

Palliative Care

2030

Working towards the future of quality palliative care for all

FEBRUARY 2019



PalliativeCare
AUSTRALIA

Recommended citation

Palliative Care Australia 2018, *Palliative Care 2030 - working towards the future of quality palliative care for all*, PCA, Canberra.

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care in Australia, representing all those who work towards high quality palliative care for all Australians. Working closely with consumers, its Member Organisations and the palliative care and broader health, aged care and disability care workforce, PCA improves access to, and promotes the need for, palliative care. PCA's vision is quality palliative care for all.

PCA affirms that palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life. Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness, ranging from palliative care when their needs are straightforward and predictable, to specialist palliative care when there are complex and persistent needs.

Palliative Care 2030 outlines guiding principles to assist the health, disability and aged care sectors, governments and the general community, to plan and prepare for the future where Australians will live longer, demand an improved quality of life, and access to high quality palliative care when living with a life-limiting illness. Underpinning this is the assumption of ongoing commitment by governments to appropriately invest in, and plan for the delivery of palliative care, in co-design with specialist palliative care and the broader palliative care sector.

In 2030 silos and system impediments will have been minimised via collaborative population-based planning across all levels of government, Commonwealth and State and Territory. There will be improved data collection and data sharing leading to ongoing quality improvement and carefully considered policy and funding decisions. Advances in technology and treatment options will mean significant changes in what people can expect as they progress through their life.

Australians will have different expectations about how they can have quality of life and a good death, including choosing the setting of their care as they approach the end of their life as well as the preferred location for their death. Dying will be viewed as a normal part of life, and grief and bereavement will be supported in the community and within workplaces. With the introduction of Voluntary Assisted Dying (VAD) in Australian jurisdictions it is also important that an individual choice to request VAD is not a choice based on a lack of access to palliative care.

Importantly, 2030 will mark 16 years after the World Health Assembly (WHA) endorsed palliative care as a human right under article 12 of the *International Convention on Economic, Social and Cultural Rights* (ICESCR), specifically stating that:

'access to palliative care and to essential medicines... including opioid analgesics ... contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being'.¹

Legislation should be introduced that strengthens Australians right to palliative care, to include provisions regarding a right to information; carer support such as adequate leave entitlements, and flexible and responsive care and location of care options.

What is expected in 2030?

Australia's demographics are changing and we need to plan ahead for the increased demand for accessible, flexible and responsive palliative care.

- » Australia's population is expected to be 30,000,000 by the year 2030.²
- » People aged 65 years and older are increasing rapidly in terms of both numbers and proportions of the population. By the year 2031 this age group is expected to be about 5.7 million (19% of the population).³
- » People living to over 85 will also increase to around 842,500 and double again by 2045 to 1.7 million.⁴
- » Currently approximately 160,000 people die in Australia each year and by 2030, this will be over 200,000.⁵ Within 40 years' time, the figure of 160,000 will have doubled.⁶
- » In 2011, the estimated resident Aboriginal and Torres Strait Islander population was 669,900 people, representing 3% of the Australian population. Population projections show that the Aboriginal and Torres Strait Islander population is expected to increase to 945,600 by 2026. The number of Aboriginal and Torres Strait Islander people 65 years and older is projected to increase from 3% to 7%.⁷
- » The unprecedented increase in deaths from dementia means that a change in focus towards people living with dementia will be required.⁸
- » Comorbidity will be an increasingly significant factor in palliative care due to multi-morbidity, chronic progressive illnesses with longer disease courses, and diseases with complex symptoms and high symptom burden.⁹



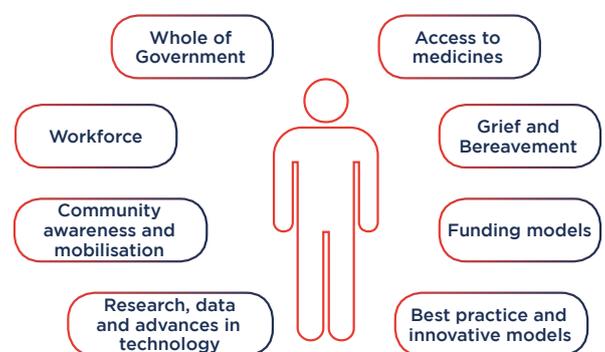
Guiding Principles for Palliative Care 2030

These guiding principles are proposed to assist policy planners to prepare for the future and work towards ensuring Australians have assured access to high quality palliative care in the future.

- » All Australians have a human right to high quality palliative care.
- » Australia will maintain the universal health system, and equity of access remains a priority for all levels of government.
- » Palliative care is highly regarded as person and family centred, where the individual needs of people who are living with a life-limiting illness, their carers and family will determine which services they access at any given time.
- » It is well-accepted that there is benefit in providing palliative care concurrently with disease-modifying therapies in response to changing needs of people living with a life-limiting illness, not only once all treatment aimed at a cure had ceased.
- » Palliative care is available for all ages, encompassing the needs of paediatric populations through to older Australians.
- » Grief and bereavement support is not just an integral component of specialist palliative care but of all healthcare.
- » Support and resourcing for the planning and development of culturally safe and culturally aware palliative care services is common place to ensure culturally relevant requirements are addressed.
- » When new technologies and advancements in health and care are developed, appropriate privacy provisions are in place that are acceptable in the wider community.

A future focus for palliative care – what should we expect in 2030?

First and foremost palliative care has remained person and family-centred care. The gap in the number of Australians who have accessed specialist palliative care versus those who would benefit has decreased considerably*. The individual receiving palliative care and their family are actively engaged and able to move seamlessly through services regardless of where the funding for that service comes from and the setting in which the services are provided. Models of care reflect what is important to a person and their family, respectful of culture, values and beliefs.



Whole of Government

Palliative care is now a national health priority. There has been a commitment since the release of the National Palliative Care Strategy in 2018/2019 for a whole of government approach to robust population and needs-based planning and adequate funding of palliative care and specialist palliative care services. This is underpinned by the National Health Reform Agreements and National Palliative Care Strategy Implementation Plan.

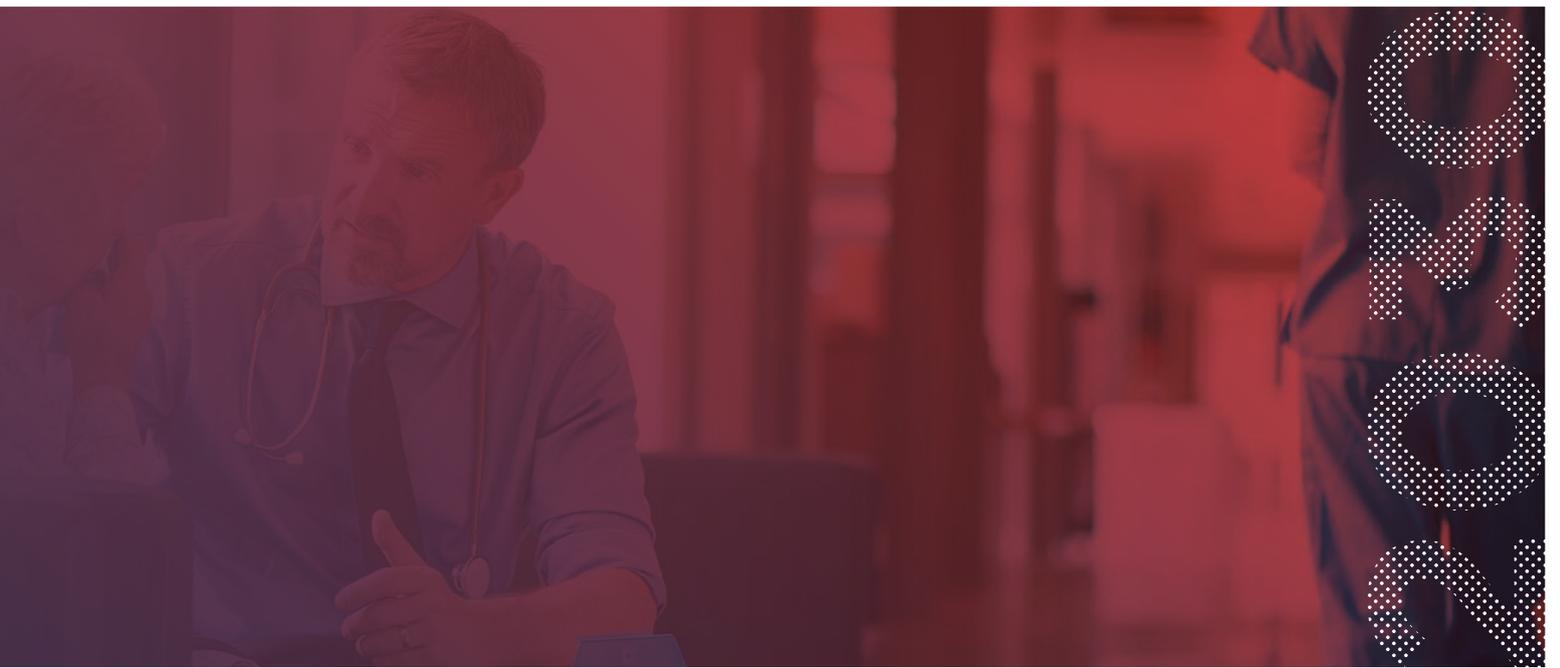
State, Territory and Commonwealth governments agreed to National Service Levels in 2019, and universal health coverage explicitly includes specialist palliative care, as there is evidence that where this has occurred the outcomes are positive both for those living with and affected by life-limiting illnesses and for the health system as a whole. When an individual requires palliative care, this need is appropriately assessed in a timely manner, and funded seamlessly through jurisdictional services and within systems such as My Aged Care and the National Disability Insurance Scheme (NDIS).

Workforce

The health, disability and aged care systems have benefited greatly from the National Palliative Care Workforce Strategy, which was developed in 2019-2020 after palliative care became a national health priority. It is well recognised that Australia must maintain and grow a strong specialist palliative care sector, and there has been ongoing investment and clear employment pathways which has enabled Australia to reach the benchmark set by PCA in 2018, of 2 full-time equivalent specialist palliative medicine physicians per 100,000 population and 3 full-time equivalent palliative care nurse practitioners per 100,000 population.

The broader health, disability and aged care systems are more engaged, and health professionals providing palliative care, including general practitioners, are supported by a robust specialist palliative care workforce, information sharing, appropriate remuneration, referral pathways and education and training options underpinned by clear competency and capability frameworks.

* There are around 100,000 predictable deaths per year in Australia. Of those, only 40,000 patients receive specialist palliative care. On referral to specialist palliative care 9% experience severe pain which is reduced to approximately 2%. Over 80% of patients receiving specialist palliative care do not have severe symptoms at the time of death. Source: Palliative Care Outcomes Collaboration (PCOC) University of Wollongong, *Palliative Care Information for Patients, Carers, Families and the General Public* [accessed October 2018]



Health professionals are supported by improved learning paradigms as the community expect all health and care professionals across primary care, community care, aged care and disability care to have an understanding of palliative care and are able to communicate information appropriately. Palliative care units were incorporated over a decade ago into all Australian undergraduate degrees in medicine, nursing and pharmacy, and included in all relevant aged and community care Certificate level qualifications.

Community awareness and mobilisation

The value of palliative care is well understood in the community, which has mobilised to provide additional support to individuals and families who are receiving palliative care. Individuals and their families have access to required information at the right time to enable informed decision making. Death literacy has improved significantly and people are now talking openly about death and dying just like they do about organ donation and having a will.

Widespread and appropriate advance care planning and development of Advance Care Directives now ensure people can clearly express their individualised preferences and choices. These documents are regularly revisited with the individual and their family/carer and there are mechanisms in place to support this, including policies, standards and remuneration to health professionals. The documents are embedded within interoperable systems such as My Health Record, eHealth solutions and patient records so that all relevant healthcare professionals and other nominated people are able to access them as needed, especially in emergency situations.

Research, data and advances in technology

The National Palliative Care Strategy was followed soon after by a co-designed monitoring and evaluation plan which paved the way for the collection of nationally consistent and linked data across jurisdictions and locations of care. This has improved population and needs-based mapping and planning of services and appropriate allocation of funding.

In 2030 the evidence base in Australia has been strengthened by significant investment via the NHMRC and Medical Research Future Fund into palliative care focused research, including:

- » the benefits of early referral to specialist palliative care for non-malignant life-limiting illnesses,
- » the off-label use of medicines,
- » systems to monitor and record improvements or changes in quality of life,
- » avoidance of clinically non-beneficial treatments and ICU presentations, and
- » life expectancy and experiences of the person and their carers working within different models of care and at different points in the illness trajectory.

Increased use of new and adaptive technologies results in care being more agile, predictive and proactive. As the medical science field developed, palliative care incorporated components of Artificial Intelligence, biotechnology, precision medicines and pharmacogenomics, as concerted focus was given within these disciplines as to how their use could benefit people receiving palliative care.

A future focus for palliative care – what should we expect in 2030?

Best practice and innovative models

Australia has seen the development of best practice models of care underpinned by evidence, population-based planning, consistent data collection and a strong specialist palliative care workforce. From the time of diagnosis, people with life-limiting illnesses and their family and carers have moved seamlessly through health, disability and aged care systems in all jurisdictions. This is facilitated by an agreed set of criteria or processes for earlier identification of when palliative care would be beneficial for an individual, and appropriate referral to specialist palliative care particularly when there are complex and persistent care needs.

Respite options are available in a timely manner, and there are integrated care sites operating throughout Australia, with navigators and multi-disciplinary care and support teams that assist those who may be at particular risk of poor care outcomes to coordinate the health, disability and aged care sectors. There has been an investment in palliative care education and support to paramedic services. This has led to less unwanted emergency department admissions and hospital transfers, thus enabling more people to stay at home, including residential aged care settings, if this is the location of their choice and appropriate care can be provided.

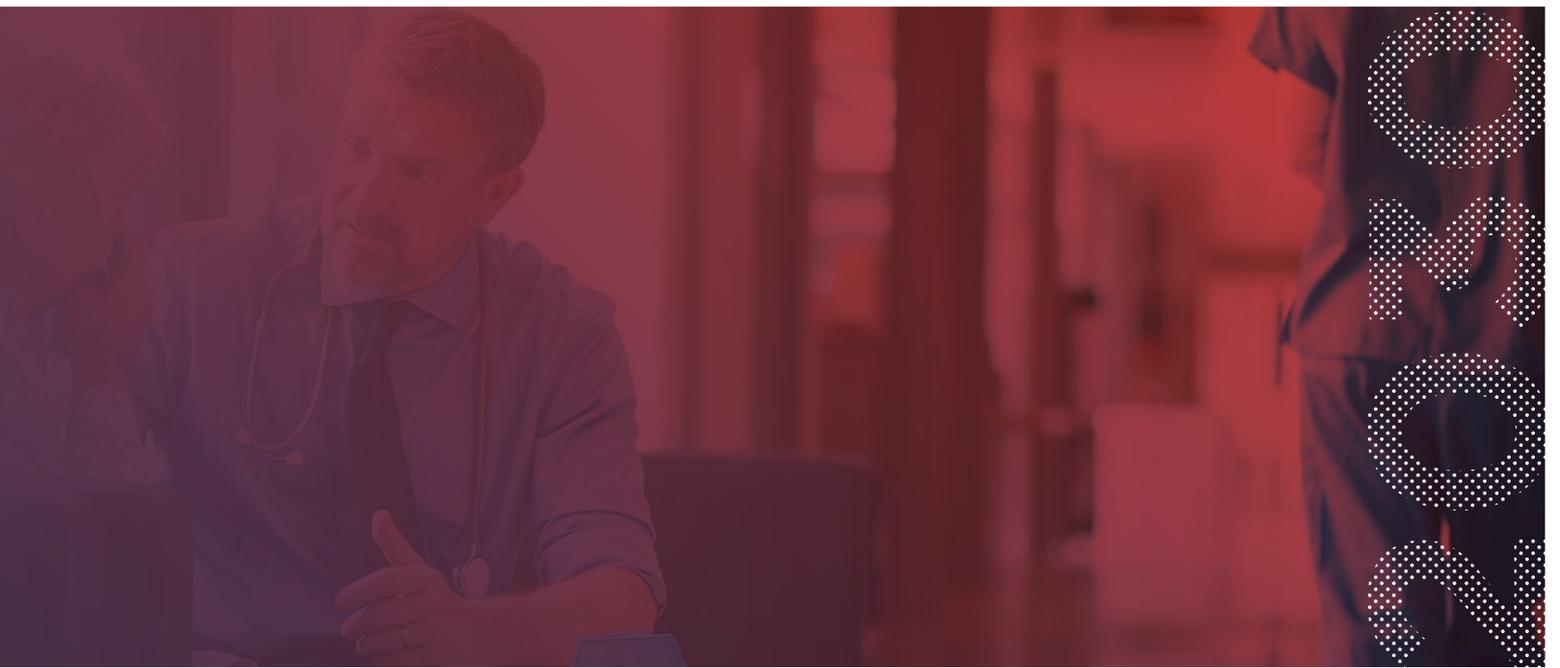
Funding models

Following on from the palliative care MBS review in 2019-2020, item numbers are more suited to provide for palliative care and specialist palliative care needs across the health sector, including tertiary and 24-hour community based care.

System impediments restricting access have been minimised through the whole-of-government approach, where a person and their family is able to receive the care and support needs they require no matter what the scheme or who the funder is. Processes are in place that are quickly able to identify risk in individual situations, protecting underserved populations or those that may be more vulnerable to 'falling through the gaps'.

Private health insurance is mandated to include specialist palliative care in all levels of coverage, and have introduced a range of innovative models of care to support individuals, their families and carers.

Funding mechanisms are in place to support Australians living in rural and remote locations to remain on country for the majority of their care if this is what they choose, which is supported by innovative models of specialist palliative care delivery. There has been significant investment via public-private partnerships in strong infrastructure to enable telehealth, which is a core component of standard care to enable quality and equitable access across Australia.



Grief and Bereavement

The gaps in knowledge from 2018 have reduced significantly in relation to the level of grief and bereavement support needed in different situations and for what length of time. There is a greater understanding and awareness of the impact that grief and bereavement support services have on improving physical and mental health wellbeing and ability to maintain active engagement in the workforce, study and other community obligations. All providers of palliative care (including general practitioners) have the capability to assess where family members and carers sit along a continuum of need for bereavement support, and are able to refer if required.

The impact of death and dying within the workplace has been supported by both the public and private sectors, and the specific needs of Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse communities and people who have experienced trauma are facilitated and well supported.

A National Grief and Bereavement Day has become a key date on the event calendar after being introduced in 2019 to provide public recognition of the impact of death and loss have on individuals, families and the broader community.

Access to medicines

A person and their family or carer is able to access appropriate medicines as and when required within a quality use of medicines safety and regulatory framework, but without the red tape and systems issues that were present in 2018. The Pharmaceutical Benefits Scheme (PBS) was reviewed and there has since been an introduction of new collaborative and appropriately funded models to support community pharmacy, general practice and other practitioners to safely provide opioids and other medicines, including off-label indications. This has led to an increase in well managed patients in the community, safer use of medicines and a reduction in hospitalisations. There is now clear data through various mechanisms to show prescribing and dispensing patterns in palliative care which is supporting policy decisions and development of further models.

References

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- 3 Ibid
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- 6 Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Canberra: 2017, p 113.
- 7 Australian Bureau of Statistics, *Estimates and Projections: Aboriginal and Torres Strait Islander Australians 2001-16*, ABS, Canberra, 2014.
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- 9 Ibid.

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Palliative Care Australia is funded by the Australian Government.

