

Quality of Life:  
Important to  
the End



2016 ELECTION  
STATEMENT



**PalliativeCare**  
AUSTRALIA

# Palliative Care Australia's 2016 Federal Election Statement

ELECTION ASK	COST
<b>Access to Care</b>	
National Cooperative for Palliative Care and End-of-Life Care	\$40 million
AHMAC subcommittee responsible for palliative care and end-of-life care	
Primary health care trials to cover palliative care	Existing funding
Palliative care workforce strategy	\$1.4 million
<b>Dying to Talk Campaign</b>	
Community awareness and engagement campaign	\$1 million*
<b>Support for Family and Carers</b>	
Increased support for families and carers	\$10 million*
Paediatric palliative care – resources and support	\$350,000
<b>Quality and Evidence</b>	
End-of-life care as a National Health Priority	Existing funding
Support research to improve palliative care	Existing funding
Quality of death study in aged care	\$350,000
Minimum data set for palliative care	\$250,000*
<b>TOTAL</b>	<b>\$53.35 million</b>

\*Cost for first year only.

# Rationale for Election Statement

Ask any Australian. Everyone will have a story about someone they love who has died. It touches us all.

When you ask, some people will have joy in their eyes. They will remember the good times and will recall the death as a positive experience. They will be sad of course, but some will remember the experience provided an opportunity to share a special time with family and friends. They may remember sitting around the bedside in their home, telling stories, holding hands, or washing and caring for their loved one.

Others will look devastated, angry, hurt. They will tell a story of their loved one losing dignity or being treated without respect. They may feel that their loved one did not receive the care they deserved. Some may have experienced their loved one being taken to hospital because the family or nursing home wasn't supported to provide them with the pain relief they needed. Their loved one may have been in intensive care after a long battle with a chronic illness.

Many people are receiving interventions they don't want or that don't have any clinical benefit. Some people are receiving care in high cost locations such as tertiary hospitals and intensive care units. 70% of Australians want to die at home. Meeting this need requires a change in the way care is delivered at the end of life.

We are all born, and we all die. We only get one chance at death. Everyone in Australia wants their death to be a good one. They want this for their family and friends. And yet, we don't give it nearly as much focus as birth. We don't resource dying in the same way we do birth, and we don't focus nearly as much on preparing for it.

This statement has been developed by Palliative Care Australia to identify specific commitments that can be made by all political parties to enhance the quality of life until the end.

It calls for all parties to correct inequitable access to palliative care. It calls for all parties to commit to improving the quality of care that people receive at the end of life and ensure that Australia delivers on the right of all in our community to have access to this care. The actions outlined in this statement should be done because it is the right thing to do. They should be done, because it will also ensure the best use of the health dollar at that time of life.

This election statement also calls for increased support for bereaved Australians. A community survey conducted by Palliative Care



Australia found that 20% of those surveyed had a family member die in the past year. Some bereaved people suffer depression, anxiety, anger and prolonged grief, impacting on their ability to engage in society. We are not doing nearly enough to identify these people, and to give them the support they need.

It is time to improve end-of-life care. We cannot have a real discussion about choice in end-of-life care unless access to high quality care at the end of life for all is addressed. Everyone needs access to high quality care at the end of life. Only then can Australians make a real choice about how they want to live until they die.

# Palliative Care Australia 2016 Election Statement Summary

	ESTIMATED COST	BENEFITS
<b>Access to Care</b>		
<p><b>National Cooperative for Palliative Care and End-of-Life Care</b></p> <p><b>AHMAC subcommittee responsible for palliative care and end-of-life care</b></p>	\$40 million	<p>The Cooperative would engage all governments in policy design to enable provision of high quality palliative and end-of-life care for all. It would provide for sharing of risks between governments to achieve the best possible service provision within available resources. The costs would allow for an upfront investment to develop the Cooperative and provide initial resources to support changes required during the implementation phase that would realise savings to the system.</p> <p>Evidence suggests that 70 per cent of people who receive good quality community palliative care can die at home rather than in hospital, with savings of an estimated \$233 million to be realised should this be achieved. Reducing fragmentation and sharing risk reduces inefficiencies in the health sector, realising savings for all governments, while achieving improved outcomes for the patient and their family. National legislation regarding advance care directives would also assist in ensuring people's wishes are respected at the end of their life.</p> <p>The Cooperative would be supported through development of an Australian Health Ministers' Advisory Council subcommittee. Palliative care is a complex area. It spans both state and Commonwealth responsibilities, and is a highly emotive topic. An AHMAC subcommittee would assist in examining the complexities of the issues relating to death and dying in Australia, including funding, medicinal cannabis, euthanasia, advance care planning as well as access for all ages, regions and communities.</p>
<p><b>Primary health care trials to cover palliative care</b></p>	Existing funding	<p>Palliative care is important for all people with complex, chronic illnesses. Measurement of critical performance indicators relevant to the provision of palliative care and end-of-life care would assist in ensuring that primary health care models such as the Health Care Homes are successful in meeting the needs of this patient population. Inclusion of palliative care in these trials would also support delivery of high quality end-of-life care for Aboriginal and Torres Strait Islander peoples, through Aboriginal Medical Services.</p>

	ESTIMATED COST	BENEFITS
<b>Palliative care workforce strategy</b>	\$1.4 million	<p>There are only 171 FTE palliative medicine specialists in Australia. (0.8 per 100,000) The previously estimated need is between 1 and 1.5 FTE per 100,000 population. Review of the target number would form part of the development of the workforce strategy and would inform planning to ensure future needs of the Australian population are met.</p> <p>Further, recent discussions have focussed on the need for appropriate staffing levels, including Registered Nurses, in residential aged care. Developing a workforce strategy will identify the skills and competencies required to deliver high quality palliative care across all sectors, including in residential aged care. This strategy would support decisions about staffing competencies and ratios to enable development of the most appropriate policy to meet the needs of residents.</p>

## Dying to Talk Campaign

<b>Community awareness and engagement campaign</b>	\$1 million per annum	<p>The ability of health care workers to deliver high quality care is hindered by the difficulties and reluctance of the medical profession to communicate the risk of dying to people with a chronic disease and the reluctance of the community to discuss death and dying.</p> <p>82% of Australians think it is important to talk to their family about how they would want to be cared for at the end of their life. Only 28% have done so.</p> <p>Facilitating discussions about end-of-life wishes and goals of care will lead to improvements in the ability to deliver patient-centred care.</p>
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## Support for Family and Carers



<b>Increased support for families and carers</b>	\$10 million per annum	<p>This activity would be three tiered:</p> <ol style="list-style-type: none"> <li>1. Enhance support to carers including through increasing options for respite.</li> <li>2. Deliver grief therapy to those experiencing complicated grief.</li> <li>3. Review the remuneration of informal carers, including the impacts of increasing the carer allowance, and legislating for leave provisions.</li> </ol> <p>Supporting families and carers is important because otherwise the costs of this care are likely to be transferred to the hospital and aged care systems.</p>
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	ESTIMATED COST	BENEFITS
<b>Paediatric palliative care advocacy, support and registry</b>	\$350,000 for the first year and then \$200,000 per annum	<p>The death of a child has long-term effects on the lives of parents and other family members. There is a gap in resources and support available in Australia for paediatric patients, their families and health care teams. Providing funding to Palliative Care Australia to replicate the UK 'Together for Short Lives' would deliver cost benefits compared with the creation of new resources and organisations to provide such support.</p> <p>The development of a paediatric palliative care registry will enhance understanding of this important population and will support workforce and funding allocation decisions into the future.</p>

## Quality and Evidence

<b>End-of-life care as a National Health Priority</b>	Existing funding	Each year over 150,000 people die in Australia. A survey of the community found that 20% of people had a family member die in the last year. This is an issue affecting all Australians. There are significant impacts of complex illnesses at the end of life as well as the impact of grief on the family and friends. These annual death rates are expected to continue to increase, creating an urgent and critical need for health policy responses that addresses this significant growth and its impact on health services and the community.
<b>Support research to improve palliative care</b>	Existing funding	Research is needed to improve the evidence base for palliative care. Palliative care should be identified as a priority area for the Medical Research Future Fund (MRFF) due to the burden of chronic disease and ageing on the population and the relevance of palliative care to the 150,000 people who die each year in Australia.
<b>Quality of death study in aged care</b>	\$350,000	Around half of all people who die in Australia have accessed an aged care service during the 12 months before they die. This study is critical to ensure high quality care at the end of life in aged care facilities. It will provide the information required to identify effective policy directions. This study is critical as the proposed changes to the Complex Care item in the ACFI are implemented.
<b>Minimum dataset for palliative care</b>	<p>\$250,000 for development of the proposed dataset.</p> <p>Implementation to be costed after the model has been developed</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. Having high quality data will support decisions about allocation of health resources now and in the future, and would ensure best use of finite resources.

## PALLIATIVE CARE AUSTRALIA INCORPORATED

 02 6232 4433  02 6232 4434  [pcainc@palliativecare.org.au](mailto:pcainc@palliativecare.org.au)  [www.palliativecare.org.au](http://www.palliativecare.org.au)

 **Street:** Level 1/21 Napier Close, Deakin ACT 2600 **Mail:** PO Box 24, Deakin West ACT 2600 ABN 85 363 187 904

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