

July 2020

Palliative Care Australia

Submission on the Reimagined Personal Care Worker Discussion Paper

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 welcomes the release of the *Reimagined Personal Care Worker Discussion Paper* and the opportunity to submit a response. PCA previously wrote to the Aged Care Services Industry Reference Committee on 20 February 2020 regarding the inclusion of palliative care units within aged care certificates III and IV. PCA has also engaged with the Royal Commission into Aged Care Quality and Safety on this issue through a range of submissions, in particular:

- [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 Counsel Assisting's Submission on Workforce](#) (March 2020)

PCA has long argued that palliative care needs to be recognised as part of the normal scope of practice of residential aged care and as a core competency for all aged care workers in both residential and community aged care, including Personal Care Workers (PCWs). During the current COVID-19 pandemic residential aged care facilities have struggled to manage the increased demands of COVID-19 patients, including their palliative care needs. If PCWs were to receive more training in areas such as palliative care, advance care planning, grief and bereavement they would be better placed to handle COVID-19 outbreaks and other emergency events.

Background

In 2017, there were 160,000 deaths in Australia, with 82 per cent aged over 65 years. Some 35 per cent of all these deaths occurred in residential aged care, equating to 57,769 people. While Australians are living longer, 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 and by 2017-18 this rate had risen to 53 per cent.¹ It is therefore essential that staff working in aged care are suitably trained and equipped to meet these increasing palliative care needs and work with residents and consumers who have palliative care needs, and their families.

At the Royal Commission into Aged Care Quality and Safety's (the Commission) Perth hearings on 27 June 2019, a panel of palliative care specialists gave evidence, including the then Chair of PCA, Dr Jane Fischer. The Commissions Counsel Assisting's Submission on Workforce noted that the panellists considered that:

- palliative care should be mandated as part of the training of the aged care workforce;
- the capacity to deliver palliative care by the aged care workforce is presently lacking; and
- palliative care should feature as part of the skill mix in aged care.²

During Palliative Care Week 2020 (24-30 May), PCA commissioned a survey of 1,000 Australian adults across Australia regarding their views on palliative care. The survey found that:

- 85 per cent think it is extremely or very important that aged care services are able to provide palliative care to their clients;
- 56 per cent agree or somewhat agree that palliative care should be core business for aged care services; and
- 62 per cent think that palliative care training should be mandatory for aged care workers.³

This submission focuses on the needs of aged care recipients receiving palliative care and the skills required by PCWs to meet these needs, both in residential and home aged care. However, many of these needs and skills are applicable across the full spectrum of aged care.

¹ 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>)

² Royal Commission into Aged Care Quality and Safety Counsel Assisting's Submission on Workforce, paragraph 106-107, <https://agedcare.royalcommission.gov.au/sites/default/files/2020-03/submissions-by-counsel-assisting.pdf>

³ Palliative Care Australia Community Survey 2020, May 2020 - further details on survey results can be supplied on request

The breadth of care recipients' needs

The World Health Organisation (WHO) defines palliative care as 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 is person and family-centred care and will vary depending on each individual's needs and circumstances. However, there is a range of core needs that individuals and their families need support with, including

- Medication management including relief of pain and other symptoms e.g. nausea and vomiting, shortness of breath. This includes 24 hour access to pain relief;
- Support with, and advice on, food and nutrition, mobility and sleeping;
- Access to equipment to aid care at home or in a residential facility;
- Referral and access to specialist palliative care services when needed;
- Support for emotional, social and spiritual concerns;
- Counselling and grief support;
- Links to other services such as home help and financial support; and
- Early involvement in decision-making, identification of goals and end-of-life care wishes through advance care planning.

Respite

Families are critical to the provision of palliative care and may require assistance to come together to talk about sensitive issues and should be able to access high-quality respite care that is responsive, respectful, culturally appropriate, and which addresses the needs of the person they care for, respecting the person's individuality, and promoting a good quality of life.

Caring for a person with dementia

Appropriate care for people with behavioural and psychological symptoms of dementia is crucial. While the age of diagnosis, speed of onset, severity and type of symptoms of dementia will vary depending on the individual and the disease that initially caused it, ultimately dementia is a life-limiting illness. Dementia is different from other terminal conditions; in part because of the long, unpredictable course of the disease, issues around capacity for decision making, difficulties in communication and lack of community understanding of the disease. Many people living with dementia struggle to access palliative care that appropriately responds to their needs and respects their wishes. Access to palliative care can be especially difficult for people from diverse backgrounds and those with behavioural symptoms of

dementia.⁴ In some instances a person will experience early onset dementia (under 65 onset) and may end up in residential aged care at a relatively young age. These residents need social supports and person centred care that recognises their unique circumstances.

Spiritual and cultural needs

It is also imperative that care recipients are supported to have their spiritual and cultural needs met. Religious and spiritual beliefs can affect decision-making about treatment, medicine and self-care as well as expectations of, and relationships, with health and aged care service providers. Religious and spiritual practices and beliefs may impact the way people understand diagnoses, illness, health, loss and recovery; their strategies for coping with illness and resilience; resources and sense of support; enhance pain management; improve outcomes following surgery; and reduce the chance of substance abuse. People can be better supported to prepare for their final months and weeks of life through reflecting on their life and its contribution, exploring unresolved issues, reinforcing their worth and having their preferences recorded and respected.⁵

The range of the skills required

PCA supports the introduction of mandated minimum qualifications for PCWs working in aged care. In particular, PCA has consistently advocated that palliative care should be a core competency for all aged care workers.

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. In order for staff within aged care to deliver effective palliative care, they must have minimum levels of core competencies to provide care for people with a life-limiting illness whose needs are relatively straightforward and to recognise when referral to other palliative care support is required. These core competencies are transferrable skills that will support PCWs to provide care to a range of care recipients, including those receiving palliative care. These competencies include, at a minimum:

- understanding difference in illness trajectories;
- recognising distress due to unmet palliative care needs
- delivering care appropriate to a care recipients care management plan;
- management of depression and anxiety;
- awareness of the importance of cultural and spiritual care needs;

⁴ Palliative Care Australia and Dementia Australia Joint Policy Statement (May 2018). *Palliative Care and Dementia*: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/04/Dementia-Policy-Statement-2018_Final-New-Template.pdf

⁵ Palliative Care Australia and Meaningful Ageing Australia Joint Policy Statement (May 2017). *Spiritual Care: Integral to Palliative Care in Aged Care*: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/Spiritual-Care-Position-Statement.pdf

- recognising deterioration and dying;
- an understanding of advance care planning and goals of care;
- delivering consistent patient centred care;
- awareness of legal responsibilities;
- effective communication with people living with a life-limiting illness and their carers and families;
- an understanding of grief and bereavement;
- self-care⁶; and
- an understanding of the clinical aspects of palliative care, including pain relief and symptom management.

In addition to these skills PCWs need to have a range of soft skills including interpersonal and communication skills, conflict de-escalation skills and increased comfort in holding discussions about death, grief and bereavement. They should have adequate language skills to understand and support the care recipients who they are providing care including understanding and supporting their cultural and spiritual needs.

Given the high dependence of aged care on PCWs, they must be skilled and equipped to make decisions where needed and in accordance with their skill level, training and experience. There is a broad spectrum of palliative care provision and it is not expected that PCWs could provide the whole spectrum of care. However, they do need to understand the basics of palliative care, what extra support is available and when to refer as needs become more complex. PCWs should know when to escalate care needs to qualified nursing staff who have also received palliative care training and know when and how to access specialist palliative care services. PCWs spend more time with care recipients than nursing and specialist staff and are ideally placed to advocate on their behalf when their needs are not being met.

With the high numbers of people receiving aged care who have dementia, mandatory training including caring for someone with advanced dementia is also required. This includes the assessment of symptoms such as pain and distress, and how to appropriately identify, care for and manage the behavioural and psychological symptoms of dementia.⁷

There are many benefits to the use of telehealth consultations in aged care facilities including to enable access to GPs and palliative medicine specialists, especially in, but not limited to, rural and remote locations. PCWs should be trained to support care recipients in accessing telehealth and providing safe, private and supportive consultations.

⁶ Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019: <https://agedcare.royalcommission.gov.au/system/files/2020-06/WIT.0159.0001.0001.pdf>

⁷ Palliative Care Australia and Dementia Australia Joint Policy Statement (May 2018). Palliative Care and *Dementia*: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/04/Dementia-Policy-Statement-2018_Final-New-Template.pdf

Individual workers versus multi-disciplinary teams

Mandatory qualifications for PCWs in aged care will ensure that they can provide more appropriate and person-centred care. However, PCWs should not be expected to carry the full burden of palliative care for those in aged care. In particular, complex palliative care needs may require support through the secondary provision of specialist palliative care from multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. It is important, therefore, for general practitioners and aged care staff to be able to identify when specialist palliative care is required and referral pathways to initiate consultation.

There must also be a clear delineation of the roles and capabilities of staff within aged care to deliver effective palliative care, and all health and care professionals must have minimum levels of core competencies to provide care for people with a life-limiting illness whose needs are relatively straightforward.

PCA believes that aged care requires the right skill mix and number of staff, available 24 hours a day, to be able to respond to the palliative care needs of residents and consumers so they can be supported to have a high quality of life right to the end of life. Staff need time to be able to carry out clinical assessments and monitoring as well as adequate time to spend with residents which is not task-oriented.⁸

PCA looks forward to being involved in any further discussions around the roles and skills of PCWs that the Aged Care Services Industry Reference Committee undertakes and working together to build a skilled and sustainable aged care workforce for the future.

⁸ Palliative Care Victoria, Palliative Care Consortia Aged Care Projects Survey results, 2018