



His Excellency General the
Honourable Sir Peter Cosgrove
AK MC (Retd), Governor-General of
the Commonwealth of Australia,
Patron

Palliative Care Australia
Incorporated

PO Box 124
Fyshwick ACT 2609

T 02 6232 0700

palliativecare.org.au
pcainc@palliativecare.org.au

ABN 85 363 187 904

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via email: dementia@health.gov.au

To whom it may concern

Specialist Dementia Care Unit Consultation

The availability of high-quality palliative care and end-of-life care for people living with dementia is an issue of high importance to Palliative Care Australia (PCA) and we highlight that palliative care or end-of-life care is not mentioned within the Specialist Dementia Care Units Consultation Paper.

Palliative care is for people of any age who have a life-limiting illness that cannot be cured, which includes dementia. Dying is a normal process with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death and to help families cope during this illness and in their bereavement. To note the *Aged Care Act 1997 (Schedule of Specified Care and Services)* stipulates that approved residential aged care providers are responsible for providing access to a qualified practitioner from a palliative care team and for the establishment of a palliative care program, including monitoring and managing any side effects for any resident that needs it.

Many people with dementia struggle to get access to appropriate palliative care that responds to their needs and respects their wishes, particularly those with severe behavioral and psychological symptoms of dementia (BPSD). Dementia is different from other life-limiting illnesses; in part because of the long, unpredictable course of the disease, difficult issues around capacity for decision making, difficulties in communication and lack of community understanding of the disease. Ultimately, dementia is a terminal condition and therefore it is essential that a palliative approach to care and support is available within the proposed Specialist Dementia Care Units (SDCU's) to people with severe BPSD and their families, which includes timely access to specialist palliative care services and an understanding advance care plans.

The stated role of the SDCU (p.6 of the Consultation Paper) is to offer transitional support that focuses on reducing and stabilising symptoms with the aim to enable the person to transition back to a less intensive care setting. When a person is assessed as requiring SDCU, transfer must also be considered in the context of palliative care pain and other symptom management. There is evidence that dementia is associated with persistent pain, which is likely to be under treated, and compounded by difficulties in assessing pain in a person living with dementia to begin with.

What PCA do not want to see is patients being transferred unnecessarily to a SDCU without appropriate assessment by specialist palliative care services to address symptoms that may be masking behavioural and/or psychological issues such as agitation, discomfort and fearfulness.

Improved access to training and continuing professional development as well as appropriate staffing mix and numbers is required to facilitate the delivery of palliative care and end-of-life care, along with access to consultancy advice from specialist palliative care services. This will also be the case for the proposed SDCU's, where staff will need to be well trained and equipped to recognise the need for palliative care and end-of-life care, including appropriate pain management and the signs of impending death. Towards the end of life, it is not uncommon for people with dementia to be sent to hospital, even though it can be a traumatic experience. This may be impacted further by a recent transfer from the person's usual place of care to an SDCU, and then further transfer to hospital.

It will also be imperative that staff of the SDCU have appropriate processes in place to facilitate good communication with the family or substitute decision maker about the person's advance care plan and wishes, and that these preferences are documented at the time the person enters the SDCU and respected throughout their care. The possibility of transfer to the SDCU, and any additional transfers from the SDCU to hospital, must be discussed as part of the advance care plan and decisions should be made early about reasons which would necessitate a transfer. This information should be documented and clearly communicated to relevant SDCU staff.

We also raise concern of the establishment of a SDCUs for each PHN without consideration of population planning, which risks a maldistribution in occupancy, varying from some SDCU's being oversubscribed with long waiting lists to those with beds empty for significant time periods. Given the proposed investment of \$72 million PCA encourage further population and needs-based planning to ensure that the SDCU's are provided in the places most likely to be utilised, and with the patients and families also in-mind, particularly for those people within rural and remote locations that may be transferred off-country.

Additional reforms that should be considered in the development of SDCU's include the current activities to harmonise the legislative requirements related to advance care planning, in-line with the National Framework for Advance Care Directives produced by the Australian Health Ministers' Advisory Council in 2011. In addition, issues surrounding staffing and skills-mix within the SDCUs should form part of the considerations of the Aged Care Workforce Strategy Taskforce and intended Aged Care Workforce Strategy "for growing and sustaining the workforce providing aged care services and support for older people, to meet their care needs in a variety of settings across Australia."

I also urge you to consider the Productivity Commission's Draft Report, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, released in June 2017 which states that lack of palliative care expertise and qualified staff to administer pain relief mean residents of aged care service often make traumatic and costly trips to hospital, where some die in unnecessary pain causing distress to themselves and the people who care for them. This report specifically notes the disconnect between the way in which the health system

considers end-of-life care and definitions used in the aged care system, where intensive nursing and other end-of-life care services are only funded in the last week or days of life, going further to then call for more staff with the skills to lead and coordinate end-of-life care for residents.

In addition, you may not be aware that the National Palliative Care Strategy 2010 identified the importance of palliative care in aged care and highlighted a number of actions, however an evaluation of this Strategy undertaken in 2016 noted challenges including the need to increase the capacity to support palliative care in the aged care setting to reduce the demand on transfers to the hospital system. The evaluation specifically noted “the level of palliative knowledge within the aged care sector varies considerably between, and within, facilities as well as states”. To note the Commonwealth will release the update National Palliative Care Strategy in 2018.

I have attached for your consideration a copy of *the Principles for Palliative and End-of-Life Care in Residential Aged Care* which we released in May 2017 during National Palliative Care Week which reflect the need to understand and meet the needs for consumers with dementia. These principles were developed collaboratively with Dementia Australia, COTA Australia, Aged & Community Services Australia, Leading Age Services Australia, Catholic Health Australia and the Aged Care Guild to present a united commitment in recognising the diverse needs of residential aged care consumers, families, carers, aged care staff and service providers in providing palliative and end-of-life care.

Finally, I note the Consultation Paper is partly based on the Aged Care Sector Committee’s Aged Care Roadmap, which also does not make specific mention of palliative and end-of-life care, where PCA are advocating to have it included in future iterations. Please do not hesitate in contacting Kelly Gourlay, National Policy Advisor, if you would like to discuss these issues further at kelly@palliativecare.org.au

Kind Regards



Liz Callaghan
Chief Executive Officer
Palliative Care Australia