

28 September 2018

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

To whom it may concern

Aged Care Quality and Safety Commission Bill 2018

Thank you for the opportunity to provide comment on the Aged Care Quality and Safety Commission Bill 2018. Palliative Care Australia (PCA) is the national peak body for palliative care in Australia, providing leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

PCA is supportive of the establishment of the Aged Care Quality and Safety Commission (the Commission) to strengthen and enhance aged care regulation to protect and assure the quality of care provided to aged care consumers. I note that the Bill before the Senate Standing Committees on Community Affairs Explanatory Memorandum refers to the compatibility with the right to an adequate standard of living and the right to health as contained in the *International Convention on Economic, Social and Cultural Rights* (ICESCR). I would like to draw the Committee's attention to the fact that the World Health Assembly (WHA) has endorsed palliative care as a human right under article 12 of the ICESCR, specifically stating that:

'access to palliative care and to essential medicines... including opioid analgesics ... contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being'.¹

With this said, **support for and enhanced quality assurance of palliative care needs greater focus within the Australian aged care sector, and I have provided a number of issues below for you to consider as you progress with this Inquiry. Most notably is the omission of palliative care within the new Aged Care Quality Standards.**

While the Standards does make reference to 'end of life planning' within Standard 2 and 'the needs, goals and preferences of consumers nearing the end of life are recognised and addressed,

¹ World Health Assembly, *Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course*, WHA Res 67.19, 67th sess, 9th plen mtg, Agenda Item 15.5, A67/VR/9 (24 May 2014) 2.

their comfort maximised and their dignity preserved’ under Standard 3, these do not encompass the entirety of palliative care.

As ‘quality of life’ features so prominently within the Bill, it is important to understand the definition of palliative care - person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life. This can be for many months or even years, and can occur at the same time as curative treatment. This is different from end-of-life care which is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered, and takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care.

In order to provide care that aligns with the strategic direction as outlined in the Bill, to ‘protect and enhance the health, safety, well-being and quality of life for aged care consumers and to promote high quality care’ palliative care needs to feature prominently within the Commissions remit.

As noted by PCA in the submission to the 2017 Review of National Aged Care Quality Regulatory Processes, we question the general awareness of people engaged in the aged care industry, including consumers, their families and people working in aged care, of their rights and responsibilities, particularly as they relate to receiving palliative care and end-of-life care. 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.

PCA have been continuously requesting that the Standards include a specific section dedicated to palliative care issues, an argument strengthened by the recent Better Quality of Care – comprehensive palliative care in aged care Budget investment announced by Minister Wyatt, to improve palliative care for older Australians living in residential aged care. It is the frailty and co-morbidities frequently found in aged care that make palliative care including end-of-life support so critical and there is concern that without an underpinning framework with which to hold providers more accountable, there will continue to be unacceptable inconsistency in palliative care delivery and make it harder for consumers, and their families, carers and representatives, to understand what they can expect from their service, whatever type that may be.

Further, the Guidance material on the Standards previously released for consultation overlooks the need to provide support with grief and bereavement even though this is an important area of need for consumers, carers and aged care staff. PCA is informed of many instances when a lack of support in grief and bereavement from aged care services significantly impacts on surviving family members. With 35% of all deaths in Australia occurring in residential aged care there is a need to ensure awareness of grief and bereavement of all staff, including non-clinical, as often long-term and close relationships are formed with residents and their families. Upskilling the workforce in this

area would not only assist in supporting the families and carers of the person who has died, but also foster an environment of support for other residents and the staff themselves, an important component of self-care and staff retention.

The availability of appropriate respite care options is an issue that also needs attention, where there is only minor references to the provision of respite services within the Aged Care Quality Standards Guidance material. PCA requests that the new Commission considers this a priority, including the need for adequate resourcing of respite care services to deliver and/or support the delivery of palliative care to older Australian, which includes access to specialised equipment and materials to manage pain and provide symptom relief.

The 2018 National Palliative Care Standards released by PCA in February has a significant focus on giving people greater choice and flexibility, and can be applied to all palliative care settings services delivered in aged care. The National Palliative Care Standards are an important part of the broader health care quality system, as they promote consistent high-quality care that is safe, respectful and consumer focused. While not compulsory for service providers, they may be applied to inform a service or organisation's accreditation process, where the service is required to meet one or more sets of quality standards.

PCA also suggests the language used in the aged care context should be reviewed, where terms such as 'quality' should not be used as a substitute for 'safety' and 'accreditation'. This interchangeable use of these words further complicates an already complex area and increases the potential for misunderstanding of the objectives of accreditation.

Finally, I draw the Committees attention to the expertise or knowledge listed as a prerequisite for membership to the Advisory Council within the Bill (clause 41), and request that palliative care is added as a specific speciality alongside geriatrics, gerontology, aged care nursing and psychiatry. PCA does not believe that the Council will meet the mandate of having 'appropriate expert and stakeholder representation' without this specific inclusion.

Ultimately PCA want to see the community recognising that death is a normal part of life and palliative and end-of-life care is integrated as core business throughout the aged care system. Please do not hesitate in contacting Kelly Gourlay, National Policy Advisor, if you wish to arrange to discuss these matters further at kelly@palliativecare.org.au or 02 6232 0700.



Kind Regards

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Palliative Care Australia