring resources are current and accessible, and build frontline workforce confidence to provide informal emotional support—particularly for those not connected to specialist palliative care pathways.

Data:

Strengthen palliative care data collection, reporting, and analysis across the ACT, improving access to specialist and community program datasets, and advancing emerging tools such as NLP programs to build a comprehensive evidence base for planning, quality improvement, and system stewardship.

Chronic Illness:

Improve equitable access to specialist palliative care for people with non-cancer life-limiting illnesses.

Workforce capacity and distribution

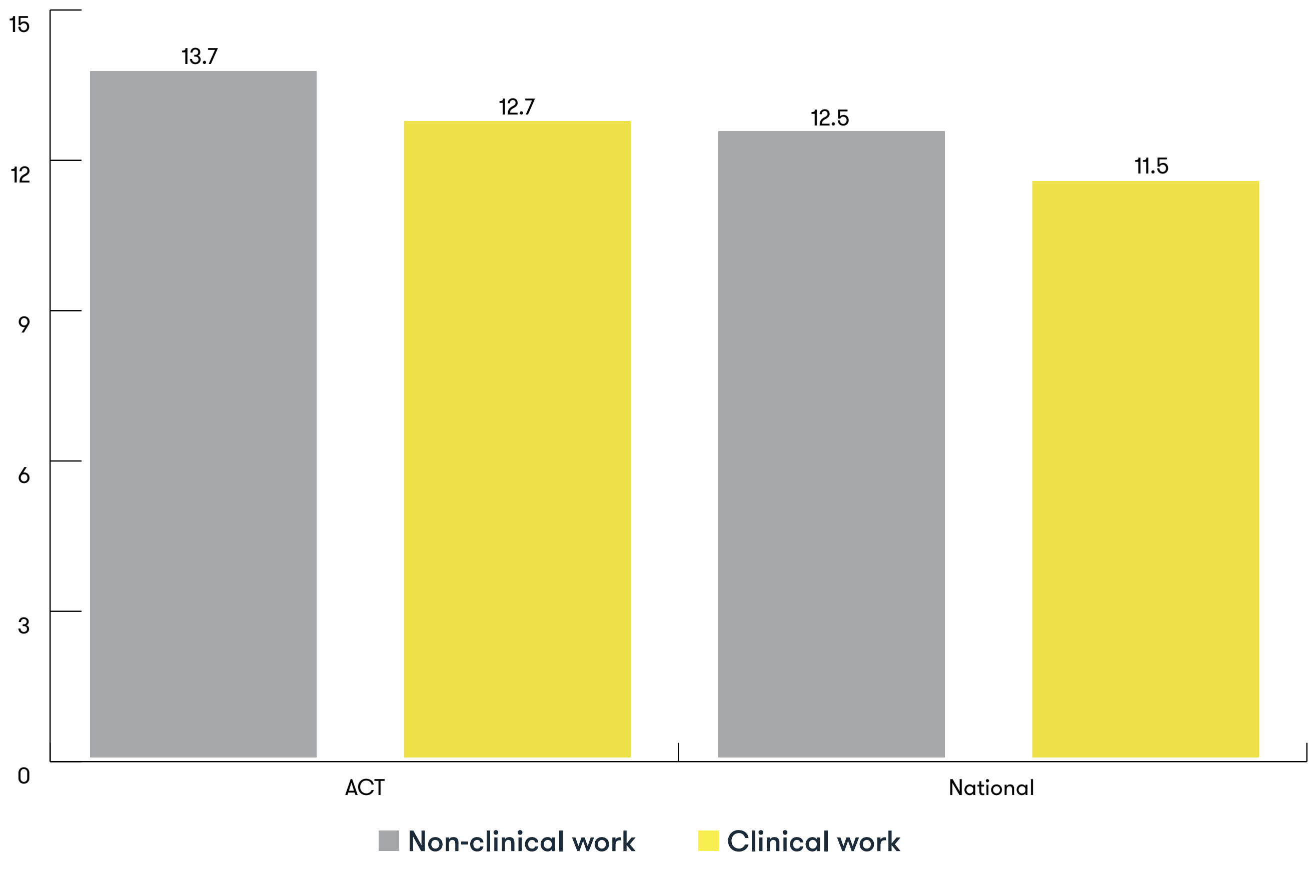
Workforce

The palliative care workforce is diverse, and is made up of specialist palliative medicine physicians, palliative care nurses, GPs, allied health professionals, and other specialists. With a diverse range of professions and skills, collecting data on the palliative care workforce is a challenge, with the AIHW only reporting on specialist palliative medicine physicians and palliative care nurses (33). This creates difficulties in understanding the true extent of the palliative care workforce nationally and in the ACT.

In 2022, there were 335 palliative medicine physicians and 3,700 palliative care nurses employed in Australia. These professionals accounted for approximately 300 Full Time Equivalent (FTE) and 3,300 FTE respectively (33).

The size and composition of the palliative care workforce are not well understood in the ACT. The number of palliative medicine physicians were not reported due to small counts. There were 64 palliative care nurses employed in the ACT in 2022, providing 62.4 FTE. This is a rate of 13.7 FTE per 100,000 population, the 4th highest of all states and territories (33). There are no paediatric palliative medicine physicians and 1.0 FTE paediatric palliative care nurse with an additional 1.0 FTE paediatric palliative care nurse being added in the near future.

Palliative Care Nurses FTE Rate per 100,000 population, ACT and National, 2022



As discussed in the ‘Available services’ section of this report, there were 422.4 FTE GPs in the ACT in 2024. According to research estimates that 1 in 100 services provided by GPs are palliative care related, it can be predicted that around 4.22 FTE GPs would be palliative care related. This is a broad estimate only and may differ to the reality of the situation. While individual GPs in the ACT may provide more or less palliative care related services based on their patient caseload (20).

A key finding of the ACT Health Service Function Review (7) was further work needs to be done to create an ACT Workforce Plan for the palliative care system. A workforce planning process will inform the requirements for meeting future demand, with palliative care needs increasing in the ACT.

Palliative care in Primary Care

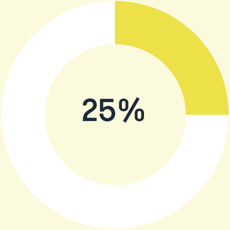
The provision of palliative care in primary care settings is a vital, and broad, often under-utilised, aspect of primary palliative care (22). Primary care practitioners, including GPs and practice nurses, have important general skills and knowledge that can be applied to assist patients with palliative needs to manage symptoms, maintain function and remain comfortable. Better understanding of breadth of the varied skill set, and their respective role within the wider palliative care system, is important to appropriately address the gaps identified within this space (22).

General practitioners

GPs are often the first point of contact in Australia's health system and play a central role in diagnosing, managing, and coordinating care. In 2023–24, 80% of the ACT population received a GP service (21). GPs frequently initiate diagnosis of life-limiting illnesses and have longstanding relationships with patients, positioning them as key pillars of the palliative care system. A confident GP workforce is essential, as GPs initiate end-of-life and ACP discussions, manage symptoms and refer to specialist palliative care. System knowledge and navigation skills are critical to delivering quality care.

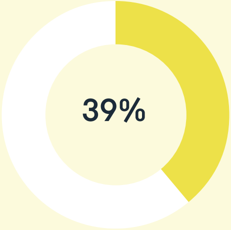
In 2017, DHDA research identified four GP segments in relation to palliative care (14):

Experts



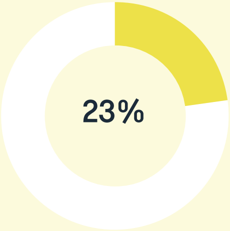
comfortable, knowledgeable, and engaged.

Aspirers



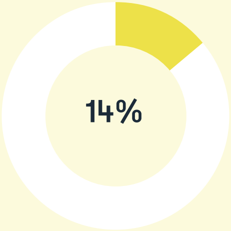
interested but limited by skills, knowledge, or exposure.

Indifferent



provide palliative care when required but do not seek it out.

Avoiders



actively avoid palliative care.

Understanding these groups and tailoring engagement, education and training accordingly is essential. There is no one size fits all approach to meet diverse needs of GPs in the ACT. Although the current distribution of ACT GPs across these segments is unknown, gaining this insight will further support and cater to future planning.

GPs work across multiple palliative care settings—clinics, homes, RACHs, hospices and hospitals. They report in-home care as the most challenging, with other settings easier due to stronger support systems. While roles vary across settings and can create uncertainty, GP involvement in palliative care remains broadly beneficial.

Primary care nurses

Primary care nurses play a key role in general practice, supporting GPs in areas such as chronic disease management and preventative care. These transferrable skills position them well within the palliative care system, enabling effective contribution to multidisciplinary care (34). The Australian Primary Health Nurses Association (APNA) Workforce 2021 survey found that although utilisation of practice nurses has increased since the COVID-19 pandemic, their skills remain under-used. The report recommended policy reforms to support nurses to work to their full scope, noting many wish to extend their clinical role (34).

DHDA research into palliative care in general practice recommended promoting the role of primary care nurses, emphasising the need to formalise their contribution to planning and care coordination (14). Stakeholder feedback across the ACT supports this, with broad agreement that primary care nurses could be better utilised throughout the palliative care journey. Enhancing their role through clearer recognition, training and education is proposed as a way to strengthen palliative care delivery (14).

Model of Shared Care

The role of primary care professionals in palliative care is varied, which can create uncertainty about responsibilities and limit involvement in decision-making. GPs work with palliative patients across multiple settings and report differing experiences depending on the level of support available in environments such as RACHs and hospitals (14).

Integration of services has been identified as a key priority in CHN's core Needs Assessment (11), echoed by palliative care stakeholders (7,8). Strengthening linkages, relationships and pathways between services would help clarify roles across the multidisciplinary team and support more coordinated care.

DHDA research into palliative care in general practice (14) recommended formalisation of a palliative care nurses' role within the general practice as a key liaison/shared care coordinator as a "quick win" to improve shared responsibility, integration between various services and disciplines ensuring better coordination of patient care.

Greater clarity is also needed for practice nurses, community nurses, and allied health professionals. Understanding scope and how these roles intersect is essential to building a system where specialists provide specialist care and are supported by a strong generalist workforce, as recommended in the 2023 Service Function Review (7).

Funding (MBS remumeration)

Potential limitations within the MBS funding model, together with low bulk billing rates may reduce a practitioner's capacity to undertake extended and repeated consultations essential to the management of palliative care patients and their carers. CHN's Palliative Care in General Practice Quality Improvement (PCiGP1) activity also identified low awareness among some GPs of relevant MBS item numbers.

General practice palliative care is supported by fee-for-service funding, which does not account for essential non-billable work such as care coordination, phone-based prescribing, extended home visits, post-death support, and complex family discussions. Emerging My Medicare reforms and multidisciplinary team-based models may begin to address these unmet needs by better recognising the time and complexity involved.

The PCA 2024 National Palliative Care Workforce Survey (37) highlights significant capacity and funding pressures. Among 129 primary care respondents, 72% reported rising demand, only 11% felt adequately funded, and just 35% believed they had enough time to meet patients' needs. Many described unpaid or under-recognised work, often provided "out of compassion," and expressed a desire to do more despite inadequate remuneration.

Stakeholders have suggested greater use of practice nurses to support coordination and administrative tasks, allowing GPs to focus on clinical work within a multidisciplinary model (14,35,36).

End-of-Life Doulas

End-of-life (death) doulas provide non-medical support to individuals nearing death and their families. Their role is to reduce fear and uncertainty by offering emotional, spiritual, and practical assistance tailored to personal values and cultural needs. Services include education about dying, ACP, advocacy, emotional reassurance, and post-death support (38).

Doulas complement—not replace—clinical and aged-care teams, promoting holistic care across settings. They help clients identify and express end-of-life preferences and maintain continuity through decline, dying, and after death (38).

Although not registered health professionals, doulas operate under the National Code of Conduct for Unregistered Health Care Workers, ensuring safe, ethical, and accountable practice (38).

Training opportunities in Australia have expanded significantly in recent years including a Certificate IV in End-of-Life Doula Services. This is a world-first and only nationally accredited training program dedicated to end-of-life doula work. Within the ACT, ten doulas have completed the intensive course and two have completed the Certificate IV, highlighting the growing presence of this profession locally (39).

Workforce roles and capabilities

Stakeholders consistently report the need for clearer role definitions, stronger palliative care knowledge and improved access to education and training.

Role clarity across the care team has been identified as a challenge, leading to confusion for clinicians, patients, and carers (7,13). Although there is broad agreement that specialist palliative care should provide advice and support towards end-of-life before handing over care to generalist or community providers, this transition does not occur consistently (7,13). A clearly defined shared-care model outlining roles and responsibilities may help address these challenges.

Stakeholders report that workforce shortages in community-based services, renal and paediatric support, and key allied health disciplines further contribute to inconsistent handover of care. Limited generalist clinician knowledge, confidence, and willingness also influence the inconsistent handover of patients from specialist palliative are to generalist providers (7).

Defining the role of GPs was also recommended in the DHDA's 2017 research into awareness, attitudes, and best practice (14). Clear expectations of GP responsibilities are important to empower all GPs to work with palliative patients, regardless of their comfort level.

Improving palliative care in the ACT requires strengthening the knowledge and confidence of non-specialist professionals. Stakeholders note that gaps and inconsistencies often stem from limited understanding of palliative care, leaving clinicians unprepared for essential end-of-life conversations and resulting in inadequate planning (7,8,10,12). Establishing a consistent baseline of training across primary care is therefore critical.

National Palliative Care Projects' resources provide a strong foundation and should be used more widely to build core and advanced skills (40). CHN has delivered a range of tailored education options drawing on national initiatives such as Program of Experience of the Palliative Approach (PEPA), End-of-Life Law for Clinicians and Palliative Aged Care Outcomes Program (PACOP), as well as guidance from peak bodies and local expertise from ACT Palliative Care, the Health Care Consumers' Association of the ACT, GPs, and specialist teams.

Training topics have been shaped by consumer and stakeholder input and informed by the CHN GCfAHPC Scoping Report (12). Despite the breadth of offerings, overall engagement remains low, with stronger participation only in areas such as grief and bereavement, and breathlessness management. Increasing uptake across the full suite of education opportunities would significantly strengthen workforce capability and improve palliative care delivery across the ACT.

Priorities

GPs:

Strengthen GP capability and engagement in palliative care by tailoring education and support to recognise and support palliative patients, improving system navigation skills, and enhancing assistance for in-home care, where challenges are greatest.

Primary Care Nurses:

Strengthen the role of primary care nurses in palliative care by formalising their contribution to planning and coordination, expanding training and education, and supporting them to work to their full scope across the palliative care journey.

Model of Shared Care:

Strengthen integration and role clarity across primary care and specialist palliative services by improving shared-care pathways, communication, and multidisciplinary coordination so generalists can confidently contribute alongside specialist teams.

Funding:

Understand the need to improve the financial viability of palliative care in general practice by exploring increasing remuneration through increased use of existing MBS items, expanding dedicated MBS support, and enabling multidisciplinary models that reduce non-billable workload and allow GPs to deliver high-quality end-of-life care.

End-of-Life Doulas:

Strengthen recognition and integration of end-of-life doulas within the ACT palliative care system by increasing awareness of their role, supporting safe and ethical practice under the national code, and exploring opportunities to connect trained doulas with clinical and community services to enhance holistic, person-centred end-of-life support.

Workforce roles and capabilities:

Strengthen palliative care capability across the primary and community workforce by establishing clear role expectations and improving access to high-quality education so clinicians feel confident, prepared and supported to deliver end-of-life care

Coordination between primary, community and specialist services

This section outlines barriers and challenges that are consistently raised by palliative care service providers and key stakeholders in the ACT.

Care navigation

Care navigation supports were identified in CHN's core Needs Assessment (11), the Service Function Review (7), PCiGP1 (13), and ongoing stakeholder feedback as an important need across the region to improve the care navigation between primary care and palliative care.

Four themes emerged during the recent ACT Palliative Navigation workshop (8).

Limited Public Understanding:

Community understanding of palliative care is low, with widespread myths and misconceptions – particularly the belief that palliative care is only for the terminal phase rather than applying a holistic, broader approach to care. This lack of awareness and understanding limits effective engagement and navigation. Stakeholders emphasised the need to close information and education gaps to strengthen community capability to understand and navigate the system.

Inconsistent Access and Referral Pathways:

Eligibility and referral processes are unclear and inconsistent, creating barriers to accessing palliative care especially for people with non-malignant conditions and those receiving primary or community-based care. Fragmented system-level processes place the burden on individuals to navigate services using their own knowledge and resources, increasing inequities and further fracturing access pathways.

Lack of Centralised Information:

There is no central, reliable hub for palliative care information in the ACT, leading to confusion and uncertainty for consumers. The absence of a clear "front door" places undue reliance on practitioners to guide patients and families, adding pressure to already stretched workloads. Stakeholders highlighted the value of a standalone, trusted single point of truth for palliative care information, supported by specialist perspectives to meet the needs of diverse communities.

Complex, Multisectoral Needs:

Palliative care spans multiple systems – including health, social, aged care, and disability - requiring people to navigate several complex pathways simultaneously. Stakeholders noted the need for a palliative care navigator that complements, rather than duplicates, existing navigation supports such as care finder and highlighted major service gaps for people under 65. A case-management approach, with a single point of contact coordinating multiple services, was seen as valuable. Broader issues with access to primary and community care, including financial barriers to GP access, further complicate navigation. Stakeholders also noted uneven pathways for NSW residents, underscoring the need for navigators to understand services within the ACT and across the ACT–NSW border.

Continuity of Care

Despite the number of palliative care services in the ACT, stakeholders report that care remains fragmented and siloed. CHN's core Needs Assessment identified fragmentation and poor integration as widespread issues across primary care, leading to weak transitions, ineffective referrals, and reduced quality of care (11). The Service Function Review (7) similarly highlighted these challenges within the palliative care sector.

Stakeholders frequently note that services operate in isolation and do not consistently provide collaborative, multidisciplinary care despite its importance for patient-centred practice. Limited collaboration contributes to poor awareness of available services, incomplete referrals, duplication, and long wait times (7,8,12).

Since the Service Function Review, two major system changes—the introduction of the ACT Digital Health Record (DHR) and the compulsory acquisition of North Canberra Hospital, including Clare Holland House—have begun to improve information sharing, communication, and transitions between CHS programs. However, general practices, ACT Ambulance Service and RACHs do not have access to DHR, including ACP and Goals of Care documentation and does not translate to the My Health Record receiving updates or communication outside the ACT to a NSW GP.

Practices involved in the Palliative Care in General Practice Quality Improvement activity reported significant improvement in end-of-life coordination including ACP, early identification of palliative patients, uptake of relevant MBS item numbers, and appropriate referrals (13).

Although funding constraints, workforce shortages and limited time all remain barriers, stakeholders consistently emphasise that stronger collaboration, coordination, and linkages between services would improve palliative care across the ACT.

Funding

The Service Function Review (7) and Palliative Care Australia (42) highlight that current funding arrangements for programs such as the NDIS and aged care, while providing essential services, often limit flexibility and delay access to support, forcing patients and carers to prioritise needs. Stakeholders emphasise the need for a stronger, better-resourced primary care system to fill service gaps, noting that although specialist palliative care in the ACT is well equipped for complex cases, many patients who do not require specialist care lack adequate support from non-specialist clinicians. Concerns were also raised about restrictive program rules, the three-month limit on services, paused Support at Home reforms (18,19), and reduced community care capacity, including providers declining home visits for those with aged care packages and funding cuts to in-home service providers. Overall, the system remains heavily weighted toward specialist palliative care, and greater investment in primary and community-based palliative care is needed to improve equity, access, and continuity of support.

HealthPathways

The HealthPathways program is a unique cross-border partnership involving CHN, ACT Health, Southern NSW Local Health District (SNSWLHD) and COORDINARE (South-Eastern NSW PHN). It is a free online resource and navigation tool for health care professionals that provides assessment, management, resource, and referral information for a wide range of conditions, including palliative care (30). Stakeholders have emphasised the importance of ensuring that HealthPathways includes referrals information to non-clinical community organisations (7,8), enabling clinicians to consider the full range of options available to patients with palliative needs.

Information sources

Clinical and community stakeholders consistently report a lack of consistent, up-to-date information about palliative care services (7,8,12,13). The 2022 Palliative Care Scoping report highlighted that clinicians and service providers often do not have reliable information about available services—a concern reiterated in the Service Function Review, the Navigation Workshop and PCiGP1 (7,8,13,). Although multiple information sources exist, including Palliative Care ACT, CHS and HealthPathways, many users find the content needs regular update to support the broader intertwined system changes and avoid confusion.

Improving clinicians' access to accurate, current information—alongside strengthening their palliative care knowledge would support better service integration, more timely referrals, and improved care delivery across the ACT. Work is already underway: the Palliative Care HealthPathways pathways are being updated, and CHS Specialist Palliative Care and CHN are collaborating to improve the accuracy and currency of information available through ACT Government and CHS websites. Once complete, these efforts present an opportunity to increase awareness of where healthcare professionals (HealthPathways) and the community can reliably access up-to-date palliative care information.

Multidisciplinary care

The Strengthening Medicare Taskforce Report highlights the importance of coordinated multidisciplinary teams working to full scope to deliver quality, person-centred care. Palliative care involves a wide range of professionals—specialist physicians, GPs, allied health practitioners, pharmacists, and paramedics—each contributing distinct expertise (41). Multidisciplinary collaboration is widely regarded as essential to holistic care.

Allied health professionals and nurses have strong palliative care competencies, including monitoring symptoms, identifying changes in condition, and providing physical, social, and emotional support. Stakeholders emphasise their value but note that their skills are often under-utilised. Many report that palliative care in the ACT is overly medicalised, with specialists' "handholding" in the end stage of life where allied health or nursing leadership could be appropriate and free up specialist capacity (7).

Improving multidisciplinary teamwork is a high priority across the ACT primary care system and is particularly relevant in palliative care, where stakeholders consistently report gaps in access to multidisciplinary support. Patients referred to SPC benefit from a broad range of disciplines, but this level of support is not available for those receiving primary palliative care (7). The Community Care Program has only 1.0 FTE palliative care nurse specialist, and allied health staff are stretched across multiple service areas. While NDIS and aged care packages may provide multidisciplinary supports, provider skills and confidence in palliative care vary, and training uptake is limited due to workforce structure and lack of remuneration.

Limited allied health availability in primary care, combined with funding and remuneration constraints, further restricts access. The CHN Social Workers in General Practice Pilot demonstrated the valuable role social workers can play in supporting palliative patients and reducing GP burden through psychosocial support (23).

Fragmentation across services continues to hinder effective multidisciplinary care. Multidisciplinary practice is essential to addressing the physical, psychological, social, and cultural needs of people requiring palliative care (4). Pharmacists also play a key role, with over 20,000 pain-relief medications prescribed in 2022–23 (26) and also reported through the CHN-funded After-hours Palliative Care Delivery Pilot Program (23).

ACT palliative care model remains predominantly medical rather than holistic, shaped by historical structures and funding (7). Transitioning toward a more patient-centred model that embeds multidisciplinary care is seen as necessary to better meet community needs. Harnessing the diverse skills of the palliative care workforce through stronger collaboration would increase flexibility and improve the quality and consistency of palliative care across the ACT.

Timely access

Initiating palliative care at the right time is essential to quality care. Patients with life-limiting illnesses may require palliative input for several years, with needs fluctuating throughout this period, creating multiple opportunities for their palliative needs to be recognised and addressed. Evidence shows that early referral can prolong life and improve overall quality of life (43).

Despite this, stakeholders across the ACT report that early discussions and timely referrals do not occur consistently (7,8). Contributing factors include limited early and timely recognition in identifying a patient is palliative; fragmented understanding and differentiation between the role of palliative care and end-of-life care; unclear roles and responsibilities; limited readiness among patients and carers to accept palliation; and poor integration between services (7,8).

Timely access to palliative care within RACHs is a particular challenge (7,8). Although a range of services exists, palliative care in these settings is variable and often initiated only at the last minute in response to urgent need, creating additional stress for residents, families, and staff. The new Aged Care Act, introduced on 1 November 2025, establishes a right to palliative and end-of-life care for all people accessing Australian Government-funded aged care services, creating a clear imperative for RACHs to strengthen palliative care support (16). Focused efforts to improve timely referrals and access within these facilities will likely be required in the coming years.

Priorities

Limited Public Understanding:

Strengthen community understanding of palliative care by addressing widespread misconceptions and improving access to clear, accurate information.

Inconsistent Referral Pathways:

Establish and communicate clear, consistent, and transparent eligibility and referral pathways to reduce inequities and improve access to palliative care.

Lack of Centralised Information:

Creation of a single, trusted and up-to-date central hub for palliative care information to support consumers and reduce reliance on individual practitioners.

Complex, Multisectoral Needs:

Implement a coordinated navigation and case-management support that spans health, social, aged care and disability systems to help people manage complex, multisectoral palliative care needs.

Continuity of Care:

Strengthen collaboration, coordination, and integration across palliative care services—supported by improved information sharing and system linkages—to reduce fragmentation and ensure consistent, patient-centred care across the ACT.

Funding:

Explore where increased investment in primary palliative care can be utilised to address funding-related gaps, improve flexibility and equity of access, and ensure community-based patients receive timely, appropriate support alongside specialist services.

HealthPathways:

Ensure ACT HealthPathways is accurate, up-to-date and inclusive of both clinical and non-clinical referral options to support clinicians in navigating palliative care effectively and providing consistent, informed guidance to professionals.

Information:

Improve access to accurate, consistent, and up-to-date palliative care information by updating key central hubs for palliative care information and increasing awareness of where clinicians and the community can reliably find current guidance.

Multidisciplinary Care:

Strengthen and embed multidisciplinary, team-based palliative care across the ACT by improving collaboration, expanding access to allied health and nursing support, and shifting toward a more holistic, patient-centred model that fully utilises the diverse skills of the palliative care workforce.

Timely Access:

Improve early identification and timely referral to palliative care—particularly within RACHs—to ensure people receive appropriate support well before crisis points.

Cultural and diversity considerations

Children

The paediatric palliative care service in the ACT currently consists of one FTE nurse, with a second FTE soon to commence. There is no paediatric palliative care physician locally, meaning end-of-life clinical care is coordinated by an adult palliative care specialist or paediatrician, often in collaboration with the Sydney Children's Network Palliative Care team. Children requiring specialist palliative inpatient support must travel to Sydney (7).

Because many paediatric palliative patients have long care trajectories and receive much of their treatment interstate, strong connections with ACT-based practitioners and community services are often not established early. As a result, when a child enters the terminal phase and families wish for end-of-life care to occur locally, they may need to form new clinical relationships and support networks during a period of profound distress, adding further burden at an already difficult time (7).

There is an opportunity to strengthen paediatric palliative care capacity in the ACT, particularly through increased medical support and by providing wrap-around support to the two nurse FTE positions via closer integration with the adult specialist palliative care service.

First Nations People

Estimates from the 2021 Census show the ACT is home to 9,525 First Nations Australians (2.1% of the population), a lower proportion than the national average but similar to other capital cities. The population is young, with a median age of 24 years and just over half aged under 25; only 10.6% are aged 55 and over (44).

Patterns of death differ markedly from those of non-Indigenous Australians. First Nations people tend to die younger and from different life-limiting illnesses, with leading causes of death in 2023 including ischaemic heart disease, diabetes, chronic lower respiratory disease, lung cancer, and intentional self-harm. The life expectancy gap remains significant, with a median age at death of 63.7 years compared with 82.2 years for non-Indigenous people (45).

Recent discussions with First Nations people in the ACT highlighted considerable fear and uncertainty about palliative care, with community members reporting limited support and inadequate information about advanced illness, death and dying. CHS is developing a culturally tailored "When Someone Is Dying" resource—Into the Dreaming—which will be made available in community and primary care settings.

No culturally specific palliative or end-of-life clinical services were identified through the Service Function Review (7). Stakeholders emphasised the importance of cultural accessibility and the need to address barriers such as travel costs, provider cultural competency, system navigation challenges, limited involvement in decision-making and longstanding mistrust of services. There was strong agreement that palliative and end-of-life care must be respectful of diverse cultural and spiritual beliefs (7,8).

The May 2025 ACT Government budget allocated funding to improve end-of-life support for First Nations people, including establishing a Community Aboriginal Liaison Officer to provide outreach and case management (46). With the opening of Yerrabi Yurwang Health, alongside Winnunga Nimmityjah Aboriginal Health Service, the ACT now has two ACCHSs delivering comprehensive primary care. These services present opportunities to distribute palliative care resources and connect with the new liaison role within CHS.

People from multicultural backgrounds

The ACT has a culturally diverse population, with more than one-quarter of residents born overseas. In 2021, 22.4% of the population were born in a non-English speaking country, and around one-quarter speak a language other than English at home (47). his diversity shapes how communities understand health, illness, the health care system, and experiences of death and dying.

At the Navigation Service Workshop, stakeholders noted that many multicultural families are unfamiliar with palliative care, with some viewing it as taboo (8). For those who do access the system, it can feel fragmented and overwhelming. These themes were echoed across the Service Function Review (7), and the CHN Needs Assessment (11), which consistently identified gaps in cultural awareness and competency among health care professionals, limited experience working with multicultural populations, language barriers and mismatches between clinical approaches and cultural preferences. Multicultural community consultations reinforced the need for palliative care services that are accessible, culturally safe, and able to support people navigating a complex and unfamiliar system.

Stakeholders identified opportunities to strengthen cultural safety, including ensuring translators have strong health literacy and cultural understanding, and promoting cultural competence training for the residential aged care workforce, such as Partners in Culturally Appropriate Care (PICAC) training. Workshop participants also emphasised the importance of stronger engagement and communication strategies, including promoting multicultural-specific services through trusted community leaders and organisations, with support extending to both patients and carers.

The Multicultural Advance Care Planning Project, delivered by the Canberra Multicultural Community Forum (CMCF) in 2023–24, was highlighted as an example of effective, culturally responsive engagement (8). The project delivered ACP forums tailored to different cultural groups, creating safe spaces for discussions about ACP, death, dying, and palliative care. CMCF worked with CHS to develop an education plan that tailored engagement to each community, addressed limited understanding of ACP, and integrated promotional activities into cultural celebrations. A monthly community radio segment provided ongoing outreach across multiple cultural groups (48).

Consultations with multicultural community leaders guided how best to encourage participation in ACP. Early engagement focused on the Chinese community, with additional outreach to Nepalese, Indian, African, and Muslim groups. Information from the ACP Australia website was translated into multiple languages, and discussions linked ACP with palliative care to build understanding. The project gained visibility through a presentation to the ACT Minister for Multicultural Affairs. A common question across communities concerned the choice of a “support person,” highlighting the need for clearer, culturally sensitive guidance (48).

Despite strong interest and collaboration, the project was short-term, and the lack of ongoing funding has limited continued engagement. CMCF remains focused on supporting communities to understand the Australian health system and local processes.

People with disability

People with disability who have a life-limiting illness often rely on non-clinical disability service providers or live-in residential disability accommodation, yet many are unable to access clinical support at home (42). This leads to avoidable symptom burden, delays in holistic care, unnecessary hospital admissions, and a higher likelihood of dying in hospital rather than at home. Early and effective connection with a palliative care team can prevent these outcomes through proactive symptom management, ACP, and coordinated community support, but significant barriers persist (42).

A longstanding challenge has been confusion about who funds and delivers different types of support. Specialist palliative care sits within the health system, while daily living assistance, equipment, and functional in-home supports fall under disability funding, but this distinction was not always applied consistently (42). Recent rule changes have clarified these responsibilities, yet many people with life-limiting illness still struggle to access timely palliative care and reliable in-home support—particularly those aged under 65 years and those whose disability arises from their illness, who often do not fit neatly into existing pathways (42).

Stakeholders also reported that some individuals are declined by home-based palliative care services because they are not considered “imminently dying,” despite needing assessment and symptom management (10). Without accessible home-based palliative care, people face higher risks of avoidable hospital admissions, reduced quality of life and dying in hospital rather than in their preferred setting. Many require simple clinical interventions that could be delivered safely at home but instead must present to hospital due to a lack of community-based clinical support, often remaining there until death.

Concerns were also raised about disability support workers’ limited ability to provide pain and symptom management—particularly their inability to administer or support the use of opioids—creating further gaps in care. These barriers highlight the need to explore and map disability end-of-life pathways in the ACT. Several new models of care, resources and toolkits have been developed to address these challenges, offering flexible frameworks to guide tailored, high-quality palliative care for people with disability (49,50). Improving clarity, increasing education, and implementing these evidence-informed models may help strengthen coordination and improve access to palliative care for people with disability in the ACT (10).

People who use drugs or accessing opioid maintenance treatment

There is a growing population of older people who use drugs, and careful consideration is needed to support them as they develop life-limiting illnesses and approach end-of-life. Their health challenges are often intensified by economic instability, social isolation, and stigma, with many having reduced social networks due to premature deaths among peers and the lifelong impacts of discrimination. These factors compound the complex and often unmet health needs experienced by older adults who use drugs (51).

Stakeholders in the ACT have identified several barriers to palliative care for this population, including social isolation, unstable housing, minimal engagement with health care due to stigma and not feeling understood, reluctance to attend hospital because of concerns about withdrawal, limited access to home visits from specialist palliative care, difficulties accessing adequate pain relief, and challenges accessing Opioid Maintenance Treatment (OMT) and Needle and Syringe Programs (NSP) at home (7,51,52). Additional issues arise in aged care, where people on OMT may face discrimination, de-prioritisation, difficulty accessing treatment and misconceptions that limit chronic pain support.

To ensure equitable access, service providers must recognise the stigma and discrimination encountered by people who use drugs or access OMT. It is important to understand that some individuals may prefer care delivered at home. Providers should use non-stigmatising language and apply health equity and trauma-informed care principles to build trust and rapport (52).

Peer partnerships play a critical role in enhancing safety, trust, and access to care. Peer workers can support marginalised individuals, improve engagement and continuity of care, and increase the confidence of nurses providing in-home or outreach support. An integrated palliative care model involving peer workers, alcohol and other drug (AOD) services and mental health service providers offers a significant opportunity to better engage and support people who use drugs, many of whom face barriers to traditional services. Strengthening collaboration between palliative care providers and peer-led services could lead to more effective and equitable outcomes for this population (52).

Priorities

Children:

Identify system level changes to build paediatric palliative care capacity in the ACT, with a focus on specialist and primary care involvement, and better integration with adult specialist palliative care to enable coordinated local care for families.

First Nations People:

Strengthen cultural safety and accessibility of palliative and end-of-life care for First Nations people in the ACT by improving culturally informed support, addressing systemic barriers, and enhancing partnerships with Aboriginal Community Controlled Health Services.

People from Multicultural Backgrounds:

Strengthen cultural safety and accessibility of palliative care for multicultural communities by improving cultural competence, enhancing communication and engagement through trusted community channels, and ensuring services can support people navigating a complex and unfamiliar system.

People with disabilities:

Improve timely, coordinated home-based palliative care for people with disability by clarifying responsibilities, strengthening community clinical support, and implementing evidence-informed models that address gaps in pain management, service pathways, and workforce capability.

People who use drugs or accessing opioid maintenance treatment:

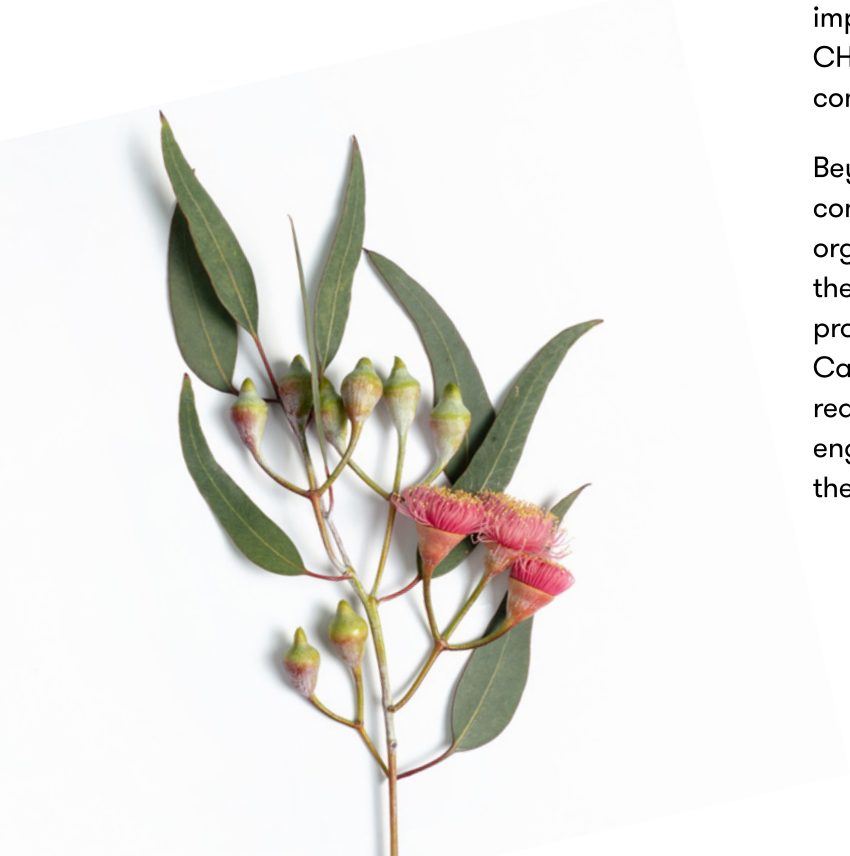
Equitable, stigma-free palliative care for people who use drugs can be improved by expanding home-based support, integrating peer workers, and improving collaboration between palliative, AOD and mental health services.

Community awareness and understanding of palliative care

Communication and shared decision making

Clinicians report they often feel under-prepared or uncomfortable initiating end-of-life discussions, and current models of care make it difficult to allow the time these conversations require (13). Yet timely, values-based, goals-of-care discussions are essential to ensure patients' beliefs, preferences and priorities guide their care as their condition progresses.

Stakeholders consistently highlight that limited clinician skill, experience and confidence can hinder these conversations, despite their importance to holistic, patient-centred palliative care (7,8). CHN's 2025 Serious Illness Goals of Care Communication Forum demonstrated strong engagement and provided practical support for identifying triggers, applying shared decision-making and understanding ACP processes. Its success suggests value in continuing and potentially expanding this initiative to further build capability across the primary and community workforce.



Palliative care knowledge

Public understanding of palliative care remains limited in the community, including the ACT, with many people only encountering the concept for the first time after a life-limiting diagnosis (54). This lack of awareness can delay engagement with palliative care and reduce opportunities to improve quality of life early in the illness trajectory (10,53). Recent CHN survey responses using the Death Literacy Index (53) reinforce that community knowledge is low on what services are available and how to navigate the care system, and that people often struggle to understand what palliative care offers and how it can support physical, emotional, social, and spiritual wellbeing.

Improving death literacy helps patients and families feel more informed, confident, and able to participate in decision-making (10,53). Palliative Care ACT has recognised this need and will introduce the Waiting Room Revolution program in 2026, offering practical tools, key questions and a clear framework to help people navigate a life-changing diagnosis. While its impact is not yet known, there is strong potential for CHN to support its promotion and delivery to broaden community reach.

Beyond this program, CHN can also strengthen community-wide death literacy by collaborating with organisations such as Palliative Care ACT, HCCA and the Canberra Multicultural Forum. Supporting and promoting initiatives like Dying to Know Day, Death Cafés and other community-led events would help reduce stigma, increase understanding, and improve engagement with palliative care services across the ACT.

Advance Care Planning

ACP supports people to document their values, beliefs, and future health-care preferences while they are still able to make decisions, helping ensure care aligns with what matters most to them and reducing stress for families and carers (54). Although ACP is particularly relevant for people with life-limiting illness, overall awareness remains low. Only around one-third of Australians are familiar with ACP, and even fewer have discussed their future health with others or with a health professional. Many people report not knowing where to start, being unsure of the process or finding it too difficult (56).

Low community awareness, limited practitioner confidence, and the absence of an ACP-specific MBS item all contribute to low uptake (13,55). Even when ACPs are completed, documentation is often inconsistent or inaccessible across systems, meaning a person's wishes may not be known or followed. Stakeholders in the ACT consistently highlight the need to better promote and record ACPs as clear documentation supports continuity of care, informs referrals, and helps integrate services around patient priorities (7,14).

The Service Function (7) Review emphasised the importance of increasing awareness and referrals to the ACP service within Canberra Health Services (CHS). Improving uptake may involve clearer referral triggers and targeted training to build primary care confidence in initiating ACP discussions and supporting patients through the process.

General Practitioners

GPs are often the first point of contact for people when discussing and managing their health needs, placing them in a strong position to encourage conversations about and completion of formal ACPs. They possess strong skills in care coordination and preventive health and maintain ongoing relationships with patients and their families throughout life. These enduring relationships provide GPs with a deep understanding of their patients' circumstances, creating opportunities to discuss future care, including ACPs.

Encouraging patients to consider their future health care needs—even when they are well—can deliver substantial benefits to the patient, their family, health care providers, and the broader health care system. These discussions are particularly important when a patient is diagnosed with a life-limiting illness, as GPs are trusted and knowledgeable parties who can guide the conversation. However, it is acknowledged that ACP discussions are time-consuming and may not be a patient's immediate priority during routine GP visits (13,14). CHN's PCiGP1 quality improvement activity highlighted that even when GPs identify a patient is in their last 12 months of life, they do not facilitate the completion of an ACP (13). Providing additional supports to facilitate these conversations would strengthen the palliative care system in the ACT and benefit the wider health care system.

Practice Nurses

Practice nurses may offer a practical solution to these challenges. Many stakeholders suggested that nurses could initiate ACP discussions and coordinate care to ensure patients are directed to the appropriate services. Involving practice nurses when a patient is diagnosed with a life-limiting illness could reduce the workload on GPs while ensuring ACP conversations occur in a timely manner. As a result of participating in CHN's PCiGP1 quality improvement activity, one practice implemented a policy to introduce and facilitate the completion of ACPs with every patient undergoing a 75+ Health Check. This initiative resulted in a significant increase in ACP completion among patients aged over 75 years (13).

Currently, there is no MBS item specifically for ACP completion. The Level E 60-minute consultation item can only be used by GPs and is not widely utilised (35). Practice nurses are not eligible to bill under this item, further limiting their capacity to contribute formally to ACP discussions (35).

Documentation and access challenges

Recording and accessing ACPs remains a significant barrier. Uptake of consumer-uploaded ACPs in My Health Record (MHR) is patchy, and health care professionals often do not consistently access or update ACPs. In the ACT, even when ACPs are uploaded to the Digital Health Record (DHR), GPs, ACTAS paramedics, and other health care providers may not have access. The CHN PCiGP1 quality improvement activity also identified that general practices have inconsistent and insufficient ACP documentation, including key elements such as preferred goals of care and place of death (13).

Priorities

Communication and shared decision making:

Strengthen clinician capability and confidence to lead timely, values-based end-of-life discussions, and continue expanding initiatives like the Serious Illness Goals of Care Communication Forum to support consistent, high-quality shared decision-making across the ACT.

Palliative Care Knowledge:

Strengthen community-wide death literacy by increasing public understanding of palliative care, by supporting the rollout and promotion of initiatives such as the Waiting Room Revolution program and collaborating with key organisations to expand awareness-building activities and reduce stigma across the ACT.

Advance Care Planning:

Strengthen ACP across the ACT by increasing community awareness, improving GP and practice nurse capability and support to initiate ACP discussions, and enhancing documentation and system access so that patients' preferences are clearly recorded, shared and able to guide care throughout the health system.

Summary of Priorities

Clinical – Community, Primary and Aged Care

Improve referral pathways, navigation, and continuity of care

- Establish clear, consistent referral and eligibility pathways.
- Ensure HealthPathways are accurate and up-to-date.
- Ensure clinicians know where to find reliable, current guidance.
- Improve information sharing and system linkages.
- Improve coordination and case management for people with complex, multisectoral needs.
- Establish a shared care model with clear communication and role clarity between primary care and specialist palliative services, including specialist responsiveness of after-hours palliative care phone services.

Equip and support primary care

- Tailor education and system navigation support for general practice.
- Formalise and strengthen the role of GPs and primary care nurses in planning, coordination, training, and full scope practice across the palliative journey.
- Address gaps in after hours GP support.

Expand and strengthen community clinical care

- Address gaps in access to essential palliative medicines at home, including after hours.
- Support breathlessness management through targeted training for in-home allied health staff.
- Strengthen palliative care capability for community nurses, allied health, and aged care staff, including confidence in communication, shared decision making, ACP, and symptom assessment and management.
- Embed and expand the Extended Care Paramedic model.

Improve equity for priority populations

- Strengthen culturally safe, accessible care for First Nations people.
- Improve cultural competence and communication for multicultural communities.
- Improve access to coordinated home based care for people with disability.
- Establish stigma free, integrated support for people who use drugs or receive opioid treatment.
- Strengthen paediatric palliative care capacity and integration.

Strengthen data and system stewardship

- Improve palliative care data collection, reporting, and analysis.
- Implement the Palliative Care Reporting Framework and explore potential access to community level datasets.

All sectors or health care service providers

- Promote timely ACP and early identification of end-of-life needs.
- Build frontline workforce confidence to provide informal emotional, grief, and bereavement support, especially for those outside specialist pathways.
- Strengthen multidisciplinary, team-based are by expanding access to allied health and ursing support.
- Embed holistic, team-based models that fully utilise the breadth of the palliative care workforce.
- Improve equitable access to specialist palliative care for people with non-cancer life-limiting illnesses.

Community / Population

Strengthen community understanding of palliative care

- Collaborate with organisations to expand community wide awareness activities to increase public awareness, address misconceptions, reduce stigma, and improve death literacy, including the benefits of ACP.

Improve access to clear, centralised information

- Collaborate with organisations to create and maintain a single, trusted, up-to-date central hub for palliative care information, including grief and bereavement information and end-of-life doula role information.

Support home based palliative care

- Monitor the impact of reduced non clinical homecare availability.
- Increase awareness of alternative pathways, including the new 65+ Support at Home End-of-Life Pathway.

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Appendix

Existing resources summary

Report	Purpose / Focus	Summary of Key Findings
ACT Health & Community Services Palliative Care Service Function Review (2023) (7)	Review unmet need, pathways, demand, costs, barriers, and demographics.	Limited service capacity Siloed system structure insufficient in-home clinical services Gaps in supportive non-clinical services Delayed referrals and limited ACP access Poor care coordination Weak transitions of care
ACT Palliative Care Navigation Workshop Summary (2025) (8)	Explore scalability of SA's Palliative Care Connect model.	Low public understanding Inconsistent access and referral pathways Lack of centralised information Complex, multisectoral needs
ACT Palliative Care-Related ED Presentations Report (2015-2022) (9)	Use NLP to identify palliative-related ED presentations and analyse patterns.	High after-hours ED use High admission rates Younger patients often live outside ACT Weston Creek shows high presentation rates NLP promising but still inaccurate; results require cautious interpretation
AHHA Exploratory Analysis of Barriers to Palliative Care (2019) (10)	Identify barriers and enablers for underserved populations.	Consumer barriers: low awareness, discomfort discussing death, mistrust, trauma, isolation, delayed diagnosis, stigma, financial constraints Service barriers: limited cultural competency, workforce skill gaps, insufficient services, late referrals, discrimination, underfunding Shared barriers: communication issues, mismatched cultural expectations

Report	Purpose / Focus	Summary of Key Findings
CHN Core Needs Assessment (2024–2027) (11)	Identify primary care priorities relevant to palliative care.	‣ Need to improve palliative care for older adults ‣ Improve accessibility and health literacy ‣ Support affordable primary care (incl. bulk billing) ‣ Strengthen collaboration and integration ‣ Expand multidisciplinary care ‣ Enhance care navigation supports
CHN GCfAHPC Program Scoping Report (2022) (12)	Identify ACT palliative care barriers, enablers, and priorities through stakeholder engagement.	‣ Need for 24/7 clinical phone support ‣ Need for consistent, up-to-date service information ‣ Lack of clear models of care and referral pathways ‣ Need for improved clinician education ‣ Limited capacity of CCHH community services ‣ Insufficient after-hours RACF support ‣ Low GP engagement in paediatric palliative care ‣ Limited bereavement support outside SPC
CHN Palliative Care in General Practice QI Activity (2024) (13)	Improve GP recognition and support of palliative patients.	‣ Poor ACP and goals-of-care documentation ‣ Low awareness of relevant MBS items ‣ Unclear referral pathways and criteria ‣ Confusing shared-care model with CHS SPC ‣ Low completion of home medicines reviews ‣ No ACT-specific GP end-of-life checklist
DHDA GP best practice research project (2017) (14)	Understand GP attitudes, skills, and behaviours.	‣ GPs provide more palliative care than assumed ‣ High willingness to collaborate with SPC nurses ‣ Four GP segments: Experts, Aspirers, Indifferent, Avoiders Implications: training for Aspirers, behavioural nudges for Indifferent/Avoiders, better resource visibility, embed palliative care in routine practice

CHN