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Palliative Care Needs Assessment Summary Report

2025

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We acknowledge the Kaurna peoples who are the traditional Custodians of the Adelaide Plains. We pay tribute to their physical and spiritual connection to land, waters and community, enduring now as it has been throughout time. We pay respect to them, their culture and to Elders past and present. We would also like to acknowledge and pay our respects to those Aboriginal and Torres Strait Islander people from other Nations who live, work, travel and contribute on Kaurna Country.

Contents

Abbreviations

ABS	Australian Bureau of Statistics
ACP	Advance care planning
AIHW	Australian Institute of Health and Welfare
CAC	Community Advisory Council
GCfAHPC	Greater Choice for At Home Palliative Care
GP	General Practitioner
LGBTIQA+	Lesbian, gay, bisexual, transgender, intersex, queer (or questioning) and asexual people
LHN	Local Health Network
NA	Needs Assessment
PCOC	Palliative Care Outcomes Collaboration
PHN	Primary health Network
RACH	Residential Aged Care Home
SA	South Australia

Executive Summary

The Adelaide Primary Health Network (PHN) is one of 31 Primary Health Networks (PHNs) across Australia with their region covering the Adelaide metropolitan area. The Adelaide PHN prepares comprehensive needs assessments to identify the key population and health service needs with the assessments informing the commissioning of programs and services to deliver better health outcomes for people living in this region.

Needs Assessment Purpose

The GCfAHPC Program is to improve coordination and access to quality palliative and end-of-life care in the community and at home. In 2017, the Program was launched with 11 Primary Health Networks as a pilot by the Department of Health, Disability and Ageing, and expanded nationally to include all 31 PHNs from 2021-25. The Australian Government committed an extension of funding to the Program from 1 July 2025 to 30 June 2029.

The Adelaide PHN Needs Assessment *Palliative Care* (NA) is in accordance with the PHN GCfAHPC Program (2025-2029) requirements and identifies palliative care priorities and opportunities across the Adelaide metropolitan region to drive future activities. It brings together data and information from the community, local health services, and workforce to inform how to improve the health and wellbeing of people living in our region. Adelaide PHN will identify opportunities and priorities to improve primary care access to palliative care for people who are experiencing a life-limiting illness, and by undertaking a detailed and systematic assessment of the health needs across the Adelaide PHN catchment area.

Methodology

Analysis was established primarily through desktop review, drawing on the detailed Health Performance Council 2025 report on *Palliative Care in South Australia*, commissioned by the South Australian Department of Health and Wellbeing. Additional insights were sourced from the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS), Adelaide PHN NA report and community consultations including conversations with select advisory council members and subject matter experts. Broader consultation activity with community, stakeholders and Adelaide PHN combined Advisory Council is planned for 2026, to further inform the Adelaide PHN Needs Assessment Palliative Care 2026.

Introduction and background

Palliative care is an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness. It prevents and relieves suffering by means of early identification, correct assessment and treatment of pain or other problems whether physical, psychological, social, emotional or spiritual. It prevents and relieves suffering by means of early identification, correct assessment and treatment of pain or other problems whether physical, psychological, social, emotional or spiritual (WHO 2020).

End-of-life care can be positioned within the broader concept of palliative care and generally refers to the last 12 months of life, where there is an increased need for services as a person approaches death. It includes the support of families and carers after death, in which care will extend into grief and bereavement (RACGP 2025; Palliative Care SA 2023).

Palliative care is not limited to a specific age or condition, is not designed to hasten or postpone death and can be applied to any life-limiting illness (WHO 2020).

The concept of a 'good death', refers to the ability to die in comfort with dignity, choice and support, with access to information, expertise and palliative care in any location, not just in hospital (SA Health 2021). This idea is fundamental to palliative care that aims to wrap around the person, informed by their wishes, health care preferences and in the place of their choice (DoH 2018).

The benefits of palliative care are well documented and have been shown to increase quality of life with fewer hospitalisations, shorter lengths of stay and reduced need for hospital-based care.

Policy, Planning and Guiding Frameworks

There is growing recognition of the importance of palliative care across Australia, reflected in both national and state-level policy. At the national level, the National Palliative Care Strategy 2018 provides a comprehensive framework for improving palliative care services, outlining priorities such as equitable access, quality care, workforce capability, and community awareness. Complementing this, the National Aged Care Quality Standards and the Australian Charter of Healthcare Rights reinforce principles of dignity, choice, and person-centred care for individuals with life-limiting conditions (ACQSC 2025; DoH 2018; ACSQHC 2020)

The Aged Care Act 2024 introduces a rights-based framework that prioritises person-centred care for older people, reflecting recommendations from the Royal Commission into Aged Care Quality and Safety. A key reform is the Support at Home Program, which replaces existing home care arrangements and includes a new integrated End-of-Life Pathway to support delivery of person-centred care for older Australians in their own home during their final months of life. These changes are underpinned by the strengthened Aged Care Quality Standards, which now include explicit requirements for palliative and end-of-life care, with providers required to demonstrate that care is respectful, culturally appropriate, and aligned with individual preferences, while ensuring timely access to symptom management, emotional support, and advance care planning (DHDA 2025; ACQSC 2025; Commonwealth of Australia 2021)

In South Australia (SA), the SA Palliative Care Strategic Framework 2022–2027 builds on the national direction, setting a state-based vision for integrated, responsive, and sustainable palliative care services. It emphasises the need for improving access for diverse populations, strengthening workforce capacity, and fostering collaboration across health and aged care sectors. Expectation that future demand for palliative care will outpace population growth at the state level, is highlighted by a 2025 Ministerial inquiry into palliative care in South Australia, emphasizing the need to improve access to generalist and specialist services, expand and enhance workforce capability, improve data systems, and strengthen cross-sector collaboration (SA Health 2021; Health Performance Council 2025).

Key considerations and limitations

Data limitations for the Adelaide PHN Needs Assessment *Palliative Care* include:

- Palliative care services and usage data are sporadic and incomplete. Some palliative care provisions are comprehensively recorded such as in public hospital settings, but there is no routine collection of data that covers all palliative care touchpoints even within the public sector providers of care (Health Performance Council 2025).
- A large volume of palliative care also occurs outside of specialised settings, such as in primary, residential aged care and the private sector which are not claimed specifically as a palliative-care related service and therefore not included in existing data collections (AIHW 2022, AIHW 2025a).
- The terms palliative care and end-of-life care are often used interchangeably throughout available literature and data, and much of the recorded information focuses on specialised public services provided in the last 12 months of life.
- The shortcomings in data collection make it difficult to capture a true picture of unmet need with significant gaps and evidence mismatch to provide an accurate number of people who would have benefited from palliative care but did not receive it (Health Performance Council 2025; AIHW 2022).

Population profile summary

Our region and people

The Adelaide Primary Health Network is one of two Primary Health Networks (PHNs) in South Australia. The Adelaide PHN region covers 1,553 square kilometres and stretches from Sellicks Hill in the south to Angle Vale in the north, and from the beaches in the west to the foothills in the east.
The Adelaide PHN boundary encompasses seventeen Local Government Areas, includes three Local Health Networks (LHNs) – Northern Adelaide, Central Adelaide and Southern Adelaide and shares the Women's and Children's Health Network with Country SA PHN.

Prevalence

The demand for palliative care services is increasing due to an ageing population and the increases in the prevalence of cancer and the rising burden of chronic diseases (WHO 2014). The leading causes of death in South Australia are dementia, coronary heart disease, cerebrovascular disease, lung cancer and chronic obstructive pulmonary disease (Health Performance Council 2025).

In 2021, 13,556 people died in SA, with an estimated 9,707 of these deaths from life limiting chronic conditions considered amenable to palliative care (Health Performance Council 2025).

A total of 71.6 percent of deaths in SA in 2021 would have been amenable to palliative care. This percentage is consistent across the Local Health Networks (LHNs) within the Adelaide PHN region (Refer Figure 1).

Figure 1: Estimated number of deaths amenable to palliative care SA and Australia-wide, 2021 (Health Performance Council 2025)

Table 2: Estimated number of deaths amenable to palliative care, by local hospital network, and type of patient, South Australia and Australia-wide, 2021

Allocation of deaths to trajectories based on the method described by the French National End-of-Life Observatory.[48]

Population group *LHNs based on place of residence*	Deaths	Deaths amenable to palliative care *Number of deaths and percentage of all deaths attributed to each trajectory* Trajectory 1 steady regression and steep decline		Trajectory 2 decline with periods of recovery		Trajectory 3 prolonged decline		All amenable deaths	
Northern Adelaide	2,639	783	(30%)	700	(27%)	390	(15%)	1,873	(71%)
Central Adelaide	3,804	983	(26%)	1,082	(28%)	631	(17%)	2,696	(71%)
Southern Adelaide	2,797	784	(28%)	753	(27%)	478	(17%)	2,015	(72%)
Metropolitan Adelaide	9,240	2,550	(28%)	2,535	(28%)	1,499	(16%)	6,584	(71%)

Mortality and modelled estimates in 2021, indicate that 55% of people whose deaths were amenable to palliative care received specific palliative services in public hospitals or from palliative care specialists or GPs. The number of deaths amenable to palliative care is expected to grow by approximately 3% a year, well ahead of population growth (Health Performance Council 2025).

Predictive modelling by the Health Performance Council estimates the potential demand on palliative care service will grow 32-57% from 2020 with the number of deaths amenable to palliative care increasing to between 13,000–15,000 people by 2032 (Health Performance Council 2025).

Place of death

In Australia 60%-70% of people would prefer to die at home (AHA 2019a). It is estimated that among those South Australians who died in 2020 from causes amenable to palliative care, 38% died in a public hospital, 37% in residential aged care and 25% elsewhere, including at home (Health Performance Council 2025).

South Australian voluntary reporting to The Palliative Care Outcome Collaboration (PCOC) from specialist palliative care services indicates that between July 2022 to June 2025 there was a decline in private residence as place of death from 35.8 % to 25.4% with an increase in Hospital/Hospice rates as place of death from 59.6% to 67.5% (Clapham et al. 2025).

Analysis of the literature suggests that supporting people to die in their preferred place of death requires a coordinated, well-planned approach. The following identifies needs to enable dying at home:

- Improve death literacy across society
- Build capacity in health workers to have difficult conversations
- The need for early conversations and advance care planning
- Access to Aged care or in-home support service and equipment
- Skilled carers and family ability to provide symptom control and manage complexity of care
- Support compassionate community care models (ARIIA 2024; RACGP 2025; APHN 2023).

A study of South Australian healthcare professionals observed that there was a lack of open conversation regarding place of death between patients and caregivers, an idealised concept of death and poor understanding regarding the realities and consequences of caring for someone who is dying at home (Sathiananthan et al. 2021). It is not uncommon that people require transfer from home to either aged care or hospital within the last few weeks of life, due to rapidly escalating patient care needs, patient safety risks or carer exhaustion (RACGP 2025).

Cancer

In 2021 there were 3,910 cancer related deaths within South Australia, equivalent to an age-standardised mortality rate of 194.5 deaths per 100,000 persons (AIHW 2025b). The estimated lifetime risk of mortality from cancer is 1 in 11 for males and 1 in 16 for females. In 2021 people aged over 65 accounted for 64.0% of all cancers and 81.3% of all cancer related deaths in South Australia (Preventive Health SA 2021).

Although cancer accounts for a third of SA predictable deaths, cancer diagnosis remains the predominant referral to specialist palliative care services (SA Health 2019). Nationally, 2 in 3 people dying from cancer receive specialist palliative care and are 5 times more likely to have a Medicare recorded consultation with a specialist palliative care physician than people dying from other causes (AIHW 2024a).

Chronic Disease

Historically palliative care has been associated with cancer but a range of chronic life limiting conditions including chronic obstructive pulmonary disease, end stage heart and kidney failure, dementia, Parkinson's and degenerative neurological disease benefit from palliative care (WHO 2020; RACGP 2025). In 2024, the leading causes of death in South Australia were chronic diseases with dementia, ischaemic heart disease and chronic lower respiratory disease, accounting for 3,951 deaths overall (ABS 2025). As these chronic diseases have a high burden of care comparable to patients with cancer a large number of people who die may benefit from palliative care but are potentially not receiving it (Health Performance Council 2025).

Research findings indicate that of non-cancerous diseases, the most common referrals to palliative care specialist services were for renal/liver disease (40%), heart disease (18%) and dementia (16%) (AIHW 2024a). People with non-cancer conditions do not access palliative care as readily, largely due to long and fluctuating illness trajectories which complicate the provision of cost-effective palliative care services when individuals continue to live for many years past diagnosis (SA Health 2019).

Dementia

Dementia is a life limiting syndrome usually of a chronic or progressive nature in which there is deterioration in cognitive function beyond what might be expected from normal ageing for which there is currently no cure (WHO 2025; Dementia Australia 2019). Dementia was the leading cause of death in South Australia in 2023, accounting for 5,887 deaths in the Adelaide PHN region from 2019-2023 (AIHW 2025b).

In the Adelaide PHN region, it is estimated that over 26,600 people were living with dementia in 2021, with a predicated increase to 54,400 by 2058. Many people living with advanced dementia transition

into residential aged care to receive the support and care they need, including end of life care. It is estimated that more than half of the people living in permanent residential aged care in 2019 had a diagnosis of one of the forms of dementia (Dementia Australia 2021).

During the end-of-life stage, people with dementia are frequently caught in a cycle of transfer from home to hospital, to residential aged care and back to hospital. Timely discussions regarding advance care planning should begin at diagnosis, to avoid unnecessary admissions to unfamiliar and stressful settings where staff lack the specialised skill set to provide quality palliative and end-of-life care (Dementia Australia 2019).

Dementia Australia recommends improving workforce training on the unique palliation needs of people with dementia across aged care, primary care (general practice) and community based care (Dementia Australia 2019).

Planning for end-of-life

Australians are generally 'ill-prepared' when it comes to end-of-life care (Sathiananthan et al. 2021). According to Advanced care planning Australia, almost 50% of people will be unable to make their own end-of-life decisions and only 33% of Australians have taken steps to plan for their future health care (ACP Australia 2025).

What is perceived as a 'good death' varies from person to person. Communication and clear end-of-life planning between patients, families and health professionals allow for co-designed pathways to informed decisions about care, including life-prolonging treatments, management of pain and comfort, and appropriate place of care (Health Performance Council 2025).

Conducted between 2023-2025, Adelaide PHN findings from consultations with stakeholders including Community Advisory Council (CAC), community members, service providers working with people identifying as LGBTQI and working with alongside people experiencing homelessness identified:

- Nearly 25% of individuals would not trust their substitute decision maker to make the right decision for them).
- The importance of palliative care discussions and ACP on entering aged care.
- The need for early, disease specific advance care planning that considers carer ability to manage the specific challenging care requirements, such as with dementia.
- Limited awareness and knowledge by service providers around ACP, information and resources for priority populations (Palliative Care SA 2024; APHN 2024, APHN 2025).

"Advance care decision making is not just about end-of-life care…it's also about best place of care for that individual, taking into account the stress on the carer…it's also a conversation around family as well" ***2025 consultation participant***

"Advance Care Planning is critical for ensuring that individuals receive care aligned with their values and preferences, particularly at the end of life. However, priority populations, such as LGBTQA+ and homeless individuals, face unique challenges in accessing and engaging in ACP discussions" ***2023 consultation participant***

General Practitioners (GPs) are well placed in the community with trusted patient relationships to initiate advance care planning discussions while giving advice on healthcare options and realistic assessment of prognosis (RACGP 2025). A study undertaken by Advance Care Planning Australia found that, despite 42% of Australians identifying health professionals as their likely source of information for advanced care planning, there is a lack of ACP as part of health care, with only 12% discussing this with a health professional and 1 in 5 storing their advance care directive with their doctor (ACP Australia 2025).

Priority populations

Older People

In Adelaide PHN region, almost one in three people (30%) aged 65 years and over reported having multiple long-term health conditions. This is five times the rate of multiple long-term health conditions for people aged less than 65 years (ABS 2021).

In 2023-2024 the AIHW data shows nearly 60% of palliative care hospitalisations were for people 75 and older and data last updated 2017 showed around 9 in 10 general practice palliative care encounters were with people aged 65 and over (AIHW 2025a). The Palliative Care Outcomes Collaboration in 2018 reported those aged 65 and over accounted for 73.2% of palliative care episodes within South Australia (PCOC 2019). PCOC recorded a national average of 77 years of age for the commencement of palliative care in 2024 (AIHW 2025a).

In 2023, 244,095 people aged 65 years and over lived in Adelaide PHN, which was 18.5% of the total Adelaide PHN population (ABS 2024). Population projections published in 2024 show that by 2032, that the number of people 65 years and older is predicted to increase to 21.0% of the population, with the number of people aged 65 years and over increasing to over 305,000 people, with over 50,000 of these being aged 85 years or older (ABS 2024) Assuming the current trends continue, the population amenable to palliative care is likely to grow at a faster rate because of an anticipated higher proportion of older people in the population and, therefore, of palliative-amenable conditions (Health Performance Council 2025).

Children and young people

The leading cause of death for children who receive palliative care are cancer, neurological conditions and genetic disorders (AIHW 2024b). Palliative care for children differs from palliative care for adults with varying diagnosis, symptoms, impact on family, support, workforce requirements and unique considerations for advance care planning (SA Health 2019; AIHW 2024b). The AIHW reports that in 2021 almost 46% of children with life limiting conditions received specialist palliative care from a children's hospital (AIHW 2024b).

Palliative care is provided through a statewide Paediatric Palliative Care service with no current paediatric hospice within the Adelaide PHN region (SA Health 2019). With a greater focus on the adult population, palliative care in young people is currently under serviced. There is a need for a better-resourced and sustainable multi-disciplinary service across a 7-day model with identified gaps in paediatric specific skills and knowledge including community nursing, general practice and grief and bereavement (SA Health 2023).

Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander peoples make up 3.3% of Australia's population and are more likely to experience chronic health conditions including kidney disease and coronary heart disease than non-Aboriginal and Torres Strait Islander people. The prevalence rates of dementia in Aboriginal and Torres Strait Islander people are 3-5 times the rate compared to non-Aboriginal and Torres Strait Islander people. Lung, liver and cervical cancers are more common among non-Aboriginal and Torres Strait Islander people, and they are more likely to be diagnosed with cancer at an advanced stage (AHA 2019b; Dementia Australia 2024).

This high rate of life-limiting conditions among Aboriginal and Torres Strait Islander people increases the need for access to palliative care. Community members experience challenges in access due to lack of culturally and linguistically appropriate services, systemic racism and discrimination, and awareness of supports for death, dying and palliative care impacting on experiences at the end of life (AHA 2019b).

Cultural and Linguistically Diverse (CALD) Communities

The Australian population includes many people that were born overseas or have a parent born overseas or speak a variety of languages. Members of the CALD community are diverse, and generalisations are not appropriate, however some members of the CALD community have a higher incidence of life-limiting conditions that are less common within the general population. Migrants from non-English speaking countries, and people born in Australia with non-English first language are more likely to experience language and cultural barriers which prevent timely access to palliative care (AHA 2019a).

Service mapping summary

Health Service Access

Access and availability

Palliative care can be provided in a range of settings, including at home, at a hospital, in a hospice, in an aged care facility, and in an institutional setting (such as correctional facility or accommodation for people living with a disability). Palliative care involves a range of clinical and other supports delivered by different providers, including volunteers, depending on the patent's needs. These may include general practice and primary care, specialist medical, nursing and allied health practitioners, community, disability, aged and social services, grief and bereavement services, and specialist palliative care services (comprising of multidisciplinary teams with specialized skills, competencies, experience and training in palliative care) for patients with complex needs (AHA 2019a).

Adelaide PHN consultation conducted in 2025 with stakeholders and community identified positive experiences of provision of quality palliative care (APHN 2025).

"The staff were very good when we came onto palliative care. I'd give them 10 out of 10" ***2025 consultation participant***

"Waiting times tend to be a bit prohibitive to actually getting help within a time frame that may make a difference for people; however, I would say palliative care is very good" ***2025 consultation participant***

Hospital Care

Hospital use for palliative care increased by 90% between 2012 and 2022, representing approximately 0.5 episodes per person amenable to palliative care (AIHW 2025a). Palliative care episodes across all metro public hospitals increased through this time, with a notable 114% increase in the Southern Adelaide Local Health Network region and a 71% increase across all metro private hospitals (Health Performance Council 2025). In South Australia 6,048 palliative care hospitalisations were recorded between 2022-23 at a high rate of 46.7 per 100,000 people, which was significantly greater than the Australian rate of 38.6 hospitalisations per 100,000 people (AIHW 2024a).

Around 4 in 5 South Australians who died from causes amenable to palliative care attended public hospitals in their last year of life with 95% having at least one episode of inpatient care (Health Performance Council 2025). In 2023-2024 people experiencing higher levels of disadvantage and being identified as being from low socioeconomic areas represented a higher proportion of public palliative care-related hospitalisations accounting for 44 per 10,000 population, compared to 25 per 10,000 population from higher socioeconomic areas (AIHW 2024a).

Access to specialised inpatient beds is limited with 41 designated sub-acute specialist palliative care beds in South Australia's metropolitan public hospitals. This is less than half the recommended 86 sub-acute beds to match the benchmark suggested by Palliative Care Australia to allow for a minimum of 6.7 designated palliative care beds per 100,000 population (Health Performance Council 2025).

Specialist Palliative Care

A National study in 2019-2020 found that access to specialist end-of-life care occurs in the last month of life, commencing on average 15 days before death, considerably shorter than the AIHW recommended 3-4 months prior to death to provide the maximum benefit (AIHW 2024a).

Specialist palliative care service is most often provided in hospital, and hospice settings but also extends into outpatient, aged care or in place of residence and provide indirect support through advice to other health professionals (Health Performance Council 2025).

There are four specialist palliative care teams in South Australia: one adult service in each of the three Adelaide Local Health Networks and a statewide service based at Adelaide's Women's and Children's Hospital. The adult palliative care services operate as an integrated service, with an inpatient palliative care and hospice unit (Health Performance Council 2025).

Community Palliative Care

Community palliative care involves a range of health disciplines with services including medical consultation, nursing and allied health interventions. Community care is provided through various funded options with eligibility and access to service based on age, clinical indicators and location (SA Health 2023). There was an increase of over 50% in the Adelaide PHN region for home and outpatient clinic usage between 2018-19 (30,940 services) and 2020-21 (47,218 services) (Health Performance Council 2025).The Southern Adelaide Local Health Network recording the lowest service delivery, providing about one third less specialist community palliative service than the other LHNs statewide (refer Figure 2 below).

Figure 2: Specialist community palliative care activity provided in home/community (Health Performance Council 2025)

Table 6: South Australia-funded specialist community palliative care activity provided in home and outpatient clinics, 2018-19 to 2020-21

	Service events			Per 100,000 population			Per 1,000 palliative-amenable deaths		
Health Network of provision	**2018-19**	**2019-20**	**2020-21**	**2018-19**	**2019-20**	**2020-21**	**2018-19**	**2018-19**	**2018-19**
Northern Adelaide	11,909	12,788	13,823	2,886	3,049	3,268	6,193	6,643	7,162
Central Adelaide	14,902	23,769	22,834	3,142	4,938	4,735	5,374	8,562	8,429
Southern Adelaide	4,129	8,525	10,561	1,110	2,268	2,794	2,059	4,150	5,197
Metropolitan Adelaide	30,940	45,082	47,218	2,458	3,531	3,680	2,840	4,781	5,006

Within the Adelaide PHN region in 2023-2024 there were 387.3 per 10,000 non-admitted palliative care service events which is significantly above the Australian rate of 356.5 per 10,000 people (AIHW 2025a). In 2023, 16 South Australian palliative care community services submitted data to the Palliative Care Outcomes Collaboration recording 4,523 episodes of palliative care to 3,790 patients, an average of 1.1 episodes per patient (Health Performance Council 2025).

A key community-based care reform under the new Aged Care Act 2024 (introduced 1 November 2025) is the Support at Home Program. The Program replaces existing community-based home care arrangements and includes a new integrated End-of-Life Pathway to support delivery of person-centred care for older Australians in their own home during their final months of life. This pathway is designed to provide eligible participants who have been diagnosed with an estimated life expectancy of three months or less and wish to remain at home with by providing discrete funding to access in-home aged care services. The End-of-Life funding pathway is accessed through My Aged Care, requires assessment and approval for access, and is for people aged 65 and over, or 50 years and over for Aboriginal and Torres Strait Islander people (DHDA 2025).

Extended Care Paramedics

SA Ambulance Service delivers an Extended Care Paramedics service covering Adelaide metro area, working in collaboration with other health care professionals to manage and treat people in their residence (SA Ambulance Service 2024). A 2019 review of palliative care in South Australia recommended integrating the use of extended care paramedics with community-based care. Extended care paramedics can intervene at the point of triage and provide an alternative to hospital care with the most commonly recorded assessments for pain, respiratory distress and death (Collier et al. 2023; SA Health 2019). In a statewide report into Palliative Care Needs for South Australia, extended care paramedics with additional training could manage approximately 25-35 palliative care patients per month, provide 24-hour coverage and respond to palliative care emergencies, symptom crisis and unexpected end-of-life deterioration (SA Health 2019).

MBS palliative care-related services

In 2022-23 MBS subsidised palliative medicine attendance and case conferencing provided by palliative medicine physicians or specialists were accessed at a rate of 26.3 per 10,000 people, almost 10 times lower than the Australian rate of 255.0 per 10,000 people. Nationally, the number of MBS-subsidised palliative medicine attendance and case conference services has declined from a peak of 90,600 services in 2018–19 to 70,400 services in 2023–24, with an average annual decrease of 4.9%. This was broadly consistent with the pattern observed for the number of people receiving these services over the same period (AIHW 2025a).

PBS palliative care-related prescriptions

In 2022–23 there were 58,312 palliative care-related prescriptions provided to 18,599 people, equating to 3.1 prescriptions per person which is consistent with the national rate. Seven in 10 (70% or 41,080) palliative related prescriptions were for pain relief. The rate of prescriptions per 100,000 people increases with age, indicating a sharp increase between people aged 55-74 at a rate of 7,867.1 and 75 years and above at a rate of 22,140. In 2023-24 in Australia general practitioners prescribed 90% of palliative care-related prescriptions (AIHW 2025a).

The use of MBS items for palliative care in the APHN region is almost 90% below the national rate. It is unclear if other MBS items are being used when palliative care services are being provided as the use of PBS funded palliative care pharmaceuticals in metropolitan Adelaide was slightly above the national rate (AIHW 2024a).

Pharmacy

Pharmacists play an important role within palliative care and provide an essential point of contact for information and advice for people, their families, carers and health professionals. While community pharmacies can dispense palliative medicines, 20 pharmacies in Adelaide PHN region are part of a Palliative Care Medicines Pharmacy Network. Network pharmacies provide access to palliative care medicines that may not be available at a person's usual pharmacy, as well as support, information and advice for people with life-limiting illnesses, their families and carers, and health professionals. To support palliative care at home, four of the Network pharmacies provide a 24-hour, 7-day a week service (SA Health 2025).

Aged Care

Older Australians entering Residential Aged Care Homes (RACHs) are increasingly experiencing unpredictable prognostic trajectories characterised by periods of disability, frailty, and illness. The older the person was when they died, the more likely they were to have been using aged care at the time of their death (AIHW 2024c).

A number of recommendations from the *Royal Commission into Aged Care Quality and Safety* highlight quality palliative care as core business for aged care services. In South Australia, 6% of aged care residents whose deaths were amenable to palliative care had a palliative care assessment recorded in the year before their death (Commonwealth of Australia 2021; Health Performance Council 2025).

The Aged Care Act 2024 introduced a rights-based framework that prioritises dignity, choice, and person-centred care for older people, reflecting recommendations from the Royal Commission into

Aged Care Quality and Safety. The changes are underpinned by the strengthened Aged Care Quality Standards, which now include explicit requirements for palliative and end-of-life care, with providers required to demonstrate that care is respectful, culturally appropriate, and aligned with individual preferences, while ensuring timely access to symptom management, emotional support, and advance care planning (ACQSC 2025).

Many residents entering aged care present with co-morbidities including cognitive problems and dementia which significantly affects their ability to make decisions about palliative and end-of-life care and capacity to complete an advance care directive (palliAGED 2025). Consequently, to have a choice in the care they receive RACH care teams need to understand the importance of advance care planning for all residents to ensure their decisions from admission to end of life are clearly documented to reflect individual preferences, values, beliefs, wishes and concerns (APHN 2021).

Continuing review of advance care planning documents is essential within RACH settings as health and care needs change, and is central to the Aged Care Quality Standards Outcome 5.7: Palliative and end-of-life care, to continue end-of-life planning conversations and ensure planning documents align with current needs, goals and preferences (palliAGED 2025; ACQSC 2025)

During consultation RACHs in the Adelaide PHN region highlighted the wide variation exists across sites and organisations in terms of systems and processes, workforce knowledge, skills to support and implement advanced care planning and ultimately safe, person-centred palliative care (APHN 2021).

Education that supports aged care staff to facilitate effective advance care planning processes can strengthen capabilities to discuss palliative care and end of life needs with residents and their families or carers, and effectively document care needs and preferences to support future care decision making (palliAGED 2025).

Bereavement

Provision of grief and bereavement support to families and carers is integral to end-of-life care. Carers may experience depression, prolonged grief, post-traumatic stress disorder before and after the patient's death. Unlike palliative care, traditional healthcare does not necessarily incorporate grief and bereavement for carers but will often fall more heavily on nursing and specialist staff in the last days of life when care is most intensive (Health Performance Council 2025).

In South Australia most bereavement care is provided through specialist palliative care services. In 2020, The Bereavement Advisory Group mapping exercise revealed that there are limited grief and bereavement counsellors for adult services with most people being referred to their GP (Swetenham 2021).

A 2022 study of unpaid carers in South Australia highlighted a lack of coordinated follow up by health teams after death and individuals rely on informal supports such as family, friends and community groups (Van Dinther and Javanparast 2024).

Service awareness and navigation

The Australian Government funded a three-year pilot program 2023 to 2026, for a Palliative Care Connect service within in South Australia (SA Navigator Pilot), to provide information and guidance on available services, care options, and bereavement support. The statewide navigation service supported

396 people in its first nine months of operation. Subject to going evaluation of effectiveness, it is important to promote awareness of this service to maximise its reach and impact (Health Performance Council 2025).

Workforce

Palliative Care workforce

National data in 2023 indicated there were 335 full time equivalent (FTE) palliative physicians and 3,500 FTE palliative care nurses employed in Australia with more than half of palliative medicine physicians and palliative care nurses working in a hospital setting (75% and 49%, respectively) (AIHW 2025a). In 2023 in South Australia the FTE of palliative care physicians was 1.4 per 100,000 population which is well above most states and territories, except Tasmania (1.7) but below the recommended benchmark set by Palliative Care Australia to achieve 2 FTE specialist palliative care medicine physicians per 100,000 population by 2030 (Palliative Care Australia 2019). In 2023 in South Australia the FTE for Palliative care nurses was 13.3 per 100,000 population which around the national average (AIHW 2025a).

Aged Care

The 2020 Aged Care Workforce Census also identified potential gaps in workforce training. While 90% of the residential aged care workforce nationally receive regular professional development only 64% receive training on Palliative Care. The proportion of Home Care Package Program and Home Support Program workforces receiving ongoing professional development is lower: 24% and 20% respectively for Palliative Care (DoH 2021).

General Practice

It is estimated that 94% of people that could have benefited from palliative care visited a GP in the year prior to death (AIHW 2024a). In the Adelaide PHN region, there is no easily accessible information regarding the number of GPs with a special interest in palliative care or a consistent data collection on services provided in general practice after commencement of a patient's palliation (Health Performance Council 2025).

In 2023 Adelaide PHN undertook community consultation that identified GPs ranked highest as the source of trusted information regarding serious illness, dying, grief and care giving (Palliative Care SA 2024). However, in 2022 a South Australia survey of unpaid carers identified inadequate and inconsistent information and communication between General Practitioners, carers and patients regarding transitioning to palliative care (Van Dinther and Javanparast 2024).

GP encounters with palliative care range from 1 in 100, to 1 in 1000. This variation being likely due in part to study variations and varied definitions of palliative care (AIHW 2025a). It is likely that encounters are under representation of the true volume of palliative care encounters by GPs because care would have been provided but not recorded using palliative-care specific item numbers (Health Performance Council 2025).

A survey of Australian GPs between 2018-2019, showed less than a third of participants had ever received formal palliative care training and highlighted significant challenges when managing end of life

care with uncontrolled symptom distress, rapid and unexpected decline, complex medical conditions, the presence of dementia and other psychosocial issues (Ding et al. 2022). A systematic review of symptom management showed that although pain management was sometimes sub-optimal, GPs felt most comfortable treating pain, and least confident with breathlessness and depression. More formal training, particularly in the use of opioids, was considered important to improve management of both pain and breathlessness (RACGP 2025).

Recommendations identified to enable GP community based palliative include; clarity of the GP role in palliative care, increase understanding of the clinical triggers for commencing palliative care, local directories to enable GPs access to palliative care resources, and improved integration and communication across the health system (e.g. referrals to specialist palliative care teams or GP with special interest (AIHW 2025a).

Informal Carers

Best-practice palliative care incorporates the wellbeing of families and carers, the ongoing burden of care making this group vulnerable with significant physical and emotional stresses along with social isolation and the financial demands that come with caring for a dying friend or family member (Van Dinther and Javanparast 2024). Carers SA, the peak body for carers in South Australia, reported a 22% increase in palliative carers accessing the Carer Gateway service in South Australia in the first half of 2024 alone (Health Performance Council 2025).

The South Australian results of the 2022 National Carer survey indicated that carers were more commonly women than men, 52% where caring for someone over 65years and 34% of respondents were caring for someone with a chronic health condition (Carers SA Australia 2022). It is anticipated that with the projected large increase in deaths requiring palliative care there will also be a proportional increase in the amount of informal carers required (Health Performance Council 2025).

There is a growing need to include carers into decision making and planning as they are becoming increasingly embedded into the resource stretched palliative care teams and are assuming some responsibility for symptom management and end-of-life care (Reymond et al. 2016). A study of voices of South Australian unpaid carers highlighted concerns about medication management and manual handling, the majority of knowledge regarding end-of-life care came directly from home nursing staff. Carers who do not receive home assistance through palliative trained staff, especially when caring for dementia, were particularly vulnerable with frustration around lack of information and knowledge (Van Dinther and Javanparast 2024).

Barriers to access palliative care services

It is identified that the current Australian healthcare system does not meet patient preferences for end-of-life care (RACGP 2025). This was reiterated in APHN community consultation across 2023-2025.

Culturally safe and appropriate services

Language and communication barriers, cultural understanding and preferences and barriers for both consumers and providers. These identified barriers are relevant to the Australian population as a whole, however are likely to be magnified for under-served populations including Aboriginal and Torres Strait Islander people and people from CALD backgrounds (AHA 2019a).

Adelaide PHN 2023/24 community consultation in collaboration with Palliative Care SA, found that while there was confidence that physical needs would be met through services, community voice reflected less assurance about the provision of appropriate services to include holistic emotional, spiritual, and social support (Palliative Care SA 2024).

Gaps in at-home palliative care

Australian Healthcare Associates identified a number of barriers for consumers in accessing quality palliative care, these include community lack of understanding, awareness and comfort discussing palliative care, delayed diagnosis and financial constraints (AHA 2019a).

Consultation with Adelaide PHN stakeholders identified several barriers to enabling death and dying at home, including:

- Death literacy
- The need for improved Advanced care planning
- The complexity of the healthcare system
- Difficulty accessing care at home
- Unpaid carers in need of more support
- Incentivisation for GPs in the delivery of palliative care (APHN 2023).

Workforce capability

Common barriers for the health workforce in identifying and providing palliative care include time pressures, a lack of awareness, skills and competencies (DoH 2022).

There is identified inconsistency in GP workforce awareness and differentiation of palliative and end-of-life care. While many GPs delivery whole of patient palliative care, including social and emotional aspects, in general GPs approach palliative care in terms of non-curative care and associate it directly with comfort care, pain and symptom management (DoH 2022, DoH 2017). It is difficult for GPs to develop and maintain palliative care skills and knowledge due to the relatively small number of end-of-life patients they encounter (Ding et al. 2022).

Referral to specialist service and commencement of palliative care is often delayed. This is especially relevant to non-malignant disease, where there is lack of knowledge and uncertainty regarding prognosis and predictability of decline, adding significant challenges around advance care planning and timely referral and commencement of palliative care (AIHW 2024a; RACGP 2025).

National Market research conducted in 2022 exploring palliative care and the Health workforce found conversations about palliative care often happened too late, with discussions only occurring when disease was advanced and curative treatments had been exhausted. Health professionals have a role in early discussions on palliative care, especially in chronic disease where there may be patient and family reluctance to consider the provision of planning for palliative care (DoH 2022).

Systems and Infrastructure

Barriers in accessing palliative medicines relate to the expenses incurred by community pharmacies in holding and storing less commonly used palliative care medicines for urgent requests, after-hours (on-call) service costs and home delivery costs that can limit access to core end-of-life medicines required to support care at home in the community (Pharmacy Guild of Australia 2023).

There is an increasing need for GPs to fill the gaps in community based palliative care with a lack of available services and support, referral issues, insufficient funding and variable access to specialist outpatient services (SA Health 2019, 2023).

Individuals receiving palliative care or experiencing end-of-life are likely to remain confined to bed at home, limiting ability to attend appointments with their general practitioner. While many GPs may facilitate home visits to support complex care management in community, the national trend of GP home visits has decreased significantly in recent years (Evans 2025; Attwooll 2023).

> *"It is not feasible in the system…to get GPs to do home visits because the renumeration for home visits is so poor. Some people go if they have an established relationship with the patient but very few GPs are going to go voluntarily"* ***(APHN 2025)***

Remuneration through Medicare for providing palliative care or shared care with a specialist service is inadequate for GPs relative to the complexity and time required. There is a lack of clarity in roles and responsibilities of primary care clinicians including GPs and state funded community Specialist Palliative Care with poor communication and reporting between healthcare professionals and across health settings (SA Health 2023; Health Performance Council 2025).

Need Identification and Prioritisation

Health and service needs identified through the needs assessment process for palliative care by Adelaide PHN are summarised below:

Table 1: Outcomes of the health and service needs analysis – Palliative Care

Need Identified	Issue	Evidence
Awareness	There is a lack of easily accessible information, training, and facilitation to support older people to complete an Advance Care Directive / Plan.	Results of Early Intervention community consultation
	Communities need better education and training around dementia.	Community consultation
Service access	There is a lack of access to coordinated palliative care services for older people living at home.	Results of Early Intervention community consultation
	Lack of affordable, accessible and flexible service options relating to multidisciplinary care for both community and health professionals.	Multidisciplinary Team Care Needs Assessment summary report and kitchen table report, 2024
	There is a need for flexibility in service delivery models, including opportunities for outreach, group activities, etc., to ensure services are accessible and appropriately meet the needs of all clients requiring support.	Care Finder Needs Assessment consultation
	There is need for timely support in conjunction with available services through My Aged care.	Community consultation
System and Infrastructure	There is a need for people working with older people to be upskilled with dementia specific education and training.	Community consultation
	There is a need for clinicians to be enabled and supported to provided person centred and holistic care for older people.	Older person and Aged Care Needs Assessment: Health Professionals survey 2025
	There is a gap between available services and client demand, with some target populations potentially underserviced.	Care Finder Needs Assessment consultation

Priority statements

Table 2 summarises the palliative care priorities arising from the analysis of the Older People and Aged Care needs identified in the Adelaide PHN region and the opportunities for how they will be addressed. A revision of priorities will be conducted in 2026.

Table 2: Adelaide PHN - Older people and Aged Care Priority Statements, 2025

Priority statements	Priority area	Priority sub-category	Expected Outcome	Potential lead agency and/or opportunities for collaboration and partnership
Older people with chronic and life limiting illness have access to information, advice, and experience consistent support through coordinated and integrated models of care	Older people and Aged Care	Chronic conditions	Older people in the PHN region are supported to enjoy a greater quality of life.	• Adelaide PHN • SA Health • Local Health Networks • Primary Care providers • Aged Care providers • COTA
Older people living in the community and residential aged care are supported by timely, accessible, coordinated primary care services in and out of hours	Older people and Aged Care	Continuity of care	Local health care system provides coordinated, quality care to older people in the PHN region.	• Adelaide PHN • Primary Health Care providers • Support at Home Aged Care Providers • Residential Aged Care providers • SA Health • Local Health Networks
Palliative and end of life experiences are aligned with the needs, wishes and care preferences of the person, their family and carers	Older people and Aged Care	Access	Older people in the PHN region are supported to access primary health care services that meet their needs.	• Adelaide PHN • Residential Aged Care • Support at Home Aged Care providers • Palliative Care Connect • SA Health • Palliative Care SA • Carers SA • Advanced Care Planning Australia • Local Health Networks • Primary Care Providers

Conclusion

The Needs Assessment was undertaken as part of the Greater Choice for At Home Palliative Care Program to identify palliative care priorities and opportunities across the Adelaide metropolitan region. Health and service needs were identified through a comprehensive desktop review, and additional insights were sourced from community consultations, subject matter experts and from the 2025 Adelaide PHN Needs Assessment.

Key findings highlight the need to increase awareness of palliative care services, improve access to timely and coordinated care and address gaps within systems and infrastructure.

The priority opportunities have been identified for consideration by Adelaide PHN with particular focus on supporting older populations through improved access to person-centred care. Further needs assessment activity continues in 2026 with community and stakeholder engagement, and Adelaide PHN combined Advisory Council consultation. These activities will further inform the Adelaide PHN Needs Assessment Palliative Care 2026.

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