

PALLIATIVE
CARE AUSTRALIA'S
PRE-BUDGET
SUBMISSION 2017-18

Quality of Life:
Important to
the end



PalliativeCare
AUSTRALIA

Executive summary

INITIATIVE	COST
National leadership	
Supporting Palliative Care Australia	\$4 million over three years
Palliative care as a COAG priority	No additional funding
Access to care	
Investment in palliative care service provision	\$35 million over three years
Access to equipment	\$4 million over three years
Community awareness and engagement	
Community awareness and engagement activities	\$3 million over three years
Quality and evidence	
Paediatric palliative care advocacy and support	\$525,000 over three years
Quality of death study in aged care	\$250,000
Palliative care service provision policy framework	\$185,000
Minimum dataset for palliative care	\$250,000
Total	\$47.21 million over three years

Rationale for pre-budget submission

There are few certainties in life. However, one thing that we can be sure of is that everyone who is born will die. Much planning and discussion is often undertaken preparing for a birth. Much less focus is placed on planning for the last stage of life. At Palliative Care Australia, our aim is to maximise quality of life, right until the end of life.

To maximise quality of life until the end, we need to support Australians to talk about their values, wishes and preferences for care at the end of life. It is never too early to start these conversations, but both the general and the medical community demonstrate a reluctance to do this. 82% of Australians think it is important to talk to their family about their end-of-life care preferences. Only 28% have done so. It is only through these conversations that people communicate what care they want – the care that suits them as an individual. If we can support people to do this, it both improves their care, but it may also reduce some of the burden of making difficult decisions from family and carers at a very challenging time. We need to better support clinicians and other care providers to build their communication skills so that all are competent and confident in encouraging, facilitating and conducting conversations about end-of-life care preferences.

To maximise quality of life until the end we need to provide high quality care. This means making sure that all people with complex symptoms have access to timely specialist palliative care. Palliative care can improve the quality of life and death for people who are dying, reduce likelihood of carers developing complicated grief, and provide economic benefits to the health system. However, in spite of these benefits, some people face difficulties in accessing care. There are less than 200 palliative medicine specialists in Australia and the majority of these are

located in metropolitan areas. The palliative care workforce not only needs to care for people with complex needs, but they also need to support general practitioners, nurses and care workers who provide high quality care to people at the end of life.

To maximise quality of life until the end we need to provide people with resources such as equipment, respite care and timely and affordable access to specialist medications to help maintain their independence, and support them to stay at home for as long as possible.

Finally, we need an integrated information system that addresses the needs of patients, carers, health workforce and policy makers. We require sophisticated data to inform service development, delivery and evaluation. We also need to update policy documents about palliative care service provision in Australia, to support decisions about resource allocation to maximise the efficiency and effectiveness of the use of those finite resources.

This submission outlines four priority areas that Palliative Care Australia is calling on the Australian Government to allocate funding to support these important initiatives. Investment in good palliative and end-of-life care has the dual advantage of improving the lives of people with a life-limiting illness until their death, while also realising savings to the health budget.

Pre-budget submission summary

INITIATIVE	ESTIMATED COST	BENEFITS
National leadership		
Supporting Palliative Care Australia	\$4 million over three years	<p>Palliative Care Australia is the peak national body for palliative care in Australia. As a national organisation with membership from all states and territories, Palliative Care Australia facilitates national discussion and action on important issues relating to palliative care and end-of-life care. Our work spans a range of activities including but not limited to:</p> <ul style="list-style-type: none">• Providing policy advice to governments.• Developing national guidance and frameworks to support delivery of high quality palliative care.• Developing, maintaining and promulgating resources to support the delivery of high quality palliative care in Australia.• Coordinating National Palliative Care Week each May.• Supporting all people in Australia to have discussions about their end-of-life care preferences including through the Dying to Talk initiative.• Increasing community understanding of and access to palliative care. <p>Funding certainty for Palliative Care Australia is critical to enable short and longer term strategic planning and program implementation.</p>
Palliative care as a COAG priority	Existing funding	<p>Palliative care spans state, territory and Commonwealth responsibilities and also spans sectors through health, aged care, community care, disability care and mental health. It is important to everyone and a focus on providing high quality care until the end of life should be a national priority. Palliative Care Australia seeks a commitment from COAG to identify palliative care (including end-of-life care) as a priority. This would be an important step toward improving access to palliative care across a range of settings in accordance with consumer-directed care.</p>

INITIATIVE	ESTIMATED COST	BENEFITS
Access to care		
Investment in palliative care service provision	\$35 million over three years	<p>For some people, care at the end of life can be provided by the general health workforce, including general practitioners, community nurses, aged care workers and allied health providers. However people with complex symptoms require care supported or provided by a specialist palliative care team. Palliative care is an interdisciplinary care model, with teams comprising many specialities including palliative medicine specialists, specialist palliative care nurses, nurse practitioners and specialist allied health providers.</p> <p>At present there are 190 palliative medicine specialists across Australia, equating to less than 0.8 per 100,000 population or one for every 828 deaths. It is proposed that funding be allocated to support additional palliative medicine specialist trainee positions, as well developing and implementing strategies to ensure these graduates have specialist positions to move into. It is also proposed that funding is allocated to supporting palliative medicine specialists and nurse practitioners to support the primary care workforce in end-of-life care.</p> <p>In addition, it is important to remunerate general practitioners and nurse practitioners to undertake advance care planning. These can be complex, emotional and lengthy discussions that do not fit well within current MBS items. This item has not been costed, but it is proposed that the resources be allocated to develop a business case for inclusion of this new item.</p>
Access to equipment	\$4 million over three years	<p>Access to equipment is vital to supporting people to stay at home for as long as possible, and for maximising independence and quality of life for them and their carers. PCA is proposing to administer a scheme to enhance access to equipment by funding the loan or purchase of equipment, where such costs are not covered under existing schemes. As with previous successful palliative care equipment funding, palliative care services would apply to PCA through its member organisations for funding to purchase or loan of equipment where the purpose was to support people to remain at home and improve their safety and quality of life, as well as that of their carers.</p>


INITIATIVE	ESTIMATED COST	BENEFITS
Community awareness and engagement campaign	\$3 million over three years	<p>The ability of health care workers to deliver high quality care is hindered by difficulties communicating prognostic information to people with chronic diseases, and the reluctance of the community to discuss death and dying.</p> <p>In the 2015 Quality of Death Index (The Economist) Australian ranked only ninth on the indicator 'community engagement', yet we know that community reluctance to deal with issues of dying and death is a significant impediment to good end-of-life care and avoidance of futile treatment. This activity would comprise a suite of community awareness, engagement and capacity building activities undertaken in collaboration with PCA's member organisations, aimed at facilitating discussions about end-of-life care preferences and improving understanding of palliative care. A key focus would be on groups who are disadvantaged and under-represented in palliative care services.</p> <p>This activity would be informed by the principles of Compassionate Communities and support the building of this movement in Australia. Compassionate Communities aims to strengthen and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities. It includes activating social, civic, volunteering and other networks so as to better support people right until the end of life.</p>

INITIATIVE	ESTIMATED COST	BENEFITS
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Quality and evidence

Paediatric palliative care advocacy and support	\$525,000 over three years	<p>The death of a child has long-term effects on the lives of parents. There is a gap in resources and support available in Australia for children with life-limiting conditions, their families and healthcare team. It is proposed that funding be allocated to Palliative Care Australia to enable us to work with the Paediatric Palliative Care Reference Group in Australia to develop resources and support to the paediatric palliative care sector. This would include updating of the Journeys resource aimed to support for families of children with a life-limiting condition, as well as supporting the collection of data on children with life-limiting illnesses to better understand their needs and those of their families and care team.</p>
Quality of death in residential aged care	\$250,000	<p>Three-quarters of people aged at least 65 used an aged care service in the 12 months before they died (Use of Aged Care Services Before Death, AIHW 2015). However, there are community concerns about the capacity of aged care services to manage pain and other suffering and to support people to die well.</p> <p>This study will aim to provide evidence about the quality of life until death in aged care. It will provide information on the drivers for achieving best quality of death in aged care facilities and will highlight services that are able to achieve a high quality of life until death, and enable these services to be used as a benchmark for provision of high quality care at the end of life. It will also enable identification of gaps in the provision of resources and training for the aged care workforce, and will facilitate future allocation of resources to ensure that the best outcome for the investment can be achieved.</p>


INITIATIVE	ESTIMATED COST	BENEFITS
Palliative care service provision policy framework	\$185,000	<p>Reference documents relating to palliative care service development and provision in Australia are outdated. These documents provide an important framework for decision-making about resource allocation and service provision to people at the end of their lives. Maintaining currency of these documents is important to ensure Australia continues to have the necessary workforce and service capability to meet the growing need for high quality palliative care and end-of-life care. Reference to these frameworks also supports greater equity of access to palliative care in rural, regional and metro areas across Australia.</p> <p>Palliative Care Australia proposes funding be allocated to update 'A Guide to Palliative Care Service Development (2005)' and 'Palliative Care Service Provision in Australia (2005)'. Updating these resources has been identified as a priority by members of Palliative Care Australia.</p>
Minimum data set for palliative care	\$250,000	<p>Data on palliative care is fragmented, making it very difficult to cost the provision of palliative care and potential savings that can be achieved through the provision of high quality palliative care. This was highlighted in the report 'Human Services: Identifying Sectors for Reform (Productivity Commission 2016), which states that there is a 'lack of comprehensive publicly available national data on even the most basic elements of community-based specialist palliative care, such as the number of patients and total government expenditure in each state and territory'. Having standardised high quality data will support decisions about allocation of health resources now and in the future, and would ensure best use of finite resources.</p> <p>It is proposed that funding be allocated to engage with states and territories to develop a data collection framework. They will provide a framework for future data collection and provide a foundation for improving access to data in the future. The data collection framework would support development of a business case to support collection of the identified data items.</p>



AT PALLIATIVE CARE
AUSTRALIA, OUR AIM IS
TO MAXIMISE QUALITY
OF LIFE, THROUGH UNTIL
THE END OF LIFE

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