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14 August 2015

**RE: House Standing Committee Inquiry into Chronic Disease Prevention and Management in Primary Health Care**

Dear Committee Members

I write to you on behalf of Palliative Care Australia to respond to the House Standing Committee's Inquiry into Chronic Disease Prevention and Management in Primary Health Care. Palliative Care Australia (PCA) welcomes this inquiry into chronic disease, and particularly the management of chronic disease within the primary health care setting. PCA is the peak body representing those who advocate for good quality palliative care for all Australians. PCA is committed to raising community awareness and understanding of palliative care to ensure all Australians access the care they need when they are at their most vulnerable.

Palliative Care is a vital part of primary health care, providing care of all people with a life-limiting condition across the range of care settings with the majority of palliative care services being provided to people with chronic conditions. For this reason, consideration of access to palliative care services and coordination of care between settings is vital in the consideration of management of chronic diseases in primary health care.

Please find attached PCA's response to a selection of the senate inquiry terms of reference relevant to PCA's goals. PCA would be happy to elaborate on the details in this submission should the Committee require it. To assist the Committee's deliberations, PCA can also facilitate a visit of the Committee to settings that are currently providing palliative care and managing chronic disease in the community.

Yours sincerely

A handwritten signature in black ink, appearing to read "Liz Callaghan".

**Liz Callaghan**

CEO

Palliative Care Australia

Palliative care is defined by the World Health Organisation as ‘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 is provided in almost all settings where health care is provided, including neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services, and generalist community services. Nationally, around 11,700 patients received a palliative medicine specialist service subsidised through the Medicare Benefits Schedule during 2012–13<sup>i</sup>. Given there are approximately 130,000<sup>ii,iii</sup> deaths per annum from chronic diseases, it suggests that many people are dying without being provided with access to palliative care services.

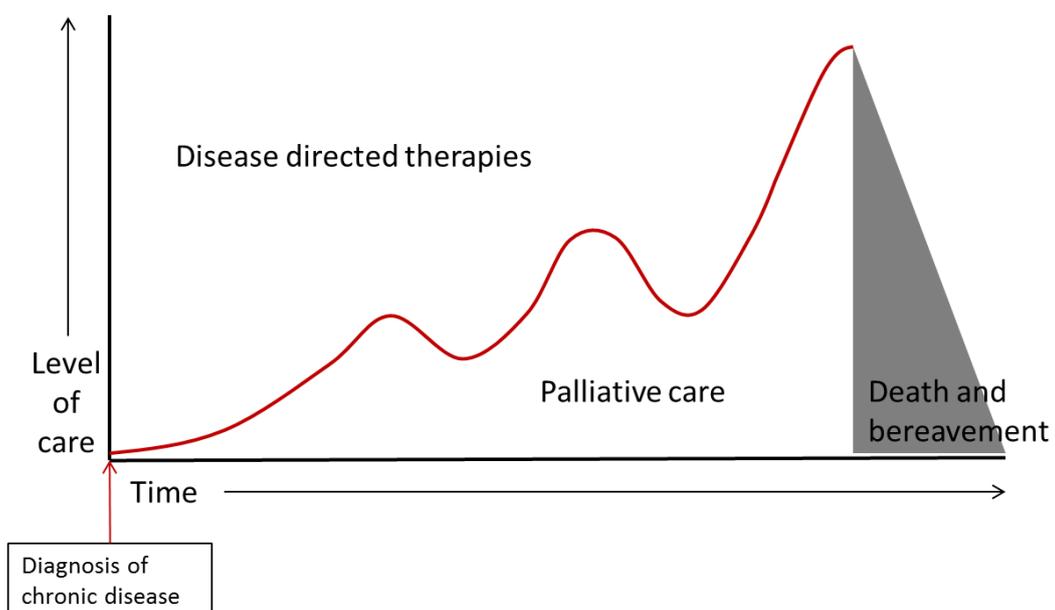
### Examples of best practice in chronic disease prevention and management, both in Australia and internationally

Palliative care is a well-established best practice model for interdisciplinary care in chronic disease prevention and management.

Palliative care may be beneficial from the point of diagnosis of a chronic disease for any life limiting condition. However, in many cases access to specialist palliative care will only be required for stages along the continuum of care. There is an important role for the primary health care sector to provide palliative care for people with chronic life-limiting conditions as part of the management of the condition including in shared care arrangements with specialist services. Providing access to palliative care and coordinating care across various health settings is important to best practice person centred care for people with chronic diseases. To achieve this it is necessary to identify triggers for referral to specialist palliative care to assist in managing complex pain and symptoms and addressing chronic needs.

## Continuum of Palliative Care

Adapted from Honoring Patients' Wishes, University of California, Berkeley 2014



Extensive research has found that palliative care services contribute to more effective and efficient use of health resources in ways that are consistent with the goals of care expressed by people with a life limiting illness and their families. This includes fewer emergency and hospital admissions, shorter lengths of stay, and the elimination of non-beneficial tests and treatments.<sup>iv, v, vi, vii, viii</sup> Importantly, the research also indicates that palliative care improves the quality of life of patients and their families, improves the management of pain and other symptoms, reduces caregiver burden and provides greater emotional support compared with usual care.<sup>ix, x, xi, xii</sup>

Palliative care has mainly focused on people with cancer. However, there is now growing evidence and acceptance of the value of early involvement of palliative care in assisting people with a wide range of life limiting chronic conditions, such as organ failure and neurodegenerative conditions.<sup>xiii</sup>

The following examples indicate the scope to improve access to palliative care for people with the following chronic conditions:

- Chronic obstructive airways disease – In 2012, chronic lower respiratory disease was the fifth leading cause of death in Australia.<sup>xiv</sup> In 2013, COPD was certified as the underlying cause of 7,148 deaths in Australia.<sup>xiv</sup> However, there were only 622 palliative-care related hospital separations for people with a principal diagnosis of COPD.<sup>i</sup> This suggests that, at best, less than 9% of people with chronic COPD access palliative care.
- Dementia & Alzheimer’s disease – 10,369 people died from these diseases in Australia in 2012, comprising 7% of all deaths.<sup>xiv</sup> However these diseases did not feature in the top ten non-cancer diagnoses for people who received palliative-care related separations.<sup>i</sup> A recent Australian survey of 783 professional carers and 236 family carers of people with dementia reported difficulties in: accessing hospice care (68%); accessing palliative care specialists (58%); getting sufficient end of life care support in the community (>50%); and in ensuring the person they were caring for received adequate pain relief.<sup>xv</sup>
- End stage renal disease – in 2013, there were 2,987 deaths in Australia due to diseases of the urinary system (including renal failure).<sup>xiv</sup> However, there were only 708 palliative care–related hospital separations for people with a principal diagnosis of renal failure across Australia.<sup>i</sup> This suggests that, at best, less than 24% of people with chronic renal failure access palliative care.

The following examples provide frameworks on which palliative care networks incorporating primary care could be based:

- In spite of the statistics above, renal services have been very successful at integrating palliative care into core practice, and many renal services have incorporated a palliative care nurse or nurse practitioner into their team. Their actions are supported by the Renal Supportive Care Guidelines<sup>xvi</sup> which covers areas including advance care planning, family conferences and end of life goals. PCA would support other chronic disease disciplines such as cardiac, respiratory and dementia, adopt similar measures.
- The McGrath breast care nurse<sup>xvii</sup> provides a model for the use of nurses (including community based nurses) in the coordination of person-centred care. The breast care nurse initiative is based on a holistic model of care providing physical, psychological and emotional support. They are available to reinforce and discuss information provided by medical specialists and provider referral to other support services where indicated. They also have a role in education

and community awareness. This model should be considered in the provision of palliative care, to support people with life-limiting conditions through the continuum of their care.

- There are some services that have well-established mechanisms for general practitioners supporting specialist palliative care providers. Studies have demonstrated that care conferences provide a useful means of communication between GPs and specialist services, noting that these need to be supported and resourced to be successful.<sup>xviii xix</sup>
- Honouring Patients' Wishes provides a strong framework for provision palliative care with a greater focus on the role of the primary/community sector<sup>xx</sup>.

### **Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management.**

General practitioners play an important role in the care of patients with chronic diseases as they approach the end of their life. The role of the GP could be one that carries oversight of coordination of care, in addition to the development and ongoing maintenance of advance care plans. Development of an advance care plan requires commitment of time specific to that activity with the patient. However, there is no specific Medicare item that GPs can use for providing palliative care. Having a specific item for advance care planning would make the provision of this important service more visible to GPs and would enable greater promotion of the GPs role in advance care planning and management. Advance care planning requires the capacity to follow through on the wishes of patients. Inclusion of item numbers specific (of similar time and value to those items for chronic disease management) to the development and review of advance care plans by GPs would support them in performing this service.

Provision of palliative care by primary health care could be supported by a review of Medicare payments to improve access to nurse practitioner services. This might provide more flexibility with service provision in the future as nurse practitioners are proving to be very flexible and adaptable to complex care arrangements and working across settings.

### **Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care**

There is an opportunity for Primary Health Networks to support provision of palliative care for people with chronic disease. This could include through the development and implementation of health management plans that focus on a preventive approach to minimise health and social care problems commonly experienced by people with progressive chronic conditions. Such approaches require inclusion of palliative care principles in chronic disease management plans early in the course of a person's chronic life limiting condition.

People with complex care needs including those with chronic diseases who receive palliative care frequently require care in multiple settings. During transitions between settings there is a risk of poor quality care and care fragmentation<sup>xxi</sup>. Primary Health Networks would be well placed to provide care coordination for palliative care for people with chronic diseases. However, primary health providers do not currently have much experience in the delivery of palliative care. For them to provide palliative care to a high quality, it would require significant investment in education in relation to communication skills, holistic patient and family centred care planning and provision and the service coordination capacity to make this a reality. It would also require the support of networks with specialist palliative care providers for consultation and referral of people with complex needs. A needs

assessment tool: Progressive Disease (NAT:PD) has been developed to assist matching the types and levels of need experienced by people with progressive chronic diseases and their carers with the most appropriate people or services to address those needs.<sup>xxii</sup>

Further, research has highlighted the importance of better identifying the palliative phase of chronic conditions 'in order to appropriately time advance care planning, access to symptom management and provision of support to patients and their families'<sup>xxiii</sup>. PCA would like to work with clinicians and medical specialists to identify the palliative phase for their specialties. Implementation could be facilitated by endorsement and support from state and territories for services in the acute settings. This could be based on international work, including in the UK, where evidence based guidelines have been developed for the referral of people to palliative care who have a range of chronic life-limiting conditions.

### **The role of private health insurers in chronic disease prevention and management**

There is a major concern with lack of coverage of palliative care by private health insurers across Australia. 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. However, many 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<sup>xxiv</sup>.

There is inequity of access to palliative care services, brought about by fragmentation of care between primary and acute care, fragmentation between public and private care, and geographical issues. For example, people in South Australia in the private hospital system face difficulties with transferring to community based palliative care services. Discharge planners in private hospitals are not able to provide access to equipment, nursing and allied health in the community. This means that people have to exit the private health system before they can enter the public system and access these services. This can provide a disincentive for people to use private health insurance when they are aged or have a chronic disease.

Many private health insurers do not offer rebates for access to privately funded palliative care services, resulting in people not being able to afford access to community based palliative care. For example in Victoria, Cabrini is the only service that offers community palliative care funded via private health insurance. Similar patterns are seen across Australia. Recently, there has been some anecdotal evidence that private health insurers are willing to commence conversations about providing coverage for palliative care. This has been demonstrated in the US, with the health insurer Medicare (US) commencing coverage for some palliative care services. PCA is very keen to engage in discussions with Australian private health insurers about coverage for palliative care.

### **The role of State and Territory Governments in chronic disease prevention and management**

Access to palliative care is essential regardless of whether the person is being treated in a hospital or hospice, or in the community by GPs, community nurses, home care or aged care. State and territory governments need to work closely with primary service providers to ensure flow of information to support patients as they move between services. Ideally, this would be through an electronic patient

record that can be accessed by the primary health care sector, the hospital sector, the private specialist sector and the allied health sector.

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<sup>i</sup> AIHW, 2014, *Palliative care services in Australia 2014*

<sup>ii</sup> AIHW 2013. *3302.0 - Deaths, Australia*. Canberra: AIHW.

<sup>iii</sup> AIHW 2014. *Australia's health 2014*. Cat. no. AUS 178. Canberra: AIHW.

<sup>iv</sup> World Health Organization, 2011, *Palliative care for older people: better practices*, WHO, P13

<sup>v</sup> Worldwide Palliative Care Alliance, 2014, *Global Atlas of Palliative Care at the End of Life*, P91.

<sup>vi</sup> Albanese T, et al, 2013, Assessing the Financial Impact of an Inpatient Acute Palliative Care Unit in a Tertiary Teaching Hospital, *Journal of Palliative Medicine*, Vol 16, Number 3, 2013, P293.

<sup>vii</sup> Canadian Hospice Palliative Care Association, Cost-Effectiveness of Palliative Care: A Review of the Literature, P12 <http://www.hpcintegration.ca/media/36290/TWF-Economics-report-Eng-final-webmar7.pdf> (accessed 20 May 2014)

<sup>viii</sup> Starks H, et al, 2013, Cost Savings Vary by Length of Stay for Inpatients Receiving Palliative Care Consultation Services, *Journal of Palliative Medicine*, Vol 16, Number 10, 2013, P1215.

<sup>ix</sup> Lorenz et al, 2008, reported in Rand Europe and the National Audit Office, 2008, *The Potential Cost Savings of Greater Use of Home and Hospice-Based End of Life Care in England*, National Audit Office, 2008.

<sup>x</sup> Casarett, D; Pichard, A; Bailey, F A; Ritchie, C; Furman, C; Rosenfeld, K; Shreve, S; Chen, Z; Shea, J A; 2008 "Do Palliative Care Consultations Improve Patient Outcomes?" *Journal of the American Geriatric Society*, 2008 No 56 pp593-599

<sup>xi</sup> Morrison, R S; Penrod, J D; Cassel, B; Litke, Ann; Spragens, L; Meier, D E, 2008, "Cost Savings Associated with US Hospital Palliative Care Consultation Programs", *Archives of Internal Medicine* 168, No 16 (2008) p1786

<sup>xii</sup> Le, B; Watt, J, 2010, "Care of the Dying in Australia's Busiest Hospital: Benefits of Palliative Care Consultation and Methods to Enhance Access", *Journal of Palliative Medicine* Vol 13, No 7, 2010, pp855-860.

<sup>xiii</sup> O'Brien T, 2013, The impact of an Aging Population on Palliative Care, 2013, *Journal of Pain & Palliative Care Pharmacotherapy*, 2013, 27, P390

<sup>xiv</sup> Australian Bureau of Statistics, *Causes of Death, Australia, 2012*

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3303.0main+features100002012> (accessed 16 May 2014).

<sup>xv</sup> Alzheimer's Australia, 2014, *End of Life Care for People with Dementia: Survey Report* February 2014: Executive Summary, Pp3-14, [http://www.fightdementia.org.au/common/files/NAT/EOI\\_ExecSummary\\_Web\\_Version.pdf](http://www.fightdementia.org.au/common/files/NAT/EOI_ExecSummary_Web_Version.pdf)

<sup>xvi</sup> Brown, M. A., Crail, S. M., Masterson, R., et al (2013), *ANZSN Renal Supportive Care Guidelines 2013*. *Nephrology*, 18: 401–454. doi: 10.1111/nep.12065

<sup>xvii</sup> <http://www.mcgrathfoundation.com.au/OurNurses/MeetTheMcGrathBreastCareNurses.aspx>

<sup>xviii</sup> Mitchell G, Cherry M, Kennedy R, et al 2005. [General practitioner, specialist providers case conferences in palliative care—lessons learned from 56 case conferences](#). *Aust Fam Physician*. May;34(5):389-92.

<sup>xix</sup> Mitchell GK, Del Mar CB, O'Rourke PK, Clavarino AM. 2008. . [Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomised controlled trial](#) *Palliat Med*. 2008 Dec;22(8):904-12.

<sup>xx</sup> [http://berkeleyhealthcareforum.berkeley.edu/wpcontent/uploads/BerkeleyForum\\_PalliativeBrief\\_nov18.pdf](http://berkeleyhealthcareforum.berkeley.edu/wpcontent/uploads/BerkeleyForum_PalliativeBrief_nov18.pdf)

<sup>xxi</sup> Coleman E. 2003. Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. *J Am Geriatr Soc*. Apr;51(4):549-55.

<sup>xxii</sup> Waller A1, Girgis A, Currow D, Lecathelinais C; Palliative Care Research Program team. 2008. Development of the palliative care needs assessment tool (PC-NAT) for use by multi-disciplinary health professionals. *Palliat Med*. Dec;22(8):956-64. <http://www.caresearch.com.au/Caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/General-Practitioners/NeedsAssessmentTool-ProgressiveDiseaseChERP.pdf>

<sup>xxiii</sup> Lockett T, Philips J, Agar M et al. 2014. Elements of effective palliative care models: a rapid review. *BMC Health Serv Res*; 14: 136.

<sup>xxiv</sup> N Sullivan, H Walker, J Brooker A Framework for the Delivery of Comprehensive Palliative Care Services in the Australian Private Sector Prepared for the Australian Centre for Health Research by Cabrini Health