

**DEVELOPING A NEW REALITY FOR QUALITY
CARE AT THE END OF LIFE:
A MEANS TO A BETTER END
PRIORITIES FOR THE 2009-10 BUDGET**



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DEVELOPING A NEW REALITY FOR QUALITY CARE AT THE END OF LIFE: A MEANS TO A BETTER END

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.¹

When someone is diagnosed with a terminal condition, the current reality they confront – apart from the personal, psychological, social and financial re-adjustments – includes having to come to grips with a health and care system which is disjointed, and does not always embrace them. They need to acquire information and then make decisions about gaining access to hospitals, hospices, residential care and home-based care.

These Australians have, on average, at least 6 other people in their lives as family members, carers and communities – all endeavouring to live with the terminal condition as best they can.

Palliative Care Australia estimates that at least 1 million Australians each year will be directly affected through either having a terminal condition or being part of family, friends, or a wider community of support for a person with a terminal condition. Each person's journey will be different and unique – but each share one common challenge: limited time. Limited time to be on waiting lists for services, to complete paperwork, to adjust their financial arrangements.

Individuals and families living with terminal conditions deserve to have their need for quality care at the end of their lives met in a timely manner.

Meeting the needs of all patients demands a vision of quality care and the will to confront the barriers to its implementation. Poor integration of services and alignment of resources across the health care system present a major hurdle on the road to quality palliative services. Realignment and better investment to enable better integration offer significant opportunities for improved services.

In this submission, Palliative Care Australia presents a number of pressing challenges that require national leadership. We outline a pathway for a better future for dying in Australia which will have an enormous beneficial social impact for all Australians through better integration of services.

We commend our recommendations and would be pleased to work with government to help develop and implement them.



Donna Daniell
Chief Executive Officer
Palliative Care Australia
24 December 2008

¹ The following definitions of end of life, end of life care and palliative care are used throughout this submission. Source: Palliative Care Australia (PCA), *Palliative and End of Life Care – Glossary of Terms*, PCA, Canberra, 2008.

End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.

End of life care: End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.

Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

1. EXECUTIVE SUMMARY

The current experience of end of life care in Australia is disparate and inconsistent and we cannot, in good faith, promise patients at the end of their life access to care that is customised to preferences and reliably delivers good pain and symptom control. Our health care system can do better.

The Government's health reform agenda offers the prospect of a means to a better end, if opportunities are seized.

In particular, Palliative Care Australia (PCA) welcomes the identification in the National Health and Hospitals Reform Commission's (NHRC) first report of "*care for and respect of the needs of people at the end of life*" as a key challenge confronting the health care system and embraces this as a first step toward planning for a health care system that can promise access to reliable, evidence-based, end of life care that accords with patients' preferences.

Good strategic planning around the management of the terminal phase of life promises better care for people at the end of life and helps alleviate the ongoing crisis around access and demand management, through a more effective and efficient use of services and the prevention of unwanted and unnecessary hospitalisation.

PCA works in collaboration with the Australian Government's Department of Health and Ageing (DoHA) to implement the National Palliative Care Strategy and to raise awareness of palliative care, improve the understanding and availability of services across Australia, and encourage discussion to support improved knowledge networks.

This strategy has been a vitally important component of the improvements that have occurred in end of life care over the last decade. However, it is time for the strategy to be reviewed as it no longer fully matches the challenges of:

- palliative and end of life care integration across the health system;
- defining the end of life population and their characteristic care needs; and
- meeting consumer needs, preferences and expectations.

Today people at their end of life need to transact with many service providers across our health and social care systems, with in many cases few links and enablers. This gives us the opportunity for new thinking, in recognition that improvement in quality care at the end of life requires a "whole of health system" approach. This highlights the imperative for robust and wide-ranging collaboration of many stakeholders.

PCA recognises that this coming Budget will only touch the edges of the major health reform processes.

There are, however, initiatives which could be introduced in this Budget at minimal cost which would improve the situation, and make a positive contribution to the reform process.

2. RECOMMENDATIONS

PCA advocates the following measures, at the Australian Government level, which will help develop a new reality for quality care at the end of life.

New measures

1. Waive the Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Schedule (PBS) safety net thresholds. This will enable immediate access to the concessional MBS and PBS copayments for people with terminal conditions and relieve the cost burden.

National Palliative Care Program

2. Develop a national communication strategy targeting consumers, health professionals and community organisations for the National Palliative Care Strategy, to ensure coordination and consistency of information about palliative and end of life care, and advance care planning.
3. Provide funds to enable the development of interdisciplinary education and training programs for specialist palliative care and generalist primary care providers in palliative and end of life care, and that end of life care be acknowledged as a basic core competency for primary health care workers and included in the core curricula of health worker education and as an element of ongoing training.
4. Provide funding to enable the establishment of a national alliance of organisations with an interest in the chronic, ageing, and disability areas with regard to quality care at the end of life issues.
5. Provide funding to support the development of a national, philanthropic and fundraising foundation to support education awareness and research, and reduce the call on the public purse.

National Healthcare Agreements

6. Provide resourcing and funding for the development and setting of performance measures for referral pathways for accessing specialist palliative care services as part of the National Healthcare Agreements.

The health reform agenda

7. Provide resourcing and funding to enable health services to develop and implement workforce and service development plans that acknowledge the end of life care responsibilities of primary care providers as part of needs-based service provision.

3. NEW MEASURES

The means to a better end ... through financial support for families

The diagnosis of a terminal condition is a very distressing experience for a person, their family, carers and communities. As an event, it opens up extraordinary emotional and financial challenges that cannot be compared to other life events.

Although experiences will vary considerably depending on the nature and prognosis of the condition, the main focus for patients and their families is making decisions about accessing quality, affordable health care, as they adjust their lives to enable the best quality of life possible.

It is not always easy for consumers to be heard, let alone heeded, in the jungle of ill-coordinated services.

Availability of palliative care is varied. Some disease prognoses require patients to access specialist palliative care physicians for the control of symptoms. Other patients can receive quality generalist palliative care from their general practitioner and community nurse. Availability of appropriate palliative care is not universal – this aspect needs to be addressed within the context of the National Healthcare Agreements.

Australia has a death-denying society. Combined with the ‘medicalisation’ of dying this has led to poor community capacity to live well with dying. Individuals have lost the skill and capacity to understand death, dying, loss and grief, and how to play an active role in care and choice.³

The duration of time between a patient being diagnosed in the terminal phase of an condition and death is on average only around four months. Palliative care may be provided for many months or even years before the patient reaches the final, intensive terminal phase. Financial support for health care costs at this time would benefit the patient and family in the immediate situation and after the death of the patient.

In Australia, approximately 130,000 people die each year.⁴ While the Australian Bureau of Statistics doesn’t code cause of death data according to ‘expected’ and ‘unexpected’ deaths, PCA conservatively estimates that at least 100,000 deaths could be categorised as ‘expected’ and thus requiring access to better planning and coordination to realise their quality care at the end of life.⁵

Yet we have cause to question whether we are meeting the needs of this population in an equitable, quality and sustainable way. One problem is the lack of comprehensive data on how the people within this population group transact and utilise the existing health and care systems and how well needs were met. A mechanism to collect and analyse this data is imperative for ongoing service planning.

The current reality of end of life care in Australia is one of inequity and inconsistency. While some patients experience quality needs-based care, the reality for others is one of fragmented care that fails to acknowledge their care preferences and, too often, delivers insufficient support to meet social, emotional and physical needs at the end of life.

While the current pool of evidence and experience does not enable a reliable prediction of the time of a person’s death, it does enable anticipation of a range of likely scenarios. Knowing what may happen

³ For further discussion of limitations in Australian’s understandings of Palliative Care see: The National Palliative Care Program. (2006) *Community Attitudes Towards Palliative Care: Summary Report*. Canberra, Commonwealth of Australia.

⁴ There were 133,700 deaths registered in Australia in 2006. Australian Bureau of Statistics, *Deaths: Australia 2006*. www.abs.gov.au/AUSSTATS [Accessed 30 April 2008.]

⁵ This estimate is based on a basic analysis of ABS cause of death data for 2006 and subtraction of all assumed deaths that were accidental, resulted from suicide or could potentially be from acute condition. This figure is expected to be an under-estimation.

informs the planning for how best to respond.

The challenge to deliver quality care at the end of life for all can be expected to be further confounded by increasing service demand. At an epidemiological level, not only is the size of the population requiring end of life care increasing (both in absolute terms and as a proportion of the population), but the duration of life lived with high care needs and the number of patients requiring complex care is increasing.

It is significant that a recent international poll by the British Medical Journal has found that “palliative care for all would make the greatest difference to health care.”⁶

Recommendation 1

Waive the Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Schedule (PBS) safety net thresholds. This will enable immediate access to the concessional MBS and PBS copayments for people with terminal conditions and relieve the cost burden.

Waiving the requirement for patients to reach the Medicare Benefits Scheme and Pharmaceutical Benefits Schedule safety net thresholds will make a difference when incomes are reduced and care costs are increased.

In 2006, PCA prepared a comprehensive costing of this proposal which demonstrated that it would have a net annual cost of some \$30 million. We believe that changes to thresholds since then may have reduced this net total cost. We would be pleased to meet with Government officers to help develop a costed proposal.

⁶ <http://makingadifference.bmj.com/>

4. NATIONAL PALLIATIVE CARE PROGRAM

\$62.8 million was allocated for the period 2006-10 under the National Palliative Care Program to improve the standard of palliative care in the community through investing in developing capacity and resources for integration. This sub program expires in 2010.

\$13.2 million has been allocated in this same period for the Australian Government to support national initiatives.

\$34 million has been allocated for the period 2005-11 to help health-related services provide better support to people needing palliative care, and their families.

While the National Palliative Care Program has been important in enhancing the provision of palliative care services, there has been too little integration and coordination within the program itself. Projects have been funded with little concern for how they interact with other aspects of the program, or of the health system, or indeed of their long-term sustainability.

As all components of the National Palliative Care Program are coming to a close in the near future, it is vital that the funding of quality end of life care be made sustainable.

The means to a better end ... through a coordinated communications strategy

Ensuring a more integrated, less ad hoc, communications strategy for the different programs and projects that come under the National Palliative Care Strategy will help ensure that the Australian community gets a clearer picture of the issues that confront us in death and dying, and of the services available.

Recommendation 2

Develop a national communication strategy targeting consumers, health professionals and community organisations for the National Palliative Care Strategy, to ensure coordination and consistency of information about palliative and end of life care, and advance care planning.

The means to a better end ... through funding education in palliative and end of life care skills to grow the palliative and end of life care workforce

Recommendation 3

Provide funds to enable the development of interdisciplinary education and training programs for specialist palliative care and generalist primary care providers in palliative and end of life care, and that end of life care be acknowledged as a basic core competency for primary health care workers and included in the core curricula of health worker education and as an element of ongoing training.

The means to a better end ... through broadening of funding partnerships

PCA is championing the establishment of an *Alliance for Quality Care at the End of Life*. This alliance will bring together the knowledge and expertise of major national stakeholders to address a range of issues, including:

- chronic conditions
- aged care
- disability
- the appropriate role of hospitals, hospices, residential aged care and community based services
- access to appropriate medicines and the development of national guidelines

- access to services and health professionals
- promotion of advance care planning.

PCA serves as the secretariat for this interim alliance. On behalf of 21 national organisations, PCA coordinated the preparation of a joint submission to the NHHRC on end of life care issues.

Recommendation 4

Provide funding to enable the establishment of a national alliance of organisations with an interest in the chronic, ageing, and disability areas with regard to quality care at the end of life issues.

Fundraising for palliative and end of life care internationally

When considering international precedents for fundraising in palliative care, in comparable economies and health sectors, it is evident that the opportunity for fundraising in Australia is considerably larger than currently realised. For example, in the United Kingdom (UK)⁷, palliative care service provision continues to occur predominantly through the charity sector and the funding base supports an extraordinary infrastructure and operational network that extends from the UK and now works to deliver programs in developing nations, such as Africa.

It is reported that the salaries of 3 out of 5 health professionals employed in palliative care in the UK are funded through fundraising.⁸ Similar arrangements exist in Canada and the USA.

Fundraising for palliative care in Australia

In Australia, domestic precedents further suggest that there is room for stronger fundraising for palliative care. As an example, The Cancer Council NSW⁹ raises \$61.4M each year, for the purposes of cancer prevention strategies. 90% of these funds are raised from the Australian community.

Philanthropy Australia, the national peak body for philanthropy, advises that \$11B¹⁰ is raised each year across the sector, with \$7.7B from the Australian community and the balance from the corporate sector. This organisation advises that Australia has yet to fully realise a culture of giving equal to those experienced by other nations.

Experience in philanthropy for palliative care in Australia

The Australian Palliative Care Fund was established in 1999 by a team of enterprising people who recognised the passion for palliative care and set out to match this passion with its fundraising potential. The Fund operated in Queensland.

The founders recognised the achievements in palliative care that could be realised through the involvement of corporate skills and relationships. The founders became involved in palliative care through participation as volunteers and were able to apply their corporate skills and relationships to the task. More recently the relationship with a high profile Olympian has made an important contribution to the Fund's performance.

The solid success of the Australian Palliative Care Fund in attracting funds manager partners, securing ambassadors and in securing sponsorship has illustrated the potential, validated by the accumulated funds

⁷ In the United Kingdom, the Help The Hospices organisation fundraising activities yielded 6.2M pounds in 2006/2007 predominantly through donations.

⁸ Advice through the experiences of Dr Peter Martin, Chair, The Palliative Care Foundation

⁹ The Cancer Council NSW, Annual Report 2006- 2007.

¹⁰ The Giving Australia Report. November 2005. Philanthropy Australia www.philanthropy.org.au

of \$300,000.

Despite these achievements, the Apcf Board recognised the barriers and constraints on further growth that include the need to:

- operate nationally
- link well with the national peak body in palliative care
- link the operations of the fund with all levels of palliative care fundraising potential
- coordinate professional community based donation programs
- realise funding opportunities available from corporate bequests and sponsorships
- partner with state and national governments.

Formal collaboration with the recognised national peak body, PCA, was identified as important to sustainable growth and this was achieved through the agreement by the respective Boards of the Australian Palliative Care Fund and PCA to establish a national fundraising foundation to be known as the Palliative Care Foundation.

International precedent suggests that through philanthropic donations, particularly bequests, communities can make a significant contribution to supporting education and research to improve palliative care. Australia now has the opportunity to invest in the growth of a philanthropic fund for these purposes by investing in The Palliative Care Foundation (established 1 November 2007).

The Foundation is pleased to have retained the involvement of the founders of the Apcf in its endeavours.

Recommendation 5

Provide funding for a national, philanthropic and fundraising foundation to support education awareness and research, and reduce the call on the public purse.

Support for this development proposal would enable the exploration of the potential for palliative care fundraising.

5. NATIONAL HEALTHCARE AGREEMENTS

The new National Healthcare Agreements have the potential to impact on the provision of quality care at the end of life. It is important that this impact be positive rather than negative.

Having only one Health Special Purpose Payment (SPP) means there will be no longer be specifically quarantined SPP funding for palliative and end of life care.

Our challenge is to ensure funding is allocated to deliver quality care at the end of life.

This policy change provides the palliative and end of life care sector with a significant opportunity to ensure its services are properly recognised as an integral, and appropriately resourced, part of the whole of health system.

It provides the Government with a significant opportunity to hit the ground running with its health reform agenda by ensuring that palliative and end of life care services are recognised and funded as an integral part of the whole of health system.

The means to a better end ... to support the development and setting of performance measures for referral pathways for accessing specialist palliative care services

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people.

The implementation of needs-based end of life care should be informed by *standardised referral criteria* that outline the requirements for upward and downward referral relevant to aged care, primary health care and specialist palliative care.

Recommendation 6

Provide resourcing and funding for the development and setting of performance measures for referral pathways for accessing specialist palliative care services as part of the National Healthcare Agreements.

6. THE HEALTH REFORM AGENDA

The capacity of the current health system to provide access to quality care at the end of life for all Australians who may require it is questionable.¹¹ As the Australian population continues to age and an increasing number of Australians live out the final stages of their life with chronic, complex conditions, both the total population, and the proportion of the Australian population requiring end of life care annually, is expected to increase. This underlines the necessity of developing an approach to end of life care that prioritises quality care and promotes broad access through the efficient use of resources.

In 2005, PCA endorsed a population needs-based approach to end of life care service development which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources.¹² PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and involves the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*¹³ define the standard of care that all Australians should be able to expect in different care settings. For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups whose care needs can be categorised as:

- complex, or
- intermediate, or
- appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible.

At the centre of the needs-based approach to care provision is an acknowledgement of heterogeneous care needs at the end of life and a recognition that the end of life needs of many patients are appropriately met by primary care providers (generalist, and other specialist and support care), with specialist palliative care providers contributing direct, indirect care or consultation advice as required.¹⁴

The Government's health reform agenda offers the prospect of a means to a better end, if opportunities are seized to better integrate palliative and end of life care with all other parts of the health and aged care sectors.

In particular, PCA welcomes the identification in the National Health and Hospitals Reform Commission's (NHHRC) first report of "*care for and respect of the needs of people at the end of life*" as a key challenge confronting the health care system and

¹¹ Palliative Care Australia, *End of life care is everyone's affair - tackling the challenge of end of life: PCA submission to the National Health and Hospitals Reform Commission*, PCA, Canberra, 2008.

¹² Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

¹³ Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, PCA, Canberra, 2005.

¹⁴ Palliative Care Australia, *Palliative and End of Life Care - Glossary of Terms*, PCA, Canberra, 2008.

embraces this as a first step toward planning for a health care system that can promise access to reliable, evidence-based, end of life care that accords with patients' preferences.

Recommendation 7

Provide resourcing and funding to enable health services to develop and implement workforce and service development plans that acknowledge the end of life care responsibilities of primary care providers as part of needs-based service provision.