

## Palliative Care Australia

# Response to the Royal Commission in Aged Care Quality and Safety Counsel Assisting's Proposed Recommendations

---

### Key Points

PCA strongly supports the recommendations made by the Counsel Assisting to the Royal Commission into Aged Care Quality and Safety (the Commission) to improve the aged care system. We believe that this bold vision for reframing the way that aged care is delivered will ensure the system provides safe, inclusive and person-centred care aligned with best evidence for all Australians. PCA acknowledges the strong emphasis on palliative care across a range of recommendations and believes the intent of these recommendations could more fully realised with the addition of the following recommendations:

1. The appointment of a Palliative Care Commissioner as a specialist Assistant Commissioner of the proposed Australian Aged Care Commission;
2. The proposed aged care public awareness campaign also seeks to improve death literacy across the community and normalise discussions of death and dying and grief and bereavement; and
3. The expansion of the proposed Aged Care minimum data set to include palliative care data.

### Introduction

**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.

PCA has been engaging with the Commission via a range of submissions and a witness appearance (see [Appendix A](#)). This has informed the recommendations in PCA's *Palli 8* plan, an eight-point plan for palliative care in aged care which outlines the essential elements to ensure palliative care becomes core business in aged care (see **Attachment A**). PCA will continue to discuss and communicate these eight recommendations with key stakeholders, to allow a whole of sector approach to better support the aged care industry to deliver palliative care.

## Counsel Assisting's Recommendations

PCA welcomes the recommendations made by Counsel Assisting. In particular, PCA would like to acknowledge and strongly support the following recommendations in relation to palliative care in aged care:

- **Recommendation 1.4** The new Act should specify a list of rights of people seeking and receiving aged care...the list of such rights should be...(c) For people receiving end-of-life care, the right to fair, equitable and non-discriminatory access to palliative and end-of-life care.
- **Recommendation 17.1** ...implement a category within the new aged care program for residential care that...(c) provides integrated and high quality and safe care based on assessed needs, which allows for personalised care, regular engagement, and a coordinated and integrated range of supports across the following domains...(iv) palliative and end-of-life care.
- **Recommendation 24.1** ...amendment of the Aged Care Quality Standards...(e) Requiring residential aged care providers to demonstrate their capacity to provide high quality palliative care, including staff capacity (number, skill and type), processes and clinical governance, for recognising deterioration and dying
- **Recommendation 44.1** ...as a condition of approval or continued approval of aged care providers that all staff engaged by providers who are involved in direct contact with people seeking or receiving services in the aged care system undertake regular approved training about dementia care and palliative care.
- **Recommendation 64.4**...the key features of the model should include...(c) access to a core group of relevant specialists, including geriatricians, psychogeriatricians and palliative care specialists...(h) a specific focus on palliative care outreach services.

PCA provides further detail below in relation to importance of these recommendations and the outcomes they can achieve. PCA also provides recommendations where enhancements to the existing recommendations made by Counsel Assisting will further optimise high-quality and person-centred palliative care in aged care.

### A New Aged Care Act

All Australians have a human right to quality palliative care. In 2014, the World Health Assembly (WHA), to which Australia is a Member State, resolved that palliative care is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals.<sup>1</sup> PCA believes that one of the guiding principles underpinning Australia's aged care system should be the right of older Australians to access highly quality palliative care services where and when they need them. These rights would be best upheld and protected by enshrining them in a new Aged Care Act (as per **Recommendation 1**).

---

<sup>1</sup> WHA, Resolution WHA67.19, *Strengthening of palliative care as a component of comprehensive care throughout the life course*, May 24, 2014.

## Workforce and Training

Currently, 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 for as long as possible 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.

To achieve this it will be critical to ensure the introduction of compulsory palliative care training as per **Recommendation 44**. Any training of aged care staff should also acknowledge that the aged care section is increasingly dependent on a migrant workforce who have a range of cultural beliefs, understandings and practices about dementia and end-of-life care, including palliative care. Training needs to recognise this and have a focus on these issues so that migrant workers have an understanding of what is required in the Australian context.

PCA also strongly agrees with **Recommendations 43 & 45** that calls for a review of certificate-based courses for aged care and health professions' undergraduate curricula to ensure they appropriately address aged-related conditions and illnesses. As outlined above, PCA believes that training for aged care staff and a review of these qualifications would provide an opportunity to ensure they provide appropriate skills for the aged care workforce. PCA would like to emphasise the importance of including training that covers palliative care, advance care planning, death and dying, and grief and bereavement into these qualifications.

PCA also endorses further recommendations that involve the training, upskilling and registration of the aged care workforce including reprofiling, revising and standardising roles (**Recommendation 40**) mandatory minimum qualifications (**Recommendation 49**), an increase in award wages and remuneration (**Recommendations 41 & 42**), funding for training and education (**Recommendations 46 & 84**) and a national personal care worker registration scheme (**Recommendation 48**).

PCA also encourages any changes to staffing levels that ensure care recipients receive the appropriate hours of care required to meet all their care needs, including care from registered nurses, allied health and other clinical staff. Our affiliate member, Palliative Care Nurses Australia (PCNA), supports the introduction of a requirement for residential aged care services to have a registered nurse on duty 24 hours a day and a legislated skill mix for registered nurses.<sup>2</sup>

**Recommendation 64** recommends the introduction of multidisciplinary outreach services and specifically outlines the specialist workforce which will be required. There is a need to ensure that there is capacity to train this workforce to ensure there are adequate numbers of palliative medicine specialists, nurse practitioners, specialist nurses and allied health professionals to meet this need.

## Residential Care

In the current aged care system, there is a narrow view of palliative care, influenced by Commonwealth aged care policy, the Aged Care Quality Standards and funding models. There needs to be a more person-centred and holistic approach to palliative care that is not only focused on

---

<sup>2</sup> Palliative Care Nurses Australia (2019). *Position Statement: Palliative Care for Older People* (Accessed at: <https://www.pcna.org.au/PCNA/files/35/35d43ba7-0d5e-4a50-a042-9a01ab9a0e81.pdf>)

dying and the last days to weeks of life. PCA supports **Recommendation 17** that calls for the introduction of a residential care category that includes delivery of high-quality care across a range of domains, including palliative and end-of life care. This will ensure that palliative care is seen as a core part of the residential care program. PCA also agrees with the recommendation to include allied health in residential aged care (**Recommendation 18**) as many allied health professions can contribute to the non-pharmacological management/treatment of common palliative care symptoms such as pain, agitation, breathlessness, fatigue, insomnia, respiratory secretions, altered mood (anxiety and depression) and constipation.

### **Home Care**

Many Australians choose to stay in their home as they age and estimates are that up to 70 per cent of Australians would prefer to die at home, but few do so.<sup>3</sup> PCA supports recommendations that allow more Australians to remain in their home as they age and receive palliative care in their home environment. This includes providing provide home care packages to all those on the current wait list and reducing future wait times (**Recommendation 9**), introducing a funding category for social supports (**Recommendation 15**) and maximum funding amounts for care at home that are equivalent to the maximum residential care funding amounts (**Recommendation 89**). People receiving palliative care at home may require specialist equipment such as beds, wheelchairs and toileting and showering aids to make them more comfortable and enable their carers to support them safely. Therefore, PCA strongly supports the recommendation to introduce a funding category to provide assistive technology and home modifications (**Recommendation 16**).

### **Aged Care Quality Standards**

Currently, 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. PCA commissioned KPMG to undertake an economic study into the value of palliative care (see Appendix A). The report, *Investing to Save: The Economics of Increased Investment in Palliative Care in Australia* (2020)<sup>4</sup> 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 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 palliative care.

---

<sup>3</sup> Productivity Commission (2017). *Introducing competition and informed user choice into human services: Reforms to human services.*, Report no. 85, Canberra.

<sup>4</sup> Palliative Care Australia & KPMG (2020). *Investing to Save – The economics of increased investment in palliative care in Australia.* (Accessed at: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>)

PCA strongly agrees with **Recommendation 24** that a review be undertaken of the Quality Standards and amendment of the standards to include a requirement for residential aged care providers to demonstrate their capacity to deliver high quality palliative care. This will further support the aged care system to embrace a more person-centred and holistic approach to palliative care that is not only focused on dying and the last weeks of life.

### **Data**

There is currently limited data about palliative care delivered in aged care. 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. The absence of data is likely to impact service planning, identifying unmet and emerging needs, and monitoring as the sector evolves in response to changing demand. With the recognition of palliative care as a key issue in aged care, the development of comprehensive information to inform policy and program development will be essential. PCA supports recommendations to improve data collection, sharing and governance in aged care including the introduction of an Aged Care National Minimum data set and data sharing agreement (**Recommendation 56**) and improving data interaction between the health and aged care system (**Recommendation 73**). PCA would like to emphasise that any future data collections in aged care should include palliative care data and the involvement of relevant stakeholders.

### **Access to Health Care**

PCA supports recommendations that ensure better coordination between the aged care and health care sectors to ensure that aged care recipients receive highly quality primary care services and specialist care services that complement the aged care services they are receiving. In particular, the introduction of Local Hospital Network-led multidisciplinary outreach services (**Recommendation 64**) that provide services in a person's place of residence, ensures access to a core group of relevant specialists including geriatricians, psychogeriatricians and palliative care specialists and includes a specific focus on palliative care outreach services. This will ensure that older Australians can receive high quality palliative care services wherever they live.

PCA further endorses the introduction of an aged care general practice accreditation (**Recommendation 62&63**), increased access to Older Persons Mental Health Services (**Recommendation 65**), establishing a Senior Dental Benefits Scheme (**Recommendation 66**), changes to Medicare Benefits Schedule to improve access to medical and allied health services (**Recommendation 67**), enhancing the Rural Health Outreach fund to improve access to medical specialists for people receiving aged care (**Recommendation 68**), expanding access to specialist telehealth services (**Recommendation 69**), increased access to medication management reviews (**Recommendation 70**), restricted prescription of antipsychotics (**Recommendation 71**) and improving the transition between residential aged care and hospital care (**Recommendation 72**).

### **National Cabinet and State & Territory Governments**

Aged Care and palliative care should be a priority for all governments including the National Federal Reform Committee, the National Cabinet and the Health Council. PCA supports recommendations that ensure aged care is a priority for all governments including ongoing consideration by the Health National Cabinet Reform Committee (**Recommendation 77**), clarification of roles and responsibilities (**Recommendation 75**) and improved access to state and territory health services by people

receiving aged care (**Recommendation 76**). In particular, PCA supports the amendment of the National Health Reform Agreement or any future health funding agreement to include:

*‘explicit commitments by State and Territory Governments to provide...(a) 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.’*

PCA believe that palliative care and aged care policy can be further reinforced by the appointment of a Palliative Care Commissioner as a specialist Assistant Commissioner of the proposed Australian Aged Care Commission (**Recommendation 3**). Portfolio responsibilities would include:

- receiving from the Commonwealth and each jurisdiction an annual update of actions taken under the National Palliative Care Strategy Implementation Plan to assess and report on progress made on the goals and priorities of the Strategy by the Commonwealth and the jurisdictions;
- identifying systemic shortfalls in the provision of palliative care in Australia and recommend options for change; and
- other functions as conferred.

### ***Diverse Needs and Underserved Populations***

Older Australians have a diverse range of life experiences, cultural backgrounds, religion, spirituality, sexuality, socio-economic status and geographic locations. Older people living in rural and remote locations face unique challenges in accessing aged care services that are person-centred, timely, flexible and allow them to remain in their community. These challenges are further exacerbated when people need to access specialist health services including allied health, nurse practitioners and palliative care specialists. Some older people with diverse needs may experience exclusion, discrimination and barriers to accessing appropriate health and aged care services. Many people with diverse needs are underserved by the current aged care and health systems and struggle to access culturally safe and inclusive services.

PCA welcomes recommendations to improve access to the aged care system for people with diverse needs including a new Aged Care Act guided by principles that recognise Aboriginal and Torres Strait Islander people’s entitlement to culturally safe care, the right of older people to access care and support irrespective of their location or personal circumstances and support for special or vulnerable groups to access care (**Recommendation 1**). PCA further agrees with the recommendations made to improve aged care for Aboriginal and Torres Strait Islander people including the delivery of culturally safe, trauma-informed and flexible services, services that allow people to remain on country, prioritising Aboriginal and Torres Strait Islander service providers and increased employment and training for Aboriginal and Torres Strait Islander workers (**Recommendations 32-38**).

PCA also agrees with recommendations regarding cultural safety and trauma-informed care training and auditing and addressing service gaps for people with diverse needs (**Recommendation 19**), equity for people with disability receiving aged care (**Recommendation 60**) and identifying and addressing services gaps in regional, rural and remote areas (**Recommendation 78-79**). PCA encourages more comprehensive recommendations to improve care for culturally and linguistically diverse people including the delivery of culturally safe, trauma-informed and flexible services.

### **Public Awareness**

PCA strongly agrees with the recommendation to improve public awareness of aged care to assist people to plan for their future needs, improve their knowledge of aged care and encourage discussions around aged care needs (**Recommendation 11**). PCA would like to emphasise that aged care public awareness campaigns should also seek to normalise discussions of death and dying and grief and bereavement. 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. 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.

Any public awareness campaign should also include targeted campaigns for Aboriginal and Torres Strait Islander and culturally and linguistically diverse groups given the differing cultural understandings and beliefs around dementia, end-of-life care, palliative care and advance care directives. Discussions around death and dying need to acknowledge cultural differences and be adaptable to the needs of each community.

### **Conclusion**

PCA welcomes the opportunity to comment on Counsel Assisting's recommendations and to contribute over the life of the Commission. These recommendations will ensure that palliative care becomes core business in aged care and that older Australians can access safe, flexible and person-centred palliative care where and when they need it.

## Submissions to the Royal Commission into Aged Care Quality and Safety

PCA has previously engaged with the Commission) via the a range of submissions available at:

<https://palliativecare.org.au/submissions-and-reports>

These include the following:

- **Issues Overview: Palliative care within aged care – prepared for the Royal Commission into Aged Care Safety and Quality** (May 2019);
- **PCA Submission to the Royal Commission into Aged Care Quality and Safety** (October 2019);
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Consultation Paper - Aged Care Program Redesign: Services for the Future** (January 2020);
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Counsel Assisting’s Submission on Workforce** (March 2020);
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Counsel Assisting’s Submission on Program Redesign** (March 2020);
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Counsel on COVID-19** (July 2020); and
- **Second Submission to the Royal Commission into Aged Care Quality and Safety** (July 2020).

## Evidence to the Royal Commission into Aged Care Quality and Safety

The former chair of PCA gave evidence before the Commission on 27 June 2019:

- [PCA Board Chair Witness Statement](#) (May 2019); and
- [Appearance at the Perth hearings by the PCA Board Chair](#) (June 2019).

## KPMG Report

PCA recently commissioned KPMG to undertake an economic study into the value of palliative care. The report, *Investing to Save: The Economics of Increased Investment in Palliative Care in Australia*, was commissioned with the assistance of The Snow Foundation by Palliative Care Australia and prepared by KPMG. It is available at: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>

The report finds that with an additional annual investment of \$365m on national palliative care reform, Australia could save up to \$464m in other health system costs while making the system work best for those experiencing it. In particular the report recommends \$75 million for the provision of palliative care within residential aged care, increases in funding of \$240 million per annum for integrated home and community-based services, and \$50 million per year for palliative care services in hospitals will also considerably contribute to optimal palliative care for older Australians regardless of where in the health care system they are receiving care. This will allow older people to receive care in their preferred location, and to minimise the unnecessary default to acute care to meet gaps in palliative care access in other parts of the system.