Palliative Care Australia

Submission to the Senate Select Committee on Health

September 2014

Contact:
Rita Evans
Interim Chief Executive Officer
Palliative Care Australia
PO Box 24
Deakin West ACT 2600

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Introduction

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.

The World Health Organization (WHO) defines palliative care as: [1]

> …an approach that improves the quality of life of patients and their families facing the problems 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 nor 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.

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[1] World Health Organisation, *WHO definition of Palliative Care*, 2008. http://www.who.int/cancer/palliative/definition/en/, Accessed 20 August 2014

Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. When an illness cannot be cured, the focus of care changes to supporting and assisting patients to have the best quality of life possible while managing their symptoms. Palliative care maintains quality of life by addressing physical symptoms, such as pain, breathlessness or nausea, as well as helping with emotional, spiritual and social needs. The aim of palliative care is to achieve a “Partnership of care”, providing the best possible quality of life for the individual, their carer/s and family.

Key Issues for PCA

PCA would like to thank the Committee for the opportunity to make a submission to the inquiry into health policy, administration and expenditure. This submission addresses each of the specified terms of reference. With reference to these terms of reference, the key issues for PCA include:

- The impact of reduced Commonwealth funding through the ceasing of the National Partnership Agreements and the related impacts, including the future of Activity Based Funding (ABF) and ceasing of payments for subacute care capacity.
- The impact of additional costs on access to affordable healthcare and the sustainability of the health system related to creating further barriers to people accessing palliative care. Also the need to have a discussion about the savings that palliative care offers and making palliative care an integral part of the health system.
- The importance of early intervention in palliative care in terms of promoting the value of introducing palliative care early on in a diagnosis, and raising awareness about palliative care services for patients and their families. This includes PCA’s call for funding for a comprehensive palliative care communications strategy and a national telephone and information service.
- The significant overlap between aged care and health care in general, but particularly for palliative care with the ageing of the population and increasing demands for access to palliative care services. Also ensuring that the reforms in aged care do not negatively impact on people needing palliative care.
- Equity in access to palliative care services in Australia, in particular not being able to meet the needs of groups with diverse needs such as children, Aboriginal and Torres Strait Islander peoples, people with disability, culturally and linguistically diverse communities, older Australians and regional and remote residents. Also the potential impact on Aboriginal and rural communities through replacing Medicare Locals with a reduced number of Primary Health Networks (PHNs), particularly with regards to planning palliative care in communities outside major metropolitan centres.
- The issue of access to palliative care medicines in improving the integration and coordination of health and Medicare services for palliative care.
- PCA’s call for a workforce strategy for palliative care and workforce being a priority action area, noting that care of the dying must be a standard education provision for every health professional across their career. Also the recent palliative care resolution passed by the World Health Assembly, which recognised palliative care as

an integral component of health systems worldwide, and called on national governments to ensure they receive proper attention.

- The issue of advance care planning and calls for the Federal Government to work with states and territories to implement nationally consistent advance care planning legislation.

Each of these issues, and other points of interest for PCA, is discussed in detail below.

a. the impact of reduced Commonwealth funding for hospital and other health services provided by state and territory governments, in particular, the impact on elective surgery and emergency department waiting times, hospital bed numbers, other hospital related care and cost shifting;

It is vitally important that there is greater certainty about future funding arrangements to facilitate service and workforce planning, and to address the growing needs associated with population growth, population ageing and the increasing incidence of chronic conditions.

A particular issue for PCA related to Commonwealth funding is the ceasing of the National Partnership Agreements and the related impacts, including the future of ABF. Despite PCA's concerns that ABF is not entirely appropriate for the complex team based delivery of palliative care, palliative care and other sub-acute services are engaged in significant work with the Independent Hospital Pricing Authority (IHPA) to adopt a model of ABF. The merging of IHPA into the Health Productivity Agency, the cessation of the *National Partnership Agreement* and changes to funding for the Commonwealth Public Hospitals raises questions around future work towards developing ABF and the commitment to this by the Australian Government. IHPA have stated that they are continuing to work and move towards ABF for palliative care, and are in discussions with the state and territory governments about the actual implementation of ABF.

PCA recently made a submission to the Draft IHPA 2014-15 Work Plan[2] focusing on how to achieve improvements to current ABF arrangements to accommodate key elements of palliative care – such as support for family carers, multidisciplinary consultations, and bereavement support. It is important that ABF, or any other funding model, is tailored to ensure that funding supports appropriate models of service provision.

There have been no specific statements from the Federal Government about the future of ABF. At the 2014-15 Health Budget briefing on 13 May 2014 the Department of Health stated the Government had committed to ABF through the 2014-15 Federal Budget, however it was noted that the Federation White Paper would look at future funding arrangements for services between the Commonwealth, states and territories and include how health funds are distributed.

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[2] Palliative Care Australia, Submission to the Draft Independent Hospital Pricing Authority Work Program 2014-15, July 2014

The National Partnership for Improving Public Hospital Services included payments for subacute care, which includes palliative care, to provide additional capacity. As noted above, the demand for palliative care is not currently being met and the number of people who would benefit from palliative care is increasing. While PCA acknowledges that the Partnership Agreement funding has delivered additional beds and capacity for palliative care, the need for increased service provision will only continue to grow. The ceasing of the subacute funding through the Partnership Agreement will have a significant impact on the ability of hospital to meet the demand for palliative care services. Current and future Commonwealth governments will need to ensure their role in hospital funding achieves maximum benefits for the community, as the future health needs of Australia's population is a responsibility of all levels of government.

b. the impact of additional costs on access to affordable healthcare and the sustainability of Medicare;

PCA raised concerns about the impact of additional costs on access to affordable healthcare and the sustainability of the health system in the submission to the Senate Standing Committee on Community Affairs Inquiry into Out of Pocket Costs in Australian healthcare.[3] PCA made the point 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-limiting 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. The introduction of additional costs could act as a further disincentive and barrier to accessing required care.

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. 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. 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 services can reduce these costs.[4] 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 life.[5] [6]

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[3] Palliative Care Australia, Submission to the Senate Standing Committees on Community Affairs – Inquiry into out of pocket costs in Australian healthcare, May 2014

[4] Palliative Care Australia, Submission to the National Commission of Audit, January 2014

[5] Shugarman l, 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.

[6] 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

The *Global Atlas of Palliative Care at the End of Life*[7], 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 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 Audit[8], 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.

c. the impact of reduced Commonwealth funding for health promotion, prevention and early intervention;

Health promotion, prevention and early intervention are important for all areas of health, including palliative care. Reducing the importance of this in funding and government policy has flow on effects for a range of issues, in particular early diagnosis and treatment which has resultant impacts on quality of life.

PCA has worked with a number of disease and condition specific organisations to advocate for and promote the value of introducing palliative care early on in diagnosis, including for dementia, chronic and end-stage kidney disease, neurological conditions and paediatrics. Palliative care can improve quality of life, symptom control, end of life care, and patient, family and carer/s support. People with more rapidly progressing conditions, such as Motor Neuron Disease (MND), will benefit from early referral to palliative care services so they can express, and be engaged in discussions about, their future care wishes and preferences.

The National Service Framework for Long-term Conditions[9] developed by the Department of Health in the United Kingdom (UK) addresses the way health and social services support people with long term neurological conditions through quality requirements that cover diagnosis to end of life care. The quality requirement on palliative care states that:

> ‘People in the later stages of long term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief; and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.’

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[7] Worldwide Palliative Care Alliance, Global Atlas of Palliative Care at the End of Life, 2014

[8] Palliative Care Australia, Submission to the National Commission of Audit, January 2014

[9] Department of Health (2005), The National Service Framework for Long-term Conditions. Department of Health Publications: London

It notes, as recognised previously, that people with more rapidly progressing conditions will benefit from early referral to palliative care services, particularly for MND where people may lose their ability to speak, so that they can be engaged in discussions about their future care plans.[10]

Health promotion and awareness raising is a key issue that impacts on the capacity of the community to deal with issues of dying, death, grief and loss, as well as their access to palliative care. When people don't discuss or plan for the end of life, it is difficult to provide care for people according to their wishes, particularly in the event that they lose capacity to make their own decisions. Promoting the benefits of palliative care and having informed communities able to make decisions about their future healthcare is essential to improving the end of life experiences of people approaching death, and their loved ones.

In PCA's 2014-15 Pre-Budget Submission[11] a priority area for action was raising awareness about palliative care services so that people are aware of what palliative care services are available and how they can support families. PCA called for the following actions:

- Fund a comprehensive communications strategy to enable PCA to build on the success of National Palliative Care Week and lead a national discussion on care at the end of life and advance care planning.
- Fund a national 1800 telephone and information service to provide palliative care advice and support for patients, families and carers.

d. the interaction between elements of the health system, including between aged care and health care;

People who are dying have complex and multifaceted needs, requiring a broad range of health and community services to effectively meet these needs. This is especially the case for older people. Palliative care is therefore greatly impacted by the interaction of different elements of the health and community care systems.

Palliative care in Australia is provided by many different health practitioners in a variety of health settings including in the community. A key feature of palliative care is that it is provided by a multidisciplinary team, with a range of disciplines and professional groups contributing individually and as part of care teams. Those involved in palliative care may include:

- Specialist providers: Medical, nursing and allied health staff who have undertaken further study in palliative care or have significant experience in the area.
- Generalist providers: Those clinicians (medical, nursing and allied health) working in other areas of the health system who have a professional involvement with people requiring palliative care.

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[10] Department of Health (2005), The National Service Framework for Long-term Conditions. Department of Health Publications: London

[11] Palliative Care Australia, 2014-15 Pre-Budget Submission, January 2014

- Support services: Including those who assist with the processes of daily living, enhancing quality of life, and/or providing emotional and spiritual support.[12]

Palliative care teams offer a wide range of care from managing the physical symptoms in patients receiving treatment for cancer, to treating depression in patients with advanced disease, to the care of patients in their last days and hours. A significant part of the work involves helping patients with complex or severe physical, psychological, social, and spiritual problems. Most palliative care organisations offer grief counselling to the patient's loves ones. Specialist palliative care services provide care to those patients with a life limiting illness whose needs exceed the capacity and resources of primary health care providers.[13]

Most people living with a life limiting illness will have intermittent involvement with a specialist palliative care service. These services provide assistance as needed in association with primary health care providers. For a smaller number of patients with symptoms needing careful management, there may be the continuing involvement of a specialist team. Palliative care services offer inpatient care, home care, day care, and outpatient services, and work in close partnership with mainstream services. Hospices often house a full range of services and professionals for both paediatric and adult patients.[14]

There is no single national collection that provides information on where people die in Australia. However, data from the National Hospital Morbidity Database (NHMD) can be used to examine what proportion of all deaths occurred within admitted patient settings.[15]

Of the 143,500 or so deaths in Australia, the NHMD estimates that 52% of these died as an admitted patient in an Australian hospital. This proportion includes deaths that occurred in hospices that were affiliated with hospitals. However, data is not available in the NHMD on the number of deaths that occurred in a hospice rather than elsewhere in the hospital system.[16] [17]

For people who receive palliative care at home, services provided through the Home and Community Care Program (HACC) that assist with day-to-day living tasks along with necessary medical assistance are essential. Just as vital is the assistance and support provided to carers of people receiving palliative care in a range of settings. The HACC Program, along with the National Respite for Carers Program, the Day Therapy Centres Program and possibly the Assistance with Care and Housing for the Aged Program, will come under one program from 1 July 2015 in the Commonwealth Home Support Program. Assessment for services and access to information about services will be through the Aged Care Gateway and telephone line.

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

[13] Ibid

[14] Ibid

[15] Ibid

[16] Tabor, B et al. 2007, *Place of death of people with cancer in NSW*. Sydney. Cancer Institute NSW.

[17] Hunt, RW et al. 2001, ‘Where patients with cancer die in South Australia 1990–1999: a population based review’. *Medical Journal of Australia*, vol. 175.

The Report of the Senate Community Affairs References Committee Inquiry into Palliative Care in Australia recommended that the Australian Government closely monitor implementation of the changes to the HACC program to ensure that the program met the needs of those over 65, and that palliative care recipients who did not fall into the aged care bracket received adequate support.

PCA is providing input on the impacts of this transition for palliative care and continues to reinforce the importance of including and considering palliative care in the various reforms that are occurring in aged care. The focus of the single program is very much on reablement and providing basic supports, and this should also ensure access to the supports that people receiving palliative care require.

The Productivity Commission report of their inquiry into aged care *Caring for Older Australians* recognised palliative care provision in the recommendations. The Report stated that the palliative and end of life care needs of older Australians were not being adequately met, and that residential and community care providers needed to receive appropriate payments for delivering palliative and end of life care. The stated benefits of this change was the increased role for residential and community care providers in delivering such services, which would provide more appropriate care and be more cost-effective than delivering the services in hospital.[18]

There is a need to develop the capacity of the aged care workforce to provide palliative care, with variability to provide this care across the sector, and to monitor the admission process to a residential aged care facility for people with a life limiting illness where continued care in an acute setting is inappropriate. There is also a need to monitor aspects of the *Quality of Care Principles,* in particular the provision that enables residential aged care services to charge additional fees for palliative care.

e. improvements in the provision of health services, including Indigenous health and rural health;

Equity in access to palliative care services is an issue in Australia. Palliative care services are currently not able to meet the needs of everyone in our community, particularly groups with diverse needs such as children, Aboriginal and Torres Strait Islander peoples, people with a disability, culturally and linguistically diverse communities, lesbian, gay, bi-sexual, trans-gender and inter-sex (LGBTI) people, older Australians and regional and remote residents. Other emerging groups whose palliative care needs have not been met include prisoners and people who are homeless. PCA has previously called on government to consider expanding the Procedural GP program to include palliative care, particularly rural and remote communities, and for the National Disability Insurance Scheme to include palliative care.[19]

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[18] Productivity Commission, Summary of Proposals, Caring for Older Australians, Productivity Commission Inquiry Report, http://pc.gov.au/__data/assets/pdf_file/0019/111772/aged-care-summary-proposals.pdf, Accessed 19 August 2014

[19] Palliative Care Australia, 2014-15 Pre-Budget Submission, January 2014

The replacement of Medicare Locals with PHNs and the reduction in number from the current 61 Medicare Locals to around 24 PHNs has an impact on a number of sectors, including palliative care, particularly in the provision of services to Aboriginal and Torres Strait Islander and rural communities. Medicare Locals potentially had a role to play, particularly in the planning of palliative care in communities outside the major metropolitan centres.

Medicare Locals brought a local perspective to the planning and delivery of primary care services. In rural and remote locations, Medicare Locals may have been the best placed services to support improved planning and coordination of palliative care services and to work with local palliative care service providers to advocate for increased access to quality palliative care. This included access to planning and burden of disease data. PCA's submission to the Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia[20] proposed a collaboration between PCA and the National Medicare Local Network (NMLN) to implement the Australian Primary Palliative Care Framework, which would have supported GPs to provide appropriate and much needed end of life care. The ceasing of Medicare Locals and the NMLN places such a proposal in doubt.

While the reduction in numbers of PHNs reduces the reach of such services in rural and regional areas, PCA would hope that they continue to be used as a way of planning and gathering data on much needed palliative care services. PCA is keen to continue to work with government and the PHNs in the future to increase knowledge of palliative care and related issues.

Palliative care in rural communities

There is a need to improve equity of access to palliative care services in rural communities. High priorities include improving access to specialist palliative care consultancy service, improved access to respite, especially in-home respite; respite after-hours during periods of end of life care; and respite for parents caring for children with life limiting illness.

PCA has previously raised concerns about the Patient Assisted Travel Schemes (PATS) in the submission to the Senate Inquiry into Palliative Care[21], which are managed by state and territory governments in each jurisdiction, and represent a significant barrier to access to health care, including palliative care, in rural and remote Australia. PCA noted that concerns about the effectiveness of the PATS have been expressed by major health bodies including the Australian Medical Association and the National Rural Health Alliance. States and territories have had responsibility for PATS since 1987, however in that time each jurisdiction has developed policies and put in place a differing set of rates of remuneration and conditions for access. PCA supports a single national program with a realistic rate of remuneration for all, accessed through a central point.

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

[21] Ibid

Palliative care in Aboriginal and Torres Strait Island communities

The Report of the Senate Committee Inquiry into Palliative Care in Australia made specific recommendations in relation to palliative care and Aboriginal people. It endorsed recommendations of PCA that Commonwealth funded programs support:

- appropriate training and education about cultural perspectives relating to palliative and end of life care issues, in core curricula for all health workers and health practitioners providing services to Indigenous people; and
- inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV continuation of Program of Experience in the Palliative Approach (PEPA) to build on or develop culturally appropriate education for Indigenous health workers.[22]

The Senate Report also recommended that the Australian Government increase funding to palliative care programs for Indigenous communities in rural and remote areas, with a particular emphasis on return to country. This initiative would require support across the health and community sector to enable Aboriginal and Torres Strait Islander people to return to country. Any expansion should be undertaken collaboratively with local services that are aware of local needs, the Aboriginal Community Controlled sector, and programs such as the PEPA, which is working to develop additional culturally safe and appropriate services for Indigenous communities in rural and remote locations. PCA also supports additional research on the nature of grief and bereavement in Aboriginal communities to inform the development and delivery of appropriate services.

f. the better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners, pharmaceuticals, optometry, diagnostic, dental and allied health services;

The improved integration and coordination of health and Medicare services is beneficial for all areas of the health service system, including palliative care.

A key issue for palliative care is access to palliative care medicines, in particular for people who receive palliative care at home. Issues include limited access to Pharmaceutical Benefits Scheme (PBS) subsidised palliative medicines, and accessing non-PBS listed drugs that are available in hospital but not in the community. An example raised by PCA in the submission to the Senate Committee Inquiry into Out of pocket costs in Australian healthcare[23] concerned medications currently not listed on the PBS and leading to out-of-pocket costs for patients and their families.

The example related 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/s. People are typically only able to access Glycopyrrolate through a

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

[23] Palliative Care Australia, Submission to the Senate Standing Committees on Community Affairs – Inquiry into out of pocket costs in Australian healthcare, May 2014

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 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 medications are more suitable than others currently listed on the PBS, particularly for people receiving palliative care at home and for the families or carer who have to administer the medications.

What this example demonstrates is that a lack of coordination between different areas of the Medicare or health system that are in effect interrelated, can cause difficulties and barriers to people receiving the care they need to prevent avoidable suffering. There is also now a focus on person centred care in discussions about policy and programs for health, disability and aged care. Having a system which is not integrated means systems continue to operate in silos and does not enable people to receive the care they need as an individual.

g. health workforce planning; and

PCA has called for a workforce strategy for palliative care through a number of forums, including in the 2014-15 Pre-Budget Submission.[24] Workforce was a priority area for action in this submission, noting that care of the dying must be a standard education provision for every health professional across their career. Without supporting the specialist and generalist workforce to provide palliative care across all settings, the needs of the dying would continue to be unmet. PCA called for action to:

- Develop a Palliative Care Workforce Strategy, which embeds palliative care into the education and training of all health professionals across their careers.
- Fund the Palliative Care Foundation Scholarship Program to support health professionals to further their palliative care knowledge and education. This was also a recommendation of the Senate Inquiry into Palliative Care in Australia.

Over the past ten years or so, there has been an increase each year in the number of hospitalisations for palliative care. There was a 51% increase in the number of palliative care hospitalisations between 2000–01 and 2009–10. In 2009–10 there were close to 56,000 hospitalisations where palliative care was a substantial component of the care provided. Patients aged 75 years and over accounted for almost half (49%) of these hospitalisations, while those aged under 55 accounted for 12%. In contrast, the corresponding percentages for all hospitalisations in the same year were 21% and 46%.[25]

The number of palliative care hospitalisations has increased substantially and steadily between 2000–01 and 2009–10, from about 37,000 to 56, 000, and was more prominent in public hospitals (60%) than private hospitals (17%). There are a range of factors that have

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[24] Palliative Care Australia, 2014-15 Pre-Budget Submission, January 2014

[25] Australian Institute of Health and Welfare, Australia's Health 2012: The thirteenth biennial health report of the Australian Institute of Health and Welfare. Canberra: AIHW

influenced this increase over the time period, however there was a genuine increase in the number of admitted patient palliative care episodes which is not just due to population growth and an ageing population. For the same period, for people who died while an admitted patient, more than 1 in 3 (37%) had been a palliative care patient during the hospitalisation, representing a 60% increase since 2000–01 (from 23%).[26]

Australian hospital statistics for 2012-13, looking at subacute and no-acute admitted care, showed that although over 39,000 separations were recorded with a care type of palliative care, there were more than 61,000 separations identified as providing some form of palliative care regardless of the care type specified. This data again shows a steady increase in palliative care separations with an average increase from 2008-09 to 2012-13 of 8.2% per year.[27]

AIHW data also indicates that in recent years the number of palliative care medical specialists has reduced.[28] Given Australia's rapidly ageing population, a reduction in the number of palliative care specialists is cause for serious concern.

PCA notes the excellent workforce strategy developed by the Australia New Zealand Society of Palliative Medicine (ANZSPM)[29] which builds upon PCA's own policies regarding service provision. ANZSPM notes the lack of quality data on the number of people accessing palliative care in Australia and in the absence of data works on a benchmark of 1 FTE Palliative Medicine specialist per 100,000 population. Using this benchmark, ANZSPM estimates that the current workforce needs to double to meet the current palliative care needs of the Australian population. PCA has previously identified a slightly higher recommended level of 1.5 FTE per 100,000 population, accompanied by 0.75-1.0 FTE nurses (dependent upon setting of care) and up to 0.25 FTE allied health professional (depending on discipline and setting of care).

The recent palliative care resolution passed by the World Health Assembly (WHA) recognised palliative care as an integral component of health systems worldwide, and called on national governments to ensure they receive proper attention. It has impacts for workforce in Australia and provides opportunities for lobbying and promoting palliative care, in particular through the focus on education and training.

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[26] Australian Institute of Health and Welfare, Australia's Health 2012: The thirteenth biennial health report of the Australian Institute of Health and Welfare. Canberra: AIHW

[27] Australian Institute of Health and Welfare (2014), Australian hospital statistics 2012-13. Health services series no. 54. Canberra: AIHW

[28] AIHW, *Palliative care services in Australia*, Canberra 2012

[29] ANZSPM, Meeting the Palliative Medical Needs of Patients in Australia 2011-2015 and beyond, http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1310671368&sid, Accessed 20 August 2014

The overall emphasis is on including palliative care across the continuum of care and having adequate funding and human resources for palliative care initiatives.[30] The resolution specifically urges member states:

> …to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:
>
> (a) basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level, including health care workers, caregivers addressing patients' spiritual needs and social workers;
> (b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;
> (c) specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom management needs.[31]

It also includes assessing palliative care needs, including pain management medication requirements, and promoting collaborative action for the adequate supply of essential medicines in palliative care.

The challenges presented by the ageing population and pressures across the entire health workforce are well-discussed. Having a workforce that is knowledgeable, skilled and competent in palliative care is an important part of having palliative care recognised and incorporated as an essential component of the health care system, along with developing the abilities for current and future health professionals. The priorities identified by PCA in the 2014-15 pre-Budget submission[32] point to these barriers and opportunities, being to develop a Palliative Care Workforce Strategy, which embeds palliative care into the education and training of all health professionals across their careers, and funding the Palliative Care Foundation Scholarship Program to support health professionals to further their palliative care knowledge and education.

PCA strongly supports the inclusion of the Palliative Care Curriculum for Undergraduates (PCC4U) in all undergraduate health care professional training to assist in addressing the need for all new health professionals to graduate with a greater understanding of palliative care and the supportive partnership model of delivery of palliative care services.

All health professionals should also receive education in communicating effectively with patients and families about a serious illness and how to engage with them about the benefits and burdens of treatments and their care wishes. Similarly, education on identifying the 'triggers' for referral to palliative care is important, as many patients are being only

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[30] Strengthening of palliative care as a component of integrated treatment within the continuum of care, 134th session, Agenda item 9.4, 23 January 2014
http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf, Accessed 20 August 2014

[31] Ibid

[32] Palliative Care Australia, 2014-15 Pre-Budget Submission, January 2014

being referred to palliative in the last weeks or days of life. The work being done by the Australian Commission on Safety and Quality in Health Care with the End of Life Consensus Statement has the potential to assist with addressing this issue.

h. any related matters.

Advance care planning
A key issue for palliative care, which is relevant for this Senate Committee Health Inquiry and has a great impact on end of life care options delivered to patients, is advance care planning. Currently advance care planning processes and legislation differ in each state and territory, which creates confusion for patients, their families and carers, and health professionals. PCA has consistently called for the Federal Government to work with states and territories to implement nationally consistent advance care planning legislation.[33]

It is also important that community awareness strategies are put in place, alongside those directed at health professionals, to foster the preparation and use of advance care plans to guide the provision of care.

Conclusion

This submission from PCA has raised a number of issues for palliative care related to the Inquiry into health policy, administration and expenditure, with reference to the specified terms of reference.

Overall, it is important that there is greater certainty about future funding arrangements to facilitate service and workforce planning, and to address the growing needs associated with population growth, population ageing and the increasing incidence of chronic conditions. Current and future Commonwealth governments will need to ensure their role in hospital funding achieves maximum benefits for the community, as the future health needs of Australia's population is a responsibility of all levels of government.

There are concerns about the impact of additional costs on access to affordable healthcare and the sustainability of the health system. 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. 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. In relation to this, health promotion, prevention and early intervention are important for all areas of health, including palliative care, in particular working to achieve early diagnosis and treatment and improve quality of life.

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[33] Palliative Care Australia, 2014-15 Pre-Budget Submission, January 2014

People who are dying have complex and multifaceted needs, requiring a broad range of health and community services to effectively meet these needs. This is especially the case for older people. Palliative care is therefore greatly impacted by the interaction of different elements of the health and community care systems. Likewise, equity in access to palliative care services is an issue in Australia and services are currently not able to meet the needs of everyone in our community, particularly groups with diverse needs.

The improved integration and coordination of health and Medicare services is beneficial for all areas of the health service system, including palliative care. A lack of coordination between different areas of the Medicare or health system that are interrelated, can cause difficulties and barriers to people receiving the care they need to prevent avoidable suffering. Having a system which is not integrated, means systems continue to operate in silos and do not enable people to receive the care they need as an individual.

Workforce is a priority area for PCA, as it impacts on the level and quality of care that people receive. Care of the dying must be a standard education provision for every health professional across their career. Peoples' needs will not be met if education is not supported across all settings for the specialist and generalist workforce to provide palliative care.