

# Palliative Care Australia

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Submission to the National Commission of Audit

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**Palliative  
Care  
Australia**

Palliative Care Australia (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. Our mission is to influence, foster and promote the delivery of quality care at the end of life through ongoing policy and advocacy, education, and developing collaborative relationships in Australia and internationally.

We believe that palliative care must be available regardless of location, age, income, diagnosis or prognosis, social and cultural background, to support Australians to live well at the end of life.

But we remain a very long way from achieving our goals. In 2011, nearly 147,000 Australians died. Of these, 107,000 would have benefitted from access to palliative care services, yet only one third to one half did.

PCA recognises the value of the National Commission of Audit in seeking to ensure efficiency in Government operations and expenditure, guided by principles which respect the input of all Australians. In response to the Terms of Reference, PCA is keen to provide brief comment regarding the Scope of government and the Efficiency and effectiveness of government expenditure, and in doing so aims to emphasise the fiscal, individual, system and workforce benefits of prioritising palliative care in the Australian health and social care systems.

### *The cost of dying*

Various international studies have found that the healthcare costs of people who are dying are extremely high, particularly in the last year of life.<sup>1,2</sup> There is a growing body of evidence suggesting that inpatient and in-home hospice and palliative care services can reduce these costs.

A review of 16 studies on cost-effectiveness of hospice and palliative care conducted for a forthcoming joint publication on palliative care by the World Health Organization and the Worldwide Palliative Care Alliance (of which PCA is a member) found that these models of service resulted in cost savings, which 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>3</sup> The majority of these studies were conducted in the US.

Other examples of studies which highlight cost savings as a result of hospice and palliative care programs include<sup>4</sup>:

- A study by Shnoor and others found that in Israel, the overall per-patient cost of care for patients with terminal metastatic cancer was \$4,761 for those receiving home hospice care (a figure that includes program operating costs) and \$12,434 for those receiving

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<sup>1</sup> Shugarman I, Decker S & Bercovitz A, Demographics and social characteristics and spending at the end of life, *Journal of Pain and Symptom Management*, 2009; 38(1):15-26.

<sup>2</sup> Fassbender K, Fainsinger RL, Carson M, Finegan B, Cost trajectories at the end of life: the Canadian experience, *Journal of Pain and Symptom Management*, 2009;38(1):75-80

<sup>3</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>4</sup> Canadian Hospice Palliative Care Association, *Cost effectiveness of palliative care: a review of the literature, The Way Forward initiative: an Integrated Palliative Approach to Care*, 2012.

conventional health care services.<sup>5</sup>

- A randomised control trial in the US showed that patients receiving palliative care had lower healthcare costs than those in usual care. Patients in palliative care had 33% lower health care costs (p=.03), the average cost per day was \$95.40 for palliative care patients vs. \$212.80 for those receiving usual care (p=.02).<sup>6</sup>
- A study by Hongoro and others in South Africa of the potential benefits of hospital outreach palliative care services concluded that palliative care programs have the potential to avert hospital admissions in generally overcrowded and under resourced settings and may improve the quality of life of patients in their home environments.<sup>7</sup>

The Queensland Government recently conducted an inquiry into palliative and community care in Queensland which confirms the cost saving benefits of palliative care and states:

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>8</sup>

The report publishes a table<sup>9</sup> of estimated costs of palliative care in different settings, demonstrating marked savings through the use of palliative care in comparison with care for the dying delivered in the acute or intensive care setting.

**Table 5: Estimated cost of palliative care in different settings**

	<b>Estimated cost</b>
Acute hospital bed	\$1,100 per day
Ambulance callout	\$300 - \$5,000 per callout
Palliative care at home	No Australian estimate located
Palliative care in residential aged care facility (average for high care residential aged care)	\$200 per day
Palliative care in a hospice	\$600 per day
Inpatient palliative care facility	\$950 per day
Intensive care unit bed	\$4,000 per day

Whilst demonstrating that some work has been undertaken to determine the exact nature of savings to the Australian health budget offered by palliative care, a comprehensive examination of all jurisdiction's palliative care related health and financial data would be a valuable foundation for the consistent allocation of funds for palliative care program development or redevelopment within an increasingly burdened health system.

<sup>5</sup> Shnoor Y, Szlaifer M, Aoberman A, et al. The cost of home hospice care for terminal patients in Israel. *American Journal of Hospice and Palliative Care*, 2007; 24:284-90.

<sup>6</sup> Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care, *Journal of the American Geriatric Society*, 2007;55(7):993-100.

<sup>7</sup> Hongoro C, Dinat N. A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa, *Journal of Pain and Symptom Management*, 2011, 41(6):1015-24. Epub 2011 Feb 17

<sup>8</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

<sup>9</sup> Queensland Parliament, Palliative and community care in Queensland: towards person-centred care, Report No. 22, Health and Community Services Committee, May 2013, p 22

The Productivity Commission would be well positioned to conduct such a study with input from all relevant stakeholders.

Notably the Senate Inquiry into palliative care also recommended:

3.81 The committee recommends that in determining the appropriate costing for palliative care services the costs of providing care in the community sector also be calculated and allocations made to support the provision of palliative care services by this sector. The committee acknowledges that any allocations of funds to community sector service providers would require rigorous and transparent governance arrangements to be established.<sup>10</sup>

The vast majority of Australians currently die in a hospital setting, and this is unlikely to change rapidly. However, it is possible to reduce costs and improve care by facilitating a change for acute inpatients from a high intervention pathway to a palliative care management plan, even if care needs to continue in the acute facility. Fostering such a pathway requires systemic support and the inclusion of palliative care education throughout the careers of all health professionals. Work currently underway by the Australian Commission for Safety and Quality in Health Care to develop a national consensus statement on end of life care in the acute setting will encourage system support, especially if this leads to a new standard.

The incidence of Australians receiving palliative care in their home would be likely to increase if Private Health Insurers (PHIs) funded this service. The general lack of willingness of private health insurers to fund more cost-effective palliative care reduces the overall efficiency of the health system and inhibits equity of access. This is an area where national leadership by the Australian government in relation to demonstrating the business case and negotiating greater participation by private health funds in the funding of palliative care, could be very helpful and productive. A minimal number of palliative care programs across the country have reached arrangements with PHIs to fund community based palliative care, but this is a rarity rather than the norm. Cabrini Health is recognised as one of the first to negotiate such an arrangement, and in a recent paper for the Australian Centre for Health Research commented:

Privately insured patients have an expectation their private insurance will cover them through all aspects of their illness journey and not cease when curative treatment is no longer appropriate. The impact of this is these private patients are unable to access palliative care and therefore are receiving more expensive, and at times, aggressive treatment in the final stages of life in a private acute hospital which may not be the best place of care on many fronts.

Considering the wish of most people to die at home, as opposed to a hospital bed which could be an intensive care bed, the issue of failing to invest in home based and inpatient palliative care services seems indefensible.<sup>11</sup>

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<sup>10</sup> The Senate, Community Affairs References Committee, *Palliative Care in Australia*, Commonwealth of Australia, 2012, p xi

<sup>11</sup> Sullivan, N, Walker, H, and Brooker, J, A *Framework for the Delivery of Comprehensive Palliative Care Services in the Australian Private Sector*, Australian Centre for Health Research, November, 2013, p 1

Similarly, the Senate Inquiry in 2012 commented:

12.50 The committee acknowledges that in the future demand for palliative care services will increase as the population ages. As more Australians invest in private health insurance, the committee calls on the private health sector and private health insurers to contemplate the role they might play in helping meet the growing demand for comprehensive palliative care.

12.51 The committee considers that further research into the potential role of the private health care sector, including private health insurers, in providing palliative care services is required and suggests that the federal government initiate such a review.<sup>12</sup>

### *Effectiveness of Palliative Care in Improving Quality of Life*

Palliative care improves the quality of life of people living with and dying from a terminal illness, 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, also supporting the bereavement of family members. While some evidence exists that palliative care extends life<sup>13,14</sup>, palliative care by definition does not seek to prolong life, but to ensure quality of life. The effectiveness of palliative care must be assessed through patient outcomes and improved quality of life. The palliative care needs for people with a range of chronic diseases are well documented as are reported improved patient outcomes as a result of palliative care include reduction in depression, reduced pain and symptoms and an improved sense of well-being.<sup>15,16,17,18,19,20</sup>

Similarly evidence indicates that use of palliative care decreases the physical and emotional distress that is frequently experienced by loved ones caring for someone with a terminal illness.<sup>21,22,23</sup>

Providing such essential support for carers contributes to the likelihood that care can continue to be provided in the community, rather than requiring admission to the acute care system.

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<sup>12</sup> The Senate, Community Affairs References Committee, *Palliative Care in Australia*, Commonwealth of Australia, 2012, p 192

<sup>13</sup> Temel. J. et al., *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer*, *New England Journal of Medicine*, 2010, 363;8

<sup>14</sup> Connor. S et al., *Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window*, 2007

<sup>15</sup> Temel. J. et al., *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer*, *New England Journal of Medicine*, 2010, 363;8

<sup>16</sup> Smith et al., *American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care Into Standard Oncology Care*, *Journal of Clinical Oncology*, 2012, 30:880-887.

<sup>17</sup> Curtis, J., *Palliative and end-of-life care for patients with severe COPD*, *European Respiratory Journal*, 2008; 32: 796–803

<sup>18</sup> Solano, J et al., *A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease*, *Journal of Pain and Symptom Management*, Vol. 31 No. 1 January 2006

<sup>19</sup> Canadian Hospice Palliative Care Association, *Cost effectiveness of palliative care: a review of the literature, The Way Forward initiative: an Integrated Palliative Approach to Care*, 2012.

<sup>20</sup> Gelfman, L et al., *Does Palliative Care Improve Quality? A Survey of Bereaved Family Members*, *Journal of Pain and Symptom Management*, 2008 July; 36(1): 22–28.

<sup>21</sup> World Health Organisation *Palliative Care is an Essential Part of Cancer Control* [www.who.int/cancer/palliative/en/](http://www.who.int/cancer/palliative/en/)

<sup>22</sup> Empeño J et al., *The Impact of additional support services on caregivers of hospice patients and hospice social workers*, *Omega (Westport)* 2013, 67:1-2 pp. 53-61.

<sup>23</sup> Hudson P, Zordon R, Trauer T, *Research Priorities Associated with Family Caregivers in Palliative Care: International Perspectives*, *Journal of Palliative Medicine*, 2011, doi:10.1089/jpm.2010.0345.

## *United Nations and World Health Assembly*

Palliative care is a vital intervention to relieve the pain and suffering of people living with and dying from a range of diseases, as evidenced by its inclusion in the 2011 United Nations Political Declaration on Non Communicable Diseases and inclusion of the related indicator in the Global Monitoring and Evaluation Framework. Yet 42% of the world's countries have no identified hospice and palliative care services, a figure which jumps to 49% in our region.<sup>24</sup>

In Australia we are far closer to achieving our goals than most. In fact we are amongst the world leaders in many aspects. Yet this position doesn't change the fact that access to palliative care in Australia is nothing short of a lottery, predominantly determined by your location, but also affected by your diagnosis, the knowledge of palliative care and education of your health professional, your cultural background, and your age. Palliative care in Australia is still fragmented, delivered in silos and lacking integration and connection with the wider health environment.

The World Health Organization clearly and repeatedly recognises palliative care as an essential health service. In its publication on national cancer control programs, it states:

The fundamental responsibility of the health profession to ease suffering of patients cannot be fulfilled unless palliative care has priority status within public health and disease control programs; it is not an optional extra... A national disease control plan for AIDS, cancer and non-communicable disorders cannot claim to exist unless it has an identifiable palliative care component.<sup>25</sup>

Furthermore, palliation is recognised as one of the essential health care services required for achieving Universal Health Coverage.<sup>26</sup>

In a report on the health rights of older persons, the UN Special Rapporteur on Health noted 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>27</sup> In a report presented to the UN Human Rights Council on March 4, 2013, the UN Special Rapporteur on Torture called on member states to "ensure full access to palliative care" as a way to protect people from inhuman and degrading treatment.

Within the UN Political Declaration on Non Communicable Diseases, there was strong commitment to the development and strengthening of palliative care services for people living with and dying from these diseases.<sup>28</sup> In addition, a palliative care indicator was selected as one of only 25 indicators to monitor progress on the implementation of the Political Declaration in the Global Monitoring and Evaluation Plan on Non-Communicable Diseases<sup>29</sup>.

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<sup>24</sup> WPCA, Mapping the development of palliative care services, 2011 [www.thewpca.org](http://www.thewpca.org) (accessed March 2013)

<sup>25</sup> WHO, National Cancer Control Programmes; Policies and managerial guidelines, 2<sup>nd</sup> edition, p. 86/87.

<sup>26</sup> WHO: 2013. 'Background note: Towards Universal Health Coverage: concepts, lessons and public policy challenges WHO/World Bank Ministerial Level Meeting 2013.

[http://www.who.int/mediacentre/events/meetings/2013/uhc\\_who\\_worldbank\\_feb2013\\_background\\_document.pdf](http://www.who.int/mediacentre/events/meetings/2013/uhc_who_worldbank_feb2013_background_document.pdf) (Accessed March 2013)

<sup>27</sup> UN Special Rapporteur on the Right to Health, Thematic study on the realization of the right to health of older persons, July 2011.

<sup>28</sup> UN Political Declaration on Non-Communicable Diseases, 2011.

<sup>29</sup> WHO: Global Monitoring and Evaluation Framework on Non-Communicable Diseases

PCA has worked closely with our international colleagues and the Australian government to provide advice to ensure the inclusion of palliative care in the Political Declaration and as a measurement indicator. Much of the above information was jointly prepared for WHO officials and government ministers with our international colleagues<sup>30</sup>.

The co-sponsorship by Australia of the resolution on palliative care through the Executive Board and the subsequent World Health Assembly is deeply appreciated by the international palliative care community, and by the health sector worldwide.

### *Number Two in the World*

Although the benefits of palliative care to individuals and their loved ones, and to the economic trajectory of the health system are well established, Australia has yet to appropriately embed palliative care as an integral component of our health system. As with most of the health sector, funding for palliative care is split across different jurisdictional mechanisms, as is responsibility for quality and outcomes.

In July 2010 the Economist Intelligence Unit published the first International Quality of Death Index.<sup>31</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.

Guided by various iterations of the National Palliative Care Strategy<sup>32</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>33</sup> (PCC4U) creates educational modules for use across the undergraduate curricula for all health professionals. At April 2013, 67% of all medical and nursing

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<sup>30</sup> Thanks to Claire Morris, Advocacy Officer, WPCA for the collation of much of this work.

<sup>31</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)

<sup>32</sup> Commonwealth of Australia, Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy 2010

<sup>33</sup> [www.pcc4u.org](http://www.pcc4u.org)

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>34</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>35</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>36</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.

The Palliative Care Outcomes Collaborative<sup>37</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>38</sup>. PCOC currently uses 14 benchmarks and 138 services have submitted results since the Program's inception in 2006<sup>39</sup> with 93 services currently actively reporting outcomes of 16,313 patients in this voluntary Program.<sup>40</sup>

Expansion of the Respecting Patient Choices<sup>41</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>42</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.

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<sup>34</sup> [www.pepaeducation.com](http://www.pepaeducation.com)

<sup>35</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>36</sup> Standards for Providing Quality Palliative Care for all Australians, 2005, Palliative Care Australia, 4<sup>th</sup> ed.

<sup>37</sup> [www.pcoc.org.au](http://www.pcoc.org.au)

<sup>38</sup> Standards for Providing Quality Palliative Care for all Australians, 2005, Palliative Care Australia, 4<sup>th</sup> ed

<sup>39</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>40</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>41</sup> [www.Austin.org.au/page/449](http://www.Austin.org.au/page/449)

<sup>42</sup> [www.caresearch.com.au/caresearch/tabid/92/Default.aspx](http://www.caresearch.com.au/caresearch/tabid/92/Default.aspx) accessed 4 Jan 2014

Arguably the world's leading resource providing relevant and trustworthy information about all aspects of palliative care, CareSearch<sup>43</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>44</sup> (PaCCSC) seeks to improve practice through building the evidence base for medications utilised in palliative care. Functioning as a national multi-centre 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>45</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 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

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<sup>43</sup> [www.caresearch.com.au](http://www.caresearch.com.au)

<sup>44</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>45</sup> [www.palliativecare.org.au](http://www.palliativecare.org.au)

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.

### *The National Palliative Care Standards*

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 [EQulP], 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.

### *Funding of service delivery*

The delivery of specialist palliative care is funded by state and territory governments. In its submission to the Senate Inquiry into Palliative Care in 2012, the (then) Department of Health and Ageing explained the Commonwealth's indirect contribution to specialist palliative care service delivery:

Firstly, the Australian Government provides financial assistance to state and territory governments to operate palliative care services, a form of sub-acute care, as part of their health and community service provision responsibilities. Since Medicare was introduced in February 1984, there has been a series of funding agreements through which the Government contributed to the cost of operation of the public hospital system and associated palliative care services.

Through the sub-acute care component of the National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR), the Australian Government provided \$500 million in June 2009 to expand states and territories' provision of sub-acute care, including palliative care, over the period 2009-10 to 2012-13.

The funding is being used to expand sub-acute care services in each state or territory by five percent annually, or 20 percent over the four years to 2012-13, and to improve the quality and mix of sub-acute care services nationally.

States and territories have prioritised and distributed their funding based on identified needs and gaps in sub-acute care within their respective jurisdiction. In most instances, this has included funding for palliative care beds and/or community based services.

States and territories report annually on service volumes for sub-acute care under the NPA HHWR. These cover public hospital patients and non-admitted public patients. States and territories are still working to improve data collection under the NPA HHWR and variations between the way that palliative care is delivered and reported on, means data cannot be reliably compared at this stage.

Reports against annual targets are publicly available on the Productivity Commission website at <http://www.pc.gov.au/gsp/national-partnership/hospital-health-agreement>

The Australian Government has committed a further \$1.623 billion over the four years 2010-11 to 2013-14 through the sub-acute care element of the National Partnership Agreement on Improving Public Hospital Services, for states and territories to deliver and operate at least 1,300 new sub-acute care beds and equivalent services nationally, in residential and community-based settings. The sub-acute services in scope are rehabilitation, palliative care, sub-acute mental health care, Geriatric Evaluation and Management and psychogeriatric services. Based on the approved Implementation Plans, palliative care comprises approximately five per cent of all planned sub-acute care beds and equivalent services.

The allocation of funding to palliative care is a matter for states and territories to assess, based on the needs of their populations and in consultation with relevant sectors.<sup>46</sup>

These National Partnership Agreements were developed in collaboration between the jurisdictions, yet the outcomes for palliative care were highly variable across the country. Some states/territories allocated some funding to palliative care under one agreement and none in the other, other states allocated only minimal amounts across both.

Only five disciplines exist in subacute care yet palliative care was allocated less than 7% of the overall funding. Shock at this outcome led to the Senate recommending:

3.80 The committee recommends that the Australian government considers extracting palliative care from the sub-acute care category and create a new funding category of 'palliative care'.<sup>47</sup>

Although the allocation to palliative care has been very small, it would appear that the states have heavily relied upon Commonwealth funding. Significant cuts to palliative care services were threatened from June 30, 2013 due to the cessation of the National Partnership Agreement on Hospital and Health Workforce Reform (HHWR). Even though most states only allocated a small percentage of this subacute funding to palliative care, vital services had been established and staff employed. These staff did not have contracts beyond June 30, for many their only option was to look

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<sup>46</sup> Department of Health and Ageing, Submission to the Senate Community Affairs Committee Inquiry into Palliative Care, April 2012.

<sup>47</sup> The Senate, Community Affairs References Committee, Palliative Care in Australia, Commonwealth of Australia, 2012, p xi

outside the sector for employment.

One area deeply affected is the South Australian Paediatric Palliative Care Service. This service was threatened with losing all medical funding, 20% of its nursing funding, all psychosocial funding and 70% of its administrative support. It can be difficult to provide support for children to die at home with their family, yet this service helps 70% of their young patients to die at home (50% if neonatal figures are also included). Drastically reducing funding to this service is likely to lead to increased hospital admissions.

In total more than 30 FTE positions were threatened in South Australia and 54 FTE in NSW.

PCA appreciates that the National Partnership Agreement on Improving Public Hospital Services (IPHS) has another six months to run and will roll out \$625.5m for subacute beds and bed equivalents in 2013-4, however this will not solve the problem. States allocated the IPHS funding in 2010 predominantly to beds and infrastructure supporting same, rather than services. As an example, South Australia allocated \$40.3m for development of the Daw Park Rehabilitation Hospital. Some states, such as SA and Tasmania, allocated no funding to palliative care in this agreement.

Of the total \$1.623 billion for subacute care in the IPHS only 3% has been allocated to palliative care.

One of the difficulties that the states have raised with PCA is that the HHWR was designed to increase the volume and quality of subacute services by 5%pa. Some services are currently experiencing growth of 25% in referrals, a situation that we can only expect to be increasingly seen with the ongoing burden of chronic disease. These same services are exploring means to restrict access because of the threatened job losses.

PCA's members have not recommended transferring funding of palliative care to the Commonwealth as is the case for aged care and primary care, but if the removal of such a small amount of funding from the states can cause such debilitating outcomes to the delivery of services to Australians needing care at the end of their life, the potential for shared funding models requires further investigation. This could potentially form another aspect of an investigation by the Productivity Commission.

With the inclusion of palliative care in Activity Based Funding (ABF) PCA is working closely with the Independent Hospitals Pricing Authority and is represented on its Subacute Care Working Group. As ABF is designed to model funding in acute care where diagnosis is the cost driver (using Diagnosis Related Groups or DRGs) its application to subacute fields is complex as principal diagnosis is not the cost driver. Costs in palliative care are related to pain, symptoms, carer support, and functional ability related to the activities of daily living.<sup>48</sup> As community care provision will remain a state responsibility, it is unclear what ramifications will be experienced with the introduction of ABF. It is possible that states may move community palliative care services to become hospital outpatient services to improve funding access. Such transfers could negate the important role such community services play in providing specialist palliative care into people's homes and their aged care facilities – locations where the vast majority of Australians would prefer to receive their care.

It is also worth noting that the capacity of community based palliative care services to collect the

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<sup>48</sup> Kathy Eagar, Presentation at Activity Based Funding Forum held by Palliative Care Australia, Canberra, October 2012

Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) data required with an ABF system is diminished by a lack of appropriate electronic systems. This is already a problem in states currently requiring such data collection.

### *Aged care and primary care*

Palliative care is delivered across a broad range of settings including hospitals, hospices, aged care facilities, in the community and in people's own homes. Whilst delivery of complex palliative care is best managed by specialist teams, the majority is managed by health professionals delivering generalist palliative care. This is especially true of the primary care workforce.

All people diagnosed with a life limiting illness, as an absolute minimum, require access to primary care providers that have knowledge and skills in the care of people with a terminal illness. These skills, attributes and knowledge applied within the context of a primary care relationship are sometimes referred to as a palliative approach or generalist palliative care (in contrast to specialist palliative care). A palliative approach uses the basic principles of palliative care, adapted to recognise and reflect the different expertise, experience and resources of primary care providers.<sup>49</sup>

A number of access pathways need to be in place for patients, primary carers and families requiring palliative care support. Many patients receiving primary care will already have an established and ongoing relationship with their primary care provider. For these patients, generalist palliative care will be introduced as part of the ongoing and comprehensive care they are already receiving. Access to primary care providers will generally utilise existing referral and relationship mechanisms.

With regards to palliative care, the term 'primary care providers' includes general practitioners, community and hospital based doctors, nurses and allied health staff, and staff of residential aged care facilities whose substantive work is not in palliative care. As these health professionals, and those within specialist palliative care teams, are split across the Medicare Local and Local Hospital Network frameworks, it is essential that clear mechanisms exist both geographically and systemically to ensure a continuum of care.

PCA recognises the important role that Medicare Locals can play to enhance system level integration of care for those with palliative care needs. From our perspective, this critical aspect of the health reform agenda creates the opportunity to enable people with terminal conditions to have seamless access to quality health services.<sup>50</sup>

Given that the establishment of localised primary health organisations in the form of Medicare Locals provided a unique opportunity to improve the provision of well coordinated multidisciplinary healthcare, PCA regrets the fact that palliative care was not addressed in the original governance and functions of Medicare Locals.

Levels of understanding of palliative care vary substantially amongst primary health professionals, so education and support mechanisms will need to be improved. Medicare Locals could play a vital leadership role in developing better integration of care services for people with terminal conditions, including developing and implementing the necessary referral criteria and the enhanced workforce

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<sup>49</sup> Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005. [www.palliativecare.org.au/Default.aspx?tabid=2016](http://www.palliativecare.org.au/Default.aspx?tabid=2016)

<sup>50</sup> Palliative Care Australia, *Health System Reform and Care at the End of Life: A Guidance Document*, PCA, Canberra, 2010.

education that will be necessary.

Clearly care of the dying must be a standard education provision for every health professional across their career. Medicare Locals could play a role in monitoring levels of knowledge amongst primary care professionals in their catchment, and assisting in the coordination of educational opportunities.

This could be further facilitated through the expansion of the Procedural GP program to include palliative care, hence beginning to redress the lack of access to quality palliative care in rural and remote communities.

To improve end of life care for all Australian communities, infrastructure and models of care will require substantial improvement, especially in the areas of after hours access, medication access, and funding. Part of the process of the review of the national Standards includes a focus on aspects of the Standards relating to primary care, and Medicare Locals could play an important role in dissemination of information regarding the Standards and encouragement of their broad adoption.

It would also be valuable for Healthy Communities Reports to include specific information on palliative and end of life care, such as statistics for the numbers of supported home and hospital deaths, the percentage of the community who have been assisted by a health professional to develop an advance care plan, and levels of training and adoption of a palliative approach across local primary and aged care services.

As well as driving more efficient use of our health resources, Medicare Locals should be expected to drive – and deliver – more effective use of our health resources to achieve truly integrated services to the benefit of all Australians. This needs to include engagement with subacute services including palliative care; bereavement support and related models of care; and the need to, and means of, identifying patients with palliative care needs, and to assess those needs.

In addition to guaranteeing access to palliative care within the community funded through private health insurance, rather than the private sector, changes to Medicare Plus would also improve access. If palliative care specialists could utilise Medicare Plus they could arrange interdisciplinary care, such as psychosocial and physiotherapy services for their patients. Current rules restrict this access to general practitioners who may have minimal recent training in optimal end of life care – again emphasising the need for compulsory education in palliative care across the continuum of the careers of all health professionals.

Potentially the group who most lack access to palliative care are ageing Australians. Whilst the Productivity Commission<sup>51</sup> declared that palliative care is core business for aged care services and should be a core educational competency for aged care workers, this remains far from the truth. Staff receive minimal education regarding end of life care, neither staff nor families are uniformly offered bereavement support, advance care planning is an often misunderstood process, funding procedures for palliative care loadings are complex, and a lack of connection with well resourced health professionals can lead to poor pain and symptom control. Given current circumstances, it is not surprising that Australians express fear about their end of life care within the aged care system.

The Productivity Commission recognised that there are large systemic problems with the financing

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<sup>51</sup> Productivity Commission, Caring for Older Australians, Report No. 53, Final Inquiry Report, 2011, Canberra

and operation of aged care and that the current models are not sustainable to meet future demand. The Report states that there is 'insufficient and inadequate funding for restorative and reablement care; and for palliative and end of life care'.<sup>52</sup>

In assessing the quality of care currently available within aged care services the Commission concluded that due to 'palliative and end of life care needs ... of older Australians ... not being adequately met under the current arrangements [there is a need to] ensure that residential and community care providers receive appropriate payments for delivering palliative and end of life care. They proposed that the main benefits of such a change would be 'a greater role by residential and community care providers in delivering these services will provide more appropriate care and be less expensive than services delivered in a hospital'.<sup>53</sup>

The latest report into palliative care by the Australian Institute of Health and Welfare<sup>54</sup> demonstrates that this remains a significant problem. Data indicates that for those aged care facility residents who had an Aged Care Funding Instrument (ACFI) appraisal, only 1 in 20 of these indicated the need for palliative care. There were 51,553 deaths of people with an ACFI assessment in residential aged care in the period 2011-12, however fewer than 15% of them were assessed as needing palliative care before they died. Even though some cases may be explained by problems with the application for the palliative care loading, it would appear that the large majority of people who would benefit from access to palliative care services just aren't getting the care they need, which is particularly worrying when research indicates that the proportion of people dying in aged care is increasing.

Whilst not directly funding aged care providers, the Commonwealth government is taking steps to improve the provision of both palliative care and advance care planning in community and residential aged care services. From mid-2014, the Specialist Palliative Care and Advance Care Planning Advisory Services project will provide a dedicated national hotline that aged care service providers and GPs can call for immediate access – 24 hours a day, 365 days a year - to specialist palliative care advice and information about advance care planning.

The free service will also provide web-based resources, with tablet and smart phone access, as well as training and linkage activities, so providers can obtain the information, where and when they need it most.

The project is being developed by a consortium of leading national health and aged care organisations with expert knowledge and experience in advance care planning and palliative care. These include Respecting Patient Choices, Palliative Care Australia, CareSearch, the University of Queensland, Queensland University of Technology, the Australian and New Zealand Society of Palliative Medicine, Leading Age Services Australia (LASA) and Aged and Community Services Australia (ACSA).

The project will also develop and provide training programs, collate clinical guidelines, and foster the development of innovative practices that link specialist palliative care and aged care.

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<sup>52</sup> Productivity Commission, *Caring for Older Australians*, Report No. 53, Final Inquiry Report, 2011, Canberra, p xxv

<sup>53</sup> Productivity Commission, *Caring for Older Australians*, Report No. 53, Final Inquiry Report, 2011, Canberra, p LXXXVII

<sup>54</sup> Australian Institute of Health and Welfare, *Palliative Care Services in Australia 2013*, Cat no HWI 123, 2013, Canberra

### *Opportunities for systemic improvement*

Palliative care is not unusual in health disciplines in that both responsibility and funding is split across Australian jurisdictions. Yet with the latest international research indicating that that around 70% of Australians who die would benefit from access to palliative care services<sup>55</sup>, this is clearly an area which needs a secure and transparent funding stream. Within the sector, quality improvement is driven by the not for profit and university sectors, building upon nationally utilised voluntary Standards developed by the sector itself. The ongoing support of Commonwealth government funding for these programs are efficient and demonstrably effective.

The evidence that a greater emphasis on palliative care, delivered by both specialist and generalist health professionals, will reduce unnecessary hospital admissions and diminish financial waste in unnecessary treatment and investigations is strong. However, a thorough economic inquiry conducted by the Productivity Commission would provide greater local evidence and potential mechanisms to ensure that palliative care is recognised as an integral component of the Australian health system.

The benefits of palliative care to those with a terminal illness and their loved ones are myriad and well established – we now need to ensure that the economic benefits are reinforced to generate systemic savings and improvements.

PCA urges the Commission to view the story of Kaye Sales, who speaks in her own words about her own journey, and that of her family since her diagnosis with peritoneal mesothelioma.

[http://www.youtube.com/watch?v=cWHPZzaeFzE&feature=player\\_embedded](http://www.youtube.com/watch?v=cWHPZzaeFzE&feature=player_embedded)

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<sup>55</sup> Murtagh FEM, Bausewein C, Verne J, Groeneveld EI, Kaloki YE and Higginson IJ, How many people need palliative care? A study developing and comparing methods for population-based estimates, *Palliative Medicine*, 21 May 2013