PALLIATIVE CARE IS CORE BUSINESS FOR AGED CARE

This document, originally published on 25 September 2020, has been updated and republished in light of the Royal Commission into Aged Care Quality and Safety's Final Report. It summarises the Royal Commission's recommendations against PCA's *Palli-8* eight-point plan for palliative care in aged care.

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PALLIATIVE CARE IS CORE BUSINESS FOR AGED CARE

Palliative Care Australia (PCA), the nation's peak body for palliative care has, together with the palliative care and aged care sector more broadly, advocated strongly for many years that palliative care must be considered core business in aged care.

As Australia's population ages and the number of people using aged care services increases, the demand for palliative care in community and residential 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.

PCA appeared before the Royal Commission into Aged Care Quality and Safety (the Royal Commission) in June 2019, highlighting the urgent need for palliative care to be considered as 'core business' in aged care. Over the last three years and across a total of eight submissions to the Royal Commission, PCA has continued to build the case.

In September 2020, PCA launched *Palli-8*, an eight-point plan to highlight these issues in palliative care and provide constructive solutions. By further communicating these eight recommendations, PCA wanted to ensure the importance of palliative care in aged care would be reflected in the Royal Commission's Final Report, which was tabled on 1 March 2021.

PCA welcomes the report's recommendations. The Royal Commission's call for greater investment in palliative care is a significant step toward better outcomes for all Australians.

The report acknowledges that evidence heard during the life of the Royal Commission shows that too few people receive evidence-based end-of-life and palliative care, and instead experience unnecessary pain or indignity in their final days, weeks and months. The Royal Commission recognises the significant role palliative care has in aged care and the need for it to be core business:

Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained, and their wishes respected. Their families should be supported and informed[1].

The recommendations are in alignment with, and a strong endorsement of PCA's recommendations as expressed in *Palli-8*, PCA's eight-point plan for palliative care in aged care. It is PCA's hope that the Government will now act swiftly to enact them.

1 Royal Commission into Aged Care Quality and Safety (2021), *Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations,* pg. 67

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 residential 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.

The Royal Commission found that while the evidence reviewed reflected a broad range of concerns about aged care quality and safety, they have singled out four concerns for immediate attention — food and nutrition, dementia care, the use of restrictive practices, and palliative care:

High quality palliative care is essential to ensuring that an older person can live their life as fully and as comfortably as possible as they approach death. Compassionate, respectful and individualised support for older people approaching the end of their lives is a necessary component of aged care services.

A number of our recommendations will contribute to ensuring high quality palliative care becomes core business for aged care services. These include a right to fair, equitable and non-discriminatory access to palliative and end-of-life care, improved access to specialist palliative care services and requirements for regular staff training. Urgent consideration should also be given to how palliative care is reflected in the Aged Care Quality Standards[2].

PCA strongly supports the need for immediate action to ensure highly quality palliative care is available in aged care.

2 Royal Commission into Aged Care Quality and Safety (2021), *Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations*, pg. 94

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 (Quality Standards). The Quality 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 Quality 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 residential aged care 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 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 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 community and residential aged care, the Quality Standards should be altered such that they define what 'good care should look like', and include specific minimum competencies for palliative care.

PCA welcomes the recommendations by the Royal Commission relating to the Aged Care Quality Standards (Quality Standards) including:

Renaming the Australian Commission on Safety and Quality in Health Care to the Australian Commission on Safety and Quality in Health and Aged Care (Commission) and conferring responsibility for formulating of standards, guidelines and indicators relating to aged care safety and quality.

Referring the Quality Standards to the Commission for urgent review and possible update including adding in 'high quality palliative care in residential aged care, including staff capacity (number, skill and type), processes and clinical governance, for recognising deterioration and dying'.

The Quality Standards be comprehensively reviewed by the Commission within three years of taking over the function and every five years after that.

These recommendations will ensure the Quality Standards comprehensibly outline the palliative care services that older Australians should be receiving from providers. Oversight by the Commission will ensure the Quality Standards reflect best practice clinical care and are aligned with current health standards.

PCA also welcomes the recommendation that home care services that provide palliative and end-of-life care be accredited in order to receive Australian Government subsidies. This will ensure that these services deliver high quality and best practice care to their clients.

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.
- 35 per cent of all Australians who die are 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.

PCA welcomes the recommendation by the Royal Commission that all workers who are engaged in direct contact with people seeking or receiving services should undertake regular training about dementia care and palliative care. The aged care workforce can be further supported through other training recommendations made by the Royal Commission including:

A mandatory minimum qualification of a Certification III.

A review of the specialist aged care Certificate III and IV courses and health professions' undergraduate curricula to better meet the care needs of older people.

Improved opportunities for learning and professional development and upgrading the skills, knowledge and capabilities of the existing workforce.

Funding teaching aged care programs to students in both residential aged care and home care settings and immediate funding to reimburse providers for the costs of educating and training of the direct care workforce.

Cultural safety and trauma-informed service delivery training for all workers who are engaged in direct contact with people receiving services.

These recommendations will ensure the aged care workforce is suitably trained and skilled to meet the needs of those receiving aged care services, including those who have palliative care needs.

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 especially 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.

PCA welcomes the recommendations made by the Royal Commission to improve data relating to older Australians receiving aged care services including:

Empowering the Australian Institute of Health and Welfare (AIHW) to undertake aged care data governance including coordinating, collecting, storing, standardising, sharing and publishing aged care related information and statistics. This includes developing and publishing a National Aged Care Data Asset, comprised of a number of national minimum aged care datasets.

Improving the data available on the interaction between the health and aged care systems including the introduction of aged care identifiers in the MBS and PBS schedule datasets and National Minimum Data Sets.

National Minimum Data Sets covering all State and Territory Government funded health services implemented by 1 July 2023.

PCA believes this improved data collection should also include comprehensive and uniform data relating to palliative care. If these recommendations are implemented and appropriately resourced and funded, they will provide a more comprehensive picture of the health issues affecting older Australians and the services they are receiving. It will support improved health and aged care planning, funding decision-making and research.

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, 35 per cent of deaths in Australia were residents of residential aged care
  - The prevalence of highly complex needs in permanent aged care residents has increased five-fold to 53 per cent 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 underserviced
  - 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.
- 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.

PCA welcomes the recommendation by the Royal Commission that a new aged care program be introduced that includes an entitlement to all forms of support and care for which a person is assessed as needing and certainty of funding based upon those assessed needs. PCA also supports the recommendations that the new aged care program include the following categories:

A care at home category, with an individualised budget or case mix classification funding model, that provides subsidies for service provision based on assessed needs and allows for supports across a range of domains including palliative and end-of-life care.

A residential care category, with a case mix classification funding model, that provides integrated and high quality care based on assessed needs, which allows for supports across a range of domains including palliative and end-of-life care.

An assistive technology and home modifications category that provides aides and equipment.

This new aged care program will ensure that aged care services are fully funded and older Australians can receive all the services they require, in both residential and home care. Funding for assistive technology and home modifications will also provide crucial support to those with complex palliative care needs.

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.

PCA welcomes the recommendations made by the Royal Commission to ensure equitable access to palliative care services including:

The introduction of a new Aged Care Act that specifies the rights of people seeking and receiving aged care 'including people receiving end-of-life care, the right to fair, equitable and non-discriminatory access to palliative and end-of-life care'.

The introduction of Local Hospital Network-led multidisciplinary outreach services that include access to a core group of relevant specialists, including geriatricians, psychogeriatricians and palliative care specialists.

An Aboriginal and Torres Strait Islander aged care pathway within the new aged care system that provides culturally respectful and safe, high quality, trauma-informed, needs-based and flexible aged care services regardless of where they live.

Maintaining and extending the Multi-Purpose Services Program to support people living in regional, rural and remote areas.

These recommendations will ensure that all older Australians have access to high quality palliative care that meets their needs regardless of where they live. They will also support Aboriginal and Torres Strait Islander people to access care that best meets their needs. These recommendations could be further supported through specialist pathways and supports for people from other vulnerable populations including people from Culturally and Linguistically Diverse Backgrounds, LGBTI people and people who are homeless or at risk of homelessness.

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 dying, grief and bereavement and build 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.

PCA welcomes the recommendations made by the Royal Commission to improve public awareness of aged care through providing education and distributing information to:

Improve awareness of the resources available to assist people to plan for ageing and potential aged care needs.

Improve knowledge about aged care among the professionals with whom older people have frequent contact.

Encourage public discussion about and consideration of aged care needs.

Support continual planning for ageing, including consideration of health care preferences, finances, housing and social engagement.

Improved public awareness will ensure that that people receiving or seeking aged care services are able to make informed and timely decisions. These recommendations could be further supported through education around death and dying, and grief to increase death literacy in the community and improve understanding of good palliative care.

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 supported nationally through the appointment of a National Palliative Care Commissioner or another governance model that provides strong oversight of palliative care in aged care.
- Good national governance would ensure improved communication across jurisdictions, consistent approaches across all settings, improved data collection and oversight of the National Palliative Care Strategy 2018.

The Royal Commission states that all levels of government need to be working together to rise to the challenge of improving aged care. PCA welcomes the recommendations made by the Royal Commission to ensure that all governments are involved in the delivery of aged care services including:

The establishment of a new National Cabinet Reform Committee on Ageing and Older Australians to coordinate the development of an integrated system of care for older people.

Clarification of the roles and responsibilities for the delivery of health care to people receiving aged care by amending the National Health Reform Agreement to include:

- *an explicit statement on the respective roles and responsibilities of aged care providers and State and Territory health care providers.*
- *commitments by State and Territory Governments to provide access by people receiving aged care to State and Territory Government-funded health services, including palliative care services, on the basis of the same eligibility criteria that apply to residents of the relevant State and Territory more generally.*

Ongoing consideration by the Australian Health Ministers' Advisory Council of the Royal Commission's recommendations related to the interface of the health care and aged care systems.

These recommendations will ensure that older Australians are provided with a continuum of care across both the health and aged care sectors, including access to the palliative care services they need.

PCA notes that the Royal Commissioners presented differing governance models for aged care. Given the strong emphasis on palliative care in the Royal Commission's recommendations, PCA believes that any governance model should include strong oversight of palliative care in aged care. There should be clear lines of responsibility and oversight of palliative care, including the implementation of the Royal Commission's palliative care recommendations.