



PalliativeCare
AUSTRALIA

ENSURING PALLIATIVE CARE IS CORE BUSINESS FOR AGED CARE

As Australia's population ages and the number of people using aged care services increases, the demand for palliative care in aged care is also increasing. It is essential that palliative care is recognised as core business for all aged care providers. Aged care providers and their staff must be supported by appropriate systems, funding and training to provide quality palliative care.

Palliative Care Australia (PCA) has developed an eight-point plan for palliative care in aged care to highlight these issues and provide constructive solutions. By discussing and communicating these eight recommendations, PCA hopes to better support the aged care industry to deliver palliative care.

1. A PERSON-CENTRED APPROACH TO PALLIATIVE CARE IN AGED CARE

- » In the current aged care system, there is a narrow view of palliative care, influenced by Commonwealth aged care policy, standards and funding models.
- » For example, the Aged Care Funding Instrument (ACFI) only recognises and funds 'palliative care' at the 'end of life', where the definition of end of life is referenced as the 'last week or days' of life.
- » There needs to be a more person-centred and holistic approach to palliative care that is not only focused on dying and the last weeks of life. It should align with the World Health Organisation (WHO) definition:
 - 'Palliative care is 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.'
- » This approach will provide better care for older Australians diagnosed with a life-limiting illness, considering their needs beyond only end of life.

2. CLEARLY ARTICULATED, ROBUSTLY IMPLEMENTED - THE AGED CARE QUALITY STANDARDS MUST INCLUDE PALLIATIVE CARE

- » Commonwealth funded aged care services are required to comply with the Aged Care Quality Standards. The Standards focus on outcomes for consumers and reflect the level of care and services the community can expect from aged care providers, yet they do not include 'palliative care'.
- » The Standards include only two references to 'end of life', with Standard two focusing on end of life planning and Standard three on meeting the needs, goals and preferences of consumers nearing the end of life.
- » Palliative Care was a standalone outcome under the previous Accreditation standards (in use prior to 1 July 2019).
- » PCA commissioned KPMG to investigate the economic value of palliative care. The report, *Investing to Save – The economics of increased investment in palliative care in Australia*, recommended that the Aged Care Quality Standards be revised to include a specific palliative care standard, for the following reasons:
 - Palliative care in residential aged care is often confined to the last hours of life and not systematically integrated into core business in residential aged care services.
 - While the current Aged Care Quality Standards contain components of palliative care, the Standards do not effectively describe the expectations for palliative care in a holistic or systematic manner.
 - In light of the clear need for palliative care for this population cohort, and the high degree of complex needs within residential aged care, the Standards should be altered such that they define what 'good care should look like', and include specific minimum competencies for palliative care.

3. PALLIATIVE CARE TRAINING FOR EVERY HEALTH AND AGED CARE WORKER

- » Most staff working in aged care receive very little, if any, formal training in palliative care. Undergraduate and vocational education and training (VET) in aged care do not currently include palliative care as core units and there is no requirement for aged care providers to include palliative care on their training calendars.
- » 36% of all Australians who die do so in residential aged care. Staff working in aged care therefore need to be suitably trained and equipped to work with residents who have palliative care needs and their families.
- » As Australians continue to show a preference for staying in their homes as they age, it is also essential that staff working in home care are suitably trained in palliative care.
- » All health and aged care professionals must have minimum competencies to provide care for people with a life-limiting illness whose needs are relatively straightforward and know when to refer when needs are complex.
- » This could be supported through all undergraduate nursing, allied health, medical courses and Certificate courses for aged care workers including mandatory units on palliative care.

4. MIND THE DATA GAP: WE CAN'T IMPROVE WHAT WE DON'T MEASURE

- » Planning and identifying unmet and emerging needs for palliative care requires demographic and service data.
- » Without adequate data collection and linkages with other health data, it is not possible to accurately analyse how older Australians access and receive palliative care services.
- » There is currently inadequate data about palliative care particularly as it relates to those also accessing aged care services. In particular:
 - The current narrow view of palliative care in aged care means that the available data does not consider palliative care beyond definitions of 'end of life'.
 - Claims for palliative care funding made under the ACFI do not reflect the number of people who needed and/or received palliative care.
 - There is no data available in the Home Care Packages (HCP) Program or the Commonwealth Home Support Programme (CHSP) on the input of specialist palliative care or if providers used funds for services relating to palliative care needs.
- » The introduction of a palliative care National Minimum Data Set (NMDS) would allow for the collection of uniform data and reporting at a national level. Aged care should be included in planning for a palliative care NMDS.

5. FUND IN FULL – WE CAN'T IMPLEMENT IF WE DON'T INVEST

- » Funding is needed to fully implement the National Palliative Care Strategy 2018, ensuring aged care is included.
- » Currently, palliative care is not appropriately recognised and funded in aged care.
- » The ACFI is the instrument used to determine levels of funding in residential aged care. The ACFI only funds 'palliative care' at the 'end of life' where the definition of end of life is referenced as the 'last week or days of life', which only enables providers to claim for:
 - *'Palliative care program involving End of Life care where ongoing care will involve very intensive clinical nursing and/ or complex pain management in the residential care setting.'*
- » Home Care Packages funding does not provide any additional funding to support care recipients who are palliative, including purchasing equipment. Providers must find funds from within the home care package funds currently being received for the client.
- » PCA commissioned KPMG to investigate the economic value of palliative care. The report, *Investing to Save – The economics of increased investment in palliative care in Australia*, found that:
 - In 2017, 36% of deaths in Australia occurred in residential aged care
 - The prevalence of highly complex needs in permanent aged care residents has increased five-fold to 53% in the last decade
 - Only one in 50 permanent residents receive ACFI-funded palliative care.
 - Palliative care services in residential aged care are under-funded and underserved
 - Funding specialist palliative care in residential aged care can reduce presentations to hospital and lead to less time in hospital.
- » KPMG estimates that a \$1.00 investment in palliative care nurses in residential aged care can return between \$1.68 and \$4.14 in savings.
- » KPMG recommended an investment of \$75 million per annum to increase the provision of palliative care within residential aged care. The investment should include both direct specialist palliative care and integrated support provided by the aged care workforce and other health professionals.
- » Development of a new funding model is currently underway, the Australian National – Aged Care classification (AN-ACC). Its ability to ensure residents' palliative care needs are met is still being evaluated.

6. ENSURE EQUITABLE ACCESS - PALLIATIVE CARE IS A UNIVERSAL HUMAN RIGHT

- » The diversity of the Australian population and geography means that no single model of palliative care will work universally. Therefore, it is important that work is done to ensure the models are able to be adapted to provide equitable access across Australia.
- » Investment in, and development of, innovative models of care are required to ensure older people have equitable access to specialist and generalist palliative care services when and where they need them.

7. SUPPORT AUSTRALIANS WHO ARE DYING TO TALK

- » Dying should be seen as a normal part of life, with grief and bereavement supported in the community and within workplaces.
- » Death literacy across the community needs to be improved significantly so people are more comfortable talking openly about death and dying.
- » Older Australians also need to be supported to understand what good palliative care means for them regardless of their prognosis.
- » Work done across the community to normalise discussions of death and dying and grief and bereavement and building a better understanding of good palliative care will make care planning discussions more common and more accepted. This will in turn support the aged care workforce to better be able to facilitate advance care planning within aged care services.

8. PALLIATIVE CARE MUST BE A PRIORITY FOR ALL GOVERNMENTS

- » Palliative care should be a priority for all governments including the National Federal Reform Council, the newly formed National Cabinet and the Health Council.
- » Palliative care policy can be nationally supported by the appointment of a National Palliative Care Commissioner.
- » The role of the Commissioner would include:
 - Engaging with the palliative care sector and facilitating improved communication across jurisdictions by encouraging consistent approaches across all settings, including primary health, community health, tertiary health, aged care and disability.
 - Overseeing the Implementation Plan, and the Monitoring and Evaluation Plan which will underpin the National Palliative Care Strategy 2018.
 - Encouraging the development of a palliative care data collection framework that includes aged care.
 - Contributing to reforms and new initiatives across the palliative care sector, and
 - Providing advice and reporting to government.
- » It is not intended that the Palliative Care Commissioner would be a fund holding body or provide services; get involved in individual cases or advocate for individual people; or undertake dispute resolution, handle complaints or undertake investigations.
- » Currently, there are a number of National Commissioner roles that the Palliative Care Commissioner could be modelled on including National Rural Health Commissioner, National Data Commissioner, National Threatened Species Commissioner and National Skills Commissioner.

<https://palliativecare.org.au/palli8-core-business-in-aged-care>



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Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote palliative care. We believe quality palliative care occurs when strong networks exist between specialist palliative care providers, primary care providers and support care providers and the community.

Palliative Care Australia Incorporated

ABN 85 363 187 904

02 6232 0700

pca@palliativecare.org.au

Unit 8, 113 Canberra Avenue Griffith ACT 2603

PO Box 124 Fyshwick ACT 2609

palliativecare.org.au