



**Palliative
Care
Australia**

Dying Well

Submission to the Productivity Commission

on the Inquiry into

Caring for Older Australians

on behalf of

Palliative Care Australia

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Palliative Care Australia (PCA) is the peak national body representing the palliative care sector, and those stakeholders who share a commitment to quality care at the end of life.

PCA welcomes this inquiry as an important opportunity to consider issues currently impacting on the vital interrelationship between palliative care and the aged care system, and on improving access to optimal end of life care for all elderly Australians.

Introduction

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.

For older people, death commonly occurs whilst receiving aged care, both residential and community, unless the patients are transferred to acute care facilities. However, there are barriers, including inadequate pain relief and symptom management, in aged care – both residential and community - preventing people being able to receive quality, seamless end of life care for their complex health needs, in the setting of their choice.

Background

With the increasing ability over the last century to identify, treat and cure disease, there has been a growing focus on curative medicine, with a concurrent societal expectation of restoration of full health. Prior to the middle part of last century, death and dying were integral parts of primary health care. Palliative care services emerged over the last thirty years to fill the gap created when cure was privileged to the extent that dying was ignored.¹

The World Health Organisation's definition of palliative care is used worldwide

¹ Lewis, MJ, *Medicine and care of the dying: A modern history*, Oxford University Press, New York, 2007.

including in Australia:²

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Towards a coordinated, whole of health, integrated system of care

As our population is ageing, the incidence of those living with chronic conditions is also increasing.³

The National Health and Hospitals Reform Commission (NHHRC) found that “the needs of people living with chronic diseases, people with multiple complex health and

² World Health Organisation (WHO), <http://www.who.int/cancer/palliative/definition/en/>

³ National Health Priority Action Council, *National Chronic Diseases Strategy*, Australian Government Department of Health and Ageing, Canberra, 2006.

social problems, and older, increasingly frail people are less well met.”⁴

The National Health and Medical Research Council (NHMRC) has initiated work into ethical issues involved when

the final phase of life is approaching, but death is not yet imminent. Typically, this time of transition involves a change in treatment and management of a chronic condition to palliative and other forms of treatment and care in what will be the final phase of life.⁵

Recognising, and providing treatment and care appropriate to this transition period, is vital to the ability of aged care services to adequately care for their clients who have terminal conditions, whether resulting from chronic or acute disease, or simply the level of frailty common to ageing.

PCA believes that 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 provision of quality end of life care for all is most efficiently and effectively achieved in accordance with a needs-based service delivery model that acknowledges that patients have different needs that may change over time.

An expansion of aged care services for older people with chronic conditions will need to be complemented by an expansion of the capacity and competence of primary health care services to provide generalist palliative care for people living in the community and in aged care homes, supported by increased collaboration and networking with expanded specialist palliative care services.

This need was also recognised by the National Health and Hospitals Reform Commission which recommended the expansion of the capacity of primary care to deliver palliative care services, and additional investment in specialist care services to

⁴ 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.

⁵ National Health and Medical Research Council (NHMRC). *Ethical issues involved in transitions to palliation and end of life care for people with chronic conditions: A discussion paper for patients, carers, and health professionals*.
http://www.nhmrc.gov.au/guidelines/consult/consultations/ethical_issues_palliation.htm

support people living at home or in residential care.⁶

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 resources⁷. 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*⁸ 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.

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.

In 2010, PCA auspiced the development of *Health System Reform and Care at the End of Life: A Guidance Document*⁹ which will help drive policy and interdisciplinary recognition of the need for effective, integrated palliative care.

⁶ Commonwealth of Australia, *A Healthier Future For all Australians*, 2009, *op cit*.

⁷ Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

⁸ Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, PCA, Canberra, 2005.

⁹ Palliative Care Australia, *Health System Reform and Care at the End of Life: A Guidance Document*, PCA, Canberra, 2010.

The Government's recent work to develop a new *National Palliative Care Strategy*¹⁰ also puts the spotlight on quality palliative care as the responsibility of the whole of health, including the aged care system.

As the Government has recognised in the 2010 Council of Australian Governments (COAG) agreements¹¹ and the National Health and Hospitals Network initiative¹², effective care in all settings, including for older people, needs to be accompanied by increased investment in a range of related sub-acute services, including palliative care. From 1 July 2010 the Government is investing \$1.6 billion over four years to fund the capital and recurrent costs of 1,316 sub-acute beds (including palliative care in a range of settings) to improve the transition between the acute hospital settings and the community.

This is a potentially important means of ensuring that aged care can play an active role in providing integrated and seamless care services to older people with sub-acute care needs. Ensuring that end of life needs are adequately included in this money, in all settings, including residential and community aged care will be a challenge in its allocation.

The vital links between palliative care and aged care

The significance of our ageing population to aged care, and to the demand on such services for end of life care, is substantial and will increase with the expected increases in the proportion of the population aged over 65 years. In 1999, 12% of our population was over 65 years of age and 2% was over 80 years. It is predicted that by 2016, 16% will be over 65 years and 4% will be over 80 years, increasing by 2041 to 25% over 65 years and 8.3% over 80 years.¹³ For dementia alone the "epidemic" affecting an estimated 162,000 people in 2002 is expected to affect over half a million Australians by 2040.¹⁴

¹⁰ Communio for the Department of Health and Ageing, *Supporting Australians to Live Well at the End of Life: Draft National Palliative Care Strategy*, 2010.
http://npcsu.comuniogroup.com/images/stories/NPCS_2010_Draft_v1.0.pdf

¹¹ Council of Australian Governments, *National Health and Hospitals Network Agreement*, April 2010.

¹² Commonwealth of Australia, *A National Health and Hospitals Network for Australia's Future – Delivering better health and better hospitals*, Australian Government, Canberra, 2010.

¹³ J Abbey, 'The reality for aged and community care and end of life'. Presentation to *A Matter of Life and Death: Confronting the new reality*, Canberra, March 2008.

¹⁴ Ibid.

Our ageing population will place ever increasing demands on residential and community aged care services. The challenge is to respond to these demands in ways which provide a quality service, in a sustainable way.

Fundamental to this evolution should be a commitment to a more human rights-based approach in which older people – including those with eventually fatal conditions – are recognised as full citizens with full rights and a continuing valuable contribution to society, and that the aged care system's is to facilitate their continuing quality of life until death.

The final report of the National Health and Hospitals Reform Commission recognised the need for, and made a number of recommendations to improve, palliative care services in residential and community aged care settings¹⁵.

Recommendation

1. *Palliative Care Australia recommends that the Productivity Commission support implementation of the National Health and Hospitals Reform Commission recommendations to improve palliative care services in residential and community aged care settings.*

PCA endorses the National Aged Care Alliance's 2009 Vision Statement *Leading the Way: Our Vision for Support and Care of Older Australians*. In particular, we look forward to the aged care system of the future where:

There will be a range of readily available support and care services linked seamlessly into the broader health system. These include easily accessible primary health care services; transition care after any acute health episode so no-one has a long term aged care assessment while acutely unwell; restorative and rehabilitative services to provide the greatest opportunity of getting back to full function after acute care; support and care services for people living with dementia; and palliative and end of life care.¹⁶

¹⁵ Commonwealth of Australia, *A Healthier Future For all Australians*, 2009, *op cit*.

¹⁶ National Aged Care Alliance, *Leading the Way: Our Vision for Support and Care of Older Australians*, 2009, page 5. www.naca.asn.au

Residential care: towards the notion of “care homes”

Government analysis of residential aged care data shows that during 2006-07, some 202,500 people received permanent residential care, at some time during the year.¹⁷ At 30 June 2007:

- 157,607 people were receiving residential care (either permanent or respite) in 2,873 aged care homes operated by 1,202 approved providers, equivalent to an occupancy rate 8.1% of people aged 70 years or over on that night
- 31.5% residents were in low care
- 68.5% residents were in high care
- the residents were predominantly female: 71.2% compared to 28.8% males
- the average age of the residents was 83.8 years.
- Of 45,148 first time admissions in 2006-07:
 - 14,854 entered high care from hospital (33%)
 - 7,700 entered high care from the community (17.1%)
 - 6,721 entered low care from hospital (14.9%)
 - 13,402 entered low care from the community (29.7%)
 - 2,372 transferred from another aged care home (5.3%).

The average total length of stay for permanent residents is 35.1 months, with 36 per cent of people staying less than 1 year, and 19 per cent staying more than 5 years. Access to, and the quality of, palliative care is diverse and inconsistent in residential aged care. Some aged care facilities enjoy ready access to primary care physicians well skilled in palliative care and to specialist palliative care physicians. Some facilities, particularly high care facilities, have systems in place to limit hospitalisations by providing care in-place.¹⁸

The *Guidelines for a Palliative Approach in Residential Aged Care*¹⁹ were launched in

¹⁷ Department of Health and Ageing, Report on the Operation of the Aged Care Act 1997, 1 July 2006 to 30 June 2007, Commonwealth of Australia, 2007; unpublished Departmental data. Sourced from *Ageing and Aged Care in Australia*, <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-aged-care-australia.htm~ageing-publicat-aged-care-australia-pt5#18>

¹⁸ Ibid.

¹⁹ Australian Palliative Residential Aged Care Project, *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines), Commonwealth of Australia, Canberra, 2004.

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).²⁰

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*.²¹

Supporting aged care facilities to work towards providing quality end of life care will require the facilities to be additionally resourced to provide appropriate palliation, pain and symptom relief. This should include appropriate access to general practitioners, to palliative care specialists under agreed and consistent referral and access criteria, and to nurses who can administer opioids. It should also include access to PBS-subsidised palliative medicines for residents of aged care facilities, and the structuring and resourcing of specialist palliative care services to enable them to provide care, and to consistently support primary health care providers in the residential aged care setting. Action needs to be taken to ensure adequate access to allied health to ensure multidisciplinary care is a reality. Policies for ensuring appropriate spiritual and religious care also need to be available for all residents.

Palliative Care Australia is well positioned to work with the aged care sector to set and achieve appropriate standards of care through the National Standards Assessment Program.²²

The aged care model that PCA would like to see emerging is one where the artificial divide between “high” and “low” care is discontinued and replaced with an emphasis on the notion of a “care home” where funding and care is allocated on a needs-based model.

²⁰ 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, retrieved 15 September 2008, <http://www.nhmrc.gov.au/publications/synopses/files/pc29.pdf> .

²¹ See <http://www.palliativecare.org.au/Default.aspx?tabid=2016>

²² See <http://www.palliativecare.org.au/Default.aspx?tabid=1895>

Recommendations

2. *Palliative Care Australia recommends that the Productivity Commission endorse the establishment of a program to support facilities to assess their ability to meet end of life care standards of care and identify system level improvement options.*
3. *Palliative Care Australia recommends that the Productivity Commission support the abolition of the artificial divide between “high” and “low” care and its replacement with an emphasis on the notion of a “care home” where funding and care is allocated on a needs-based model.*

The PCA Position Statement *Residential Aged Care and End of Life*²³ makes a number of recommendations which are adapted below for the purposes of this inquiry.

Recommendations

4. *Palliative Care Australia recommends that the Productivity Commission endorse end of life care as a basic competency for aged care workers (regardless of the setting in which they work) and inclusion of this competency in the core curricula of aged care worker education and ongoing training.*
5. *Palliative Care Australia recommends that the Productivity Commission support aged care services developing and implementing workforce and service development plans that acknowledge their end of life care responsibilities as part of needs-based service provision, recognising that this will require increased levels of staffing with practitioners who can prescribe, access, and administer pain and symptom management drugs.*
6. *Palliative Care Australia recommends that the Productivity Commission endorse the need for safe systems for coordinating the management of pain and symptom relief for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents’ care needs are met in a timely and ongoing manner.*
7. *Palliative Care Australia recommends that the Productivity Commission endorse the integration of the National Palliative Care Standards with the Aged Care Accreditation Standards.*

Costs

Increasingly aged care, both residential and community, cares for people with

²³ Palliative Care Australia. *Residential Aged Care and End of Life*. PCA Position Statement 2008, available at <http://www.palliativecare.org.au/Default.aspx?tabid=1942>

complex, chronic conditions. A major handicap is that there is no clear idea of the real costs of providing this care.

Recommendation

8. *Palliative Care Australia recommends that the Productivity Commission undertake an initial independent review of the cost of aged care and support (including the cost of caring for people needing palliative care) to ensure that current care prices are based on contemporary care practices and standards, having regard to benchmarks of care.*

Aged Care Funding Instrument

The Aged Care Funding Instrument (ACFI) is used by the Government to determine the level of care payments for residential aged care. Some real weaknesses persist with the ACFI system's inadequate framework for assessing residents' needs for palliative care. PCA understands that there is a mistaken belief in the application of the ACFI that palliative care within residential aged care facilities lasts only for a matter of days, or at most, a few weeks. Consistent with the WHO definition that palliative care "...is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life..."²⁴, this is not so. It is also not just about pain and symptom relief, important though they are.

The transition to a palliative care pathway needs to be seen as, in many cases, a gradual one, involving seamless care, which with good management, can occur over many months.

These weaknesses in both the funding model (and underlying perceptions) need to be resolved if the aged care system is to adequately deal with our rapidly ageing population. For example, the disaggregation of families leading to the normalisation of residential aged care usage is stretching workforce capacity to safely and effectively manage in what is rapidly becoming a sub-acute treatment service. Unless residents are transferred to acute care facilities - which should only be necessary for acute care reasons - it is entirely appropriate, and necessary for aged care to manage their care needs.

Accordingly, it is both a short-term and a long-term strategic planning need for resourcing to support aged care facilities to work towards providing quality care for

²⁴ World Health Organisation (WHO), <http://www.who.int/cancer/palliative/definition/en/>

people with an eventually fatal condition, including appropriate palliation, pain and symptom relief, as well as spiritual support, and bereavement counselling and support, both for the dying resident and their family and loved ones, and also for other residents and staff.

Currently, some real weaknesses persist with the ACFI system not being relevant to what is actually occurring around resident needs for palliative care.

Despite increasing trends for hospitals to discharge terminally ill patients to aged care if they are aged over 55 years, ACFI does not adequately cover the frequency and skill intensity of care and treatment needed for palliation to be effective. The current ACFI subsidy is around one third of the amount that specialist palliative care services receive in state and territory jurisdictions. An additional ACFI supplement is therefore needed if residential aged care is to adequately and effectively provide quality palliative care services.

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 subsidy, and thus the salaries of aged care staff with appropriate palliative care qualifications.

These weaknesses need to be resolved in readiness for a rapidly ageing population which will place greater demands on aged care services.

Recommendations

9. *Palliative Care Australia recommends that the Productivity Commission proposes that the Aged Care Funding Instrument (ACFI) support the provision of palliative care within aged care services by increasing the ACFI subsidy for palliative care to ensure greater equivalence with payments to specialist palliative care services in state and territory jurisdictions.*
10. *Palliative Care Australia recommends that the Productivity Commission proposes a palliative care loading be added to 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.*

Community care

Access to community care for people with eventually fatal conditions is both limited and inconsistent. Inequities and inconsistencies are aggravated by limited access to appropriately trained and resourced health workers. This can lead to unnecessary hospitalisations when carers are overwhelmed by care requirements, or patients are unable to access appropriate pain and symptom relief from community providers.

Quality care at the end of life requires a multidisciplinary approach that draws together a range of service providers to meet the patients' and families' physical, social and emotional needs. In many situations community care is fragmented across providers and provider settings, leading to a lack of continuity of care and impeding the ability to provide high quality, interdisciplinary care.

End of life care is, and should be regarded as, part of the normal scope of practice of all primary health care professionals. To achieve this, end of life care must be acknowledged as a basic core competency for primary health care workers and aged care staff, and included in the core curricula of health and aged care worker education and as an element of ongoing training.²⁵

The role of primary care providers includes assessment, triage, clinical management, referral to specialist palliative care providers where appropriate, and care coordination using a palliative approach for patients with end of life care needs.²⁶ Primary care providers thus require, as a core skill, the capacity to perform this role effectively.

In recent years the end of life care educational requirements of primary care providers have been increasingly acknowledged, most notably by the Palliative Care Curriculum for Undergraduates (PCC4U) Project, and projects designed to promote competency in end of life care among currently practising primary care workers in the aged care sector. The reach of these projects to date has been, understandably, limited. Notably, however, the PCC4U Project represents both a recognition of the necessity of undergraduate education in end of life care for all primary health care professionals, as

²⁵ Palliative Care Australia. *Primary Health Care and End of Life*. PCA Position Statement 2008, available at <http://www.palliativecare.org.au/Default.aspx?tabid=1942>

²⁶ Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

well as a significant step towards achieving this goal.

Staff employed by Home and Community Care (HACC) programs need to be considered as part of this mix.

Limitations imposed through the Medicare Benefits Schedule (MBS) and as a result of disparity between the access to medicines in hospital compared to the community under the Pharmaceutical Benefits Schedule (PBS) need to be addressed.

Draft *Guidelines for a Palliative Approach for Aged Care in the Community Setting* are currently being considered by the NHMRC. The implementation of these *Guidelines* upon approval will considerably enhance community based care.

A health service delivery model that increases in-home support, integrating primary care, residential aged care, and community-based care with specialist palliative care services, promises to better meet patients' care needs and preferences, and to save unnecessary demand for, and expenditure on, hospital beds. PCA strongly supports the reform direction of building the capacity and competence of primary health care services to provide generalist support for their dying patients.

Underpinning this is the requirement to ensure that primary care services offer a team-based range of services including general practice, allied health and nursing supports, with referral pathways to and from specialist services, to ensure that they can provide well coordinated multidisciplinary care to meet the needs of people at the end of life.

Advance care planning

Quality end of life care is realised when it meets the person's needs and upholds their care preferences. All Australians should be supported to consider, and provided the opportunity to specify, the type of care they would like to receive at the end of life. Continual reassessment of current circumstances and likely future scenarios are part of this consideration.²⁷

Advance care planning is an important social investment to help ensure quality care at

²⁷ Palliative Care Australia. *Advance Care Planning*. PCA Position Statement 2008, available at <http://www.palliativecare.org.au/Default.aspx?tabid=1942>.

the end of life that accords with the individual's needs and preferences. Advance care planning should be consumer driven and controlled, providing a reliable and flexible mechanism to anticipate and express care choices, in partnership with and supported by the health system. Broader application and coordination of advance care planning provides a mechanism to plan and thus better meet patients' needs, while limiting unnecessary hospitalisations.

Health and aged care workers across all levels of the health and aged care systems should be skilled and educated to engage in end of life care discussions and advance care planning with patients and their families, significant others and carers. The role of substitute (or proxy) decision makers for when people have lost decision-making capacity needs to be considered, and promoted.

Recommendation

11. *Palliative Care Australia recommends that the Productivity Commission support the enhancement of advance care planning and substitute (or proxy) decision making within aged care settings.*

Conclusion

The end of life care needs of ageing Australians are not being well met under the current arrangements for both community and residential aged care. There are numerous opportunities for improvement through training, revision of funding instruments and enhancement of integration of service provision. The ideal of quality end of life care for all is an achievable outcome for all ageing Australians.