



**Palliative  
Care  
Australia**

**Submission to the Treasurer**  
**on**  
**Priorities for the 2011 Federal Budget**  
**on behalf of**  
**Palliative Care Australia**

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### on behalf of Palliative Care Australia

#### Background

Palliative Care Australia (PCA) is the peak national organisation representing all state and territory peak palliative care organisations, the Australian and New Zealand Society of Palliative Medicine and the interests and aspirations of all who share the ideal of quality care at the end of life.

PCA believes that all Australians should be able to expect to die with their preventable pain and other symptoms well managed, with the people they wish to be present and, whenever possible, in the place of their choice.

PCA encourages the Government to consider pressing issues about the ability to achieve greater integration of palliative care services with broader health services within the forthcoming Budget.

PCA strongly supports the aim that 'the National Health and Hospitals Network will ensure that services are designed around the needs of patients, and more strongly oriented to early intervention and high quality integrated care in the community.'<sup>1</sup>

If we are to improve access to needs-based quality care at the end of life, we need to provide resources to enable the home to be used, when appropriate, as the primary place of end of life care. The goal is to enhance access to optimal palliative care and end of life care, when and where it is needed.

- Studies indicate most people prefer to die at home.<sup>2</sup>
- Currently, 43 per cent of people who are admitted to a residential aged care facility as high care residents will die within six months of admission<sup>3</sup> and 51 per cent will die within one year.<sup>4</sup>
- The National Health and Hospitals Reform Commission (NHHRC) recommended a needs-based approach that acknowledges that patients have different needs that may change over time and that ensures people can access the right care in the right setting.<sup>5</sup>
- Access to optimal palliative care and end of life care is the responsibility of the entire health, aged care and disability services system.
- The national health reforms must improve service system capacity and coordination so that optimal palliative care and end of life care can be provided, when and where it is needed.

The draft report of the Productivity Commission inquiry into Caring for Older Australians identifies a current problem as being that 'Palliative and end-of-life care needs of older Australians are not being adequately met under the current arrangements.'<sup>6</sup>

To resolve this problem, the Productivity Commission proposes 'that residential and community care

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<sup>1</sup> Commonwealth of Australia, *A National Health and Hospitals Network for Australia's Future – Delivering better health and better hospitals*, Australian Government, Canberra, 2010, p 9.

<sup>2</sup> Foreman, LM et al. 2006, 'Factors predicative of preferred place of death in the general population of South Australia'. *Palliative Medicine*, vol. 20, pp .447–53.

<sup>3</sup> Australian Institute of Health and Welfare 2010, *Residential aged care in Australia 2008–09: a statistical Overview*, Aged care statistics series no. 31. Cat. no. AGE 62. Canberra: AIHW.

<sup>4</sup> Ibid.

<sup>5</sup> Commonwealth of Australia, *A Healthier Future For all Australians: Final Report of the National Health and Hospital Reform Commission – June 2009*, Australian Government, Canberra, 2009.

<sup>6</sup> Productivity Commission 2011, *Caring for Older Australians*, Draft Inquiry Report, Canberra, available online at [http://www.pc.gov.au/\\_data/assets/pdf\\_file/0011/104879/aged-care-draft.pdf](http://www.pc.gov.au/_data/assets/pdf_file/0011/104879/aged-care-draft.pdf) page LX

providers receive appropriate case mix payments for delivering palliative and end of life care,' noting that '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.'

Supporting the needs of people living with terminal illness, and their carers and families, requires a well resourced and well integrated service delivery model that supports specialist palliative care services, and enhances in-home support through better integration of community care with specialist palliative care services. Such a system minimises unnecessary demand for, and expenditure on, hospital beds.

Some options that will help Australia to move towards this end are outlined below. PCA is confident that implementation of these measures will go a long way to achieving real and measurable health reform at minimal net cost.

### **1. Improved financial incentives for GPs and specialists such as palliative medicine physicians and geriatricians to provide medical services in residential and community care settings**

The draft report of the Productivity Commission inquiry into Caring for Older Australians found that

With entry to residential care being increasingly confined to people at a higher level of frailty (with the major exception of dementia), there will be increased need for palliative and end-of-life care services to be delivered in both the residential and home environment.<sup>7</sup>

In the Commission's view, there is a strong case for a greater role for residential and community care providers to deliver palliative care. Not only is this less expensive than services delivered in a hospital, but more appropriate care can be provided.<sup>8</sup>

The Productivity Commission's draft conclusion is that 'Residential and community providers should, in the Commission's view, receive appropriate case mix payments for delivering these services, which would reduce the strain on public hospitals.'<sup>9</sup>

Draft recommendation 8.3 from the draft Productivity Commission report is that

The Australian Government should ensure that, through the Independent Hospital Pricing Authority, residential and community care providers receive appropriate case mix payments for delivering palliative and end-of-life care.<sup>10</sup>

Other mechanisms to enhance service provision could include:

- enhanced Medicare items for GP provision of palliative care services in the community, and in residential aged care
- enhanced Medicare items for specialists such as palliative medicine physicians and geriatricians to provide services in the community, and in residential aged care
- funding for aged care service providers to contract service provision with GP group practices, and
- funding of GP coordinators who will liaise between clinicians including GPs and palliative medicine physicians, and aged care facilities and specialist palliative care services about consultation and appointment times and arrangements. This role may potentially fall to Medicare Locals, and should incorporate close liaison with community based specialist care services.
- a specific Medicare item for clinicians to work with patients on preparing advance care plans.

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<sup>7</sup> Ibid, p 259

<sup>8</sup> Ibid, pp 259-260.

<sup>9</sup> Ibid, p 261.

<sup>10</sup> Ibid.

It is important that any incentives be subject to the attainment of suitable credentials and competency in providing palliative care (see item 3).

In terms of palliative care being provided in residential aged care facilities and for recipients of community aged care, the draft report of the Productivity Commission inquiry into Caring for Older Australians has made pertinent observations and recommendations about ways forward. PCA urges the Government to commence the reform process in this Budget.

The Budget cost of such incentives would vary depending on the mechanism/s chosen, but would be offset by savings to acute care costs because people with non-acute palliative care needs will be better able to be supported in community-based settings, reducing the number of avoidable acute care admissions.

## 2. Better resourcing of tertiary services

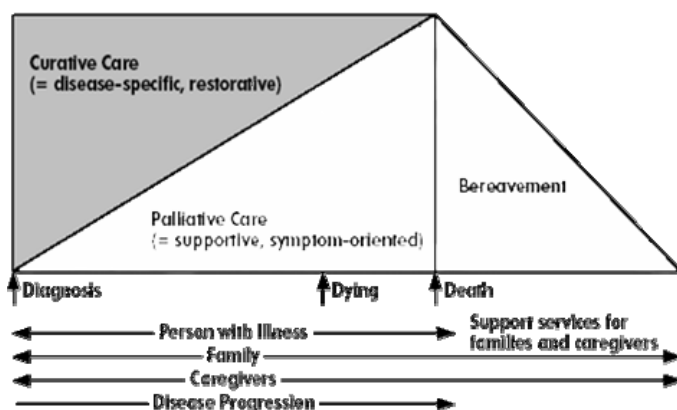
Seamless integrated care across care settings assumes quality care in all settings.

Specialist palliative care services – primarily funded by the State and Territory Governments - provide consultative and ongoing care for patients with a life limiting illness and provide support for their primary carer and family in a range of care settings - at home, in hospital, in a hospice and in an aged care home - during and after the patient’s illness.

In recognition of the needs of people with chronic conditions and improved treatments for cancer, palliative care and curative treatment may be offered at the same time as an increasing role of palliative care services, as the disease progresses (see Fig. 1 below).

This model requires seamless integration of palliative and curative care, transfer of information, mutual understanding of goals and possibilities of care and liaison between multiple service providers working in diverse sites of care wherever the patient is at the time.

FIGURE 1: Palliative care and curative care<sup>11</sup>



This model is not adequately recognised in current funding, targets or models of service provision for palliative care.

A recent journal article notes that

Optimizing resource allocation in end-of-life care is one of the most difficult issues

<sup>11</sup> WHO 1990, *Cancer Pain Relief and Palliative Care*, Report of a WHO Expert Committee, World Health Organization, Geneva

currently being addressed within the U.K. National Health Service. Decision rules and cost-effectiveness thresholds that would appear to be appropriate for acute interventions may significantly undervalue extensions in quantity and quality of life provided to the terminally ill. Arguably, the value placed on improving quantity and quality of life is dependent on the context in which they are derived.<sup>12</sup>

In answer to the rhetorical question ‘when does the process of palliative care provision begin?’ this article continues:

How do we define the initiation of the process of “dying” and at what stage does the balance of care provision switch from curative to palliative intent? Clinicians may be reluctant to diagnose a patient as dying, as they may perceive this to be a recognition of their failure. However, such acknowledgment is essential in refocusing clinical effort from cure to care and ensuring that the quality of care provision is maintained during the crucial palliative phase of the patient’s care pathway. Optimizing the patients’ remaining quantity and quality of life requires clinical standards to be maintained or even enhanced, with clinical thresholds (e.g., initiating blood transfusions in response to low haemoglobin levels or providing antiemetics in response to nausea) being maintained unless it is in the patients’ interest or in response to their expressed wishes to relax them.<sup>13</sup>

Currently, in many acute settings in Australia, patients with palliative care needs are not identified and are thus not appropriately referred or are referred for inappropriate treatment. There is limited discharge planning and coordination of subsequent care. As a result, patients may not be provided with adequate care, may face unreliable transitions between services, and find it difficult to navigate the complexities of the healthcare system.

The consulting service role of palliative medicine physicians and specialist palliative care services continues to expand with increasing demands to:

- Provide outpatient clinic based services;
- Provide seven-day-a-week service;
- Manage the palliative care needs from a referrals base which increasingly involves patients with non-cancer life limiting illnesses;
- Provide palliative care input to advance care frameworks and advance care planning in hospitals; and
- Meet the increasing need for palliative care response to ICU / MET calls.

Better resourcing of tertiary palliative care services would (in respect to the goal of greater emphasis on home care):

- Assist a greater numbers of patients to clarify palliative goals of care that might enable patients to return to home, who otherwise remain in acute settings receiving 'futile' treatments at the end of life;
- Reduce the expenditure on hospital beds; and
- Improve liaison between tertiary and primary providers.

Allowing this model to develop provides one window of opportunity for implementing cross-jurisdictional health program reform in a discrete but vital care environment, that of palliative care.

*PCA proposes that the Government allocate \$30 million over 3 years from 2011-12 to 2013-14 to*

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<sup>12</sup> Haycox, Alan, ‘Optimizing Decision Making and Resource Allocation in Palliative Care’. *Journal of Pain and Symptom Management* 2009;38:45e53, p 45.

<sup>13</sup> *ibid*, p 49.

*enable acute care hospitals to better identify and provide appropriate care services for people with palliative care needs. This could appropriately be by way of increased resourcing for internal specialist palliative care consultancy within acute hospitals. This reform should not be sole mechanism for palliative care case finding. Both community and primary care models also need development.*

### **3. Development of a framework for palliative care in a primary care setting**

Most of the last year of a person's life is spent at home, and most health care is provided by a person's general practitioner (GP). However, providing high-quality care at the end of life is among the most complex challenges for general practitioners (GPs).<sup>14</sup> Patient symptoms may be severe, disease trajectories difficult to predict, family issues complex and the GP's own beliefs and fears about death and dying challenging.<sup>15</sup> There are also a number of structural and resource barriers including lack of time and remuneration, lack of training, knowledge and resources, and experience in palliative approaches.<sup>16</sup>

Despite these barriers there is evidence that the proactive involvement of GPs enables more terminally ill patients to die at home and that this is the preference of patients and their carers.<sup>17</sup> There is also wide-spread agreement that a high value health care system needs to be built around a primary care focus with the primary medical responsibility being borne by the GP, supplemented by specialist teams on the basis of complexity of need.<sup>18</sup> It is imperative therefore that GPs and the primary care teams that support them are well equipped to provide care to people as they approach the end of their life.

Developing, refining and rolling out an Australian primary palliative care framework would help fulfil a number of the government's health reform objectives and is considered by AGPN and PCA to be a high priority task.

A project will be developed through a collaboration between AGPN, PCA and an academic team headed by Professor Geoff Mitchell and Associate Professor Claire Johnson. The main components of the proposed approach will be

- Establishment of a steering committee comprised of experts in the delivery palliative care services in primary care settings drawn from general practice, allied health and specialist community based palliative care services, and academics with expertise in major elements that may be required for the framework.
- Roll out of a pilot program and framework refinement which will involve the trialling of the primary palliative care framework in up to 12 Medicare Locals who can demonstrate a significant interest and capacity to undertake a pilot program.
- System-wide adoption of the Australian Primary Palliative Care Framework, involving a system-wide roll out of a final framework among those Medicare Locals that are 'system ready' to adopt it.
- A comprehensive evaluation of system (i.e. primary care provider, specialist services etc) outcomes and patient/family outcomes needs to be built into the program from the inception of the system-wide roll out.

*PCA proposes that the Government allocate \$1.5m 2011-12 to 2013-14 to move from development*

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<sup>14</sup> Mitchell, GK et al. 2008, 'Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomized controlled trial'. *Palliative Medicine*, vol. 22, pp. 19.

<sup>15</sup> National EOL Framework Forum. *Health System Reform and Care at the End of Life: A Guidance Document*. Palliative Care Australia, 2010 pp. 35

<sup>16</sup> Rhee, JJO et al. 2008, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners'. *Journal of Palliative Medicine*, vol. 11, pp. 980-5.

<sup>17</sup> *ibid.*

<sup>18</sup> National EOL Framework Forum, p. 70

to an 'implementation ready' phase of the Australian Primary Palliative Care Framework to support general practitioners to provide appropriate and much needed end of life care to Australians.

#### **4. Increased funding for training places for medical practitioners who want to do further training in palliative medicine**

Advanced training in Palliative Medicine is available through the Royal Australasian College of Physicians, but there are great inequities between the States and Territories in funding of training positions.

Funding all state and territory-based training, on a similar model to the Victorian Palliative Medicine Training Program, would greatly enhance the future training of Palliative Medicine specialists.

*PCA proposes that the Government allocate \$6 million over 3 years from 2011-12 to 2013-14 to support enhancement and furtherance of palliative medicine education and training programs.*

#### **5. Support for aged care services to develop workforce skilled in end of life care**

The draft report of the Productivity Commission inquiry into Caring for Older Australians has found that 'Opportunities for skills development, career paths and increased scopes of practice are important aspects of aged care that can be improved to attract and retain quality direct care staff.'<sup>19</sup>

Residential aged care facilities are increasingly providers of palliative care. The majority of people admitted to residential aged care facilities die in those facilities, so it is important that the facilities have the capacity to provide quality care at the end of life.

The *Guidelines for a Palliative Approach in Residential Aged Care*<sup>20</sup> were launched in 2004 and distributed to every aged care home in Australia to help aged care team members to apply a palliative approach in residential aged care facilities. An Enhanced Version was issued in May 2006 after approval by the National Health and Medical Research Council (NHMRC).<sup>21</sup>

*GPs Supporting Palliative Care in Aged Care Homes* is a free resource kit produced by Palliative Care Australia. It is designed for use by organisations to facilitate discussion and education of GPs and decision-makers in aged care homes on the *Guidelines for a Palliative Approach in Residential Aged Care*.<sup>22</sup>

One of the challenges is to redress the health and aged care professional workforce shortage by making both aged care, and specifically palliative care within aged care, an attractive career path. PCA would recommend introducing a palliative care loading for the salaries of aged care staff with appropriate palliative care qualifications.

*PCA proposes that the Government add a palliative care loading to the Aged Care Funding Instrument (ACFI), and thus the salaries of aged care staff with appropriate palliative care qualifications, to reflect the additional training acquired by a facility's staff.*

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<sup>19</sup> Productivity Commission 2011, op. cit. p 368.

<sup>20</sup> Australian Palliative Residential Aged Care Project, *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines), Commonwealth of Australia, Canberra, 2004.

<sup>21</sup> Australian Palliative Residential Aged Care Project, *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines), Enhanced Version approved by National Health and Medical Research Council, Commonwealth of Australia, Canberra, May 2006.

<http://www.nhmrc.gov.au/publications/synopses/files/pc29.pdf> .

<sup>22</sup> See <http://www.palliativecare.org.au/Default.aspx?tabid=2016>

## **6. Funding for research into effective and appropriate means for management of S8 medications in low care residential aged care**

Partly because of 'ageing in place', an increasing number of people with palliative care needs live in low care residential facilities. These people can have difficulties in accessing and administering necessary pain relief medications because the facility in which they live does not have the policies and systems in place to safely administer Schedule 8 medications.

While our information is that the availability of S8 medications is not a problem for all low care aged care residents, Palliative Care Australia believes a research project is needed to audit the extent of the problem, the number of affected facilities and residents across the country, and to scope solutions. PCA notes the establishment of the Aged and Community Services Australia National Aged Care Medication Roadmap Project funded by Workforce Australia, which does include palliative care expertise in its reference group, and submits therefore that such a research project would be timely in terms of reinforcing the increasing importance of palliative care and the interface between aged care and specialist palliative care services. PCA would be pleased for this research to interact with the work of the Roadmap project.

PCA also notes that effectively redressing this issue of access to palliative care medicines in aged care may involve support for the development and deployment of an electronic medication management solution for aged care initially targeted to residential care, and encourages allocation of funds to support the development of appropriate e-medication management.

*PCA proposes that the Government allocate \$450,000 over 3 years from 2011-12 to 2013-14 to fund a research project into effective and appropriate means for management of S8 medications in low care residential aged care.*

## **7. Funding for national implementation of the National Advance Care Directives Framework initiative**

The provision of care that accords with people's preferences is often hindered by failure to discuss and implement advance care plans.

For many people, whether or not they are even aware of this option is dependent on their care location and care provider. In practice, advance care plans can be disregarded in acute care and other hospital settings, particularly if they are not in a legally binding format and the patient is transitioning from another care setting, or if advance care plans are not relayed, but also if the care plan does not accord with the service provider's care protocols. For the patient this can mean unwanted 'heroic' care interventions to extend life with little consideration of its quality. It also results in unnecessary and unwanted hospitalisations.

PCA supports the Productivity Commission's Draft Recommendation 12.9 that '[t]he Council of Australian Governments should identify and remove, as far as possible, onerous duplicate and inconsistent regulations, including in relation to ... advanced care plans.'<sup>23</sup>

*PCA proposes that the Government's initiative in commencing the development of a national framework through the COAG process be continued and further developed by an allocation of \$30 million over 3 years from 2011-12 to 2013-14 to implement a national program of action to increase awareness of and access to advance care planning, with a national communication strategy targeting consumers, health professionals and community organisations.*

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<sup>23</sup> Op cit, p 427

## **8. Funding for a national program of action to increase awareness of and access to advance care planning and palliative care for people with dementia**

*PCA supports the Budget submission from Alzheimer's Australia for Federal funding of \$3 million over 3 years from 2011-12 to 2013-14 to implement a national program of action to increase awareness of and access to advance care planning and palliative care for people with dementia.*

## **9. Support for a national 1800 Telephone Information and Support Service**

Over one hundred thousand Australians each year require information and education to inform their end of life decision making. This type of information typically includes information regarding medico-legal issues such as advance care planning, information regarding health services and medical treatments at end of life including palliative care, and information about or linkage to the services and supports that can provide care such as hospices, specialist services and community services.

Currently, Australians' access to this information is often limited to the knowledge of their individual health professional. Although much information is accessible from various websites, many Australians either do not have access to the internet, are not cyber literate, or are unable to judge the legitimacy of online health information.

For this reason, PCA proposes to develop a national free call 1800 telephone based information and support service to provide another layer of support to people with end of life needs.

The service would operate from Canberra, and would utilise PCA's existing 1800 freecall telephone number, advertised previously during PCA's national education campaigns. The service would be staffed by information officers who have been specifically trained to provide information, education and emotional support within a risk reduced environment. Information officers will field calls from across Australia with the aim of providing information and referral to relevant service providers.

PCA has undertaken some preliminary estimates of the costing of the 1800 number proposal, but would encourage comprehensive scoping by the Department of Health and Ageing with their benefit of access to figures for similar enterprises.

It is important to realise that such a service would be very different to the Care Link 1800 service operated by the Department of Health and Ageing for aged care inquiries.

Palliative care is required across all age groups and the end of life is a time of heightened emotions for patients and their loved ones, so the skills base and training must include the ability to deal effectively with great emotion surrounding impending death.

In addition, there is a need to impart more information about clinical care options and issues, and about advance care planning.

*PCA proposes that the Government allocate \$2.3 million over 3 years from 2011-12 to 2013-14 to support the development of a national free call 1800 telephone based information and support service to provide another layer of support to people with end of life needs.*

## **10. National Palliative Care Volunteering Strategy**

Currently in Australia the essential role of the volunteer in the palliative care team is acknowledged through such policies as the original Commonwealth-State *National Palliative Care Strategy*<sup>24</sup>, the

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<sup>24</sup> Commonwealth Department of Health and Ageing, 2000, *National Palliative Care Strategy*, p 23.

*Australian National Palliative Care Standards (Standards 12 and 13)<sup>25</sup>, and the PCA Health System Reform and Care at the End of Life Guidance Document<sup>26</sup>.*

The important role of volunteers is also recognised in the draft report of the Productivity Commission inquiry into Caring for Older Australians.<sup>27</sup>

Volunteers are vital core members of the interdisciplinary palliative care team yet very little palliative care volunteer workforce development has been undertaken in Australia. Volunteers across the country do not work to a common set of palliative care volunteer standards, education and training and little data collection is available to measure this workforce.

Palliative Care Australia and its member organisations investigated the establishment of a national network of Managers of Volunteers in recognition of the crucial role volunteers play within the palliative care team. A planning meeting for the proposed network was held in February 2010 in Canberra. The meeting funded by the Department of Health and Ageing, was attended by twenty representatives of Managers of Volunteers from around Australia, with representation from every state and territory. This meeting identified the need for a national palliative care volunteer workforce strategy.

The key components of a national palliative care volunteer strategy include, but should not be limited to:

- development and implementation of a National Managers of Volunteers Network;
- national volunteer service data collection to assist with building an evidence base;
- The development of National Palliative Care 'Volunteer' Standards and their incorporation into the National Standards for Palliative Care and the palliative care National Standards Assessment Program;
- development and implementation of a nationally consistent competency based education and training framework for palliative care volunteers.

2011 has significance as the 10<sup>th</sup> Anniversary of the International Year of the Volunteer. Accordingly, this Budget provides a wonderful opportunity to begin this work.

*PCA proposes that the Government allocate \$400,000 over 3 years from 2011-12 to 2013-14 to support the development of a National Palliative Care Volunteering Strategy.*

## **Conclusion**

This Budget gives the Commonwealth the opportunity to commence implementing important aspects of the health reform agenda in areas that will gain community support to enhance the provision of integrated care for people who are dying of terminal conditions.

Implementing these measures at minimal net cost would greatly enhance the quality and the efficiency of the health system.

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<sup>25</sup> Palliative Care Australia, *Standards for Providing Quality Palliative Care for all Australians*, PCA, Canberra, 2005, pp 25, 33,39-40.

<sup>26</sup> Palliative Care Australia, 2010, op. cit., p 15.

<sup>27</sup> Productivity Commission 2011, op. cit., pp 376-379.