

Palliative Care Australia

**Submission to the Senate Standing Committees
on Community Affairs – Inquiry into
Out-of-Pocket Costs in Australian healthcare**

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Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life. Our mission is to influence, foster and promote the delivery of quality care at the end of life through ongoing policy and advocacy, education, and developing collaborative relationships in Australia and internationally.

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

But we remain a very long way from achieving our goals. In 2011, nearly 147,000 Australians died. Of these 70% would have benefitted from access to palliative care services, yet only 30-50% did.

The National Palliative Care Strategy endorsed by the Australian Government in 2010 signalled the combined commitments of the Commonwealth, State and Territory Governments to the development and implementation of palliative care policies, strategies and services that are driven by standards and consistent across Australia. This sent a clear message that in order for Australians to live well at the end of life, its implementation is necessary if Australia is to continue to be a world leader in the provision of first class palliative care services.

PCA would like to thank the Senate Standing Committees on Community Affairs for the opportunity to make a submission to the inquiry into out-of-pocket costs in Australian healthcare. There are a number of key issues for palliative care regarding out-of-pocket costs relating to the terms of reference for the inquiry, including current and future trends on out-of-pocket expenditure; the implications for the ongoing sustainability of the health systems; key areas of expenditure; and the role of private health insurance.

Out-of-pocket costs and co-payments

An important point to make at the out-set in relation to out-of-pocket costs and co-payments, is that for people needing palliative care the first point of access is likely to be through primary care, such as a General Practitioner (GP), or the acute hospital system. These people will be experiencing a chronic or life-threatening illness or condition, and access to palliative care would improve their quality of life and prevent and relieve suffering. We already know that many people who would benefit from palliative care don't access it, and costs in accessing health services is a major barrier to addressing the symptoms of an illness or condition. Out-of-pocket costs are already an issue in accessing palliative care and related needs, such as medications, equipment, respite and carer support, and the introduction of additional costs could act as a further disincentive and barrier.

Before considering the need to introduce co-payments and additional costs to access health services, there should be a genuine discussion about savings that create benefits for people's health. As will be demonstrated below, there are costs associated with dying and these can be addressed through the savings offered by

palliative care, and by encouraging the health care system to see palliative care as an integral part of service delivery.

The Cost of Dying

International studies have found that the healthcare costs of people who are dying are extremely high, particularly in the last year of life, and there is growing evidence that inpatient and in-home hospice palliative care service can reduce these costs¹. These studies have examined the ageing population and changes in social and demographic structures, which raise issues around the future of healthcare and how it is funded, including the significant amount of healthcare resources used at the end of life²³.

The *Global Atlas of Palliative Care at the End of Life*⁴, produced by the Worldwide Palliative Care Alliance (WPCA), of which PCA is a member, included in its analysis of global palliative care need, a literature summary of hospice program cost-effectiveness. Sixteen articles from North America were reviewed, and the overall findings were that both hospital-based programs and in-home hospice and palliative care services significantly reduced the cost of care and provided equal if not better care. Cost savings were due to reductions in the use of medical services, hospital costs, laboratory and intensive care unit costs, and decreases in hospital and nursing home admissions, emergency department visits, and the use of outpatient consultation services. The findings of these international studies are considered to be transferrable to the Australian setting.

The vast majority of Australians currently die in a hospital setting, and this is unlikely to change. As PCA highlighted in the submission to the National Commission of Audit⁵, it is possible to reduce costs and improve care by facilitating a change for acute inpatients from a high intervention pathway to a palliative care management plan, even if care needs to continue in the acute facility. Fostering such a pathway requires systemic support and the inclusion of palliative care education throughout the careers of all health professionals.

The Australian Commission for Safety and Quality in Health Care have developed a national consensus statement on end of life care in the acute setting. This may encourage broader health system support and an approach that more closely aligns service provision with consumer expectations, and improves quality through adherence to standards and accreditation.

¹ Palliative Care Australia, Submission to the National Commission of Audit, January 2014

² Shugarman I, Decker S & Bercovitz A, Demographics and social characteristics and spending at the end of life, *Journal of Pain and Symptom Management*, 2009; 38(1):15-26.

³ Fassbender K, Fainsinger RL, Carson M, Finegan B, Cost trajectories at the end of life: the Canadian experience, *Journal of Pain and Symptom Management*, 2009;38(1):75-80

⁴ Worldwide Palliative Care Alliance, *Global Atlas of Palliative Care at the End of Life*, 2014

⁵ Palliative Care Australia, Submission to the National Commission of Audit, January 2014

The role of private health insurance

In the submission to the National Commission of Audit⁶, PCA addressed issues around palliative care's inclusion in private health insurance. The incidence of Australians receiving palliative care in their home would be likely to increase if Private Health Insurers (PHIs) funded this service. The general lack of willingness of private health insurers to fund more cost-effective palliative care, reduces the overall efficiency of the health system and inhibits equity of access. This is an area where national leadership by the Australian Government, in demonstrating the business case and negotiating greater participation by private health funds in the funding of palliative care, could be very helpful and productive. A minimal number of palliative care programs across the country have reached arrangements with PHIs to fund community based palliative care, but this is a rarity rather than the norm. Cabrini Health is recognised as one of the first to negotiate such an arrangement and in a paper for the Australian Centre for Health Research commented:

Privately insured patients have an expectation their private insurance will cover them through all aspects of their illness journey and not cease when curative treatment is no longer appropriate. The impact of this is these private patients are unable to access palliative care and therefore are receiving more expensive, and at times, aggressive treatment in the final stages of life in a private acute hospital which may not be the best place of care on many fronts. Considering the wish of most people to die at home, as opposed to a hospital bed which could be an intensive care bed, the issue of failing to invest in home based and inpatient palliative care services seems indefensible.⁷

The report from the inquiry of the Senate Community Affairs References Committee, Palliative Care in Australia⁸ provides a Committee comment calling on the private health sector and PHIs to contemplate their role in meeting the demand for palliative care. The Committee considered that there should be further research into the potential role for PHI in providing palliative care, and suggested the federal government initiate a review. PCA has stated gaining greater participation by the private health funds required national leadership by the Australian Government, and would call for this leadership to be shown and a review undertaken.

The Palliative Care Council South Australia, a PCA member organisation, highlighted the situation in South Australia (SA) where privately insured patients, who want to be discharged home for ongoing palliation of their illness, are unable to access publicly funded care, support and equipment to aid care at home. This decision appears to be made on the basis that patients with private health insurance can afford to pay for these services themselves. As noted, private health insurers in Australia do not fund

⁶ Palliative Care Australia, Submission to the National Commission of Audit, January 2014

⁷ Sullivan, N, Walker, H, and Brooker, J, A Framework for the Delivery of Comprehensive Palliative Care Services in the Australian Private Sector, Australian Centre for Health Research, November, 2013

⁸ The Senate Community Affairs References Committee Palliative Care in Australia, October 2012, Commonwealth of Australia

any benefits for palliative care at home and people in SA pay for private health insurance, a universal Medicare levy, and are then required to pay for the services or equipment required. This raises the issue of people who pay the Medicare levy being unable to access to public services and equipment.

Key areas of expenditure including pharmaceuticals, primary care visits, medical devices or supplies

Out-of-pocket costs impact on many areas of health such as access to necessary pharmaceuticals or medical devices, including palliative medications.

In the Palliative Care Clinical Studies Collaborative (PaCCSC) 2006-2014 Research Report⁹, it notes that part of the background to the formation of this collaborative was a survey in 2000 of Australian and New Zealand Society of Palliative Care Medicine (ANZSPM) members to compile a list of medicines they considered essential to palliative care. A number of the medicines identified were available through the Pharmaceutical Benefits Scheme (PBS), but many others commonly used were not listed and were not affordable for patients outside hospitals.

A recent report looked at the economics of cancer in Australia and internationally, and sought stakeholder opinions on access to cancer medications. Concerns were raised around costs for patients accessing new and more expensive cancer medications, particularly at the end of life. One clinical stakeholder noted that hospital clinicians sometimes do not choose medicines if they are not PBS listed, even if they are the most appropriate treatment options for a particular patient. This decision is made to avoid the patient having significant out-of-pocket expenses following hospital discharge¹⁰.

PCA addressed barriers and disincentives for people accessing palliative care in the submission to the Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia¹¹. For people receiving palliative care in residential care, barriers and disincentives include a lack of appropriate funding for the delivery of palliative care, including appropriate aids and equipment. This is as the funding under the Aged Care Funding Instrument (ACFI) for palliative care is only about one third of the amount that specialist palliative care services receive per individual and is only provided for terminal care.

Community care barriers and disincentives included funding not including explicit provision for palliative care and an assumption that this is provided through the health system. There is a lack of clarity in the Home and Community Care (HACC) Program guidelines around the provision of and access to specialist palliative care services. Co-payments for people are also an issue with HACC. Additionally in some regions, people who receive palliative care are denied access to packaged care and

⁹ PaCCSC: Palliative Care Clinical Studies Collaborative, PaCCSC 2006-2014 Research Report

¹⁰ Deloitte Access Economics, Access to Cancer medicines in Australia, Medicines Australia Oncology Industry Taskforce, July 2013.

¹¹ Palliative Care Australia, Submission to the Australian Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia, April 2012

the reverse can occur with people who are receiving packaged care being denied access to palliative care services.

An example of out-of-pocket costs related to accessing palliative care through HACC has been raised with PCA by the Tasmanian Association for Hospice and Palliative Care, where even a small fee or an increase in a small fee can have an impact on people.

Currently in Tasmania, there is no fee charged to clients by the specialist palliative care service, whether clients receive a visit from the nurse, medical specialist, social worker or other health professional. Primary providers of care, such as a community health nurse, are required to charge a HACC fee of \$5.00 per visit with a maximum of \$10.00 for two or more visits a week for pensioners or healthcare card holders. Even small fees can be a burden for older people and pensioners. Self-funded retirees or people who are still in the workforce, pay a fee of \$20.00 per visit with a maximum of \$30.00 for two or more visits per week. This amounts to around \$120.00 per month, which is a considerable sum for someone who is ill and has no wage or income. There is a waiver system and many nurses try to gain a waiver for palliative care clients, but this requires means testing and a large amount of paperwork. Any increase in these fees would be likely to place increased pressure on public hospitals and emergency departments, and some people would forego having a nurse visit them due to the expense, leading to unmonitored health and well-being.

Shared barriers in the residential care and community setting included limited access to GPs, palliative care specialists, nurses and other health practitioners to ensure multidisciplinary care, and limited access to PBS subsidised palliative medicines. A further issue can be access to non-PBS listed drugs that are available in hospital, because the state governments fund them, but not in the community, creating a disincentive to return to the community.

An example regarding medications currently not listed on the PBS and leading to out-of-pocket costs for patients and their families, has been raised with PCA by Palliative Care Victoria.

It relates to medications commonly used in palliative care - Glycopyrrolate and Midazolam. Both these medications are not listed on the PBS, creating difficulties and out-of-pocket costs for individuals wanting to receive palliative care at home from a family member or carer. People are typically only able to access Glycopyrrolate through a hospital pharmacy, not a local or community pharmacy. If they live in a rural or regional area, this may mean travelling significant distances to collect it from a hospital pharmacy. Midazolam is a very commonly used drug in palliative care and supplied on outpatient prescriptions when someone wants to die at home. Many palliative care patients are on a concession or have reached their safety net threshold, but the cost of the Midazolam is not reduced or covered by either of these schemes. Both the medications are more suitable than others currently listed on the PBS, particularly for people receiving palliative care at home and their families or carer who have to administer the medications.

The Senate Standing Committee's report on the palliative care inquiry recommended support for the provision of additional equipment and aids for use in the community, which PCA strongly supports.

PCA had previously received funding for an Equipment Loans Scheme which supported the expansion of equipment and aids held and managed by services. PCA has sought further funding to enable further rounds under an Equipment Loans Scheme for the purchase of equipment and aids by member organisations. A scheme managed on a national scale, but utilising local member organisations to ensure local responsiveness, is a successful model to continue.

Conclusion

This submission has highlighted key issues for palliative care regarding out-of-pocket costs in Australian healthcare. It also points to the need to look at savings that create benefits for people's health, before considering introducing further costs to access health services, in particular the significant costs associated with dying that can be addressed through the savings offered by palliative care. International studies have found that the healthcare costs of people dying are extremely high and there is growing evidence that inpatient and in-home hospice palliative care service can reduce these costs. It is possible to reduce costs and improve care by facilitating a change from a high intervention pathway to a palliative care management plan.

In terms of costs, there should also be greater participation by private health funds in palliative care. The incidence of Australians receiving palliative care in their home would be likely to increase if PHIs funded this service.

Out-of-pocket costs impact on many areas of health such as access to necessary pharmaceuticals or medical devices, including palliative medications, aids and equipment. Commonly used medications will be unaffordable for patients, particularly out of hospital, if they are not listed on the PBS and clinicians may be reluctant to prescribe them if this is the case. This creates particular difficulties for people wanting to receive palliative care at home.

Many people who would benefit from palliative care don't access it, and with out-of-pocket costs already being an issue in accessing palliative care and related needs, such as medications, equipment, respite and carer support, the introduction of additional costs could act as a further disincentive and barrier.