MAY 2023

Budget Submission

PalliativeCare AUSTRALIA

People, at the heart of quality palliative care

Palliative Care Australia's 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.

Priorities for Australian Government investment in palliative care

PCA is seeking

$240 million per year
for more in-home and community palliative care services

$250 million over five years ($50 million per year)
for a new National Agreement between the Commonwealth and States/Territories to increase access to specialist palliative care services

$2.75 million over three years
to develop a national palliative care workforce plan

$20.1 million over three years
to upskill Registered Nurses employed in residential aged care in palliative care

$1.2 million over three years
for Palliative Care Australia, to continue to advocate for the care of people with life-limiting illness as the sector's peak organisation

Key facts

Demand for palliative care is expected to increase by **50%** between now and 2035, and to double by 2050.[1]

Palliative care leads to improved social, psychological, emotional, spiritual and practical outcomes for people with a life-limiting illness, their carers, families and loved ones.[2,3]

It is conservatively estimated that demand for services rose by **30%** during COVID-19.[4]

Palliative care also leads to **improved wellbeing and productivity** for carers[5] and lower bereavement costs.[6]

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.[7]

Investing in high quality palliative care delivers a very high return on investment. It does this because people who receive care from palliative care health professionals have their pain and symptoms managed. This means less visits to Emergency Departments, reduced Intensive Care Unit admissions and usage, less emergency calls to ambulances and **less days spent in hospital**.[8]

About PCA and palliative care

PalliativeCare AUSTRALIA

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.

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.[9]

What is needed to provide palliative care for all Australians who need it

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

Investing in palliative care improves the lives of those with life-limiting illness as well as improving the efficiency of the health system and so:

- **PCA is advocating for significant investment in palliative care services and the workforce in the 2023/24 Federal Budget to ensure that care services are available for all Australians into the future.**
- **PCA is also seeking investment in the capability of Registered Nurses employed in residential aged care, to provide palliative care to a greatly underserviced population.**
- **PCA is asking for reinstatement of its core funding as the national peak body for palliative care in Australia.**

1

Investing in Palliative Care Services

a. Expand access to palliative care via in-home and community settings

Most people who have been diagnosed with a life-limiting condition can be managed in the primary and community care sector for most of their care journey.[10]

The *2020 KPMG report: Investing to Save*, recommended a $240 million per year investment to provide more palliative care at home. This would provide a return on investment of $0.53 to $1.56 per dollar spent, with more people dying at home, fewer hospital admissions and fewer emergency department presentations.

Upskilling the existing primary care workforce to build core capabilities in palliative care is an efficient use of our existing workforce, and will reduce demand for acute services and increase access to palliative care.

Providing more health professionals with capability to provide and coordinate the delivery of palliative care in the community is essential if Australia is to meet future needs for palliative care. More General Practitioners (GPs) and Nurse Practitioners (NPs) will be key to increasing this capacity. More health providers with palliative care skills are especially critical for access to palliative care in rural and remote areas where specialist support is not accessible. More palliative care-trained allied health workers and volunteers will also be critical.

Linkages between state-provided specialist palliative care services and community-based services should be developed through trials of service models. This is particularly important for rural and remote communities where metropolitan models are not suitable. These linkages are important for the continuity of care of patients/people with more complex needs, and will support palliative care provided in primary care settings.

FUNDING SOUGHT

$240 million per year

KPMG estimates that a $1.00 investment in integrated home-based palliative care delivers a return of between $0.53 and $1.56

b. Negotiate a National Palliative Care Funding Agreement

To grow the specialist palliative care workforce required for the future, the Commonwealth should seek to negotiate a cost-shared funding agreement with States and Territories. This would be informed by the workforce development proposal 2a (below).

The purpose of the National Agreement would be to:

- Fund the training and employment of more specialist palliative care physicians, nurses and allied health professionals
- Increase palliative care beds in acute settings
- Support linkages with primary care and aged care services providing palliative care.

The Agreement would include key performance indicators and reporting requirements to ensure goals are achieved and that access to specialist palliative care is measured.

KPMG recommends a $50 million investment to increase specialist palliative care services. The actual amount required should be informed by recent increases in the cost of delivering health care as well as the analysis of workforce requirements developed under the workforce plan in proposal 2a.

FUNDING SOUGHT

$250 million over five years ($50 million per year), plus matching funds from States/Territories

KPMG estimates that a $1.00 investment in hospital-based palliative care delivers a return of between $1.36 and $2.13

2

Investing in the Palliative Care Workforce

a. Develop a National Palliative Care Workforce Plan for 2023-2033

PCA is seeking financial support to bring together key stakeholders to develop evidence-based, sustainable palliative care service models which would then form the basis for further workforce planning and service delivery. This exercise would identify what models of palliative care can be delivered in community and primary care settings, building on the capability of the existing workforce, and how services can be provided in rural and remote areas in a sustainable way.

This initiative would underpin the development of a cost-shared National Agreement between Australian and State/Territory Governments (proposal 1b).

Available data show that the need for palliative care in Australia is increasing and is predicted to double by 2050.[11] This demonstrates the need for more specialist palliative care physicians, trained palliative care nurses, allied health professionals and volunteers.

As the national peak body for palliative care, PCA brings together health professionals, consumers their carers and loved ones, researchers and educators, and is strongly linked to a network of State- and Territory-based member organisations.

FUNDING SOUGHT

$2.75 million over three years

b. Palliative care training for Registered Nurses in residential aged care

The Royal Commission into Aged Care Quality and Safety recommended compulsory dementia and palliative care training for aged care workers (recommendation 80). It is essential that Registered Nurses (RNs) in residential aged care, who often play a leadership role in their service, have palliative care knowledge and skills.

Core capabilities required include:

- 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.

PCA is seeking Australian Government funding to support aged care services with funds to backfill nurses while they undertake training, and to assist with travel costs for those in more remote areas to undertake placements.

Training could be provided through programs already funded by the Australian Government, such as the Program of Experience in the Palliative Approach (PEPA).

FUNDING SOUGHT

$20.1 million over three years

$1 → → $1.68–$4.14

KPMG estimates that a $1.00 investment in palliative care nurses in residential aged care can return between $1.68 and $4.14

3

Fund Palliative Care Australia as the Peak Advocacy Body

Palliative Care Australia seeks a commitment from the Australian Government to secure core peak funding to support its advocacy for palliative care. This advocacy is critical to drive national improvements in and access to palliative care.

PCA does not have secure ongoing core funding, with the former government instead granting PCA a one-year contract extension to June 2023. This occurred because the core peak funding grant program, the Health Peak and Advisory Bodies (HPAB) Program, was changed in January 2022 to focus on the former government's *National Preventive Health Strategy*.

While we recognise the critical importance of preventive health and the role of those organisations who continue to receive funding under the HPAB Program, the narrowing in focus disregards critical issues affecting the sustainability of the health system, the care delivered to Australians and broader health outcomes.

PCA's advocacy and policy expertise should continue to be supported by the Australian Government. PCA provides the Government with a single point of contact for input from clinicians, academic experts, carers and consumers, and a national and unified voice on palliative care policy. The value of this single national advocacy is evident most recently in PCA's contributions to reforms in aged care.

PCA continues to lead activities to raise awareness of palliative care and what it can offer individuals, their families and loved ones. This is important work in the current context of all States now implementing legislation relating to Voluntary Assisted Dying.

For all these reasons PCA respectfully seeks reinstatement of core peak funding, either through the HPAB Program or otherwise.

FUNDING SOUGHT

$1.2 million over three years from 2023/24

CORE PEAK FUNDING ENABLES PCA TO:

- Deliver campaigns to increase awareness and access to palliative care. The provision of palliative care can contribute to reducing costs within the health system
- Provide informed submissions and advice to Government on health reforms
- Contribute to national task forces and working groups
- Engage with State and Territory members, clinical and consumer panels and provide Government with holistic and informed advice on palliative care.

4

Broader Reform Options

This submission identifies what PCA and its members believe are the most critical priorities for the May 2023 Federal Budget. However, there is much more to do to ensure quality palliative care is accessible for all Australians who need it.

The *PCA Roadmap 2022–2027* identifies the following areas of need:

- Greater investment in dedicated palliative care services across Australia including rural and remote areas
- Making palliative care core business in aged care – a key finding of the Royal Commission into Aged Care Quality and Safety
- Supporting and growing the palliative care workforce, including in specialist palliative care, primary care and aged care
- Augmenting palliative care data and research
- Providing more support to carers so they can care for their loved ones in the place of their choice
- Fully funding the implementation of the Paediatric Palliative Care National Action Plan
- Investing in palliative care awareness campaigns to raise community awareness about death, dying, bereavement, grief and palliative care
- Supporting Palliative Care Australia to undertake national palliative care advocacy, consult with stakeholders and provide policy advice as the national peak body beyond 30 June 2023

PCA would be delighted to further explore any of these options for reform with Government as it prepares the 2023 Federal Budget.

Explanatory Notes

1. Investment in palliative care services

a. Expand access to palliative care via in-home and community settings

What

This investment would increase access to community palliative care and allow people to die at home, as recommended in KPMG's 2020 *Investing to Save* report.

How

Commonwealth funding would be provided through general practice with links to State/Territory community-based specialist outreach services for management of complex cases. It would include enhanced training for GPs and Practice Nurses to work with and across state-provided specialist palliative care services. It would also provide for an increase in palliative care NPs to provide more services in the home. This workforce would then provide palliative care to:

» patients early in their disease trajectory

» allow people to die at home with palliative care support for them, their families and loved ones, where possible.

In years one and two, there would be a trial of service models to identify sustainable models to support the provision of home-based palliative care via primary care. There would also be an increase in numbers and training of NPs, and an increase in training opportunities for GPs.

Subsequent roll out of this initiative (from year three) would be determined by the trial outcomes.

Costing of investment

The KPMG *Investing to Save* report shows that a return of this investment through reduction in deaths in hospitals and savings made through more people dying at home. Based on the cost of in-home palliative care to be on average $6,500 per person, KPMG estimates that an investment of $240 million would provide for 37,000 more in-home palliative packages.[12]

Total funding sought
$240m per year from 2023/24 onwards

b. Negotiate a new five-year Palliative Care National Agreement between the Commonwealth and States/Territories from mid-2024

What

This investment would increase the number of specialist palliative care services, dedicated palliative care hospital beds, hospice beds and outreach specialist services, as recommended by KPMG's 2020 *Investing to Save* report.

How

A National Agreement would be sought to guide the increase in service levels and accessibility that is achievable with this combined investment, informed by the development of a workforce plan (proposal 2b). The agreement would include the Key Performance Indicators (KPIs) and reporting metrics required to measure the impact of this investment.

Costing of investment

» Year one (July 2023 – June 2024) for negotiation of National Agreement

» Years two, three, four and five (July 2024 – June 2029)

» $250m ($50m per year from the Commonwealth, State/Territory contribution to be negotiated)

KPMG costings for this proposal were derived from Independent Hospital Pricing Authority reporting of sub-acute palliative care costs. KPMG found an average cost of $7,697 for an average length of stay of six days across the nation.

Total funding sought
$250m over five years from 2023/2024 to 2028/29

2. Investing in the palliative care workforce

a. Develop a National Palliative Care Workforce Plan for 2023-2033

What

This investment would provide the evidence and analysis necessary to estimate the numbers of specialist palliative care health professionals (specialists and trained palliative care nurses and other health professionals) required to provide palliative care to all Australians who would benefit from it. This work would also look at increasing capability in the existing health workforce to improve access to palliative care, and consider sustainable models of care in rural and remote areas. Finally, it would identify what levers are available across various systems to promote growth and retention in the palliative care workforce.

The outcomes of this investment are to:

- Improve access to specialist palliative care for all Australians
- Increase access to palliative care at home
- Increase access to palliative care through enhancing the palliative care capability of health professionals already employed across the health and aged care systems
- Improve the distribution of the palliative care workforce so that rural and remote communities have access.

This approach would incorporate 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
- Align with priorities in the *National Medical Workforce Strategy 2021–2031* and other key government measures to grow the workforce in health and aged care.

How

PCA would convene a collaboration between health professionals, academics, peak Non-Government Organisations (NGOs) and Governments to negotiate and commission work to identify service models, investment levels and appropriate levers to grow the workforce and to upskill the existing workforce. This would include other medical specialists, GPs, NPs, RNs and allied health professionals, as well as specialist palliative care physicians and nurses.

PCA would be funded to lead this process, and would draw on its State and Territory organisations to drive this workforce development in each jurisdiction.

This collaboration would also develop KPIs for a new National Palliative Care Funding Agreement. KPIs would in turn drive workforce increases (and measure them) and improved access to specialist palliative care services, (see proposal 1b).

Costing of Investment

- 2.3 FTE positions in PCA $141,379 FTE/year $325,171/year for three years
- $186,666 per year for sector and volunteer collaboration and engagement
- Data gathering and analysis $250,000 per year (in collaboration) with the Australian Institute of Health and Welfare (AIHW) and State/Territory governments
- $155,000 per year for travel and meetings

Total funding sought
$2.75m over three years from 2023/24 to 2025/26

b. Upskill RNs in Residential Aged Care (RAC) to provide palliative care

What

This investment would upskill RNs in RAC services to provide palliative care. This would facilitate a key recommendation of the Royal Commission into Aged Care Quality and Safety: that palliative care be core business in aged care.

With training and some mentoring provided in the first year after training, RNs will acquire the following core competencies:

- Palliative care assessment for residents
- Support advanced care planning
- Management of symptoms and administration of medication
- Support psychosocial needs
- Identify complex needs and refer to specialist palliative care
- Provide grief and bereavement support.

How

This investment would use the existing Commonwealth funded PEPA. PEPA organises the training through placements. RNs attending training would be backfilled (which has been factored into the costings below).

Training would begin in October 2023 (to provide time for services to organise training). The numbers trained would steadily increase over the next two financial years.

Costing of Investment

- Assumes 2,722 RAC services (2020 figure) 24/7 RN = 8,200 RNs requiring training (PCA has assumed that approximately 400 RNs would already be palliative care trained)
- Government mandates 24/7 RNs from July 2023
- Cost @ five days training, backfill based on NSW RN mid-career, $38.66/hr 38 hrs = $1,469 per nurse

- Post training mentoring $38.66/hr @ 2hrs per RN once per month =$927 per nurse:
  - October 2023 – June 2024 1,850 trained $4,432,600
  - July 2024 – June 2025 2,950 trained $7,068,200
  - July 2025 – June 2026 3,000 trained $7,188,000
- Travel for up to 300 nurses from rural and remote areas for training over the three years @$2,000 per RN accommodation and travel, up to $600,000 ($200,000/year)
- Funding for two research officers to undertake a survey of impact of increased RN training in RAC services - @total $141,379 each over three years =$848,274:
  - Salary and superannuation @$122,000 per officer per year
  - Staff costs $12,747/officer per year (rent, cleaning, staff welfare, HR, phone, etc.)
  - IT access to software, mobile workstations etc. $4,970/office per year
  - One-off staff purchase (e.g. laptop, monitor, keyboard, chair: $4,985.35 per officer)

Total funding sought
$20.1m over three years from 2023/24 to 2025/26

3. Fund Palliative Care Australia as the peak advocacy body

This investment would reinstate core funding for the nation's peak palliative care advocacy body from July 2023.

What

As a national charity and peak body for palliative care, Palliative Care Australia provides:

- Authoritative policy advice from a single national source on palliative care, drawing on clinicians, consumers and carers and palliative care services
- Advocacy for palliative care to be core business in aged care
- People living with life-limiting illness to have access to appropriate pain and symptom relief through medications and clinical care
- Collaboration with other peak bodies for increased access to palliative care for people living with dementia and complex diagnoses
- Increased access to palliative care for those living in rural, regional and remote Australia
- Advocacy for capacity building in the Australian health and aged care sectors to provide appropriate palliative care to Aboriginal and Torres Strait Islander peoples
- Advocacy for and liaison with organisations with similar objectives across the Indo-Pacific region and internationally
- Dissemination of high quality information about palliative care, in easily accessible ways
- Promote high standards for the delivery of palliative care

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 the palliative care schedule of the Pharmaceutical Benefits Scheme
- Supporting people living with life-limiting illness throughout Australia and their carers to access critical information through PCA channels and platforms 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 Australia's health and aged care sectors to provide culturally-safe and appropriate palliative care to Aboriginal and Torres Strait Islander peoples

How

Provide recurrent funding commensurate with the HPAB Program.

Total funding sought
$1.2m over three years from 2023/24 to 2025/26

End Notes

1. 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.
2. Internal Survey for PCA and its Member Organisations conducted by KPMG 2022.
3. Ibid.
4. 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-analsis. Palliative Medicine*, 33(3): 332-345.
5. Beresford, P., Adshead, L. & Croft, S. (2007). *Palliative care social work and service users: making life possible*. London, Jessica Kinglsey Publishers.
6. 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.
7. 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.
8. 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.
9. Australian Government, *National Palliative Care Strategy*, 2018, page 42.
10. Swerissen, H and Duckett S, (2014) *Dying Well*, Grattan Institute, Melbourne.
11. 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.
12. Note these figures from KPMG were derived from 2017-18 health data and consideration would need to be given to the change in health costs since that period.

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