Summary of palliative care services in Australia

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Palliative care aims to prevent and relieve suffering and improve the quality of life of people (adults, children and their families) facing problems associated with life-limiting illness. Palliative care can be delivered by a wide range of health and community providers, is not limited to any specific condition, can be delivered at any stage of illness, and can accompany curative treatments. With an ageing and growing population, it is projected that the demand for palliative care and end-of-life care will rise substantially.

Identifying and accessing information on when palliative care has been provided and by whom remains a significant challenge (see below for further details).

See Glossary and Technical Information for further details on the definitions, data, and data sources used on this page.

PDF VERSION OF THIS SECTION

Overview of palliative care services and availability

In Australia, government agencies, as well as private and not-for-profit bodies, deliver palliative care in many health care settings, including but not limited to specialist inpatient and community-based palliative care services, neonatal units, paediatric services, geriatric services, public and private hospitals, general practices, disability services, and residential and community aged care services.

Identifying palliative care and end-of-life care in existing data collections and across all health settings remains a significant challenge, particularly care delivered in community, primary care, and residential aged care settings. For example, limited national data are currently available on palliative care-related expenditure, community-based palliative care services, Medicare Benefits Schedule-subsidised services provided by general practitioners and non-palliative care medical specialists, and the number of palliative care beds in hospitals, both acute and subacute. The data on this page is focused on specific settings where systems are in place to record a palliative care service, in particular specialist palliative care.

The AIHW is working with palliative care stakeholders to help address data gaps in palliative care reporting. The AIHW in collaboration with the End-of-Life Care Data Development Working Group released the National Palliative Care and End-of-Life Care Information Priorities report (PDF, 890KB) in January 2022. This document outlines an aspirational vision for the future of national palliative care and end-of-life care information development over the next decade and articulates priorities aimed at supporting that vision.

Hospitalisations

Palliative care-related hospitalisations are those where palliative care was provided during all or part of an episode of admitted patient care. It includes hospitalisations where the primary clinical purpose is palliative care and care is provided in a palliative care unit or by a palliative care specialist (referred to as palliative care hospitalisation) and hospitalisations with a recorded diagnosis of palliative care but where the primary clinical purpose of care is not recorded as palliative care (referred to as other end-of-life care hospitalisation; see Technical Information).

In 2019–20, there were **87,000 palliative care-related hospitalisations** (49,200 for palliative care and 37,700 for other end-of-life care).

- **1 in 2 (52%)** palliative care hospitalisations recorded a principal diagnosis of cancer.
- **3 in 5 (60%)** patients who died in hospital received palliative-related care during their final hospitalisation.
- Average length of stay for palliative care-related hospitalisations was almost **twice as long** as for all overnight hospitalisations (9.6 days for palliative care and 11.1 days for other end-of-life care compared with 5.5 days for all hospitalisations).



Between 2015–16 and 2019–20, palliative care-related hospitalisations increased by almost one fifth (18%) – this increase was at a steeper rate than that for hospitalisations for all reasons (6%) over the same period.

For more information refer to the section on admitted patient palliative care.

Medicare-subsidised specialist services

Medicare-subsidised palliative medicine specialist services (identified through specific MBS items) are those provided by palliative medicine physician/specialist. These services cover patient attendances (or consultations) provided in different settings – hospital/consulting room or other setting (such as a person's place of residence, including home, residential aged care or institution) – as well as services such as case conferencing (community case conference and discharge case conference).

In 2020–21, **15,800 patients** received **77,000 palliative medicine specialist services**.

- Patients received an average of **4.9 services per year**.
- **4 in 5 (80%)** were for palliative care attendances in consulting rooms or a hospital and **1 in 8 (12%)** were for palliative medicine case conferences.



• **\$6.3 million** was paid in benefits for these services.

The decline in the number of MBS-subsidised palliative medicine specialist services first observed between 2018–19 to 2019–20 continued in the 12 months to 2020–21 (8.7% decline between 2019–20 and 2020–21). This is in contrast to the 3 years leading to 2018–19 where services had been increasing.

For more information refer to medicare-subsidised palliative medicine services.

Medications

Palliative care-related prescriptions are an important component of care for palliative patients. One of the attributes of palliative care is to 'provide relief from pain and other distressing symptoms' (WHO 2020a). Palliative care-related prescriptions are defined as those listed in the Palliative Care Schedule of the Pharmaceutical Benefits Scheme (PBS). This schedule aims to improve access to essential and affordable medications for patients receiving palliative care.

In 2020–21, there were **1.2 million palliative care**related prescriptions provided to almost **515,000** patients.

- **1 million prescriptions** were for pain relief, accounting for **89%** of all palliative care prescriptions.
- **9 in 10 (92%)** palliative care-related prescriptions were prescribed by general practitioners.



Between 2016–17 and 2020–21, the number of palliative care-related prescriptions increased on average by 6% per year, with the steepest increase being for gastrointestinal symptom prescriptions (13% average annual increase).

For more information refer to the section on palliative care-related medications.

Residential Aged Care

The Australian Government subsidises residential aged care services for older Australians whose care needs are such that they can no longer remain living in their own homes. The data used here are based on Aged Care Funding Instrument (ACFI) appraisals, which are used to determine Australian Government subsidies for people living in permanent residential aged care (PRAC) services.

In 2020–21, there were **4,500 people** using permanent residential aged care with an ACFI appraisal indicating the need for palliative care (only **1.9% of the 243,500 people** using PRAC).

- 3 in 5 (59%) were aged 85 years and over.
- **1 in 4 (22%)** had cancer listed as the first condition on their appraisal, compared with **3.5%** for those appraised as requiring other care.
- **1 in 2 (50%)** exited within 8 weeks of admission, compared with **8.5%** for those appraised as requiring other care.

For more information refer to the section on palliative care in residential aged care.



Outcomes

Key measures of quality care are the outcomes that patients, their families and carers achieve. The Australian Palliative Care Outcomes Collaboration (PCOC) is a national program that aims to systematically improve patient and carer outcomes, using standardised validated clinical assessment tools (clinician and patient-rated scales) to benchmark and measure outcomes. These include timelines of palliative care, responsiveness to urgent needs, and responsiveness and appropriateness of the care plan in place.

In 2021, **58,700 patients** received palliative care from the **177 palliative care services** participating in PCOC.

- 2 in 3 (66%) patients had a diagnosis of cancer.
- **3 in 4 (77%)** palliative care closed episodes ended within 30 days, with most ending within 2 weeks (62%).
- **9 in 10 (88%)** unstable phases (urgent needs) were resolved within 3 days or less.
- **9 in 10** palliative care phases that started with absent/mild patient pain remained absent/mild at the end of the phase.



Achieving an absent/mild symptom outcome is less likely when the patient has moderate/severe symptoms to begin with, especially for those with distress from fatigue and breathing problems:

- **3 in 5** palliative care phases that began with moderate/severe patient pain reduced to absent/mild by the end of the phase.
- **1 in 2** of those starting with moderate/severe distress from fatigue or breathing problems reduced to absent/mild by the end of the palliative care phase.

Between 2017 and 2021, there was a 36% increase in the number of services participating in PCOC, with the rate of increase in services slowing in the 12 months to 2021.

For more information refer to the section on Palliative care patient outcomes.

Workforce

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

In 2020, there were **300 palliative medicine physicians** and **3,800 palliative care nurses** employed in Australia.

- 2 in 3 (64%) employed palliative medicine physicians and 9 in 10 (92%) employed palliative care nurses were women.
- **4 in 5 (84%)** employed palliative medicine physicians and **3 in 4 (72%)** employed palliative care nurses worked in *Major cities*.
- 3 in 4 (75%) employed palliative medicine physicians and half (56%) of all employed palliative care nurses worked in a hospital setting.



Between 2016 and 2020, there was a 29% increase in the number of employed palliative medicine physicians and a 9.5% increase in palliative care nurses.

For more information refer to the section on the Palliative care workforce.

Impact of COVID-19 on palliative care services

The COVID-19 pandemic was anticipated to impact palliative care in a number of ways, including disruptions in service delivery and increased demand of palliative carerelated resources such as palliative care specialists and medications (WHO 2020b). A high proportion of people using palliative care services and in permanent residential aged care are aged 70 and over and/or are immunocompromised and so are at an increased risk of dying due to COVID-19.



By looking at monthly service activity data we can assess whether the public health response to the COVID-19 pandemic had an impact on the delivery and receipt of palliative care services during 2020 and 2021.

- There was a large decrease in MBS-subsidised palliative care specialist services in April, May and September 2020 (25%, 12% and 18% decrease from 2019 levels). While the number of services was similar to or above March 2020 levels between November 2020 and June 2021, it did not fully recover to the levels observed in the corresponding months in 2019 (remained 10–18% lower). Note, palliative care physicians/specialists were able to use new MBS COVID-19 telehealth items from March 2020 in response to the pandemic, which may have contributed to the above mentioned declines in face-to-face consultations with palliative care physicians/specialists.
- In March 2020 there was a large increase in palliative care-related prescriptions (13% increase from 2019 levels), followed by a large drop in April (20% from March 2020 and 7% lower than in April 2019), with prescription numbers then returning to relatively similar levels observed in previous years between July and December 2020. Another large drop was observed for most months between January to May 2021 (3–15% below the 2019 levels for the corresponding months).
- A large decrease in the new admissions to permanent residential aged care was also observed in May 2020 (28% and 24% decline from March 2020 for people appraised as requiring palliative and other care, respectively), reaching its lowest level in May 2020 in the 3 years to June 2021. Another decrease was also observed in October 2020 and January 2021 for palliative care admissions and in August 2020 and January 2021 for other care. By February 2021, the number of admissions had largely recovered to similar levels observed prior to the COVID-19 pandemic in March 2020.

These falls coincided with the stricter public health restrictions and lockdowns in certain regions at these times, however fluctuations in counts may reflect a number of factors that may or may not be related to the COVID-19 pandemic.

Annual palliative care outcomes and workforce data also provides insights on how people were accessing and receiving palliative care services and their outcomes during the COVID-19 pandemic:

- In the 12 months to 2021, the rate of **increase of services participating in PCOC slowed**, 4% increase compared with annual increases of 11% and 15% between 2018 and 2020. This pattern was driven by community-based episodes, which remained relatively stable between 2020 and 2021, while inpatient patient episodes increased steeply over this period. Most outcome measures remained relatively similar in the 2 years to 2021, except for those assessed as ready for care where there was a steady decline (from 93% to 86%).
- The rate of **increase in employed palliative medicine physicians more than halved** between 2019 and 2020 compared with the increases observed in previous years (3.4% increase between 2019 and 2020 compared with 7.7%–8.8% annual increases between 2017–2018 and 2018–2019). This is consistent with pattern observed for all employed specialist medical practitioners. However, rate of increase remained stable for palliative care nurses, despite the increase for all employed nurses and midwives slowing in 2020.

The most recent hospitals data only captures the first 3 months of the COVID-19 pandemic in Australia. More data over a longer period of time, and including patients experiencing COVID-19 who received palliative care, is needed to provide insights on the effects of the COVID-19 pandemic on palliative care service activity and outcomes.

Where do I go for more information?

For more information on palliative care services see:

- Palliative care services
- Department of Health Palliative care website
- Palliative Care Australia website
- Medicare Benefits Schedule website
- Pharmaceutical Benefits Scheme website
- Palliative Care Outcomes Collaboration

References

WHO (World Health Organization) (2020a) *Global atlas of palliative care at the end of life*, Geneva: WHO, accessed 23 March 2022.

WHO (2020b) *Discussion on palliative care in the time of COVID-19. 8 April 2020*, Geneva: WHO, accessed 9 July 2021.