

PRE-SUBMISSION  
TO THE FEDERAL  
BUDGET 2020-21

# Palliative Care Australia



**PalliativeCare**  
AUSTRALIA

Palliative Care Australia (PCA) welcomes the opportunity to make a submission on the Federal Budget 2020-21. In this submission, PCA calls upon the Australian Government to support funding measures and initiatives that will:

- a. improve access to palliative care in aged care, and
- b. result in robust implementation of the National Palliative Care Strategy 2018.

The need to improve access to palliative care in aged care is a theme that has been highlighted by evidence presented to the Royal Commission into Aged Care Quality and Safety. The initiatives proposed in this submission would provide a sound framework for the Australian Government to act quickly and comprehensively on the Royal Commission's final report in November 2020. Other initiatives in this submission would ensure that the National Palliative Care Strategy 2018 is implemented robustly, resulting in more equitable access to palliative care for all who need it, when they need it and where they need it.

## Initiatives in this budget submission

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### A. Improve access to palliative care in aged care

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1. Boost funding to meet the palliative care needs of people in residential aged care who have a life-limiting illness
2. Introduce a Palliative Care Supplement for recipients of Home Care Packages (HCPs) who have a life-limiting illness

### B. Robust implementation of the National Palliative Care Strategy

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3. Establish a National Palliative Care Commissioner
4. Invest in the Palliative Care Workforce and develop a National Palliative Care Workforce Strategy
5. Develop an education program for health and aged care professionals on the quality use of opioids for palliative care patients
6. Establish National Minimum Data Sets (NMDS) for palliative care
7. Ensure the Medicare Benefits Schedule (MBS) supports more equitable access to palliative care in all care settings
8. Commit dedicated specific funding each year for palliative care research from the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) funding grants

# 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 subscribes to the World Health Organisation (WHO) definition of palliative care:

*Palliative care is an approach **that improves the quality of life of patients and their families** facing the problems associated with life-threatening 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.**<sup>1</sup>*

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.

Investment in palliative care also makes economic sense. Research consistently shows that 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).<sup>2</sup>

## Setting the direction for future funding of palliative care

PCA welcomed the release of the National Palliative Care Strategy (2018). The Strategy highlights the need to plan for the increasing demand for palliative care as the Australian population ages and people with chronic disease and disability live longer:

*“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.”<sup>3</sup>*

A key measure of success is that there are services on the ground for palliative care patients when and where they need them.

PCA believes the Australian Government should consider the development of a **National Health Agreement on Palliative Care** to be signed by the Australian Government and all State and Territory governments, with performance indicators and incentive payments built in.

A **National Health Agreement on Palliative Care** should be supported by the establishment of a **National**

**Palliative Care Commissioner**, which PCA put forward in its 2018-19 Budget Submission and reiterates in this 2020-21 Budget Submission.

Aged care in Australia is receiving attention through the Royal Commission into Aged Care Quality and Safety. Thirty-five per cent of all deaths in Australia occur in residential aged care<sup>4</sup>, yet the palliative care funding to support residents has been vastly inadequate. Furthermore, palliative care has not been included as an Aged Care Quality Standard and PCA has advocated that it should be.

If Australia is to meet its obligations to support older Australians in residential aged care, increased funding support for palliative care in residential aged care must be a priority for Government.

## Context for this submission

The demographics of the Australian population are changing and we need to plan ahead for the increased demand for accessible, flexible and responsive palliative care. The next Intergenerational Report, due in July 2020, is expected to show further ageing of Australia's population. Within 10 years, Australia's population is expected to be 30,000,000 and the number of deaths over 200,000 per year (current deaths are around 160,000 per year).<sup>5</sup>

Not only are Australians living longer, as they age their care needs can become more complex. The complexity of palliative care will continue to increase as people live longer with multiple chronic conditions. This often results in more complex symptoms and higher symptom burden.<sup>6</sup>

In January 2020, the Australian Government published a series of ten reports on barriers to accessing quality palliative care for people with complex needs or from under-served populations. The reports also identified a number of universal barriers common to all Australians.<sup>7</sup> Separate reports cover some nine, though not all, under-served populations. These include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds (CALD), people with disabilities, people experiencing homelessness, people who are incarcerated, people who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI), refugees and veterans. The findings and recommendations from these reports need to be considered and addressed by all Australian Governments. This should be done in the

context of the implementation of the National Palliative Care Strategy, which calls for all Australians to be able to access quality palliative care, including population groups that are currently under-served. The Strategy – endorsed by all Australian health ministers – emphatically states:

*While many people across society will experience varying levels of access and quality of care, these population groups generally experience additional barriers in accessing services, **which will be addressed in initiatives** to improve access and quality.<sup>8</sup>*

Australia's palliative care system is not meeting current demand; investment and policy changes are required urgently to meet current as well as emerging need.

All Australians have a human right to quality palliative care – **when and where they need it.**

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 families will determine which services they access at any given time.

Palliative care is available for all ages, from paediatric populations through to older Australians.

PCA has a vision document, ***Palliative Care 2030: Working Towards the Future of Quality Palliative Care for All***. It sets out guiding principles to assist the health, disability and aged care sectors, governments and the general community, to plan and prepare for future need, when Australians will live longer, demand an improved quality of life, and expect access to high quality palliative care when living with a life-limiting illness. Underpinning this vision 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.

*Palliative Care 2030* sets the framework for PCA's Budget Submission alongside PCA's ***Submission to the Royal Commission into Aged Care Quality and Safety*** in which PCA has articulated the following key recommendations:

1. Aged care policy should align with the World Health Organisation definition of palliative care and not be restricted to 'end of life' or last days/weeks.
2. Palliative care must be included and clearly articulated in the Aged Care Quality Standards, which all Commonwealth funded aged care services are required to meet.
3. All undergraduate nursing, allied health, medical courses and Certificate courses for care workers must include mandatory units on palliative care.
4. National Minimum Data Sets for palliative care which include both health and aged care.
5. Funding is needed to fully implement the National Palliative Care Strategy ensuring aged care is included.
6. Investment and the development of innovative models of care are required to ensure older people have equitable access to specialist palliative care.
7. Greater focus on community awareness on death and dying, palliative care and advance care planning.
8. Palliative care should be a COAG priority supported by the appointment of a National Palliative Care Commissioner.

Access to palliative care in aged care is a critical and pressing issue. With an ageing population and the rise in chronic disease, it is essential that palliative care is recognised as core business for all aged care providers. Aged care staff must be supported by systems, funding and training to provide quality palliative care. At the same time, aged care must not be seen in isolation from the broader health system. More work needs to be done to ensure older people do not fall between cracks created by interjurisdictional and intersectoral policy decisions, and fragmented and siloed funding models.

# Improve access to palliative care in aged care

## INITIATIVE 1

### Boost funding to meet the palliative care needs of people in residential aged care who have a life-limiting illness

#### Rationale and benefits

PCA has lodged a comprehensive submission to the Royal Commission into Aged Care Quality and Safety. In its submission, PCA presented several recommendations aimed at improving access to palliative care in aged care settings.<sup>9</sup>

PCA welcomes the recognition by the Australian Government that a new approach for a residential aged care funding model is necessary, and notes that alternate models to the Aged Care Funding Instrument (ACFI) are being considered.

PCA also welcomes the Royal Commission's renewed focus on palliative care as outlined in its *Consultation Paper 1: Aged Care Program Redesign*. It notes that people who access aged care towards the end of life are entering care with increasing frailty, reduced mobility, multiple chronic health conditions and high care needs. They are not well supported in aged care, and their palliative care and end of life care needs are not well met. The Consultation Paper also notes the importance of specialist palliative care, recognising that "these services are funded and provided separately from aged care. They are difficult to access, particularly for people in residential aged care."<sup>10</sup>

The palliative care needs of residents in aged care facilities have been recognised by the Royal Commission. PCA now calls for an increase in funding to support palliative care needs of people living with a life-limiting illness in residential aged care.

Improving palliative care for people in residential aged care will require increased funding in the Aged Care Budget. PCA anticipates that the Royal Commission into Aged Care Quality and Safety will be articulating the quantum of funds that are necessary to deliver an appropriate standard of palliative care for people living in residential aged care facilities.

The Royal Commission released a research paper in January 2020, prepared by Flinders University, which compares the approach to long-term care for older people in 22 countries. Australian governments' collective spending on long-term care for older people is assessed at 1.2% of GDP. Best practice in some Scandinavian countries (Denmark and Sweden) is more than 4%. Australia's spending on long-term care is, the Commission notes in an accompanying media release, among the lowest of the countries in the study.<sup>11</sup>

## INITIATIVE 2

### Introduce a Palliative Care Supplement for recipients of Home Care Packages (HCPs) living with a life-limiting illness

#### Rationale and benefits

PCA acknowledges and applauds the Australian Government for the additional investment in late 2019 in aged care, which will see close to \$500 million provided for an additional 10,000 Home Care Packages (HCPs). This investment will go some way to meeting current need. There is, however, a lack of clarity about eligibility for the Commonwealth Home Support Program (CHSP), delayed access to HCPs (noting the recent extra funding will go some way to alleviate this) and significant barriers for people living with a life-limiting illness to access necessary services and choose where they receive care as they near the end of their life.

For people who have a life-limiting illness and a short prognosis, wait times for HCPs often mean that:

- » The person has died prior to receiving the care they were assessed as requiring;
- » Periods of hospitalisation are extended due to the lack of support for them to return home;
- » People who could otherwise be supported in the community move to residential aged care.

PCA is concerned that the level of HCP funding currently available for people with a life-limiting illness is inadequate. People in this population group may require increased personal care and continence support, nursing support and hire of expensive equipment including lifters. For people in remote areas, the cost of freight can often cost more than the equipment they require. Many people therefore end up needing to move to residential aged care, with higher associated costs to the community than being able to be supported at home.

PCA believes that a palliative care supplement would better meet the needs of people living with a life-limiting illness. The palliative care supplement could operate in a similar way to the dementia and cognition supplement and be accessed by people on any level of HCP. The supplement would provide more support, sooner, to people living with a life-limiting illness.

PCA recommends a palliative care supplement equivalent to the Dementia and Cognition and Veterans' Supplement, Level 4 of Home Care Supplements, therefore be introduced.

In addition, measures to support the robust implementation of the National Palliative Care Strategy 2018 (detailed in the following section) would also improve access to palliative care in aged care.

# Robust implementation of the National Palliative Care Strategy 2018

## INITIATIVE 3

### Establish a National Palliative Care Commissioner

#### Rationale and benefits

PCA has welcomed the National Palliative Care Strategy and its endorsement by all health ministers, federal, state and territory. PCA notes an implementation plan is under development.

When it comes to implementation, the Strategy itself calls for a “formal governance structure with links to the Australian Health Ministers’ Advisory Council”. This would ensure that palliative care is recognised and resourced as an integral component of the health system.

PCA strongly supports the establishment of such a governance structure. To complement this, we also believe that the position of a National Palliative Care Commissioner should be established. This could be a position that could work with – and be supported by – all jurisdictions.

The position should work with the Strategy’s ‘governance structure’ to help drive implementation. Such a position should also - with agility - work across jurisdictions, agencies, the non-government, consumer and community sectors to coordinate activities and help drive change.

PCA has previously put forward the need for a Palliative Care Commissioner (PCA Pre-Budget Submission 2018-19) and has also raised it with the Royal Commission into Aged Care Quality and Safety at its Perth hearings on 27 June 2019. The release of the National Palliative Care Strategy and the soon to be released Implementation Plan have further amplified the need for a National Palliative Care Commissioner to help address the current fragmentation of palliative care services in Australia.

PCA considers the role of the Commissioner could include a range of important functions:

- » oversee implementation, monitoring and evaluation of the National Palliative Care Strategy
- » work with the National Palliative Care Strategy’s ‘governance structure’
- » improve communication across jurisdictions
- » support clarification of roles and responsibilities of each jurisdiction
- » facilitate consistent approaches to supporting the palliative care sector across all settings, including primary health, community health, tertiary health, aged care and disability
- » in partnership with state and territory governments, assess the needs of different regions and populations, in particular Aboriginal and Torres Strait Islanders, rural and remote populations and Australia’s culturally and linguistically diverse populations
- » facilitate harmonisation of advance care planning laws
- » examine existing palliative care services and programs across federal, state and territory governments, private and non-government sectors
- » address palliative care workforce issues across settings, including aged care, tertiary care, primary health care and community-based care
- » engage with the Australian Institute of Health and Welfare (AIHW) to develop a palliative care data collection framework.

PCA estimates this initiative will cost under \$15 million over three years.

## INITIATIVE 4

# Invest in the Palliative Care Workforce including the development of a National Palliative Care Workforce Strategy

### Rationale and benefits

A National Palliative Care Workforce Strategy is needed to 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. A National Palliative Care Workforce Strategy should address the 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.

Currently there are 249 palliative medicine physicians across Australia<sup>12</sup>, equating to less than one for every 646 deaths.

There is a need to support additional palliative medicine trainee positions in Australia, particularly in rural and regional areas. *The Palliative Care Service Development Guidelines* set a benchmark of 2.0 full-time equivalent Specialist Palliative Medicine Physicians per 100,000 population.<sup>13</sup> This means that by 2030, with an expected population of 30,000,000, Australia should be aiming for 600 Specialist Palliative Medicine Physicians. This is more than double the current number.

Similarly, investment that supports nurses to achieve the qualification of Palliative Care Nurse Practitioner is required. Scholarships would assist in this area and help ensure that Australia has an appropriate number of qualified Palliative Care Nurse Practitioners to meet the palliative needs of Australians now and into the future.

A National Palliative Care Workforce Strategy that includes the role of GPs, nurses, aged care staff, community pharmacy, allied health and other health professionals in palliative care should be considered critical. Such a Strategy would enable broader workforce issues to also be examined. It should also 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.

Specifically in aged care, PCA is advocating for the inclusion of mandatory palliative care units in aged care certificates III and IV. Palliative care is primarily about quality of life for the person with a life-limiting illness and all aged care staff who interact with residents and consumers have a role to play. Palliative care modules should be considered essential in aged care certificates III and IV.

Linked with this, PCA supports the implementation of the recommendations of the Aged Care Workforce Strategy Taskforce. Employment conditions and job security both impact on staff retention in aged care. This leads to staff turnover and lack of consistency in staffing, which already impacts the ability of aged care services to deliver quality palliative care.

A palliative care workforce that is appropriately trained and qualified is essential if Australia is to meet the growing palliative care needs of Australians now and into the future.



## INITIATIVE 5

# Develop an education program for health and aged care professionals on quality use of opioids for palliative care patients

### Rationale and benefits

Appropriate access to opioid medication is critical to managing and relieving pain and symptoms associated with a life-limiting illness, such as chronic breathlessness.

A number of Australian health professional bodies have co-signed a Position Statement ***Sustainable Access to Prescription Opioids for Use in Palliative Care***<sup>i</sup> which recognises the need to increase knowledge about appropriate use of opioids within the Australian palliative care context while providing leadership and guidance in the regulatory processes for the community and prescribers.<sup>14</sup> It supports safe, evidence based and appropriate clinical oversight of opioid prescribing in palliative care, while recognising legitimate concerns related to inappropriate use and prescribing in other clinical settings.

PCA calls for an education program to be developed for prescribers and the community in order to boost awareness of responsible and appropriate use of opioids for palliative care patients.

General practitioners (GPs) are aware that their prescribing of opioids is monitored. If they perceive that appropriate use in the palliative setting may be seen to be over prescribing opioids, and is putting them at risk of sanctions and restrictions placed on their prescribing, the unintended consequence can be that palliative care patients do not receive appropriate opioids to manage their pain and symptoms, leading to unnecessary suffering.

Access to palliative care medicines for pain and other symptom management, in particular opioids, is also problematic in aged care. As the Productivity Commission states:

*“Too often, people are transferred back and forth between hospitals and aged care facilities, as aged care facilities lack palliative care expertise and qualified staff to administer pain relief.”<sup>15</sup>*

Limited staff skill and availability can be a barrier to appropriate access to necessary medicines in aged care. If staff are not trained or confident in identifying deterioration and symptom onset they will be unable to identify when symptom relief may be needed. If timely access to prescribers is limited or prescribers are not familiar with contemporary medication regimes, including anticipatory prescribing, access to medications may be delayed or not forthcoming. If aged care services do not store appropriate stocks of anticipatory medicines on site using an imprest system, breakthrough symptoms may not be adequately addressed.

PCA estimates this initiative will cost under \$15 million over three years.

i. Australian College of Nurses (ACN), Australian College of Nurse Practitioners (ACNP), Australian College of Rural and Remote Medicine (ACCRM), Australian Healthcare and Hospital Association (AHHA), Australian and New Zealand Society of Palliative Medicine (ANZSPM), Australian Pain Society (APS), Painaustralia, Paediatric Palliative Care Australia and New Zealand (PAPCANZ), Palliative Care Nurses Association (PCNA), The Pharmacy Guild of Australia, Royal Australasian College of Physicians (RACP), and Society of Hospital Pharmacists of Australia (SHPA).

## INITIATIVE 6

### Establish National Minimum Data Sets (NMDS) for palliative care in both health and aged care

#### Rationale and benefits

The importance of establishing a Palliative Care National Minimum Data Set has been highlighted by the Productivity Commission (2017):

*“The effectiveness of...reforms will depend on governments implementing broader improvements to their stewardship of end of life care. This should involve the Australian, State and Territory Governments, through the COAG Health Council...developing and implementing an end of life care data strategy that establishes a national minimum data set for end life.”<sup>16</sup>*

Without targeted data collection and better linkages, Australia is not in a position to analyse adequately how many people are accessing palliative care services and in what settings, the demographics of those accessing care and what their preferences are for place of care and place of death and where they die. This data is essential for governments to adequately plan for, and invest in, palliative care needs into the future.

PCA estimates this initiative will cost \$10 million over three years.

## INITIATIVE 7

### Ensure the MBS supports more equitable access to palliative care in all settings

#### Rationale and benefits

PCA has made several submissions to the MBS Review Taskforce. While PCA is confident that the Taskforce has considered our recommendations, PCA reiterates a concern regarding the inability of palliative care specialists to access the same MBS items for inpatient case conferencing and family meetings that rehabilitation specialists and gerontologists do. Many tasks often focus on the conduct of family meetings and case conferencing with other health professionals while a person is receiving palliative care.

PCA supports measures identified by the MBS Review Taskforce to invest in infrastructure and measures that will increase uptake of telehealth services in Australia. PCA has called for telehealth measures that will not place geographic restrictions on palliative care patients accessing telehealth consultations. PCA notes:

- » Some palliative care patients who are unable to attend appointments from home or a residential facility, or live on the other side of a jurisdictional border from the service, may have difficulty travelling to their consultant specialist even if the travel distance is short.
- » In situations where rapid specialist palliative medicine responses are required and the patient is in their home, a telehealth consultation may avert an avoidable hospital admission and this can apply regardless of how close the person is in relation to the consultant specialist.

PCA supports measures identified by the MBS Review Taskforce to introduce new attendance items for acute, urgent and unplanned attendances. This is subject to appropriate funding through the MBS schedule fee that recognises the associated costs of providing attendances outside of consulting rooms or emergency departments (for example, if the consultant specialist is providing the service in a residential aged care facility or person's home).

PCA has called for the descriptors for attendance items for acute, urgent and unplanned attendances to allow for the nature of palliative care, where specialist care needs to be facilitated within non-acute settings and after hours, particularly towards the end of life and when a person is dying in order to provide care that aligns with the person's wishes and to avoid unnecessary or unwanted transfers.

Furthermore, PCA has noted throughout the MBS Taskforce Review (and as part of other consultation processes) that the practice of palliative care medicine occurs in a range of settings (e.g. hospital, ambulance, community, correctional facilities and residential aged care). In any of these settings, there may be different consultation types, such as initial reviews, follow-ups, and/or case conferences. It is important that MBS items cover these settings and consultation types.

PCA has also reiterated to the MBS Review Taskforce that the role and remuneration under the MBS for general practice and nurse practitioners must be explored to facilitate family meetings, advance care planning discussions and best practice community-based palliative care, including the provision of home visits, after-hours support and the needs of residents within aged care services.

## INITIATIVE 8

### Commit dedicated specific funding per annum for palliative care research from the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) grants

#### Rationale and benefits

Australia has benefited from a strategic investment in palliative care projects, which has created a large network of clinicians, academics, researchers and policy makers, such as the Palliative Care Outcomes Collaboration (PCOC), CareSearch and the Palliative Care Clinical Studies Collaborative. The research outcomes from this network have contributed significantly to the quality of palliative care provided in Australia.

However, to meet the emerging clinical and policy challenges, research in these areas needs to continue to grow to ensure optimal evidence informed interventions and services. Research that is specifically focused on palliative care within the aged care services setting, as well as more broadly the care of older Australians, must also be a priority.

Investment in these areas of research is hampered, as palliative care is not currently acknowledged as a stand-alone Field of Research for the review of applications for either the National Health and Medical Research Council

Increased funding to deliver more equitable access to palliative care items on the MBS, including the use of telehealth settings, would help achieve quality palliative care for all Australians when they need it, and where they need it. Allocating appropriate funding to these items should be a priority for the Australian Government.

(NHMRC) or the Medical Research Futures Fund (MRFF) grants. PCA calls for the introduction of a Palliative Care “Field of Research” including funding specific to palliative care within aged care research.

Furthermore, the introduction of voluntary assisted dying into Australian jurisdictions will have a major impact on palliative care providers and potentially the way that people in Australia view their care options as they near the end of their life. The consequences (intended and unintended) of the introduction of voluntary assisted dying on palliative care need to be better understood to ensure all Australians with a life-limiting illness have access to the care they need, when and where they need it.

PCA urges the Australian Government to allocate a minimum amount of funding, per annum, from the NHMRC and MRFF research funding grants to palliative care and other end of life care research.

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