His Excellency General the Honourable David John Hurley AC DSC (Retd), Governor-General of the Commonwealth of Australia, and Her Excellency Mrs Linda Hurley, Patrons

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Palliative Care Australia
Submission to the Royal Commission into Aged Care Quality and Safety on Palliative Care in Aged Care

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 previously engaged with the Royal Commission into Aged Care Quality and Safety (the Commission) via a range of submissions and a witness appearance (see Appendix A). Through these submissions, PCA has made numerous recommendations in relation to palliative care in aged care, in particular:

1. Aged care policy should align with the World Health Organisation definition of palliative care and not be restricted to 'end of life' or last days/weeks.
2. Palliative care must be included, and clearly articulated, in the Aged Care Quality Standards, which all Commonwealth funded aged care services are required to meet.
3. All undergraduate nursing, allied health, medical courses and Certificate courses for care workers must include mandatory units on palliative care.
4. Establish National Minimum Data Sets for palliative care which include both health and aged care.
5. Funding is needed to fully implement the ***National Palliative Care Strategy 2018*** ensuring aged care is included.
6. Investment and the development of innovative models of care are required to ensure older people have equitable access to specialist palliative care.
7. Ensure a greater focus on community awareness on death and dying, palliative care and advance care planning.
8. Palliative care should be a priority of the National Federal Reform Council, National Cabinet and the Health Council, supported by the appointment of a National Palliative Care Commissioner (PCA has previously called for palliative care to be a COAG priority).

Further to this plan, PCA has also made some key recommendations, stemming from the COVID-19 pandemic:

1. Funding infrastructure for aged care providers that currently do not have adequate telehealth capability.
2. Continued commitment by the aged care sector to adopt compassionate and balanced approaches to aged care visitors, especially for residents receiving palliative care. This includes an understanding that palliative care is not only limited to the last days/hours of a resident's life.
3. Investing in a national system to ensure residential aged care facilities (RACFs) have imprest stock of essential palliative care medications and the ability to change levels in response to emergency events.
4. Continued investment by the Australian Government to increase Australia's supply of Personal Protective Equipment (PPE) and essential medications held in the National Medical Stockpile.
5. Establishing systems to ensure that residential aged care and community care providers have guaranteed supplies and access to approved PPE, as well as appropriate training in its use and disposal.
6. National consistency in the granting of exemptions from influenza vaccination requirements (including on compassionate grounds) – as well as to the proof of vaccination ordinarily required.
7. A proactive and coordinated approach to allow the delivery of best practice infection control and individualised clinical care in facilities that have COVID-19 outbreaks with national guidance on integration of health services and residential aged care, communication and shared decision-making with residents and their families. This needs to include approaches to manage scenarios where clinical care requires the resident to move between and across settings.
8. Provision of timely and appropriate mental health, grief and bereavement and employee assistance programs, and support for aged care workers, families and residents.
9. Increased measures to ensure that aged care professionals support a best practice approach to advance care planning and planning for future clinical problems with their residents, ensuring residents and their families are provided with information from professionals who are equipped to explain their specific condition and treatment options, as part of regular ongoing conversations and care planning. This provides a basis for further conversation and shared decision-making in relation to preferences for end-of-life care in the context of a pandemic.
10. In line with the ***National Palliative Care Strategy 2018*** and in recognition that if Australia experiences further waves of the current COVID-19 pandemic or other pandemics of a similar nature, the demand for palliative care will grow and increased investment in palliative care in aged care will be needed to ensure that residents are provided with the high-quality palliative care where and when it is needed.
11. The development of pandemic triage guidelines and a 'crisis palliative care' guidance strategy to bring together learnings and strategies from the current COVID-19 pandemic to be applied in other pandemic and crisis situations where increased numbers of people dying is possible.

As PCA has already covered a range of issues relating to palliative care in aged care in previous submissions to the Royal Commission, this submission will focus on the findings and recommendations of a recently released report commissioned by PCA into the economics of investing in palliative care, and the palliative care needs of diverse and underserved populations.

The Economic Value of Palliative Care

Currently in Australia, around 160,000 people die each year. This will reach 200,000 by 2030[1]. The great majority of these deaths are what is described as 'expected' or 'predictable' deaths, that includes many people who have had terminal conditions, or have been elderly and frail.

As Australia's population rapidly ages, and also grows, it is expected that more people will live longer but with more complex chronic conditions, including dementia. The need for palliative care and advance care planning will consequently surge, and specialist palliative care may be needed for more people, for longer periods of time.

Recognising these future trends, 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* (2020) (referred to in this submission as *the KPMG Report*- see Appendix A for full citation) noted that the provision of palliative care in residential aged care has actually been declining while complexity of need has been growing. KPMG found in particular that::

- In 2017, 36 per cent of all deaths in Australia occurred in residential aged care facilities (RACFs), that is almost 1 in 4.
- The volume of people with complex care needs in residential aged care has grown rapidly in the last ten years. In 2008-09, 10 per cent of residents in aged care had highly complex needs; by 2017-18 this rate had risen to more than half (53 per cent).
- The number of permanent residential aged care admissions and residents related to palliative care has been on the decline. Between 2013 and 2018, permanent admissions dropped by half, from 8 per cent of total admissions to 4 per cent of total admissions.
- In 2018-19, only one in 50 permanent residents received Aged Care Funding Instrument ACFI-funded palliative care.

The report recommends an increase in funding of $75 million per annum for palliative care within residential aged care. This investment should include both direct specialist palliative care services and integrated support that includes the residential aged care workforce and other health professionals such as General Practitioners (GPs) and Nurse Practitioners.

KPMG provides the example of the INSPIRED trial 'needs round' concept that uses Nurse Practitioners to provide proactive, integrated palliative care to high complex needs individuals in RACFs. KPMG estimates that a $75 million investment in this kind of initiative would fund an extra 265 staff per annum to provide specialist palliative care support. Such investment, tailored to jurisdictions and local circumstances, is estimated to deliver between $135 million and $310 million in reduced hospitalisation and emergency transportation costs, and free up between 100,000 to 220,000 hospital bed days, or up to 600 beds at full utilisation. In addition, the report also finds that a $1 investment in palliative care nurses in residential aged care can return between $1.68 and $4.14 in savings elsewhere in the health and aged care system.

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[1] Australian Bureau of Statistics (2012). *3222.0 Population Projections, Australia, 2012 (base) to 2101*. (Accessed at: www.abs.gov.au/ausstats/abs@.nsf/mf/3222.0)

Additionally, investment in advance care planning is estimated to save between $395 and $1,783 per person in health costs during the last year of life, due to reduced hospitalisations costs, reduced intensive care unit costs and reduced emergency department costs. KPMG estimates that a $1.00 investment in advance care planning can return on average between $0.47 and $2.99.

Based on the KPMG report, it is clear that investment in palliative care can assist in avoiding the higher costs of care elsewhere in the health sector.

Home Care

In its report, KPMG estimates that the proportion of deaths that occur at home is between 4 and twelve per cent of all deaths in Australia. This contrasts with some estimates that suggest up to 70 per cent of Australians wish to die at home.[2] An increase in appropriately funded and staffed home care services would help to link aged care recipients to specialist palliative care services, support advance care planning and enable people to remain in their homes for longer. Staff who have been trained to understand differences in illness trajectories and recognise distress due to unmet palliative care needs would better support care recipients to receive appropriate and timely care, and avoid early entry to residential aged care or hospital.

The recommendations in the KMPG report align closely with PCA's previous palliative care in aged care recommendations:

- *Recommendation 2.2: Explicitly identify palliative care in the Aged Care Quality Standards.* Palliative care in residential aged care is often confined to the last hours of life and not systematically integrated into the core business of RACFs. While the current Aged Care Quality Standards contain components of palliative care they do not effectively describe the expectations for palliative care in a holistic or systematic manner.
- *Recommendation 4.4: Expand the palliative care workforce and increase palliative care literacy across the wider health sector.* Palliative care education and training should be compulsory for all staff in RACFs. Vocational education and training (VET) for aged care workers, specifically Certificate III in Individual Support and Certificate IV in Ageing Support should include palliative care as mandatory units in recognition that palliative care is core business in aged care.
- *Recommendation 4.3: Develop a palliative care minimum dataset.* Routine collection of a wide range of palliative care service data can be used to improve service delivery as current data and information related to palliative care are not integrated or are incomplete. This minimum dataset could be collected by the Australian Institute of Health and Welfare (AIHW) and be able to be linked with other AIHW datasets across inpatient and community settings.

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[2] Productivity Commission (2017) '*Introducing competition and informed user choice into human services: Reforms to human services*', Report No. 85, Canberra. Accessed at: https://www.pc.gov.au/inquiries/completed/human-services/reforms/report

- *Recommendation 4.5: Deliver community awareness and education programs*. Palliative care and discussions about dying need to become core business so that people and their families and carers feel empowered to be active participants in their end-of-life decisions. Continuous community education and awareness are essential to mobilise appropriate use of palliative care and normalise discussions about dying.
- *Recommendation 4.1: Establish a permanent National Palliative Care Partnership Agreement with State and Territory Governments and appoint a National Palliative Care Commissioner.* A lack of service coordination has resulted in poor access across the aged care system, especially for those who require palliative care. A State and Federal partnership agreement would define the levels of responsibility across each stakeholder, and form a united front for promotion and delivery of palliative care across Australia. A National Palliative Care Commissioner would act as a champion for improved awareness and promotion of palliative care. An independent board of experts and policy makers could oversee the Commissioner.

Palliative Care for Diverse Needs and Underserved Populations

Older Australians have a diverse range of life experiences, cultural backgrounds, religion, spirituality, sexuality, socio-economic status and geographic spread. Some older people with diverse needs may experience exclusion, discrimination and barriers to accessing appropriate health and aged care services. The *Aged Care Act 1997* (Cth) acknowledges these barriers by specifying nine groups of people with special needs that should be considered in the planning and delivery of aged care:

- people from Aboriginal and/or Torres Strait Islander communities
- people from culturally and linguistically diverse (CALD) backgrounds
- people who live in rural or remote areas
- people who are financially or socially disadvantaged
- people who are veterans of the Australian Defence Force or an allied defence force including the spouse, widow or widower of a veteran
- people who are homeless, or at risk of becoming homeless
- people who are care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations)
- parents separated from their children by forced adoption or removal
- people from lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) communities.

The Aged Care Diversity Framework (Diversity Framework) seeks to embed diversity in the design and delivery of aged care and support action to address barriers to care using a human rights based approach:

> *Quality care ensures that the dignity and human rights of each individual is embraced. It also requires that the diverse characteristics and life experience of the individual, that may influence their care needs, are met.*[3]

The Diversity Framework is underpinned by:

- Aged Care Diversity Framework Government Action Plans, Consumer Actions Plans and Providers Action Plans.[4]
- The following requirements under the Aged Care Quality Standards:
  - **Requirement (3)(a):** Each consumer is treated with dignity and respect, with their identity, culture and diversity valued.
  - **Requirement (3)(b):** Care and services are culturally safe.[5]

Despite these initiatives, there continues to be a range of older Australians who struggle to access appropriate and timely palliative 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. The aged care industry needs to better understand the barriers to care and the reasons why some populations may be underserved. There also needs to be broader awareness of culturally safe care and, how to deliver this to care recipients. supported by workforce training and stronger enforcement of the relevant Aged Care Quality Standards.

Access to services

There are many barriers that older Australians with diverse needs face when accessing services, including:

- Perceived or actual racial/gender/sexual orientation bias, discrimination and stereotyping at individual and/or service level. This includes care provided without touching the person or with excessive precautions.
- Services refusing care due to cultural identity, sexual orientation, gender identity or HIV status. This may lead to people feeling compelled to hide their cultural background, sexuality, transgender or intersex status and HIV status for fear of negative responses.
- Feelings of uncertainty, fear and distrust due to past and ongoing experiences of discrimination in health care settings.
- Historical trauma experienced by some groups, leading to reluctance to access mainstream services. This includes:
  - Intergenerational trauma, family removal and medical abuses experienced by Aboriginal and Torres Strait Islander peoples;
  - Criminalisation, persecution and medical abuses experienced by LGBTI people;

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[3] Aged Care Sector Committee Diversity Sub-group, December 2017, *Aged Care Diversity Framework*

[4] Australian Government Department of Health, *Aged Care Diversity Framework Action Plans*, https://www.health.gov.au/resources/collections/aged-care-diversity-framework-action-plans

[5] Aged Care Quality and Safety Commission, *Standard 1. Consumer Dignity and Choice*, https://www.agedcarequality.gov.au/providers/standards/standard-1

- Discrimination and persecution faced by people from CALD backgrounds;
- Persecution, exposure to conflict, physical deprivation, torture and other human rights abuses experienced by refugees and asylum seekers;
- Post traumatic stress disorder (PTSD) brought on by conflict experiences for veterans; and
- Family removal and institutional abuse of care levers.

- High rates of chronic disease and low access to prevention and screening services.
- Perceived or actual lack of culturally appropriate services and health practitioners.
- Isolation and lack of a practical support and advocacy network due to family removal or separation.
- Lack of staff knowledge of issues affecting diverse populations.
- Higher likelihood of financial hardship.
- Lack of access to suitable transport, increased travel times and distances and/or having to receive services away from home and family.
- Insecure or poor housing and lack of adequate sites to receive palliative care.
- Communication and language barriers.
- A lack of knowledge of the Australian health care system
- For asylum seekers, not being granted access to Medicare and the PBS while their application for asylum is being processed
- In the case of refugees, variable access to Medicare and the PBS depending on their visa type.

Culturally Safe Care

PCAs believes that quality palliative care for all Australians is a human right. Palliative care services should be accessible, inclusive and affirm a person's right to dignity and respect. It is important that all aged care providers create a culturally safe and inclusive environment that allows people to live and die with equity, respect and dignity, and without fear of prejudice and/or discrimination. Their self-designated family and chosen carer(s) should be treated with the same dignity and respect.

Care recipients, their families and carer/s determine culturally safe care. Cultural safety is individually determined, and varies between and within cultural groups. Cultural safety results from care provided where there is no challenge of the care recipient's identity, needs, expectations and rights.

Aged Care providers need to ensure they are delivering culturally safe palliative care and end-of-life care including:

- Awareness of cultural customs and practices, particularly those surrounding treatment, medication, end-of-life, grief and bereavement.
- Respect for Aboriginal and Torres Strait Islander people and their connection to their traditional country.
- Awareness of, and respect for, each individual's family structure including biological, cultural and friendship networks.
- Awareness of factors that may influence the responses of the care recipient, family and carer(s) to illness, end-of-life and related issues.

- Effective communication, including access to trained and qualified interpreters and translated materials for care recipients and their families. This includes an understanding that proficiency in English does not necessarily translate to a full understanding of complex conversations around health, death and medical terminology.
- Knowledge of how to approach important concepts including disclosure, consent, decision-making and conflict resolution.
- Developing and implementing protocols for identifying how and when to consult for further expertise including accessing interpreters, liaison officers and other support workers.
- Building networks with local cultural and community groups, particularly those that represent the diversity of care recipients at the service.
- Supporting care recipients to access culturally appropriate activities including art, dance, music and religious services.
- Advocating for clients, especially those that have limited or no family support.
- Effective procedures to address discrimination and breaches of confidentiality by staff and other service users.

Culturally unsafe care can lead to unnecessary distress for the care recipient, their family and carer/s, and reduced willingness to seek health care in the future. A diagnosis of a life-limiting condition is distressing enough without the additional concerns of isolation, inequality and discrimination from aged care providers. It is essential that staff treat all people in a respectful, person-directed manner, and maintain their physical, social, cultural, spiritual and emotional wellbeing.

The delivery of culturally safe care can be further supported by ensuring that staff undertake education and training on the provision of palliative care and end-of-life care to vulnerable groups, as well as more broadly across the general population. Providers can also access accredited training and materials produced under the Aged Care Diversity Framework.[6]

Culturally Specific Services

The ongoing funding and establishment of culturally specific aged care services can support older Australians to receive services tailored to their specific needs. This can include services for Aboriginal and Torres Strait Islanders, CALD groups, veterans and people who are homeless or at risk of becoming homeless. These services can ensure that people receive care specific to their individual needs whilst ensuring they are free from discrimination, fear and bias. They can also recruit staff that can provide care in the appropriate language, have community connections and have an experience of the person's culture, religion and/or lived experience.

Culturally specific services often have high operational costs due to the need to recruit specific staff, caring for care recipients with a higher burden of disease, providing tailored services and activities and the costs of constructing custom-made facilities. There needs to be a recognition by government of these higher costs and support provided through increased funding, flexible care models and increased services.

[6] Australian Government Department of Health, *Working with Diverse Groups in Aged Care*, https://www.health.gov.au/health-topics/aged-care/providing-aged-care-services/working-in-aged-care/working-with-diverse-groups-in-aged-care

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); and
- **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)

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);
- Appearance at the Perth hearings by the PCA Board Chair (June 2019);

KPMG 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