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## PALLITIVE CARE AUSTRALIA

# RESPONSE TO THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY CONSULTATION PAPER - AGED CARE PROGRAM REDESIGN: SERVICES FOR THE FUTURE

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## Introduction

**Palliative Care Australia (PCA)** is the national peak body for palliative care.

Palliative Care Australia represents all those who work towards high quality palliative care for all Australians. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.

We believe quality palliative care occurs when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community.

This submission builds on previous PCA submissions and engagement with the Commission, including:

- PCA Submission to the Royal Commission into Aged Care Safety and Quality (October 2019): <https://palliativecare.org.au/wp-content/uploads/2019/11/PCA-Submission-to-the-Royal-Commission-into-Aged-Care-Quality-and-Safety-October-2019.pdf>
- PCA Issues Overview: [https://palliativecare.org.au/wp-content/uploads/dlm\\_uploads/2019/07/Palliative-care-in-aged-care-Royal-Commission-Issues-Overview-May-2019.pdf](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/07/Palliative-care-in-aged-care-Royal-Commission-Issues-Overview-May-2019.pdf)
- PCA Board Chair Witness Statement: <https://agedcare.royalcommission.gov.au/hearings/Documents/exhibits-2019/27-june/WIT.0159.0001.0001.pdf>
- PCA Appearance at the Perth hearings in June by the PCA Board Chair: <https://agedcare.royalcommission.gov.au/hearings/Documents/transcripts-2019/transcript-27-june-2019.pdf>

- Palliative Care Common Ground Propositions:  
<https://agedcare.royalcommission.gov.au/hearings/Documents/exhibits-2019/24-june/exhibit-7-7-perth-general-tender-bundle/RCD.9999.0092.0001.pdf>

PCA's principal submission makes 25 recommendations to the Commission, including:

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 includes both health and aged care.
5. Funding is needed to fully implement the National Palliative Care Strategy 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. Greater focus on community awareness on death and dying, palliative care and advance care planning.
8. Palliative care should be a COAG priority supported by the appointment of a National Palliative Care Commissioner.

### What is palliative care?

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life. Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness, ranging from palliative care when their needs are straightforward and predictable, to specialist palliative care when there are complex and persistent needs.<sup>1</sup>

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<sup>1</sup> Palliative Care Australia (2018), *Palliative Care 2030 – working towards the future of palliative care for all*, PCA: Canberra.

Palliative care is a human right. 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, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.<sup>2</sup>

PCA subscribes to the World Health Organisation (WHO) definition of palliative care:

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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.<sup>3</sup>

## The Australian Context: The National Palliative Care Strategy

PCA welcomed the release of the National Palliative Care Strategy (2018). The National Palliative Care Strategy represents the commitment of the Commonwealth, state and territory governments to ensuring the highest possible level of palliative care is available.

The Strategy is intended to provide direction and accountability so that people affected by life-limiting illnesses are able to receive the care they need and can live their lives as fully as possible.<sup>4</sup>

Further, the Strategy highlights the need to plan for the increasing demand for palliative care as the Australian population ages and people with chronic disease and disability live longer:

***“Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care when and where it is needed.”<sup>5</sup>***

<sup>2</sup> WHA, Resolution WHA69.17, *Strengthening of palliative care as a component of comprehensive care throughout the life course*, May 24, 2014.

<sup>3</sup> World Health Organisation, WHO Definition of Palliative Care: <https://www.who.int/cancer/palliative/definition/en/>

<sup>4</sup> Australian Government, *National Palliative Care Strategy* 2018.

<sup>5</sup> Australian Government, *National Palliative Care Strategy* 2018. Page 20

The measure of success is always that there are services on the ground for palliative care patients when and where they need them. This is critical for older Australians who are living with life-limiting illness.

Some 35 per cent of all Australians who die do so in residential aged care, equating to approximately 60,000 people each year.<sup>6</sup> Staff working in aged care therefore need to be suitably trained and equipped to work with residents and consumers who have palliative care needs, and their families.

Redesign of the aged care system should support full and robust implementation of the National Palliative Care Strategy. In order to achieve effective implementation, PCA argues for the creation of a National Palliative Care Commissioner tasked with working across jurisdictions and with the broader palliative care community to ensure the Strategy's priorities are addressed and its goals are met.

PCA notes and applauds the creation of a Palliative Care and End-of-Life Project Reference Group in 2020 under the Health Services Principal Committee of the Australian Health Ministers Advisory Council. However, this is still – in effect- a sub-committee of a sub-committee of a sub-committee and may lack the authority to achieve the Strategy's objectives.

### Palliative Care and Aged Care

As the Australian population ages, the number of people dying with chronic conditions, and in many cases complex needs, will increase. Due to the confluence of an ageing population and the increased acuity of residents and consumers, particular focus on palliative care is required in aged care.

The following is a response to particular questions raised in the Royal Commission into Aged Care Quality and Safety – *Aged Care Program Redesign: services for the future* released in December 2019. PCA has sought the input of our Member Organisations in preparing this input.

Design questions:

**1. What are your views on the principles for a new system, set out on page 4 of this paper?**

PCA supports the proposed principles and in particular acknowledges that there is a specific principle to:

- Support older people to have a good death

PCA considers it would be appropriate to extend this principle to be:

- Support older people to have access to palliative care when and where they need it and to have a good death.

It is important here to state that these principles need to be supported by the Aged Care Quality Standards.

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<sup>6</sup> Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. page 109.

PCA reiterates that in order to drive improvement in the provision of palliative care in aged care, it is critical that palliative care be recognised as core business for aged care.

Palliative care therefore must be included within the organisational requirements of the Aged Care Quality Standards.

The fact that palliative care has not been included in the Standards puts them out of step with the Government's own National Palliative Care Strategy 2018, which includes 'Goal 7 – Accountability' with 'Priority 7.5 indicators for quality palliative care are reflected in the accreditation processes of all care settings'.<sup>7</sup>

## 6. Care Stream

***As people's care needs increase and go beyond what can be managed with entry-level support or with their carer, they may need care services – personal care, as well as nursing and allied health. What are the advantages and disadvantages of developing a care stream, independent of setting?***

Palliative care receives only a brief mention in the consultation paper. It is important to recognise that many people receiving aged care services, particularly in Residential Aged Care Facilities, also require some level of palliative care, or will in the not too distant future. Some people will need access to specialist palliative care. Others living with life-limiting illness may have needs that are straightforward and predictable, which can effectively be met through their existing health and aged care teams.

Palliative care should be a core part of training for staff working in the aged care sector. It cannot be left solely to a consulting Specialist Palliative Care service, who is not going to be present 24 hours a day.

It is in the Residential Aged Care Facilities, where presence or lack of knowledge and understanding about palliative care can have the greater influence on the quality of care at end-of-life and how well the person dies.

Complex palliative care needs may include the presence of multiple co-morbidities that may increase the likelihood of additional symptoms such as pain, nausea, vomiting or breathlessness and may include symptoms related to polypharmacy. However, complex care needs often go beyond physical symptoms to include psychosocial or spiritual issues or conflict between family and patient.<sup>8</sup> These complex palliative care needs may require support through the secondary provision of specialist palliative care. Specialist palliative care comprises multidisciplinary teams with specialised skills, competencies, experience and training in palliative care.<sup>9</sup>

It is important, therefore, for general practitioners and aged care staff to be able to identify when specialist palliative care is required, as quality palliative care occurs when strong networks exist between a person's health and aged care professionals across all settings.

<sup>7</sup> Australian Government, *National Palliative Care Strategy 2018*.

<sup>8</sup> Dr Jane Fischer in Transcript of Proceedings Royal Commission into Aged Care Quality and safety 27 June 2019 page 2764.

<sup>9</sup> World Health Organisation (2018) Fact sheet: Palliative Care [accessed online], Palliative Care Australia, 2018 Palliative Care Service Development Guidelines.

A key concern of PCA is the quality and availability of after-hours care including weekend care for residents. Residents and their families need assurance that appropriate care will be provided in any 24-hour period including on weekends.

In its Submission to the Royal Commission into Aged Care Quality and Safety (October 2019)<sup>10</sup>, PCA called for appropriate staff mix at all hours with the staffing sufficient to ensure residents are able to receive palliative pain medication and symptom management at any time of the day or night.

There should also be capacity within the staff to respond in emergency situations even if they occur after-hours.

#### Home Care Packages:

Palliative care needs to be part of any care stream linked to home care packages (HCPs). PCA appreciates the competing priorities for people requiring a home care package and supports a single package assignment process which ensures equity of access. However, the time critical nature of the need for care for people living with a life-limiting illness with a short prognosis needs to be considered when assessing priority for access to an HCP.

PCA is also concerned that the level of funding available for people with a life-limiting illness is currently often inadequate within an HCP. People may require increased personal care and continence support, nursing support and hire of expensive equipment including lifters. For people in remote areas, the cost of freight often costs more than the equipment they require. For some Aboriginal and Torres Strait Islander people wanting to return to country to die, the travel costs can be exorbitant. Many people therefore end up needing to move to residential aged care, with the higher associated costs to the community, than being able to be supported at home as their needs increase, which may be their choice.

PCA believes that a palliative care supplement would better meet the unique needs of people living with a life-limiting illness. The palliative care supplement could operate similarly to the dementia and cognition supplement<sup>11</sup> and be accessed by people on any level HCP and would provide greater support in a more timely manner, which is essential for people living with a life-limiting illness. A higher package level would only be available to a very small number of people and the process for access would necessarily disadvantage people with a short prognosis as is currently the case.

## **7. Specialist and in reach services**

**How could the aged care and health systems work together to deliver care which better meets the complex health needs of older people, including dementia care as well as palliative and end life care? What are the best models for these forms of care?**

There are models in place for specialist aged care, dementia care and palliative care that can be replicated. There is potential to share successful models by identifying strengths in successful palliative care models and piloting these to other areas, particularly in relation to providing care

<sup>10</sup> PCA Submission to the Royal Commission into Aged Care Safety and Quality (October 2019): <https://palliativecare.org.au/wp-content/uploads/2019/11/PCA-Submission-to-the-Royal-Commission-into-Aged-Care-Quality-and-Safety-October-2019.pdf>, page 15.

<sup>11</sup> Department of Health The dementia and cognition supplement in home care <https://agedcare.health.gov.au/aged-care-funding/residential-care-subsidy/supplements/the-dementia-and-cognition-supplement-in-home-care>.

for disadvantaged groups. A redesigned aged care system should build on established services and not replace them, which would just fragment the services further.

For metropolitan areas, and larger regional centres, the concept of residential in-reach has strong support, and an in-reach service that is able to combine both geriatric and palliative care skills has much to commend it. Most geriatricians are able to manage the more straight-forward behavioural challenges of dementia and straight-forward end-of-life care. Access to General Practitioners and Nurse Practitioners as and when needed are important. Having good relationships with community palliative care and bringing the specialist service in when needed is essential. The residential in-reach model could also be extended (not duplicated) to enable visits to a person's home for consultations. In more remote areas, access to the more specialised skills is always a challenge but funding for tele-health consultations would help to reduce some of the inequity.

PCA contends that palliative care in aged care needs to improve in terms of general palliative care skills and awareness within aged care and extend to improving access to specialist palliative care when needs become more complex. Residents need better clinical support and all aged care workers and health staff involved need to provide improved symptom management, advance care planning and medication management.<sup>12</sup>

Other priority areas raised by PCA Member Organisations include:

- Improving continuity across the care continuum, particularly in relation to transitions between home-based care to acute care to aged care facility.
- Increasing the number of early Advance Care Planning discussions.
- Increasing the awareness of consumers about the value and role of palliative care.
- Ensuring all aged care services have access to a specialist palliative care service according to the Palliative Care Services Development Guidelines.<sup>13</sup>
- Exploring the feasibility of a 24-hour support service for aged care providers to access generalist and specialist palliative care advice.
- Improving transitions between facilities and services and explore the role of transition coordinators/nurse navigators in generalist palliative care service delivery.
- Create palliative care graduate positions (with an associated program of training and support) for clinicians based in geriatrics and general medicine.
- Integrate specialist palliative care services into settings beyond hospital including community and residential aged care to support Australians across the lifespan who prefer to die at home.
- Invest in communications technologies that support collaborative practice between hospital-based specialist services and (1) community-based generalist services; (2) rural and remote specialist services; and (3) community-based specialist services.
- Align reimbursement for general practitioners who offer generalist palliative care services to aged care patients with contemporary business models for medical services.

<sup>12</sup> Forbat, Liu, Koerner, Lam, Samara, Chapman and Johnston 2019, 'Reducing Time in Acute Hospitals: a stepped wedge randomised control trial of a specialist palliative care intervention in residential care homes. Forthcoming.

<sup>13</sup> PCA, (2018), *Palliative Care Service Development Guidelines*, Canberra: PCA.