



OCTOBER 2022
Budget
Submission



PalliativeCare
AUSTRALIA

Delivered July 2022, supplementary to 2022/23 Pre-Budget Submission

Palliative Care Australia's (PCA) Member Organisations:



Acknowledgement of Country

Palliative Care Australia (PCA) is in Canberra on the land of the Ngunnawal People. PCA wishes to acknowledge the traditional owners of this land, the Ngunnawal People and their elders past and present. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region.

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote palliative care.

PURPOSE

Palliative Care Australia leads a unified voice to strengthen our collective impact towards excellence in palliative care.

VISION

We see a world where quality palliative care is available for all, when and where they need it.

PCA subscribes to the World Health Organization (WHO) definition of palliative care which is the definition used in the National Palliative Care Strategy (2018):

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- » Provides relief from pain and other distressing symptoms
- » Affirms life and regards dying as a normal process
- » Intends neither to hasten or postpone death
- » Integrates the psychological and spiritual aspects of patient care
- » Offers a support system to help patients live as actively as possible until death
- » Offers a support system to help the family cope during the patient's illness and in their own bereavement
- » Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- » Will enhance quality of life, and may also positively influence the course of illness
- » Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹

People living with a life-limiting illness deserve high quality care. They and their families, carers and loved ones want to know that high quality palliative care will be available when and where people need it.

Investment in palliative care means people can live well until their death, with optimal management of symptoms, support and care in the place of their choice.

People living with a life-limiting illness who receive palliative care, compared with those who do not, have fewer hospitalisations, shorter hospital stays, reduced use of Intensive Care Units and fewer visits to Emergency Departments (EDs).

1. Australian Government, National Palliative Care Strategy, 2018, page 42

Key facts



Demand for palliative care is expected to increase by **50%** between now and 2035, and to double by 2050².



It is conservatively estimated that demand for services rose by **30%** during COVID-19.³



Apart from the COVID-19 affect, palliative care services across the board are experiencing over **11% increase** in demand for their services each year. The funding for palliative care services is not keeping pace with this increase.⁴



Palliative care leads to **improved** social, psychological, emotional, spiritual and practical outcomes for people with a life limiting illness, their carers and families.^{5,6}



Palliative care also leads to **improved wellbeing and productivity** for carers⁷ and lower bereavement costs⁸



Investing in high quality palliative care delivers a very **high return on investment**. It does this because people who are receiving their care from palliative care health professionals have their pain and symptoms managed. This means less visits to Emergency Departments, reduced ICU admissions and usage, less emergency calls to ambulances and **less days spent in hospital**.⁹



The return on investment of dollars spent in palliative care is high with KPMG estimating that (in 2019 Australian dollars):



A \$1.00 investment in palliative care nurses in residential aged care can return between \$1.68 and \$4.14



A \$1.00 investment in palliative care in hospital delivers a return of between \$1.36 and \$2.13



A \$1.00 investment in integrated home-based palliative care delivers a return of between \$0.53 and \$1.56

2. KPMG (2020), 'Investing to Save: the economics of increased investment in palliative care in Australia,' page 32. <https://palliativecare.org.au/kpmg-palliativecare-economic-report>
3. Internal Survey for PCA and its Member Organisations conducted by KPMG 2022.
4. Ibid.
5. Warth, M., Kessler, J., Koehler, F., Aguilar-Raab, C., Bardenheuer, H. & Ditzen, B. (2019). Brief psychosocial interventions improve quality of life of patients receiving palliative care: A systematic review and meta-analysis. *Palliative Medicine*, 33(3): 332-345.
6. Beresford, P., Adshead, L. & Croft, S. (2007). *Palliative care social work and service users: making life possible*. London, Jessica Kinglsey Publishers
7. Hudson, P.L., Remedios, C., and Thomas, K. (2010). "A systematic review of psychosocial interventions for family carers of palliative care patients," *BMC Palliative Care*, Vol 9, No 17.
8. Genevro, J.L., and Miller, T.L. (2010) 'The emotional and economic costs of bereavement in health care settings,' vol 50, no 1-2, pp69-88.
9. KPMG (2020), 'Investing to Save: the economics of increased investment in palliative care in Australia' <https://palliativecare.org.au/kpmg-palliativecare-economic-report>

What is needed to support people with life-limiting illness in Australia?

To be able to offer people with life-limiting illness the care and support they and their families need requires investment. This is recognised in the National Palliative Care Strategy (2018) agreed to by the Australian government and all state and territory governments:

Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care when and where it is needed.¹⁰

Drawing on our 2022-2023 Pre-Budget Submission and the Palliative Care Australia (PCA) Roadmap 2022 – 2027: Investing to secure high-quality palliative care for those who need it this October 2022 Budget submission outlines some urgent areas of investment needed for the palliative care sector.

In the PCA Roadmap 2022 – 2027, PCA states what is needed for palliative care in Australia:



PCA's priorities are in alignment with the Government's five-point plan to put security, dignity, quality and humanity back into aged care:

1. Registered nurses on site 24/7
2. More carers with more time to care
3. A pay rise for aged care workers
4. Better food for residents
5. Dollars going to care

Three Budget Announceables for the Government

PCA recommends the Government review the PCA 2022-2023 Pre-Budget Submission and the Palliative Care Australia (PCA) Roadmap 2022 – 2027: Investing to secure high-quality palliative care for those who need it for a thorough plan for investing in palliative care in the future.

As immediate measures to support the palliative care sector, PCA recommends the Government fund three key projects:

- 1** Build on the Government's plan to have Registered Nurses 24/7 in Residential Aged Care ensuring they have essential palliative care skills
- 2** Fund a National Palliative Care Workforce Strategy
- 3** Support the palliative care sector with commitment to fund the peak body for palliative care in Australia

10. Australian Government, National Palliative Care Strategy, 2018 (The National Palliative Care Strategy 2018 | Australian Government Department of Health and Aged Care), p29.

Build on the Government's plan to have Registered Nurses 24/7 in Residential Aged Care ensuring they have essential palliative care skills

Palliative Care Australia (PCA) congratulates the Government on its commitment to a policy for aged care reform and investment that will require all residential aged care facilities to have a registered nurse (RN) on site 24 hours a day, 7 days per week (24/7). PCA advocates that these registered nurses are trained in palliative care as a key building block of this policy.

Currently, over one third of all deaths in Australia occur in residential aged care facilities.¹¹ It is currently a post code lottery as to whether older people can access palliative care in these facilities. As Australia's population ages, the number of people using aged care services will further increase as will the demand for palliative care in both community and residential aged care. In April 2022, PCA conducted its annual national attitudes survey which showed that 96% of Australians believe it is important that aged care services are able to provide palliative care to residents and clients.

Through submissions from PCA and other aged care peak bodies, the Royal Commission into Aged Care Quality and Safety recognised the significant role palliative care has in aged care and the need for it to be core business for aged care providers. The Royal Commission made a range of palliative care recommendations including:

- » Compulsory dementia and palliative care training for aged care workers (recommendation 80). PCA believes that in order for palliative care to be core business in aged care and to support the recommendations, it is essential for aged care service RN workforce to have palliative care skills.

RNs must be trained in minimum levels of core competencies to provide care for people with a life-limiting illness with straightforward needs including:

- » Palliative care needs assessment and setting goals of care
- » Supporting people with advance care planning
- » Symptom management and administration of medications
- » Supporting psychosocial needs
- » Providing support to personal care workers
- » Identification of complex needs and referral to specialist palliative care services when needed
- » Grief and bereavement support

This initiative will provide support for Aged Care Providers through:

- » Access to free palliative care training
- » Training and maintaining their RN workforce, with an emphasis on direct, permanent employment over a casual workforce
- » Providing access to clinical supervision for RNs involved in providing palliative care
- » For providers in rural and remote areas, funding to support staff housing, relocation costs and remote allowances

11. KPMG (2020) based on AIHW data, Investing to Save: The Economics of Increased Investment in Palliative Care in Australia, page 23.



This support package should complement any support given to aged care providers to upskill and support the residential aged care facilities work force.

PCA proposes a three-stage project over four years to embed palliative care skills into the RN workforce in residential aged care facilities.

Stage 1

By 30 June 2023 PCA research and modelling to develop a human resourcing framework, as well as the design of the aged care support package and the evaluation process will have been completed.

Stage 2

By 30 December 2024 there is a minimum of **one RN at each residential aged care facility** who has undertaken palliative care training and has the core competencies as outlined above. Nurses will be trained incrementally over two years with a total of 2,700 registered nurses recruited and trained in palliative care.

Stage 3

By 30 December 2025 there is a minimum of **one RN on every shift (24/7) at each residential aged care facility** equating to 8,200 nurses who have undertaken palliative care training and have the core competencies as outlined above.



ANNOUNCEABLE FUNDING SOUGHT

\$36 million over four years

Fund a National Palliative Care Workforce Strategy

Proactive measures must be put in place to ensure the increased workforce and diversified skills and education of all those working in palliative care and caring for people with life-limiting illness to meet the needs of the future.

The proposed National Palliative Care Workforce Strategy project aims to address palliative care workforce issues including:

- » Collaborating on national workforce planning and design
- » Rebalancing the supply and distribution of workforce across locations
- » Reforming training pathways
- » Building the capability of the palliative care workforce outside specialist palliative care, including primary health and aged care; and
- » Building a flexible and responsive workforce regardless of the service setting
- » Addressing the specific needs of the paediatric palliative care workforce

The Strategy will also include five overarching contextual priorities that aim to:

- » Grow the Aboriginal and Torres Strait Islander workforce and improve cultural responsiveness
- » Adapt to, and better support, new models of care
- » Improve workforce wellbeing
- » Develop a paediatric palliative care specific workforce model; and
- » Align with priorities in the *National Medical Workforce Strategy 2021 – 2031*

Primary areas of focus/end beneficiaries

- » Specialist palliative care workforce, including interdisciplinary care providers
- » Health professionals and aged care workers delivering palliative care in non-specialist palliative care settings
- » Palliative care patients:
 - Improved access to high quality palliative care, and its interdisciplinary providers
 - Better quality of life for patients (adults and children) with life limiting conditions, and their families.
- » Expanded and well-integrated Aboriginal and Torres Strait Islander palliative care trained workforce for improved cultural safety and responsiveness for patients and families.

The National Palliative Care Workforce Strategy will provide guidance on the appropriate staffing mix and numbers that are required to facilitate the delivery of palliative care to all Australians with a life-limiting illness regardless of age or diagnosis. The Strategy will clearly address workforce needs across all health settings, including tertiary, community-based and residential aged care settings, and ensure appropriate access to consultancy advice from specialised palliative care services.



The National Palliative Care Workforce Strategy will reach beyond the needs of the palliative care specialty, and into the role of primary care providers, including:

- » General Practitioners (GPs)
- » Nurses
- » Aboriginal Health Workers
- » Community pharmacy
- » Allied health
- » Aged care staff
- » Paediatric health professionals
- » Paramedics; and
- » Other health professionals able to contribute to the principles of palliative care such as spiritual health workers.

The Strategy will enable broader workforce issues to also be examined and will enable disparities in access to palliative care (for example, across the states and territories and inner city, regional and rural and remote locations) to be identified and addressed.



ANNOUNCEABLE FUNDING SOUGHT

\$2.5 million over two years

Support the palliative care sector with commitment to fund the peak body for palliative care in Australia

PCA has traditionally received funding through the Department of Health to support our peak body advocacy work to represent our membership base and people living with life-limiting illness, as well as carers and the health, aged care and disability workforce. The funding has been allocated through the Health Peak and Advisory Bodies Program (HPAB Program).

The HPAB Program, established in 2016, has been viewed by all health care peak body organisations as a key mechanism for ensuring there is a robust non-government health sector to provide expert advice and represent a community perspective to Government.

However, in January 2022, the previous Government changed the focus of the HPAB Program funding to align specifically with the National Preventative Health Strategy and only a very limited number of peak body organisations were funded. PCA was granted a one year extension to our current grant so that our current peak body funding expires on 30 June 2023.

While recognising the critical importance of the National Preventative Health Strategy and the role of those organisations who received funding, the narrowing in funding priority disregards critical issues currently facing the sustainability of the health system, the care delivered to Australians and the health outcomes they can achieve.

Prior to this lens being applied, the HPAB Program enabled health peaks and advisory bodies to contribute to the national agenda by providing expert, evidence-based and impartial advice to inform health policy and program development, as well as supporting communication and consultation activities within our unique communities.

PCA seeks a commitment from the Government to secure core peak funding to support PCA's advocacy and peak body work beyond 30 June 2023.

PCA has used its core peak funding wisely over many years and without this ongoing funding, the following activities will be at risk:

- » Supporting palliative care to be core business in aged care including PCA's advocacy for the aged care workforce to be skilled in caring for people as they near the end of life;
- » Supporting people living with life-limiting illness to have access to appropriate pain relieving and symptom relieving medications through PCA advocacy for the palliative care schedule of the Pharmaceutical Benefits Scheme (PBS);
- » Supporting people living with life-limiting illness throughout Australia and their carers to access critical information through the PCA phone system and website which has been supported to date with peak body funding;
- » Supporting the work that PCA undertakes with other peak bodies to advocate for increased access to palliative care for people living with dementia and complex diagnoses;
- » Supporting the work that PCA undertakes with other peak bodies to advocate for increased access to palliative care for those living in rural, regional and remote Australia;
- » Working to build capacity in the Australia health and aged care sectors to provide appropriate palliative care to Aboriginal and Torres Strait Islander people;



- » In the absence of funding for a paediatric palliative care peak body, PCA will be unable to offer full support for paediatric palliative care in Australia;
- » Offering independent and expert advice to the Australian government about issues affecting the Australian health system where higher than normal deaths can be expected such as during pandemics and natural disasters; and
- » Supporting Australia's neighbours in the Western Pacific region to build their palliative care capacity.

ANNOUNCEABLE FUNDING SOUGHT

\$400,000 per year for next three years

Future funding for National Palliative Care Projects and the Paediatric Palliative Care National Action Plan Project

PCA also brings to the Government's attention that Palliative Care Australia (PCA) is funded to deliver essential projects under the Australian Government's National Palliative Care Projects. PCA has also been funded to deliver the Paediatric Palliative Care National Action Plan Project. Funding for both of these expires in June 2023. The projects are ongoing and require security of funding for the future.

To date there has not been an announcement about future tender or application processes for these projects beyond 30 June 2023.

PCA calls on the government to announce the processes for applying for palliative care project funding and to support the ongoing and essential work of PCA to support palliative care patients (adults and children), carers and the palliative care workforce spread across Australia.

Summary of asks

PCA will support the agenda of the Government with three announceable funding opportunities:

- » Build on the Government's plan to have Registered Nurses 24/7 in Residential Aged Care ensuring nurses have essential palliative care skills.
- » Fund a National Palliative Care Workforce Strategy so that Australia can plan for the increasing numbers of people who will need and benefit from palliative care as the population ages and lives with increasing rates of chronic illness.
- » Ensure the palliative care workforce and those in need of palliative care have the voice of a peak advocacy organisation.

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