

QUALITY CARE AT THE END OF LIFE: CREATING THE NEW REALITY

PRIORITIES FOR THE 2008-09 BUDGET



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Confronting the new reality of death: Creating a new reality for quality care at the end of life

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 for all.

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 illness as best they can.

PCA estimates that terminal illness affects at least 1 million Australians each year. Each person's story 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 to match their unplanned lives.

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 healthcare system present a major hurdle on the road to quality palliative services. Realignment and 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.

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Palliative Care Australia
18 January 2008

TABLE OF CONTENTS

FOREWORD FROM THE CHIEF EXECUTIVE OFFICER.....	1
1 EXECUTIVE SUMMARY	3
1.1 THE CURRENT REALITY OF CARE AT THE END OF LIFE.....	3
1.2 ACHIEVING A NEW REALITY FOR QUALITY CARE AT THE END OF LIFE.....	3
1.3 RECOMMENDATIONS	4
2 CREATING THE NEW REALITY FOR SERVICE DELIVERY	5
2.1 THE REALITY OF SERVICE DELIVERY.....	5
2.2 A NEW REALITY FOR SERVICE DELIVERY	5
2.3 PRIORITIES TO ACHIEVE CHANGE.....	5
3 CREATING THE NEW REALITY: INTEGRATION OF AGED CARE SERVICES.....	6
3.1 THE REALITY OF AGED CARE	6
3.2 TOWARD INTEGRATION OF AGED CARE SERVICES.....	6
3.3 PRIORITIES TO ACHIEVE CHANGE.....	6
4 CREATING THE NEW REALITY FOR PRIMARY CARE.....	7
4.1 THE PRIMARY CARE REALITY.....	7
4.2 A NEW REALITY FOR PRIMARY CARE	7
4.3 PRIORITIES TO ACHIEVE CHANGE.....	7
5 CREATING THE NEW REALITY FOR CONSUMERS AND COMMUNITY	8
5.1 THE REALITY FOR CONSUMERS	8
5.2 A NEW REALITY FOR CONSUMERS	8
5.3 PRIORITIES TO ACHIEVE CHANGE.....	9

1 EXECUTIVE SUMMARY

1.1 THE CURRENT REALITY OF CARE AT THE END OF LIFE

Healthcare and other care services do not always perform well for people who are dying. People with terminal conditions all too often face:

- crippling financial burdens as a consequence of the terminal condition;
- no right to access superannuation despite diagnosis of a terminal condition;
- an inability to access appropriate care, compounded by:
 - no real choice in care locations – with funding, systems, medicines access, equipment access, respite services and availability of health professionals, all presenting barriers to quality home-based care;
 - an absence of an integrated health system that is resourced to provide seamless services for the dying, across community, hospital, aged care facilities, respite and specialist palliative care services;
 - shortage of appropriately trained doctors, nurses, and other health professionals, enabled with the right incentives and service provision models to really deliver quality care – regardless of whether they are in metropolitan, rural or remote Australia;
- lack of coordinated community networks that bring increased resilience and work to reduce the impact of loss, grief and bereavement;
- inflexible workplaces that fail to accommodate living with, caring for, or working with someone with a terminal condition.

1.2 ACHIEVING A NEW REALITY FOR QUALITY CARE AT THE END OF LIFE

Changing this unfortunate reality does not need to be either complex or horrendously expensive.

As Armstrong, Gillespie, Leeder, Rubin and Russell observed in the lead up to the 2007 federal election,

The next Australian Government will confront major challenges in the funding and delivery of health care. Australia's health care system...[is] now under threat as our health system is stretched by an ageing population, the growing burden of chronic illness, and the increasingly outmoded organisation of our health services.¹

There are, however, initiatives in place or on the table which improve the situation, albeit in a piecemeal fashion. There are opportunities to develop more equitable access to services through integration across the health system and to lead improvement by realigning administrative overheads associated with the multiple layers of services. As the above-mentioned authors argue in an open letter to the new Government, we “need a strategy, so that ...reforms and policies are not just isolated initiatives, but form a coherent plan that will ensure that current problems are addressed and health benefits maximised.”²

At minimal fiscal cost, this Government has the opportunity to achieve a new reality by adopting policies and developing programs which will enhance the integration of services for quality care at the end of life, within the broader health and social service spectrum.

¹ Armstrong BK, Gillespie JA, Leeder SR, Rubin GL and Russell LM. (2007) ‘Challenges in health and health care for Australia.’ *Medical Journal of Australia*, 187 (9): 485-489.

² Russell L, Leeder SR, Armstrong BK, Gillespie JA and Rubin GL. (2007) ‘The first 100 days: an open letter to the new Minister for Health.’ *Medical Journal of Australia* 187 (11/12): 608-609.

1.3 RECOMMENDATIONS

Palliative Care Australia (PCA) advocates the following measures, at the Australian Government level, which will help create a new reality of quality care at the end of life.

HEALTH CARE SERVICE DELIVERY

- 1) Enable additional medicines, currently available for hospital inpatients, to become available for prescription under the palliative care section of the Pharmaceutical Benefits Schedule (PBS) for palliative care in the home. This will mean that more people with terminal conditions will have the choice to receive quality care at the end of life, and at far less cost than in acute care hospitals.*
- 2) Require private health insurers to provide meaningful choice options for Australians living with a terminal illness to improve choice and reduce impact on the public health system.*
- 3) Ensure that the 2008-2013 Australian Health Care Agreements rank palliative care as a priority area for adequate funding, and commit to training, resourcing, data collection, and research in accordance with the needs-based service provision model.*

AGED CARE INTEGRATION

- 4) Improve funding for Aged Care Assessment Teams to provide timely access to specialist palliative care services, especially pain and symptom management, in a manner accordant with a needs based palliative care assessment model.*
- 5) Remove system and procedural barriers to ensure rational transition between care settings including the individual's home, hospices, residential aged care facilities, and acute care hospitals.*

PRIMARY CARE

- 6) Develop and introduce new Medicare Benefits Scheme (MBS) item number/s to enable multidisciplinary primary care team coordination to deliver palliative care in the home and in residential care, in accordance with a needs-based service provision model.*

CONSUMERS AND COMMUNITY

- 7) 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.*
- 8) Promote the harmonisation of State and Territory laws governing the use of Advance Directives and develop a national communication strategy to promote greater access to advance care planning and the uptake of Advance Directives by Australians.*
- 9) Develop a national communication strategy for the National Palliative Care Strategy to ensure coordination and consistency of information to the consumer, health professionals and community organisations.*
- 10) Provide seed funding to support the establishment of a national, independent fundraising foundation to enable philanthropy to support education, awareness and research and reduce the call on the public purse.*

2 CREATING THE NEW REALITY FOR SERVICE DELIVERY

2.1 THE REALITY OF SERVICE DELIVERY

Many – perhaps most – terminally ill people die in hospital, when in most cases they neither need nor desire acute care beds. Because these people have limited alternatives of home based care which includes essential pain relief and care, they spend their last days or months in hospital, unnecessarily occupying these highly expensive acute care beds.

2.2 A NEW REALITY FOR SERVICE DELIVERY

The new Rudd Labor Government has the opportunity to create a new reality for service delivery in which a new paradigm of health and care options for people with complex, chronic, and terminal conditions meets these needs in socially inclusive, seamless, and more cost effective ways.³

Enabling people with terminal conditions to access non-hospital-based quality care at the end of their lives would be both cost-effective, and in line with the needs and wishes of most people with terminal conditions.

An integrated approach to improving health services will include enhanced access to collaborative health professional services for palliative care through the Medicare Benefits Schedule, enhanced access to palliative medicines through the Pharmaceutical Benefits Schedule, and an expansion of palliative care services which are both hospice and community-based, and specialist and generalist.

The National Palliative Care Strategy has made a good start to recognising the integral role of quality care at the end of life in a civilised, caring society.⁴ This strategy was endorsed by Commonwealth and State/Territory Ministers in 2000, and needs reviewing – an issue we will be taking up with appropriate Ministers.

2.3 PRIORITIES TO ACHIEVE CHANGE

- 1) *Enable additional medicines, currently available for hospital inpatients, to become available for prescription under the palliative care section of the Pharmaceutical Benefits Scheme (PBS) for palliative care in the home. This will mean that more people with terminal conditions will have the choice to receive quality care at the end of life, and at far less cost than in acute care hospitals.*
- 2) *Require private health insurers to provide meaningful choice options for Australians living with a terminal illness to improve choice and reduce impact on the public health system.*
- 3) *Ensure that the 2008-2013 Australian Health Care Agreements rank palliative care as a priority area for adequate funding, and commit to training, resourcing, data collection, and research in accordance with the needs-based service provision model.⁵*

³ For further discussion of a cost-effective model for providing equitable access to palliative care services see: Palliative Care Australia,(2005) A Guide to Palliative Care Service Development: A population-based approach. Canberra, Palliative Care Australia.

⁴ Commonwealth Department of Health and Ageing. (2000) National Palliative Care Strategy: A national framework for palliative care service development. Canberra, Commonwealth Department of Health and Ageing.

⁵ For a comprehensive consideration of a needs-based approach to palliative care see Palliative Care Australia,(2005) A Guide to Palliative Care Service Development: A population-based approach. Canberra, Palliative Care Australia.

3 CREATING THE NEW REALITY: INTEGRATION OF AGED CARE SERVICES

3.1 THE REALITY OF AGED CARE

Older people have much greater and more complex health problems than younger people, which can often involve acute, chronic, and terminal conditions. Increasingly, those in aged care are older and frailer, with complex conditions and co-morbidity.

Australia's health and care services have evolved to deal with this, but in the main without coordination or integration between and among types of services (for example, what sorts of health professionals or other care providers are involved in the care), the environment in which the care is provided (including acute-care hospital, other institutional including hospice and residential aged care, and community-based), or who is responsible for paying for the services (including the individual, their health insurance fund, their State or Territory Government, or the Commonwealth).

Despite efforts in recent years, there is still far from a seamless path to service provision for older people needing care, including those with terminal conditions.

Aged care teams are faced with the challenge of meeting the complex and diverse care needs of their patients. Even more than the rest of the health sector, there is an acute shortage of health professionals in the aged care workforce, and poor integration among services.

3.2 TOWARD INTEGRATION OF AGED CARE SERVICES

Older people need fair and equitable access to the full range of health services for optimal independence and wellbeing to be achieved. Progress toward a continuum of care for older people requires policies and strategies across the acute, community and residential aged care settings.

Health and aged care services need to be integrally linked to achieve a system of services where access is determined by the needs of people, rather than the particular point of contact or service setting, taking into account culture, geography and means.

Palliative care services – both specialist and generalist – need to be an integral part of this process if we are to provide quality care for all at the end of life, and avoid the unnecessary situation of the acute care hospital being the default service provider.

Aged Care Assessment Teams assess the care needs of older people. They should be better equipped to recognise palliative care needs and to refer people to specialist palliative care services. The evidence-based, 'Guidelines for a Palliative Approach in Residential Aged Care' provides guidance for the delivery of quality palliative care in the 3,000 residential aged care facilities across Australia.⁶

3.3 PRIORITIES TO ACHIEVE CHANGE

- 4) *Improve funding for Aged Care Assessment Teams to provide timely access to specialist palliative care services, especially pain and symptom management, in a manner accordant with a needs based palliative care assessment model.*
- 5) *Remove system and procedural barriers to ensure rational transition between care settings including the individual's home, hospices, residential aged care facilities, and acute care hospitals.*

⁶ National Palliative Care Program. (2006) Guidelines for a Palliative Approach in Residential Aged Care. Commonwealth of Australia.

4 CREATING THE NEW REALITY FOR PRIMARY CARE

4.1 THE PRIMARY CARE REALITY

While a majority of terminally ill people die in hospital, evidence attests that between fifty and seventy percent of these patients would prefer to die in their own home.⁷

While for many patients the care they require can be provided in the comfort of familiar surroundings, home care is frequently not a viable, sustainable option.⁸ Often this is because patients and their carers cannot access the level of support they need from home care services.

Without access to appropriate services, patients and carers frequently experience difficulties in controlling symptoms and in providing the required level of care, necessitating increased hospitalisation and lengthier hospital stays. For patients and their loved ones this can significantly diminish quality of life. For the hospital system this means unnecessary extra burden.

While access to home based palliative care services across Australia is varied, it is a common scenario for services to be under-resourced and over-stretched and for patients to be faced with lengthy waiting periods.

Limitations in listings of home based care items on the Medicare Benefits Scheme significantly compound the inaccessibility of required services and are a financial barrier to services delivering the care appropriate care.

4.2 A NEW REALITY FOR PRIMARY CARE

Living and dying in the home, widely acknowledged as a desirable alternative to inpatient care for many patients, is an achievable reality.

Dying in the home offers the opportunity of the best possible quality of life to patients. Bolstering home-based palliative care services also promises a more efficient use of health care resources. Evidence supports home based palliative care as a more cost effective alternative than hospital based palliative care.⁹

The needs of most palliative care patients can be met through the primary health care system via home-based palliative care services. In caring for the patient, carers are supported by a multi-disciplinary palliative care team, accessed on a needs basis. This may include the services, for example, of a medical specialist, general practitioner, nurse, social worker, bereavement support worker and dietician.

Enhanced access to multi-disciplinary, home-based care teams for those who are dying can be achieved through the introduction of MBS items to support the required service provision.

4.3 PRIORITIES TO ACHIEVE CHANGE

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| <p>6) <i>Develop and introduce new Medicare Benefits Scheme (MBS) item number/s to enable multidisciplinary primary care team coordination to deliver palliative care in the home and in residential care, in accordance with a needs-based service provision model.</i></p> |
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⁷ Grande GE, Addington-Hall JM and Todd CJ. (1998) 'Place of death and access to home care services' *Social Science Medicine*, 47 (5); 565-579.

⁸ Palliative Care Australia,(2005) A Guide to Palliative Care Service Development: A population-based approach. Canberra, Palliative Care Australia.

⁹ Chochinov HM and Kirstjanson LK. (1998) Dying to pay: the cost of end of life care. Winnipeg, University of Manitoba.

5 CREATING THE NEW REALITY FOR CONSUMERS AND COMMUNITY

5.1 THE REALITY FOR CONSUMERS

The diagnosis of a terminal illness 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 illness, 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 Australian Health Care 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.¹⁰

5.2 A NEW REALITY FOR CONSUMERS

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.

Advance directives allow people to set out their wishes for the future, so they can stop worrying and live well. They help reduce family conflict at a time of great trauma and stress. As with ethical considerations, the law should adequately and appropriately protect the interests of people with terminal conditions at all levels of health care policy and services.

Through thinking and talking about death and dying as a community the attitudes, knowledge and understanding with which people experience dying begin to change. Rather than being ill-prepared to confront dying, people can encounter life limiting illness with the resources in place to make informed decisions. The community will be better equipped to support one another through experiences of death and loss.

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.

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.)

¹⁰ 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.

5.3 PRIORITIES TO ACHIEVE CHANGE

- 7) *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.*
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