



palliAGED Aged Care Standards Insight

November 2019

End of life and aged care

Professor Jennifer Tieman

Our ageing population

Most deaths in Australia occur among older people with a median age at death of 78.9 years for males and 84.8 years for females¹. Coronary heart disease, dementia and Alzheimer disease, and cerebrovascular disease (which includes stroke) are now the top three causes of death². We are living longer and dying older of chronic diseases associated with ageing. This has major implications for our community and our care systems given that the proportion aged 65 and over has steadily increased over the last two decades. In 2018, there were around 3.9 million older Australians³.

A study of older Australians who died between July 2012 and June 2014 showed that four in 5 of them had used an aged care program sometime before their death. The study also showed that coronary heart disease was the leading cause of death for those who had last used an aged care program delivered in the community while dementia was the leading cause for people who had last used permanent residential aged care before death⁴. At a population level, cause of death may reflect care needs before death and hence be associated with type of aged care use. In addition, care needs influence service use beyond aged care. An older person may move through aged care as their needs and situations change, requiring more involvement of other

services, such as those provided through the health-care system such as primary care and hospital services. This suggests that aged care services are an important partner in the provision of care at the end of life to older Australians.

Palliative care and older people

Similar patterns of ageing and dying are seen internationally. Issues around ageing, caring and dying are influencing aged care and health care policy approaches. In 2014, the World Health Assembly passed a resolution calling for member states to strengthen palliative care as a component of comprehensive care across the life course⁵. This resolution highlighted the importance of palliative care being available across the whole of the health system including primary and community care.

Our National Palliative Care Strategy recognises that people die in a range of care settings, including in the home, hospitals, residential aged care facilities and hospices⁶. It also notes that palliative care is person-centred care⁷. Palliative care recognises the person in their context and that care is provided in a manner that is sensitive and culturally appropriate to the preferences and needs of the person, their family and carers. This reflects human rights principles of the Aged Care Quality Standards, which describe

the right of the consumer to dignity and respect and to make choices about their care and services. The importance of the end of life context is explicitly noted in Requirement 3c which states that ... *The needs, goals and preferences of consumers nearing the end of life are recognised and addressed, their comfort maximised and their dignity preserved.* p66⁸

Palliative care needs may change over time highlighting the importance of ongoing assessment and the ability to plan for and change care as needed. The End of Life Directions in Aged Care Project⁹ has identified a series of elements to describe palliative care: advance care planning; recognising end of life; assessing palliative care needs; providing palliative care; working together; responding to deterioration; managing dying; and bereavement. Fundamental to appropriate care provision is the recognition that an older person is not just older but entering the end stage of their life.

Palliative care evidence for aged care practice

Evidence helps us understand what makes a difference. There is a growing body of evidence to guide care delivered to older people at the end of life. The research literature covers a broad range of areas including clinical care, community and population diversity, models of care and service delivery, and digital applications.

The Australian Palliative Approach in Residential Aged Care (APRAC) guidelines were the first guidelines in the world that provided evidence based support for health professionals providing palliative care in residential aged care facilities. A companion set of guidelines published in 2011 provided evidence based guidance for a Palliative Approach for Aged Care in the Community Setting (COMPAC). This landmark work acknowledged the importance of aged care as a setting in which palliative care needs would be found and the impact of an ageing population on demand for palliative care. Replacing the two guidelines with online guidance has extended the reach and enabled ongoing currency¹⁰.

The ability to provide meaningful person-centred care and/or palliative care depends on the capabilities of the workforce. Having a strong and accessible evidence resource is part of the infrastructure needed to ensure an effective aged care workforce and that quality care is provided across ageing, caring, dying and grieving for all Australians.

References:

1. ABS (2019) Death is Australia 2018 Available at <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/3302.0Main%20Features32018?opendocument&tab-name=Summary&prodno=3302.0&issue=2018&num=&view>
2. AIHW (2019) Leading Causes of Death. Available at <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death>
3. Australian Bureau of Statistics (ABS). Australian Demographic Statistics, Jun 2018 [Internet]. 2018 [cited 2019 Apr 17]; ABS cat. no. 3101.0.
4. AIHW 2018 Cause of death patterns and people's use of aged care: a Pathways in Aged Care analysis of 2012–14 death statistics. Available from <https://www.aihw.gov.au/reports/aged-care/cause-of-death-patterns-peoples-use-of-aged-care/contents/summary>
5. World Health Assembly 2014 Resolution 67.19 http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf
6. Australian Government Department of Health National Palliative Care Strategy 2018 Available from [http://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BD-B047E2FCA257BF000206168/\\$File/12291_PC-Strategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BD-B047E2FCA257BF000206168/$File/12291_PC-Strategy.pdf)
7. Tieman J 2019. Person centred, Patient centred, Consumer directed care! Does it matter? Available from <https://www.palliaged.com.au/Portals/5/News/In-Focus/Aged-Care-Standards-Insight-person-centred-care.pdf>
8. Aged Care Quality and Safety Commission 2019 Guidance and Resources for Providers to support the Aged care Quality Standards Available at <https://agedcarequality.govcms.gov.au/sites/default/files/media/Guidance%20and%20resources%20for%20providers%20to%20support%20the%20Aged%20Care%20Quality%20Standards%20v3.pdf>
9. End of Life Directions for Aged Care website Available at <https://www.eldac.com.au/tabid/4890/Default.aspx>
10. palliAGED Project 2018 <https://www.palliaged.com.au/tabid/5546/Default.aspx>