

# Palliative Care Australia

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2014-15 Pre-Budget Submission

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**Palliative  
Care  
Australia**

**If the old proverb “*nothing is certain but death and taxes*” remains true, then the 2014-15 Budget must prioritise much needed action on palliative care.**

### **Why?**

Because the facts show that Australia has been a poor performer in addressing this important issue over time and, ultimately, governments have been short changing themselves and our community as a whole.

### **So what are the facts?**

- 75% of Australians would prefer to die at home, but less than 20% do.
- 70% of people who die each year would benefit from palliative care services, yet only about 25% access these services.
- Only 20% of aged care residents receive adequate palliative care.
- Fewer than 15% of people who died in residential aged care in 2011-12 were assessed as needing palliative care before they died.
- There are very few referrals to palliative care for people with diagnoses other than cancer.
- More than 50% of people who recently lost a loved one had not discussed end of life care with them, nor were confident their loved one’s end of life wishes were carried out.

Furthermore, research shows that 70% of Australians think we don’t talk about death and dying enough.

While the conversation about death is an uncomfortable one, it is a conversation that all Australians need to have at some point. And as the research suggests, the majority in our community now feel there is a need for greater public dialogue on this issue. With an ageing population, this groundswell of opinion is certain to rise.

This changing sentiment is reflective of international developments, with palliative care gaining greater prominence in global politics. The World Health Organisation frequently refers to palliative care as an essential health service; and this month the World Health Assembly Executive Board unanimously passed a resolution<sup>1</sup> co-sponsored by Australia, which stated that palliative care should be integral to health systems and available to all, with greater improvements required to education and training in this field. The resolution will now be put to the World Health Assembly for consideration in May.

In addition, the United Nations Special Rapporteur on Health noted in a recent report that older persons “must be treated with as much dignity during the process of dying as...in earlier phases of their life course” and recommended “important funding and mobilisation of...the medical sector...to ensure death in dignity”<sup>2</sup>. Furthermore, the United Nations formally included palliative care in the

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<sup>1</sup> [http://apps.who.int/gb/ebwha/pdf\\_files/EB134/B134\\_R7-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf)

<sup>2</sup> UN Special Rapporteur on the Right to Health, Thematic study on the realization of the right to health of older persons, July 2011.

2011 United Nations Political Declaration on Non Communicable Diseases and it is also now part of the Global Monitoring and Evaluation Framework on Non-Communicable Diseases.

The Australian Government has an obligation to observe international developments, to listen to its community and to keep in step with changing attitudes. Australians rely on Government to provide strong leadership and set the national agenda, so we can become the society we want to be. Growing demand for services and an ageing population mean palliative care must become core business in national health and aged care policy. The 2014-15 Budget presents an important opportunity to work towards this critical aim.

### **So what are the benefits?**

The benefits of palliative care are increasingly recognised around the world. As services have expanded, evidence has been mounting to suggest access to such services not only significantly improves the experience of patients with terminal illness at the end of life but also reduces pressure on health budgets.

A paper released this month, *Evidence on the cost and cost-effectiveness of palliative care: A literature review*, evaluated all studies on the cost of palliative care intervention between 2002 and 2011, and found consistently that palliative care was less costly compared to conventional/acute care, and in most cases the difference in cost was statistically significant.<sup>3</sup>

Furthermore, a review of 16 studies on cost-effectiveness of hospice and palliative care conducted for the World Health Organisation and the Worldwide Palliative Care Alliance found that cost savings from these models of service were attributed to reductions in the use of medical services, reductions in overall hospital costs, reductions in laboratory and intensive care unit costs and significant decreases in hospital admissions, emergency department visits, the use of outpatient consultation services and residential care facility admissions.<sup>4</sup>

While no data is currently available to determine the nature of savings in Australia, a recent inquiry into palliative and community care by the Queensland Government, reported that:

The committee believes that an investment in specialist palliative care services to provide consultation services and support home-based care could be offset by a reduction in acute hospital costs from unnecessary and unwanted hospital admissions.<sup>5</sup>

From a social perspective, it is well documented that palliative care improves the quality of life of people dying from a terminal illness, but also their carers, family members and other loved ones. It addresses pain and suffering and distress in relation to physical, psychological, spiritual and other problems from the point of diagnosis until the end of life, thereby minimising potential flow-on healthcare costs.

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<sup>3</sup> Smith S, Brick A, O'Hara S, Normand C: Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine* 2014 28: 130. 9 July 2013. [www.pmj.sagepub.com/content/28/2/130](http://www.pmj.sagepub.com/content/28/2/130)

<sup>4</sup> To be published in the forthcoming *Global Atlas on Palliative Care at the End of Life*. References for 16 studies are included in Appendix 1.

<sup>5</sup> Queensland Parliament, *Palliative and community care in Queensland: towards person-centred care*, Report No. 22, Health and Community Services Committee, May 2013, p xli

Despite these compelling facts, Australia's approach to providing adequate palliative care services has been piecemeal. Although we are recognised as being at the forefront of international research in this field, our commitment to applying this knowledge on the ground to deliver quality services in our community, is well short of demand. The systems we rely on are fragmented, siloed and lacking integration with the wider health environment. In fact, for most Australians, gaining access to adequate services is nothing short of a lottery that is predominantly determined by a person's location, diagnosis, the knowledge of palliative care and education of their health professional, as well as their cultural background and age.

In 21<sup>st</sup> century Australia, this situation is unacceptable. Palliative care is a basic human right and should be available to all our people, when and where they need it. The community expects and deserves this, and Governments have an obligation to act.

As the national peak body representing all state and territory organisations, the Australian and New Zealand Society of Palliative Medicine and the interests and aspirations of all who share the ideal of quality of care at the end of life, Palliative Care Australia is well placed to understand what needs to be done to improve our national approach. It is looking to the Australian Government to take a vital, and leading, role in this regard.

While the *Living Longer, Living Better* initiatives have been a step in the right direction, the 2014-15 Budget must build on these foundations and create a system that is sufficiently resourced and managed to enable all Australians to live well to the end of life. Only then, will we be better positioned to cope with the future demands of an ageing population, to capitalise on potential efficiencies and advances in medical technology and to meet the needs of our community.

### **Budget essentials**

Whilst extensive international evidence indicates that palliative care is economically beneficial to health systems, we need Australian evidence. PCA calls on the Australian government to request the Productivity Commission to build upon the work they have already undertaken in the *Caring for Older Australians* study, and conduct a clear economic analysis of the financial benefits of palliative care in the Australian context.

To build a quality palliative care system for Australia, the 2014-15 Budget must maintain funding for existing National Palliative Care Programs, as they underpin the system as a whole. All of these programs are subject to contract renegotiation this year, and all are experiencing significant expansion in demand. It must also address some areas of urgent need to fix shortcomings in education and training, access and equity.

Many of the essential projects below are not costly in monetary terms, in fact some are cost neutral, but they have enormous potential to address structural weaknesses in the system. If government fails to act, the price to be paid by the community over time will be significantly higher, both socially and economically.

The priority areas for action are:

1. Workforce - Care of the dying must be a standard education provision for every health professional across their career. Without supporting the specialist and generalist workforce

to provide palliative care across all settings, the needs of dying Australians will continue to be unmet. We call for action to:

- Develop a Palliative Care Workforce Strategy, which embeds palliative care into the education and training of all health professionals across their careers.
  - Fund the Palliative Care Foundation Scholarship Program to support health professionals to further their palliative care knowledge and education. (Note that this was also a recommendation of the Senate Inquiry into Palliative Care in Australia<sup>6</sup>.)
2. Access – Demand for palliative care services is growing, Australia’s population is ageing, deaths from chronic diseases and dementia are rising, but current access to adequate palliative care services is very limited. We call for action to:
- Fund Medicare Locals to assess access and assist in planning palliative care services to meet local needs.
  - Develop a national equipment and aids library to provide access to these items regardless of location.
3. Awareness – When people don’t discuss or plan for the end of life, it is difficult to provide care for that person according to their wishes, particularly in the event that they lose capacity to make their own decisions. Family members are often left feeling anxious and stressed at an already difficult time. People aren’t aware of what palliative care services are available, or how they can support families. We call for action to:
- Fund a comprehensive communications strategy to enable PCA to build on the success of National Palliative Care Week and lead a national discussion on care at the end of life and advance care planning.
  - Fund a national 1800 telephone and information service to provide palliative care advice and support for patients, families and carers.
4. Equity – Palliative care services are not currently able to meet the needs of everyone in our community, particularly minority groups such as children, Aboriginal and Torres Strait Islander peoples, people with disability, culturally and linguistically diverse communities, older Australians and regional and remote residents. We call on the Government to:
- Expand the Procedural GP program to include palliative care and begin to redress the lack of access to quality palliative care in rural and remote communities.
  - Expand the National Disability Insurance Scheme to include palliative care.
5. Advance Care Planning - Advance care planning processes and legislation differ in each state and territory, creating confusion for patients and health professionals alike, and prevents confidence in health choices being recognised in different jurisdictions. We call for action to:
- Work with the states and territories to implement nationally consistent advance care planning legislation.

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<sup>6</sup> The Senate, Community Affairs References Committee, Palliative Care in Australia, Commonwealth of Australia, 2012

6. Quality - The *Standards for Providing Quality Palliative Care for all Australians* should inform good palliative care practice wherever it is delivered, be included within broader accreditation programs and be promoted as one way in which the community can be sure they will receive high quality services. We call for action to:
  - Support the incorporation of the *Standards* in all settings where palliative care is delivered.
7. Research – There are gaps in palliative care data collection and research, presenting challenges for the development of quality service provision to meet the growing demand for palliative care services. We call for action to:
  - Prioritise funding for palliative care research to support the development of innovative service models.
8. Volunteers – The importance of the role of volunteers in providing emotional and practical support to patients and families is not fully recognised and there is no national strategy for training and coordination which would help meet the growing demand for palliative care, particularly in the community setting. We call for action to:
  - Develop a National Palliative Care Volunteer Strategy coordinating education and management of volunteers.
9. Carers – The needs of carers who support family members to die at home are inadequately recognised. A lack of support for carers will prevent people from being able to be cared for, and die, at home. We call for action to:
  - Fund in-home respite care for people receiving palliative care at home.
  - Improve bereavement care provision for carers delivering palliative care at home.

#### 10. The National Palliative Care Programs

In July 2010 the Economist Intelligence Unit published the first International Quality of Death Index.<sup>7</sup> Australia ranked second in the world to Great Britain across a broad range of categories including healthcare spending and availability of pain medication. The project methodology included weighting of certain indicators to achieve a comprehensive score. The indicators included in the category Quality of End of Life Care were weighted highest.

Significantly enhancing Australia's position, hence boosting us to the number two spot, these indicators strongly correlate with programs which are supported by the Commonwealth government under what has been known as the National Palliative Care Program. These primary indicators include Public awareness of end of life care; Training for end of life care in medical schools; Availability of painkillers; Accreditation for end of life care providers; Doctor-patient transparency; Government attitude to end of life care; and Do Not Resuscitate (DNR) policy.

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<sup>7</sup> Economist Intelligence Unit, The quality of death: Ranking end of life care across the world, 2010, [www.eiu.com/sponsor/lienfoundation/qualityofdeath](http://www.eiu.com/sponsor/lienfoundation/qualityofdeath)

Guided by various iterations of the National Palliative Care Strategy<sup>8</sup>, the National Palliative Care Program has funded the outsourcing of services to the not for profit and university/hospital sectors to ensure the highest quality and most cost efficient means of service provision. The majority of these contractual arrangements are subject to renewal from July 2014. With apparent cessation of funding allocated specifically to the National Palliative Care Program, it is essential that arrangements are made to quarantine and enhance funding arrangements to these highly successful programs.

Examples of these programs and how they contribute to improvement in end of life care, and gain Australia international accolades, include:

- Palliative Care Curriculum for Undergraduates<sup>9</sup> (PCC4U) creates educational modules for use across the undergraduate curricula for all health professionals. At April 2013, 67% of all medical and nursing courses were implementing the PCC4U courses, with a number of other disciplines such as physiotherapy and pharmacy also actively engaged.
- The Program of Experience in the Palliative Approach<sup>10</sup> (PEPA) provides free placements for practicing health professionals for 2-5 days in palliative care services to enhance confidence and skill in those providing generalist palliative care. The program also provides workshops and has a specific program targeting Aboriginal and Torres Strait Islander health professionals. Since the Program began in 2003, over 2600 health professionals have undertaken a PEPA placement, of which 9% identified as being of Aboriginal and Torres Strait Islander heritage.
- The National Standards Assessment Program<sup>11</sup> (NSAP) is a voluntary quality improvement program available to all specialist palliative care services across Australia. Services are supported to engage in continuous quality improvement through self assessment against the National Palliative Care Standards<sup>12</sup> (the Standards). The Program includes workshops, collaborative improvement programs on topics identified by the sector as valuable, and peer mentorship by experts in the field. Despite being a voluntary Program in which services are not paid for participation, 99% of the 172 specialist palliative care services identified at the time of funding are now participating in NSAP, with many now engaged in their third two year cycle. With a review of specialist palliative care services recently indicating an increase in services to 237, at least a proportionate increase will be needed to enable this valuable program to continue to drive quality improvement. NSAP works closely with its program partners CareSearch and PCOC, holding joint workshops and sharing information avenues.

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<sup>8</sup> Commonwealth of Australia, Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy 2010

<sup>9</sup> [www.pcc4u.org](http://www.pcc4u.org)

<sup>10</sup> [www.pepaeducation.com](http://www.pepaeducation.com)

<sup>11</sup> [www.palliativecare.org.au/Standards/NSAP.aspx](http://www.palliativecare.org.au/Standards/NSAP.aspx) or

[www.caresearch.com/caresearch/tabid/2168/Default.aspx](http://www.caresearch.com/caresearch/tabid/2168/Default.aspx)

<sup>12</sup> Standards for Providing Quality Palliative Care for all Australians, 2005, Palliative Care Australia, 4th ed.

- The Palliative Care Outcomes Collaborative<sup>13</sup> (PCOC) is a voluntary quality network which uses standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in PCOC enables palliative care service providers to improve practice and meet the Standards for Providing Quality Palliative Care for all Australians<sup>14</sup> PCOC currently uses 14 benchmarks and 138 services have submitted results since the Program's inception in 2006<sup>15</sup> with 93 services currently actively reporting outcomes of 16,313 patients in this voluntary Program.<sup>16</sup>
- Expansion of the Respecting Patient Choices<sup>17</sup> (RPC) Program has been funded by the Commonwealth and the Victorian governments to support advance care planning through implementation in one lead hospital in each jurisdiction, and then into a number of health services and aged care services in Victoria.<sup>18</sup> The program provides a valuable source of awareness raising and advocacy regarding the importance of advance care planning in addition to assistance in completion of the RPC advance care planning documentation.
- Arguably the world's leading resource providing relevant and trustworthy information about all aspects of palliative care, CareSearch<sup>19</sup> is closely linked with all of the other Programs. In addition to providing links to information for patients, carers, loved ones, health professionals and researchers, CareSearch also synthesises evidence based studies into easily accessible information pages. Recognising the multidisciplinary nature of palliative care, CareSearch uses Hubs to best serve the information needs of different professional groups.
- The Palliative Care Clinical Studies Collaborative<sup>20</sup> (PaCCSC) seeks to improve practice through building the evidence base for medications utilised in palliative care. Functioning as a national multicentre collaboration of palliative care researchers, the PaCCSC team undertakes medication trials which support the agendas of the Therapeutic Goods Administration and the Pharmaceutical Benefits Advisory Committee.
- Palliative Care Australia<sup>21</sup> (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life. PCA influences, fosters and promotes the delivery of quality care at the end of life through

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<sup>13</sup> [www.pcoc.org.au](http://www.pcoc.org.au)

<sup>14</sup> Standards for Providing Quality Palliative Care for all Australians, 2005, Palliative Care Australia, 4th ed

<sup>15</sup> Palliative Care Outcomes Collaboration, Palliative Care Outcomes Collaboration: Three years of progress (2010 to 2013), 2013, Australian Health Services Research Institute, University of Wollongong, Wollongong.

<sup>16</sup> Palliative Care Outcomes Collaboration, National Report on Patient Outcomes January 2013 – June 2013, Report 15, 2013, Australian Health Services Research Institute, University of Wollongong, Wollongong.

<sup>17</sup> [www.Austin.org.au/page/449](http://www.Austin.org.au/page/449)

<sup>18</sup> [www.caresearch.com.au/caresearch/tabid/92/Default.aspx](http://www.caresearch.com.au/caresearch/tabid/92/Default.aspx) accessed 4 Jan 2014

<sup>19</sup> [www.caresearch.com.au](http://www.caresearch.com.au)

<sup>20</sup> [www.flinders.edu.au/clinical-change/research/palliative-care-clinical-studies-collaborative-paccsc.cfm](http://www.flinders.edu.au/clinical-change/research/palliative-care-clinical-studies-collaborative-paccsc.cfm)

<sup>21</sup> [www.palliativecare.org.au](http://www.palliativecare.org.au)

the provision of advice and policy to governments and other stakeholders; the development and dissemination of educational resources for consumers and health professionals; awareness raising regarding all aspects of palliative care including advance care planning through mechanisms such as administration of the annual National Palliative Care Week; professional support such as the biennial Australian Palliative Care Conference; ongoing advocacy to improve end of life care outcomes; represents the sector nationally; develops collaborative linkages with local and international stakeholders such as through membership of the National Aged Care Alliance; and contributes to the development of relevant policy decisions at an international level.

The success of PCA's endeavours is evidenced through the growth in demand for resources and policy expertise, along with international recognition. The number of consumer resources ordered quarterly has doubled in the past two years, peaking at a quarter of a million items during National Palliative Care Week in May 2013. Leveraging nurtured relationships, as a not for profit organisation PCA has been able to grow the reach of National Palliative Care Week (NPCW) within a limited budget. Media during the 2013 NPCW reached 7 million Australians, many of whom actively engaged through talkback radio and PCA's social media pages. PCA is proud and grateful that the 2011 National Palliative Care Week campaign Let's Chat About Dying was awarded a Golden Quill Excellence Award in the Non-profit Campaign category by the International Association of Business Communicators (IABC). The Gold Quill Excellence Awards are the highest honour bestowed by the IABC and recognise communications excellence on a global scale. The 2013 campaign Palliative Care... Everyone's Business, was a finalist in the Asia-Pacific SABRE Awards 2013, also recognising excellence in communications campaigns.

In addition to conducting annual surveys of the Australian public to ensure that our messages are relevant and targeted, PCA also actively collaborates with other organisations to develop policy position statements. Most recently Australian of the Year, Ms Ita Buttrose, launched the Palliative Care and Dementia position statement developed with Alzheimer's Australia, and PCA is currently working with Diabetes Australia, Kidney Health, the Heart Foundation, the Lung Foundation and the Paediatric Palliative Care Reference Group in finalising a series of relevant papers.

- One of PCA's key roles is as the standard bearer. PCA first auspiced the Standards for Providing Quality Palliative Care for all Australians in 1994, and is currently reviewing them for a fifth edition. Whilst PCA manages the review of, and publishes the Standards, they are developed by the palliative care sector themselves. Despite being voluntary, the Standards are universally adopted by specialist palliative care services, are supported by each jurisdiction which has a palliative care strategy or plan, and are the basis of the two major quality improvement initiatives in the sector – NSAP and PCOC. Accreditation services are asked to incorporate the national Standards as part of their assessment of palliative care and other services. The national Standards have been designed for use alongside other standards for health services (for example The Australian Council of Healthcare Standards – Evaluation and Quality Improvement Program [EQuIP], Quality

Improvement Council, Royal Australasian College of General Practitioners, or the Aged Care Accreditation Standards) and therefore do not specifically address areas covered by those standards. The national Standards can be used in conjunction with, or as part of service accreditation with these bodies.

PCA and the sector have developed Standards which are meaningful in palliative care through engaging and collaborating with the sector in their development – working with the people with the expertise and who will be using them; reflecting the core values of palliative care; being key drivers for quality improvement; and undertaking regularly reviews to ensure ongoing relevance.

By addressing these priority action areas, Australia will be in a much stronger position to relieve pressure on the overburdened hospital system; to provide quality, accessible care for all reaching the end of life, and to support those who love and care for them.

We look forward to continuing our work with government, educators and health professionals to address these challenges and to collectively achieve this important goal.