Submission to the Royal Commission into Aged Care Quality and Safety

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PalliativeCare
AUSTRALIA

Recommended citation

Palliative Care Australia 2019, Submission to the Royal Commission into Aged Care Quality and Safety, PCA Canberra.

Contents

Key points

This submission highlights a range of systemic factors which underpin the poor recognition of, and structural impediments to, the delivery of quality palliative care in aged care and makes recommendations to address them:

- Palliative care should be core business for aged care.
- Aged care policy should align with the World Health Organisation (WHO) definition of palliative care.
- Palliative care should not be restricted to 'end of life' or last days or weeks of life.

Summary of recommendations

Whole of Government

- Improve communication systems between services and sectors to minimise inappropriate transfers, support discharge planning and ensure necessary information is provided at the time of transfer.
- Fully implement the National Palliative Care Strategy 2018 ensuring aged care is included.
- Appoint a National Palliative Care Commissioner.
- Make palliative care a COAG priority.
- Ensure clearer funding and program responsibilities across State, Territory and Commonwealth jurisdictions.

Workforce

- The Australian Government should fund the full implementation of the Aged Care Workforce Strategy.
- Mandatory palliative care training for all those working in aged care including nursing, allied health, medical and care workers.
- Appropriate remuneration for GPs attending residents in aged care facilities and conducting home visits which recognises the complexity of the clinical care required by some older people living with life-limiting illness.

Community awareness and mobilisation

- Fund a sustained multifaceted community awareness campaign to normalise and support discussions of death, dying and palliative care.
- Promote the benefits of advance care planning discussions.
- Promote better understanding of the holistic nature of palliative care so people recognise the benefits of commencing palliative care early after diagnosis with a life-limiting illness.

Research, data and advances in technology

- Establish National Minimum Data Sets (NMDS) for palliative care which includes both health and aged care.
- Introduce a Palliative Care 'Field of Research' with the addition of funding specific to palliative care within aged care research.

Best practice and innovative models

- Palliative care must be included and clearly articulated in the Aged Care Quality Standards.
- Develop and fund innovative models of care to ensure older people have equitable access to palliative care and specialist palliative care.

Grief and bereavement

- Aged care providers should be supported, resourced and funded to provide grief and bereavement support, including for staff.

Funding models

- The operation of the National Prioritisation System for Home Care Packages (HCP) be more transparent.
- Require greater consistency in how priority for HCPs is assessed.
- Simplify all communication with consumers about assessment, approval and assignment of their HCP.
- Additional funding be allocated to reduce the length of time people are waiting for an HCP at the level for which they have been assessed.
- A palliative care supplement be made available for people in receipt of any level of HCP living with a life-limiting illness whose needs exceed the value of their package.
- Undertake a micro study to ensure the new residential funding model (Australian National – Aged Care Classification AN-ACC) adequately addresses palliative care needs.
- The MBS Review Taskforce consider how relevant MBS items can be better aligned with contemporary palliative care clinical evidence and practice, including the roles of general practitioners, nurse practitioners, allied health and community-based specialist palliative care providers.
- The Australian Government should provide adequate funding to ensure timely access to high quality respite care.

Access to medicines

- Anticipatory prescribing for people with palliative care needs should be accommodated by establishing imprest systems in residential aged care.
- Education and ongoing support in handling, storing, administering and disposing of medicines safely to be available to carers and family of older people living at home with a life-limiting illness.

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care, representing all those who work towards high quality palliative care for all Australians. Working closely with consumers, Member Organisations and the palliative care and broader health, aged care and disability care workforce, PCA aims to improve access to, and promote the need for, palliative care.

This submission is underpinned by three key points:

- palliative care should be core business for aged care
- aged care policy should align with the WHO definition of palliative care
- palliative care should not be restricted to 'end of life' or last days or weeks of life.

The Royal Commission into Aged Care Quality and Safety provides a unique opportunity to set the direction for the aged care we want now and into the future. This must include the provision of palliative care in aged care.

With an ageing population and the rise in chronic disease, it is essential that palliative care is recognised as core business for all aged care providers. Aged care staff must be supported by systems, funding and training to provide quality palliative care. At the same time aged care must not been seen in isolation from the health system nor our social constructs. Work must be done to ensure older people do not fall through the cracks created by interjurisdictional and intersectoral policy and funding decisions. Aged care must be a key voice in the implementation of the National Palliative Care Strategy 2018.

PCA notes that 'palliative care' is not included in the terms of reference for the Royal Commission into Aged Care Quality and Safety (Royal Commission), where the Letters Patent included the direction 'for the purposes of your inquiry and recommendations, to have regard to the following matters:…ix. End of life care..'[1] However many of the case studies presented at the hearings of the Royal Commission (at September 2019) have raised significant issues concerning the provision of palliative care in aged care[2] and the term palliative care has been raised 558 times in 27 of the 46 days of hearings (to the end of June).[3]

PCA is providing this submission to the Royal Commission, building on previous communications including the *Issues overview: palliative care within aged care – prepared for the Royal Commission into Aged Care Safety and Quality* (see appendix 1)*, Statement of Dr Jane Fischer* (Voluntary Board Chair for PCA) and *Dr Jane Fischer's testimony* at the hearing held on 27 June 2019, which focussed on person-centred care. PCA also contributed to the documentation of *Common Ground Propositions* on palliative care prepared for the Perth hearing.[4]

This submission aims to focus on learnings from people's experiences as shared with PCA[5] to demonstrate the very real impact the systemic issues have on older people living with a life-limiting illness, their families, aged care staff and the community. Older Australians are not an homogenous group and the examples used in this submission reflect the experiences of people from a diversity of backgrounds.

PCA has outlined a vision for the future of palliative care in *Palliative Care 2030 Working towards the future of quality palliative care for all.*[6] PCA has proposed the following guiding principles to assist policy planners to prepare for the future and work towards ensuring Australians have assured access to quality palliative care in the future.

These guiding principles underpin the work needed in Australia, to ensure everyone including older people receiving aged care services, can receive quality palliative care.

- All Australians have a human right to quality palliative care.
- Australia will maintain the universal health system, and equity of access remains a priority for all levels of government.
- Palliative care is highly regarded as person and family centred, where the individual needs of people who are living with a life-limiting illness, their carers and family will determine which services they access at any given time.
- It is well-accepted that there is benefit in providing palliative care concurrently with disease-modifying therapies in response to changing needs of people living with a life-limiting illness, not only once all treatment aimed at a cure has ceased.

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[1] Royal Commission into Aged Care Quality and Safety Letters Patent 6 December 2018 [viewed online Royal Commission into Aged Care Quality and Safety website]

[2] For example: Alkira Gardens case study Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 27 June 2019; Assisi Aged Care Centre Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 10 July 2019; Bupa Aged Care Australia (Willoughby) Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 13 May 2019;

[3] Mr P Rozen SC, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 24 June 2019, P-2197

[4] *Common Ground Propositions for the Perth Hearing: Palliative Care,* The Royal Commission into Aged Care Quality and Safety, Exhibit 5 – 7 Perth General Tender Bundle Tab 68 – RCD 9999.0092.0001 [viewed online] https://agedcare.royalcommission.gov.au/hearings/Documents/exhibits-2019/24-june/exhibit-7-7-perth-general-tender-bundle/RCD.9999.0092.0001.pdf

[5] PCA has de-identified the experiences and feedback used throughout this submission at the request of those involved. PCA held 8 consultation sessions across 5 states and territories and met individually with service providers and family members between November 2018 and July 2019 who shared their experiences with us. Quotes and feedback received from these consultations are therefore not attributed to individuals but rather referenced to the series of consultations held.

[6] Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.

- Palliative care is available for all ages, encompassing the needs of paediatric populations through to older Australians.
- Grief and bereavement support is not just an integral component of specialist palliative care, but of all healthcare.
- Support and resourcing for the planning and development of culturally safe and culturally aware palliative care services is common place to ensure culturally relevant requirements are addressed.
- When new technologies and advances in health and care are developed, appropriate privacy provisions are in place that are acceptable in the wider community.[7]

Work is required across the following domains to move toward this vision for the future. The recommendations made in this submission are multifaceted having been framed to align with both the domains from PCA's 2030 vision and the seven goals of the National Palliative Care Strategy 2018 ie. Understanding, Capability, Access and choice, Collaboration, Investment, Data and evidence and Accountability.

Acknowledgments

PCA would like to thank our Member Organisations, Affiliate Members and the many people and services who have shared their stories and experience with us, for this submission and the broader work of PCA.

This feedback appears throughout the submission attributed to the consultations held, rather than to the individuals involved at their request.

PCA would like to acknowledge and highlight the dedication, work and creativity demonstrated by the many working in aged care who, on a daily basis, strive to improve the lives of people living with a life-limiting illness.

This submission also acknowledges the many case studies presented during the Royal Commission hearings which have raised issues relevant to palliative care in aged care.[8]

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7. Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.
8. For example: Alkira Gardens case study Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 27 June 2019; Assisi Aged Care Centre Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 10 July 2019; Bupa Aged Care Australia (Willoughby) Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 13 May 2019;

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.[9]

Palliative care, while originally associated primarily with the diagnosis of cancer, is appropriate for anyone with life-limiting illnesses including other chronic conditions, dementia, and non-malignant degenerative diseases.[10]

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.[11]

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.[12]

A person and family-centred approach to palliative care and end of life care accepts that an illness has an impact on both the individual and their family and carers. The focus of care should be on the individual and the family unit which requires effective communication, supported or shared-decision making and respect for personal autonomy. People must be empowered to direct their own care whenever possible, as the more choice and control a person has over their own health and care, the better the outcomes. This is particularly important for those within aged care services that are living with dementia and other types of cognitive impairment.

Barriers to the use of palliative care and aged care services driven by a lack of engagement with community include, but are not limited to:

» communication and cultural issues about the approach to dying

» lack of knowledge and understanding about palliative care and the support this can provide, particularly within Indigenous and CALD communities

» the costs of transport and accommodation to access services that are off country for people living in rural and remote communities and the disruption this results in for the family and broader community

» a lack of understanding and/or policies and procedures of aged care services that impact on the ability of people to follow tradition at the end of life after death.

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.

As the Australian population ages, the number of people dying with chronic conditions, and in many cases complex needs, will increase. In 2014-15 there were almost one in three (29 per cent) people aged 65 years and over living with three or more chronic diseases.[13] Further, eighty percent of people aged over 65 years who die in Australia have used at least one aged care program.[14] Aged care recipients come from many diverse backgrounds. Australians identify with more than 300 ancestries and there are more than 260 different languages spoken in Australia today, including Indigenous languages.[15] Aged care providers need to be supported and funded to deliver palliative care equitably to all care recipients, regardless of background.

'Without significant policy reform, tens of thousands of Australians will die in a way and in a place that does not reflect their values or their choices'.[16]

– Productivity Commission

'Palliative care must be seen as core business for aged care no matter the setting'.

– Dr Jane Fischer, Board Chair for PCA[17]

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[9] Palliative Care Australia (2018), *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.

[10] Department of Health, *National Palliative Care Strategy 2018*

[11] World Health Organisation and Worldwide Palliative Care Alliance (2014) *Global Atlas of Palliative Care at the End of Life* ISBN: 978-0-9928277-0-0 [accessed online].

[12] WHA, Resolution WHA67.19, *Strengthening of palliative care as a component of comprehensive care throughout the life course*, May 24, 2014.

[13] Australian Institute of Health and Welfare 2016, *Australia's health 2016*, AIHW: Canberra

[14] Australian Institute of Health and Welfare 2018. *Cause of death patterns and people's use of aged care: A Pathway in Aged Care analysis of 2012–14 death statistics*. Cat. no. AGE 83. Canberra: AIHW

[15] Commonwealth of Australia (Department of Social Services),2015 National Ageing and Aged Care Strategy For people from Culturally and Linguistically Diverse (CALD) backgrounds

[16] Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Productivity Commission Report 2017

[17] Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.

Most recipients of government funded aged care services are in the last years of their life and they should be supported to have a high quality of life right to the end of life. Aged care providers are not supported by policy or funding to deliver palliative care, resulting in palliative care not being embedded in aged care services and in many there is neither capacity nor models of care that support it.[18]

> *'My attitude …. would be we need to get palliative care into (that) facility….. And it's unfortunate where it gets to the situation where a family member has to say, "I want my mother to die in a hospice because they're not getting good palliative care in their home," which is the aged care facility. I think that's very sad. Obviously, some places do not have services, and then it's, possibly, they may have to die in hospital, they may have to die in a hospice, but if the services can be set up, then that's the best way to provide that care'.*
> **– Associate Prof Peter Gonski[19]**

It is important to distinguish 'palliative care' or a 'palliative approach' from 'specialist palliative care'. As highlighted by the WHO definition, palliative care is care that is provided by all health and aged care professionals involved in supporting people living with a life-limiting illness, their families and carers.

Not all people living with a life-limiting illness will require specialist palliative care. Many people living with a life-limiting illness have needs that may be straightforward and predictable, which can effectively be met through their existing health and aged care professionals.[20] This is still considered palliative care, where aged care services and staff, in conjunction with others including general practitioners, should be able to provide for these needs.

Some people however, may develop more complex and persistent, or intermediate and fluctuating palliative care needs,[21] that go beyond the skills of the treating team to cope with.[22]

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.[23] 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.[24]

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 *(see Figure 1)*.

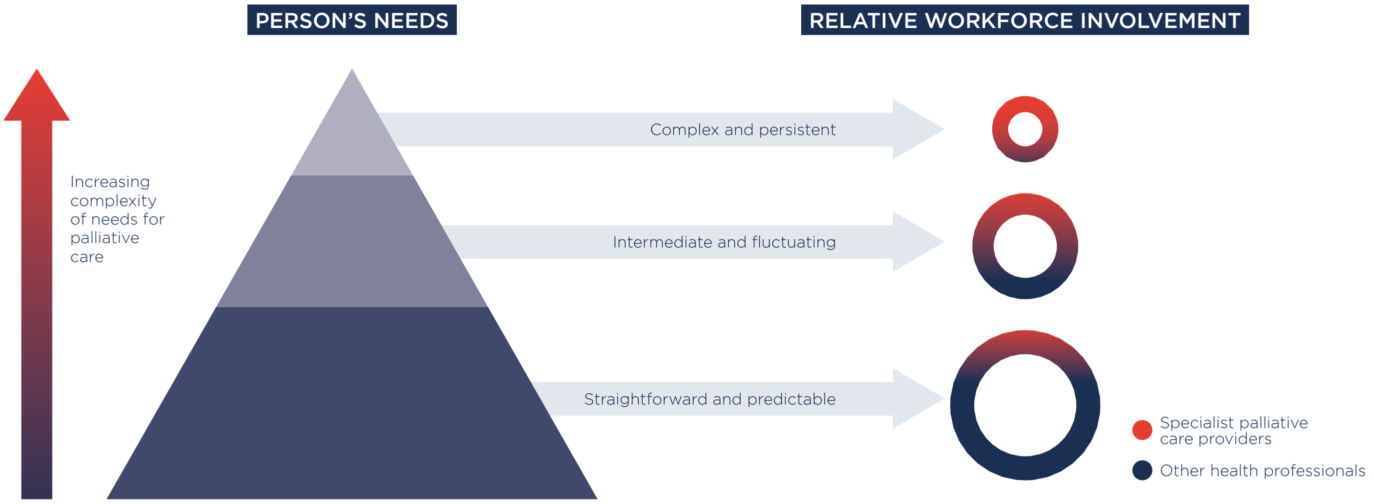

Figure 1: Alignment of need for palliative care against workforce capability[25]

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18. Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
19. Assoc Prof Peter Gonski, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 11 July 2019, P-3227-8
20. Palliative Care Australia 2018, *Palliative Care Service Development Guidelines* – January 2018
21. Palliative Care Australia, *Palliative Care Service Development Guidelines* – January 2018
22. Dr Elizabeth Reymond in Transcript of Proceedings Royal Commission into Aged Care Quality and Safety, 27 June 2019 page 2764
23. Dr Jane Fischer in Transcript of Proceedings Royal Commission into Aged Care Quality and safety 27 June 2019 page 2764
24. World Health Organisation (2018) Fact sheet: Palliative Care [accessed online], Palliative Care Australia, 2018 *Palliative Care Service Development Guidelines*
25. Palliative Care Australia, *Palliative Care Service Development Guidelines* – January 2018

Palliative care is often erroneously associated only with dying and the very 'end of life'. This is particularly true within aged care which equates palliative care with the last days or weeks of life. This can be traced in part to policies and systems that take this narrow definition as detailed in *PCA's Issues overview: palliative care within aged care – prepared for the Royal Commission into Aged Care Safety and Quality*.[26] The Letters Patent establishing the Royal Commission take the same narrow view by only referring to 'end of life'.[27] Yet 'the concept that palliative care is relevant only to the last few weeks of life (when no other treatment is beneficial) is outdated'.[28] Despite the narrow focus in the Letters Patent, at the hearing of the Royal Commission focussing on person-centred care the Counsel Assisting acknowledged that palliative care as the broader term 'will generally be adopted during this hearing'.[29]

The narrow focus on the dying phase means opportunities for earlier support are often overlooked in aged care *(see Figure 2)* despite there being good evidence that:

» Integrating palliative care with disease-modifying therapies improves pain and symptom control, quality of life for the dying person and family satisfaction; and

» Early access to palliative care can reduce aggressive or futile (non-beneficial) therapies at the end of life, prolong life in some patient populations and significantly reduce hospital costs.[30]

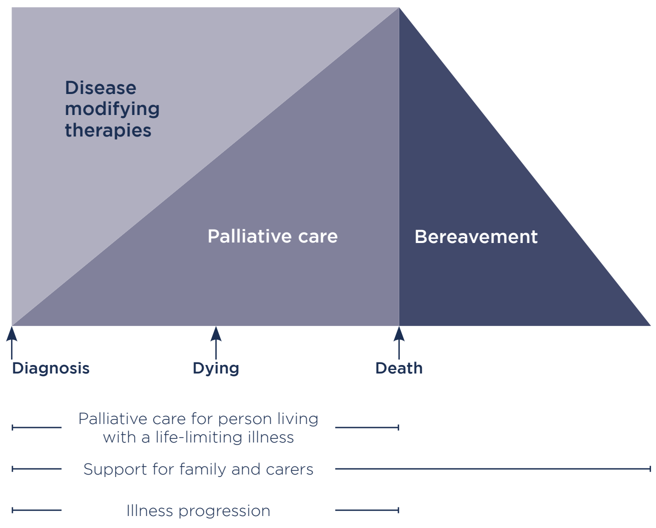

Figure 2: Proposed approach to integrating palliative care[31]

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26. Palliative Care Australia, *Issues overview: palliative care within aged care – prepared for the Royal Commission into Aged Care Safety and Quality*, May 2019
27. Royal Commission into Aged Care Quality and Safety *Letters Patent* 6 December 2018 [viewed online Royal Commission into Aged Care Quality and Safety website]
28. World Health Organisation, Palliative care for older people: better practices (2011) [accessed online]
29. Mr P Rozen SC, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 27 June 2019, P-2208
30. Palliative Care Australia 2018, *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne.
31. Australian and New Zealand Society of Palliative Medicine 2008, Submission to the National Health and Hospitals Reform Commission, ANZSPM: Canberra. In PCA, Background Report to the Palliative Care Service Development Guidelines – January 2018

Whole of Government

One of the greatest challenges for palliative care in aged care is the varying responsibilities across Commonwealth and state and territory governments. There is a need for silos and system impediments to be minimised if equitable access to quality palliative care is to be realised.

Inter-jurisdictional challenges

'Many people are entering residential care for what everybody knows will be a short stay. Palliative care is actually predominantly at the moment a function and responsibility of State Governments, although the Federal Government started looking at improving palliative care in residential care. But residential care providers don't get funded at the level that palliative care gets funded in the rest of the health system.... So there clearly will be part of residential care, that's about the palliation process but that needs to be much more integrated into that process'.

– Ian Yates, Chief Executive, COTA Australia[32]

'Older Australians have increasingly complex care needs that frequently require multidisciplinary services drawn from across the aged care and health care systems. However, funding and jurisdictional boundaries and professional silos can impact on access to care and the care experience for the older person and increase costs for older people and governments'.

– Aged Care Workforce Strategy Taskforce[33]

'There is currently overlap in the roles of the different levels of government, which has led to uncertainty and buck passing over how stewardship is shared and service provision is coordinated across different settings...[consumers] may miss out on specialist palliative care because it is unclear whether it is the Australian Government's responsibility as steward of the aged care system, or the role of State and Territory Governments as providers of specialist palliative care'.

– Productivity Commission Inquiry Report into Human Services[34]

Operational silos create a range of problems with communication and coordination that can impact on the care provided to an older person.

'The timing of discharges from health services are often the result of system issues such as bed management and emergency department ramping, rather than based on the individual's needs. This leads to poor discharge planning and limited provision of information to the facility which impacts the care the person receives on transfer'.[35] This also results in increased stress for family members who are often pressured to quickly find a residential aged care vacancy with little time to determine suitability of the placement.

EXAMPLE

An 88 year old Italian man was diagnosed with mild dementia five years ago. He was recently diagnosed with advanced pancreatic cancer with a 3–6 month prognosis. He is on multiple medications, some of which have increased his confusion. He is not eating, has nausea, vomiting and pain. He is currently in a rehabilitation hospital having been transferred from an acute hospital. His daughter said she felt he was moved to the rehabilitation hospital to free up the bed in the acute hospital, not because he needed rehabilitation. His family has been told he will need to be discharged to an aged care facility as he needs full-time care. His daughter feels the priority is on freeing up the hospital bed, not on what is in the best interests for her father.

His daughter has looked at a number of aged care facilities but is concerned about lack of Registered Nurse and medical support. Aged care facilities she has visited only have one RN available and she is concerned about him receiving medications when necessary and his condition being monitored appropriately.

Her father's current GP does not visit nursing homes, nor does home visits, so he would need to find a new doctor. She is concerned if his condition deteriorated it would take some time for this to be identified and then for a doctor to be called.

His daughter said she feels she is not being given enough information. She said she has spent 'hours and hours' investigating and researching. She said she would prefer to be able to spend quality time with her father rather than spend her time on the internet, phoning people or visiting aged care facilities or having to monitor his care if he goes to an aged care facility.

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[32] I Yates, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 11 February 2019, P-82.

[33] Aged Care Workforce Strategy Taskforce, A matter of care: Australia's aged care workforce strategy, 2018, p 2 cited in Royal Commission into Aged Care Quality and Safety Navigating the Maze: An Overview of Australia's Current Aged Care System – Background Paper 1, 2019 pg 16

[34] Productivity Commission (2017) *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services,* Report No. 85, Canberra.

[35] PCA consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

EXAMPLE

A resident was transferred to hospital from an aged care facility following a fall. When he was transferred back to the facility from the hospital, a referral was made to specialist palliative care. However, the facility was not provided any information, no updated medication list and no discharge summary therefore there was a delay in the person being provided with appropriate pain relief.

The level of support that state and territory funded specialist palliative care provide to residents of aged care facilities or within the home differs greatly with varying eligibility requirements, between and within jurisdictions, based on the interpretation by specialist palliative care as to who should fund what. For example, in Victoria the eligibility criteria for community specialist palliative care services differs for each Local Government Area.

Eligibility for Commonwealth Home Support Program (CHSP) services when in receipt of state and territory funded palliative care support is unclear. While the CHSP Manual states that 'state and territory governments are responsible for the provision and delivery of palliative care and hospice services as part of state health and community service provision responsibilities', it says 'CHSP clients are able to receive palliative care services from their local health system in addition to their home support services', and 'as with any palliative care arrangement, the palliative care team would coordinate the skills and disciplines of many service providers to ensure appropriate care services. This would include working with the client's CHSP service provider(s)'.[36] However, My Aged Care staff undertaking screening, Regional Assessment Service (RAS) and Aged Care Assessment Team (ACAT) assessors often dispute whether a CHSP personal care service should be provided when a specialist palliative care service is involved.[37] Lack of consistency about service provision responsibilities at the state and territory and Commonwealth levels lead to lack of clarity about eligibility, all resulting in delayed or limited services being provided to older people with a life-limiting illness.

EXAMPLE

An older man lived at home with his wife. His care was overseen by the community specialist palliative care team. As his condition deteriorated he was unable to manage his own personal care. His wife was unable to assist him as he was a larger man and she had her own medical issues. He was referred to My Aged Care for assistance with showering. However, when assessed by the Regional Assessment Service he was deemed ineligible for Commonwealth Home Support Program (CHSP) as he was receiving 'palliative care'. The specialist palliative care team while overseeing his medical care, did not provide assistance with showering. The man was admitted to residential aged care because he was unable to receive the assistance with showering and personal care that he needed to remain at home.

EXAMPLE

A 79 year old man with end-stage pulmonary hypertension and a past history of scleroderma was referred to the specialist community palliative care service following discharge from hospital. He had been admitted for infective exacerbations and was oxygen dependent.

Short-term flexible in-home respite was arranged by his Case Manager to support family who were not coping with his care. He was receiving a level 2 Home Care Package (HCP) and while assessed as eligible for a higher level package, he had been placed on the waiting list. As the level 2 HCP was unable to provide the additional support he needed and the family were under considerable financial stress, the specialist community palliative care service provided a personal care assistant to provide additional personal care support in the interim. Other respite options were being explored including short-term inpatient palliative care and admission to an aged care facility. However, he deteriorated rapidly and died at home as was his family's wish.

Aids, Equipment and Assistive Technologies

The ability to access suitable equipment and medical supplies can influence whether people can remain at home or need to be cared for elsewhere. The lack of access to equipment, often because of cost, has been identified as one of the barriers to dying at home.[38] Access to equipment for older people with palliative care needs can be hampered by lack of clarity around Commonwealth and state and territory responsibilities.

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36. Commonwealth of Australia, Department of Health, *Commonwealth Home Support Programme Program Manual* 2018 pg 72
37. PCA consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19
38. Palliative Care Australia, *Palliative Care Service Development Guidelines* – January 2018 pg 19

The list of equipment that may be required in homebased palliative care is extensive. In addition to medical equipment such as syringe drivers, oxygen and intravenous fluids, equipment needs can include commodes, continence aids and equipment, hospital beds, over-toilet seats, patient lifting hoists and slings, pressure relieving mattresses, sheepskins and cushions, shower chairs, walking frames and sticks, wheelchairs and wheelie walkers. Equipment may be accessed through a range of different programs that are variously funded in each of the health, aged care and disability sectors, with some equipment also funded by private health insurers and non-government organisations. In most states and territories, public hospitals also provide some equipment and home modification services for at least some people after a hospital admission to support their return home and rehabilitation.[39] However equipment access is not equitable across the country and different eligibility requirements make it difficult to find out what is available and to access necessary equipment when needed. 'Once someone is deemed 'palliative' they cannot access equipment via CHSP service so care is compromised', 'health services are very reluctant to provide equipment to anyone living in a remote area as they will never see it again', 'freight for equipment (in rural and remote areas) can cost more than the cost of the equipment'.[40]

PCA supports the recommendation of the National Aged Care Alliance (NACA) that 'clearer funding and program responsibilities across state and territory and Commonwealth jurisdictions should be created as a priority to improve consumer understanding regarding eligibility' (for assistive technology).[41]

Implementing the National Palliative Care Strategy 2018

An international study found that the proportion of residents who received palliative care in long-term care facilities (equivalent to Australian aged care facilities) could be related to the establishment of national palliative care policy and guidelines, initiatives aimed at developing palliative care such as care standards or guidelines regarding palliative care provision in long-term care facilities, and organisation of (palliative) care in long term care facilities.[42]

The National Palliative Care Strategy 2018 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. [43]

Due to the importance of fully implementing the Strategy and the need for the aged care sector to be involved in all aspects of implementation, the appointment of a National Palliative Care Commissioner is recommended to:

- Oversee the Implementation Plan, and the Monitoring and Evaluation Plan which will underpin the Strategy; and
- To facilitate improved communication across jurisdictions by encouraging consistent approaches to supporting the palliative care sector across all settings, including primary health, community health, tertiary health, aged care and disability.

✓ PCA RECOMMENDS

- Improve communication systems between services and sectors to minimise inappropriate transfers, support discharge planning and ensure necessary information is provided at the time of transfer.
- Fully implement the National Palliative Care Strategy 2018 ensuring aged care is included.
- Appoint a National Palliative Care Commissioner.
- Make palliative care a Council of Australian Governments (COAG) priority.
- Ensure clearer funding and program responsibilities across State, Territory and Commonwealth jurisdictions.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

- Understanding
- Access and choice
- Collaboration
- Investment
- Data and evidence
- Accountability

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39. Palliative Care Australia, *Palliative Care Service Development Guidelines* – January 2018 pg 19
40. PCA consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19
41. National Aged Care Alliance, Position Paper, *Assistive Technology for Older Australians* June 2018 pg 14
42. M ten Koppel, B D Onwuteaka-Philipsen et al, *Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European counties* in Palliative Medicine 2019, 1-13.
43. Department of Health, National Palliative Care Strategy 2018

Workforce

To inform PCA's submission to the Royal Commission, a number of consultations were held with PCA's member organisations around the country. Workforce issues were consistently identified as requiring attention in order to improve the delivery and quality of palliative care in aged care services.[44] The aged care workforce needs support and funding to make palliative care core business.

Understanding what palliative care is

> *'All health professionals including care staff have a vital role to play in palliative care, where providers across all health disciplines will be required to meet the needs of people who are dying across many settings including aged care'*
>
> **– Aged Care Workforce Strategy Taskforce[45]**

Factors contributing to lower provision of palliative care in aged care include:

- lack of knowledge about palliative care among some nurses and other staff
- limited implementation of effective advance care planning practices, and
- gaps in the availability of suitably trained and experienced staff.[46]

35 per cent of all Australians who die do so in residential aged care, equating to approximately 60,000 people each year.[47] 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.

Understanding what palliative care is, is essential. 'The level of palliative knowledge within the aged care sector varies considerably between, and within, facilities as well as states'.[48] As in the broader community 'there is little understanding in aged care that palliative care is for everyone with a life-limiting illness, not only for people with complex needs who require specialist palliative care',[49] however the need for specialist palliative care is not always recognised. Some specialist palliative care services report they receive the bulk of their referrals for people living in residential aged care from hospital admissions, rather than from the aged care facility, as the need and potential benefit for a person is not always recognised.[50]

> *'The referral for (specialist) palliative care services into aged care facilities … we believe that we are not referred to early enough…. because the rules aren't clearly defined. The referral pathways are not clearly defined. The staff in aged care facilities are not always trained. I'm sure that … people are supported, but not with specialist palliative care'.*
>
> **– Dale Fisher, Chief Executive Officer, Silver Chain Group[51]**

> *'In 2018, we had over 200 clients referred to us from residential aged care facilities who died within three days of admission to our service. We believe that if clients were referred earlier, they would realise greater benefits from our services.'*
>
> **– Dale Fisher, Chief Executive Officer, Silver Chain Group[52]**

Education and training

PCA has long advocated that palliative care should be recognised as part of the normal scope of practice of residential aged care, and as a core competency for all aged care workers.

> *'Aged care nurses need to be – need to have a very diverse skill set. They need to be very proficient in palliative care and complex care and respiratory medicine. They need to be very good at assessing a deteriorating resident. They need to have very good interpersonal skills. They need to have very good conflict de-escalation skills. They need to have very, very advanced leadership skills. You need to be an expert in a number of domains in aged care, and contrary to perceptions within the industry, nurses in aged care have to have a very highly developed skill set to meet the various and many demands that they have within their roles'*
>
> **– Darren Midgley, Chief Executive Officer, Chaffey Aged Care Inc.[53]**

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44. PCA consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19
45. Aged Care Workforce Strategy Taskforce, *A Matter of Care Australia's Aged Care Workforce Strategy* June 2018
46. Palliative Care Australia, *Palliative Care Service Development Guidelines* – January 2018 page 14
47. Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. page 109
48. Urbis, *Evaluation of the National Palliative Care Strategy 2010 Final Report*, September 2016 [Accessed online]
49. Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
50. Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
51. Ms Dale Fisher, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 26 June 2019 P-2561
52. Statement of Dale Fisher, prepared for The Royal Commission into Aged Care Quality and Safety, 26 June 2019
53. Mr Midgley, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 31 July 2019 P-4106

However, a study of nurses and assistants in nursing at high care residential aged care facilities in Sydney identified significant gaps in knowledge of palliative care, highlighting the need for ongoing education in palliative care.[54]

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. This includes, at a minimum:

» understanding difference in illness trajectories;
» management of physical symptoms;
» management of depression and anxiety;
» awareness of the importance of cultural and spiritual care needs;
» recognising deterioration and dying;
» appropriate goals of care discussions;
» advance care planning;
» 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; and
» self-care.[55]

Undergraduate and vocational education and training (VET), including nursing, allied health, medicine and Certificate III in Individual Support and Certificate IV in Ageing Support, do not include palliative care as core units and there is no requirement for aged care providers to include palliative care on their internal training calendars. As a result most people working in aged care have received no formal training in palliative care.

Access to this training should be facilitated by palliative care being a core or mandatory unit in all undergraduate nursing, allied health, medicine and VET certificate based training for those working in aged care.

Skills mix and availability

People 'who require care in residential aged care facilities (RACF) will continue to have more complex healthcare needs because they have remained within the community until they can no longer be safely cared for in that setting. This will require a more highly skilled RACF workforce including skills in palliative care and end of life care'.

– Royal Australian College of General Practitioners[56]

Skills required by the aged care workforce include the ability to recognise deterioration, the need for pain and other symptom management, and the signs of impending death,[57] confidence with medications, especially PRN (Pro Re Nata or 'as needed') medications and education to 'enable staff to understand symptom management, including administering pain relief before personal care'.[58]

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.[59]

There has been much debate about whether or not staff-to-resident ratios should be mandated for residential aged care, yet there is little consensus on the issue.[60] When discussing staff ratios the focus tends to be on registered nurses, rather than other staff. However, there is no one fixed model that suits all circumstances. The outcome PCA seeks when discussing staff numbers, skill and mix, is to ensure that a predictable standard of care is provided and that staffing ensures the ability for timely identification and management of symptoms whenever they occur.[61]

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. PCA calls 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. 'Pain relief options are not always what we would want. Registered Nurses (RN) have many residents and other staff responsibilities'.[62] 'There is just insufficient staff to turn people at night and administer pain

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54. Palliative Care Australia 2018, *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne
55. Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.
56. RACGP submission to the Senate Community Affairs References Committee: Inquiry into the future of Australia's aged care sector workforce, 2016, page 8
57. PCA Media Release, "Budget Shows Palliative Care Should be Core Business in Aged Care," 8 May 2018.
58. Johnston N, Lovell C, Liu W-M, et al. BMJ Supportive and Palliative Care, *Normalising and planning for death in residential care : findings from a qualitative focus group study of specialist palliative care intervention* downloaded from http://spcare.bmj.com/ on August 13, 2017
59. Palliative Care Victoria, Palliative Care Consortia Aged Care Projects Survey results, 2018
60. Royal Commission into Aged Care Quality and Safety, Navigating the Maze: An Overview of Australia's Current Aged Care System – Background Paper 1, 2019 pg 40
61. Palliative Care Australia, *Submission to the Senate Standing Committees on Community Affairs Inquiry on the Future of Australia's Aged Care Sector Workforce*, page 5
62. Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

medication at night'.[63] There should also be capacity within the staff to respond in emergency situations even if they occur after-hours.

EXAMPLE

A woman receiving specialist palliative care was admitted to a small 40 bed aged care service in a rural area. The woman's daughter was concerned that there was no RN available at times and staff on duty gave this as the reason why her mother could not be given certain 'as required' medication 24 hours a day including Mylanta for indigestion. The woman ended up requiring a morphine infusion which caused great concern for the daughter knowing there was no RN available at times to manage this.

The daughter was subsequently advised of her mother's death after several hours delay as the staff of the facility waited for a doctor to certify her mother's death before notifying her.

'About 12 months ago, (we) had a resident who was …end stage palliative care. She was very fearful of hospitals. She made us – you know, wanted us to promise her she would never go to the hospital. Staff went above and beyond to ensure that she was comfortable in her home, she called it, and up until the last 48 hours, we managed to keep her there. That was a lot of volunteer time, people just being with her, sitting with her, and then she had a fall. Thankfully, by that stage, she probably wasn't quite aware that she had been transferred. But that was a major effort and everyone felt so proud that they were pretty well able to keep her wish'

– Gaye Whitford[64]

With the high numbers of people receiving aged care who have a dementia, mandatory training including caring for someone with advanced dementia is also required. 'Residents (can be) labelled as having behaviour changes when in fact they are dying'.[65] 'People are seen as sick rather than recognising they are dying, so end up being sent to hospital – there is a need to upskill staff about what the end of life looks like'.[66]

Without adequate training and skilled staff, there can be a 'fear of giving the last dose' resulting in PRN medications not being given for symptom management for fear that the person will die and the staff will somehow be blamed, even if clinically indicated.[67]

Ongoing information and support

Multipronged approaches to empower residential aged care facilities to better deliver palliative care are needed including free education, clinical assessments and onsite mentoring.[68] An example of a successful program is palliAGED (Palliative Care Aged Care Evidence) which provides palliative care evidence and practice resources for aged care.[69]

Many education programs and projects only get funded for short periods with one-off funding, and when they end there is no follow up. While there are many good education resources available, time, ability to translate the resources into practice and staff turnover make it difficult to sustain change. Without ongoing support, management commitment and service based champions, staff turnover and time constraints erode progress made.

EXAMPLE

A new manager took over an aged care facility. All staff were provided with self-directed palliative care learning modules. This provided a good baseline of knowledge among staff and resulted in improved management of dying over the next few years. [70]

Organisational culture in facilities, including teamwork, communication and leadership, is reflected in the care delivered to residents. [71]

A greater focus on communication skills is important as well as increased comfort holding discussions about dying to ensure better planning for end of life occurs. Staff need to be confident in talking to families about what to expect toward the end of life; to understand the person's wishes for end of life; where they want to die and what is important to them. Confidence in chairing family meetings and case conferences are essential skills for delivering palliative care in aged care. Training alone, however, is not sufficient for embedding skills in these areas. Providing ongoing mentoring and modelling helps to reinforce these skills and builds confidence through provision of feedback.

Successful programs such as Program of Experience in the Palliative Approach (PEPA) and End of Life Directions for Aged Care (ELDAC) have recognised the importance of making available additional support to enable learning to be translated into practice. The PEPA program provides education, clinical placements and Reverse PEPA Placements where a specialist palliative care staff member travels to the applicant's place of employment to facilitate learning.[72] ELDAC includes

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[63] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
[64] Ms Gaye Whitford, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 26 June 2019, P-2534
[65] Palliative Care Victoria, Palliative Care Consortia Aged Care Projects Survey results, 2018
[66] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
[67] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
[68] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.
[69] palliAGED Palliative Care Aged Care Evidence website www.https://www.palliaged.com.au
[70] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19
[71] M ten Koppel, B D Onwuteaka-Philipsen et al, *Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European counties* in Palliative Medicine 2019, 1-13.
[72] PEPA Program of experience in the Palliative Approach, website https://pepaeducation.com/

the option of ELDAC facilitators to support providers who wish to develop palliative care and advance care planning activities within their organisation.[73]

Workforce issues that impact on the provision of palliative care in aged care go beyond staff employed by aged care services. Increasingly, aged care providers report difficulty in arranging GP visits to aged care facilities and similarly not all GPs will do home visits to older people living in the community.[74] In some regions this is due to a shortage of GPs. However, more broadly this reflects a view that current remuneration levels can act as a barrier.[75] [76] This is particularly true for urgent after-hours visits. Feedback to PCA is that these items are not viewed as cost effective for GPs or their practice and it is thus the business model to not provide after-hours visits even for patients who are receiving palliative care.

Lack of timely access to GPs can result in transfer of the person to emergency or hospital care because there is no suitable access to required health professionals or treatment both in the community and within residential care. It may also result in a reliance on locum or delegated GP services meaning treatment and care is decided by practitioners with limited knowledge of the person. Poor continuity of care or a lack of knowledge and/or confidence about the management aspects of palliative medicines, such as legal obligations and opioid prescribing, can result in lack of anticipatory prescribing and ineffective complex pain and symptom management. Risk averse locum GPs may also facilitate unnecessary hospital transfers.

The Aged Care Workforce Strategy

Aged care workforce issues are well known, having been canvassed most recently by the Aged Care Workforce Strategy Taskforce.[77] As the Aged Care Workforce Strategy Taskforce notes, the impediments to those accessing 'aged care' services to also access 'health care' services creates confusion over who has responsibility for managing care needs. This contributes to ineffective management of complex care needs and poor coordination, placing tremendous stress on the aged care workforce to manage complex medical care needs beyond their scope of practice, without adequate support from medical specialists.[78]

Employment conditions and job security impact on staff retention. This leads to staff turnover and lack of consistency in staffing which impact aged care services being able to deliver quality palliative care. Undervaluing the work of caring for people in aged care also influences staff retention. Pay parity for registered nurses and the need for personal care workers to be paid appropriately for the 'mission critical' [79] work they do, is key. Aged care needs 'the right staff, the right amount, paid appropriately', 'people can be paid more stacking shelves at Aldi'.[80]

→ **EXAMPLE**

A local Care Manager was inducting new care workers to her RACFs. One staff member commented that she had originally tried to get work at McDonald's as the pay rates were similar, but because her English language was not good enough she decided on aged care instead.[81]

→ **EXAMPLE**

A 58 year old Indigenous lady couldn't receive the care she needed and had to leave country and move to a nursing home in town. Staff in the nursing home were mostly from overseas and there was a huge staff turnover. In that nursing home no staff member had been working longer than six months and not all of them spoke English well. Many were recent arrivals in Australia and did not have a good understanding of Australian and Aboriginal culture. Care was not culturally adapted, nor person centred.

PCA supports the implementation of the recommendations of the Aged Care Workforce Strategy Taskforce. However, there currently seems to be little urgency in doing so. Aged care workforce issues should not be considered in isolation, but rather considered in the broader health workforce context. The primary health sector, including general practitioners, need to be supported by a robust specialist palliative care workforce, information sharing, appropriate remuneration, referral pathways and education and training options underpinned by clear competency and capability frameworks.[82]

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[73] End of Life Directions for Aged Care, website https://www.eldac.com.au/tabid/4887/Default.aspx

[74] Palliative Care Victoria, Palliative Care Consortia Aged Care Projects Survey results, 2018

[75] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

[76] RACGP – News GP, Residential aged care visits not financially viable for GPs, expert says https://www1.racgp.org.au/newsgp/professional/residential-aged-care-visits-not-financially-viabl

[77] Aged Care Workforce Strategy Taskforce, *A Matter of Care Australia's Aged Care Workforce Strategy* June 2018

[78] Aged Care Workforce Strategy Taskforce, *A Matter of Care Australia's Aged Care Workforce Strategy* June 2018

[79] A Matter of Care Australia's Aged Care Workforce Strategy, Aged Care Workforce Strategy Taskforce, June 2018 page 28

[80] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

[81] Palliative Care Australia, *Submission to the Senate Standing Committees on Community Affairs Inquiry on the Future of Australia's Aged Care Sector Workforce*, (February 2016) page 6

[82] Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.

A National Medical Workforce Strategy is currently being developed and a national workforce development framework for palliative care is proposed as a priority in the National Palliative Care Strategy 2018. It is important that there are strong linkages forged between these and the Aged Care Workforce Strategy and careful consideration is given as to how they will work together.

EXAMPLE

70 year old man with a cancer diagnosis agreed to move to an aged care facility as he lived alone and a home care package was not available. On admission he was clear that he did not want to go back to hospital and when the time came he wanted to remain at the nursing home to die. He had falls almost every day and as a result was found with a decreased level of consciousness. He was transferred to the Emergency Department without the family, GP or 24 hour on-call specialist palliative care service being contacted. The specialist palliative care service saw the man in hospital the next day and contacted the family to tell them he had been admitted. The man had multiple bruises and skin tears from his falls. The specialist palliative care team arranged for him to be admitted to the hospice for the last few weeks of his life. They were concerned about the inadequacy of care, the lack of willingness of the staff to step up and put in place strategies to better manage his care. With only one GP in the community and no locum, it was likely the GP would have arranged for the ED transfer if he had been called even though it was against the man's preference.

EXAMPLE

An 89 year old female with cardiac disease and dementia was living in a residential aged care facility.

Staff at the facility had recognised deterioration with declining function, increased confusion and reduced appetite.

Staff had spoken to the family (three adult children) regarding her changing health status and requesting a review of her goals of care and advance care plan which was for full active treatment. The family were of a CALD background and did not speak English.

The family were in denial regarding her changing health. They had complained that the facility was not caring for her adequately. A family meeting was requested to have a conversation to address the current issues and to communicate clearly the realistic expected outcomes in view of her current decline. The GP was not able to attend.

The meeting was held with the three adult children and the community specialist palliative care RN supported by an interpreter. The family were helped to understand that their mother's current condition was no longer reversible due to the progression of her heart condition. They agreed that she would not benefit from efforts to resuscitate and were accepting of palliative care once they fully understood how it could support her care.

The following day the resident became unwell with a urinary tract infection. The GP was not available so a locum was called who prescribed anti-biotics. The medication was not delivered for 24 hours by which time the resident was delirious. The GP was not able to visit so the family requested transfer to hospital. She died the following day. The palliative care service was not contacted throughout.

✓ PCA RECOMMENDS

- The Australian Government should fund the full implementation of the Aged Care Workforce Strategy.
- Mandatory palliative care training for all those working in aged care including nursing, allied health, medical and care workers.
- Appropriate remuneration for GPs attending residents in aged care facilities and conducting home visits which recognises the complexity of the clinical care required by some older people living with life-limiting illness.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

- Understanding
- Capability
- Access and choice
- Investment

Community awareness and mobilisation

Within our community, there is a lack of awareness and understanding of palliative care that is reflected in our aged care services.[83] People are not comfortable talking about death and dying. Death was once seen as part of everyday life, with people primarily dying at home. However, over the past century death has been removed from the community, becoming more institutionalised and is seen as something to be hidden away.

> *'Seventy per cent of Australians want to die at home yet only 14 per cent do so. Despite their wishes, about half of people die in hospital and a third in residential care'.*[84]
>
> **– Grattan Institute**

Death literacy

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 just like they do about organ donation and having a will.[85]

Work done across the community to normalise discussion of death and dying and grief and bereavement will make care planning discussions more common and more accepted which, in turn, will support the aged care workforce to better be able to facilitate advance care planning within aged care services.[86]

Achieving this requires significant cultural change, requiring sustained community education and awareness to normalise death and dying. This will, in turn, provide a solid basis for improved understanding of palliative care and how palliative care contributes to health and healthy dying.

PCA believes the community needs to be more engaged with palliative care, dying, grief and bereavement and to this end undertakes community awareness activities including the *Dying to Talk* initiative and National Palliative Care Week.

Our health services are often so focussed on keeping people alive, that they can forget that everyone dies and this is not a failure on their part. Unrealistic expectations of modern medicine can also result in delayed referrals to palliative care services and militate against a healthy approach to death and dying.[87] Dying should be given as much focus, care, attention and planning as given to birth.

Aged care policy is currently focussed on wellness and enablement. While this is very important, it is crucial that this focus does not shut down conversations and planning for a person's inevitable death. Both palliative care and wellness and enablement share the common goal of maximising quality of life and both should be able to exist equally within aged care.

There needs to be an enormous public and clinical cultural shift to accept death as a universal health outcome so that end of life issues can be more openly discussed and proactively managed.[88]

Public Health Palliative Care

There is a growing recognition of the importance of public health approaches to palliative care, end of life care and bereavement in Australia, drawing from WHO's Ottawa Charter for Health Promotion to focus on and respond to the medicalisation of palliative care, address the social determinants that influence people's health and wellbeing at end of life and ensure equity of access to palliative care and other supports.[89] PCA encourages the Royal Commission to consider how elements of public health palliative care, particularly models that are led and driven by formal health or aged care services, are demonstrating the development of a person, family and community-centred approach, maintaining strong engagement with GPs, specialist palliative care units and other health care services and building community capacity.

> *'We know historically that the community had a greater role in caring for people with a life-limiting illness and at end of life. While the growth of palliative care as a medical field has made improvements in care and quality of life, there has been an unintended reduction in community skills and 'wrap-around' informal support provided for families and carers by sectors and local communities, leading to increased isolation, and fear through low awareness of palliative care, death and dying.'*
>
> **– Grindrod A, Rumbold B, Healthy End of Life Project[90]**

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[83] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

[84] Swerissen, H and Duckett, S., 2014, *Dying Well*. Grattan Institute ISBN: 978-1-925015-61-4 [accessed online]

[85] Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.

[86] Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.

[87] NSW Agency for Clinical Innovation 2014, Diagnostic report to inform the model for palliative and end-of-life care service provision, ACI: Sydney in Palliative Care Australia 2018, *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne.

[88] Statement of Elizabeth Reymond, prepared for Royal Commission into Aged Care Quality and Safety 30 May 2019.

[89] Department of Health, Final Report: *Compassionate Communities Feasibility Study*, 6 July 2018, Nous Group.

[90] Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. Ann Palliat Med 2018;7(Suppl 2):S73-S83. doi: 10.21037/apm.2018.04.01

The aim is to complement the health, disability and aged care systems through collaborative, community focused care and formal and in-formal partnerships between community members and health, aged and social care providers. This can provide an alternative source of appropriate and sustainable care and support, and reallocate resources of health and aged care professionals to 'formal' palliative care and end of life care. It is also important to draw attention to volunteers in palliative care who offer support and practical help that improves the quality of life of older Australians living with a life-limiting illness and their families, and can often make it more possible for a person to receive care and support in their place of choice for as long as possible. It is estimated that 6,000 people already volunteer in palliative care across Australia, largely through the establishment of not-for-profit groups, to supplement a lack of local services or to enhance the capacity of local community and aged care services. PCA's member organisations have played a significant role in supporting and promoting volunteering in palliative care. In NSW, the number of volunteers engaged in palliative care has increased by 33 per cent over four years.[91] With research showing that the number of hours palliative care volunteers provide is equivalent to 30 per cent of paid full-time employees[92], there is a need to invest in building a strong community to mobilise and support each other.

Advance care planning

There is general confusion in the community about the differences between advance care planning, advance care plans and advance directives and the legality or otherwise of each. Advance care planning is important for everyone but especially for people receiving aged care services.

Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions. An advance care planning discussion will often result in an advance care plan that states preferences about health and personal care and preferred health outcomes and can be made on a person's behalf but guided by their perspective. Advance care directives are one way of formally recording an advance care plan, recognised by common law or authorised by legislation, that is completed and signed by a competent adult. [93]

> *'There tends be to be more of a global movement now towards the conversation, towards moving away from legal set-in-stone documents to having a conversational approach about what you want for your care and advance care planning fits very well with that, whether they're a values-based document or not.'*
>
> **– Dr Elizabeth Reymond[94]**

Advance care planning documents should not replace discussions about the person's values and their preferences for health care. Advance care planning conversations should be undertaken early, not left to be done in a 'crisis' situation or at the 'end of life'.

Mechanisms to support discussions

An important step to achieving community awareness and mobilisation is to work with the community to normalise discussion of death, dying, grief and bereavement. If this occurs it will make care planning discussions more common and more accepted. PCA acknowledges the funding already committed in this area, however cautions without sustained funding and ongoing promotion, early gains will not be sustained.

✓ PCA RECOMMENDS

» The Australian Government to fund a sustained multifaceted community awareness campaign to normalise and support discussions of death, dying and palliative care.

» Promote the benefits of advance care planning discussions.

» Promote better understanding of the holistic nature of palliative care so people recognise the benefits of commencing palliative care early after diagnosis with a life-limiting illness.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

» Understanding

» Access and choice

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91. Bowman, K & Huntir A 2018, Snapshot 2018: a review of palliative care volunteering in NSW. Palliative Care NSW, Sydney.
92. Salau S, 2013, Victorian Palliative Care Volunteering Strategy 2013-16. Palliative Care Victoria, Melbourne
93. Australian Government Department of Health and Ageing, *A National Framework for Advance Care Directives*, Canberra 2011.
94. Dr Reymond, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 27 June 2019 page 2774.

Research, data and advances in technology

There is a significant need for research and a commitment to data collection which focuses on palliative care in aged care. The fragmented and incomplete nature of palliative care data is well recognised across health and social care settings.[95]

Inadequate data

Planning for the future, identifying unmet need and creating innovative services to address current and emerging palliative care needs will require data relating to local demographics, existing service reach and identifying local systems of care as well as the realisation of linked big data. Yet there is currently inadequate data about palliative care to understand current need, to plan for future demand and to understand workforce requirements particularly as it relates to those also accessing aged care services. Australia does not have a palliative care National Minimum Data Set (NMDS) of data elements agreed for mandatory collection and reporting at a national level. An NMDS would allow for the collection of uniform data as part of a national collection.[96] Aged care should be included in planning for a palliative care NMDS.

Eighty percent of people aged over 65 years who die in Australia have used at least one aged care program.[97] However, the current narrow view of palliative care in aged care means that what data is available does not consider palliative care beyond definitions of ‘end of life’. Even with this caveat, the available data in residential aged care is further restricted to funding claims for palliative care made under the Aged Care Funding Instrument (ACFI) which does not reflect either the number of people who needed palliative care nor how many received palliative care. In HCPs and CHSP there is no data available about the input of specialist palliative care, nor if these community aged care programs are providing funding for general palliative care such as provision of nursing services or allied health services relating to palliative care needs.

Data sources do not identify which services provided care leading up to death, whether people dying in hospital were also recipients of aged care services, how long before death older people may be transferred to a hospital, or transfers that specified the admission was for palliative care.[98]

Reports suggest people aged 75 and over represent 53.1 per cent of palliative care-related hospitalisation,[99] however the way palliative care-related hospitalisations are defined and recorded within hospitals, including discharge information,[100] is not an accurate reflection, as evidenced by the ‘Fact of Death Analysis’ by the Agency for Clinical Innovation.[101] This analysis examined use of hospital services in the last year of life in NSW and identified that 60 per cent of patients who might benefit from palliative and end of life care had emergency (unplanned) admissions, while only 7 per cent of all hospital admissions were coded as palliative care admissions.

> *”The effectiveness of …reforms will depend on governments implementing broader improvements to their stewardship of end of life care. This should involve the Australian, State and Territory Governments, through the COAG Health Council… developing and implementing an end of life care data strategy that establishes a national minimum data set for end of life care.”*
>
> **– Productivity Commission[102]**

Without targeted data collection, and better data linkage across data sets there is an inability to accurately analyse how older Australians access services, how many Australians receive palliative care and in what setting, what their preferences are for place of care and place of death and where they die. This data is essential if we want to understand and plan for palliative care needs for older Australians into the future.[103]

A National Palliative Care Commissioner could play a significant role in encouraging the development of a palliative care data collection framework that includes aged care.

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95. Australian Institute of Health and Welfare 2018. *Australia’s health 2018*. Australia’s health series no. 16. AUS 221. Canberra: AIHW.
96. Australian Institute of Health and Welfare, *National minimum data sets and data set specifications* – on METeOR Metadata Online Registry website [viewed online 18 July 2019]
97. Australian Institute of Health and Welfare 2018. *Cause of death patterns and people’s use of aged care: A Pathway in Aged Care analysis of 2012–14 death statistics.* Cat. no. AGE 83. Canberra: AIHW
98. Australian Institute of Health and Welfare 2016. Australia’s Health 2016: 6.18 End-of-life care Australia’s health series no. 15. Cat. no. AUS 199. Canberra: AIHW
99. Australian Institute of Health and Welfare 2019 Palliative care services in Australia [web report: last updated 22 May 2019]
100. Australian Institute of Health and Welfare 2019 *Admitted patient care 2017–18: Australian hospital statistics* Health services series no. 90. Cat. no. HSE 225. Canberra: AIHW.
101. NSW Ministry of Health Agency for Clinical Innovation 2015. *Fact of Death Analysis 2011/12 Use of NSW public hospital services in the last year of life by NSW residents* [accessed online]
102. Productivity Commission, Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Canberra: October 2017, page 129.
103. Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.

A robust evidence and research base

The investment in research relating to palliative care for older people living with a life-limiting illness is an issue of high importance to PCA where a robust evidence and research base is required to promote best-practice and innovative models. The recommendations within the submission are either based on current evidence and the need to translate this into practice and systems, or highlight the need for investment and prioritisation of research and the lack of an evidence-base, either internationally or within the Australian context.

Examples of needed research include:

- the benefits of early referral to specialist palliative care for non-malignant life-limiting illnesses;
- the off-label use of medicines;
- systems to monitor and record improvements or changes in quality of life;
- avoidance of clinically non-beneficial treatments and ICU presentations;
- life expectancy and experiences of the person and their carers working within different models of care and at different points in the illness trajectory; and
- use of emerging technologies.

Australia has benefited for many years from a focussed national research agenda, which has created a large network of clinicians, academics, researchers and policy makers, such as the Palliative Care Outcomes Collaboration, where the outcomes of this research have contributed significantly to the quality of palliative care provided in Australia.[104] However research specific to the context of palliative care within the aged care services setting, as well as more broadly for the care of older Australians must be a specific priority. The investment into such research is hampered as palliative care is not currently acknowledged as a stand-alone field for the review of applications for National Health and Medical Research Council (NHMRC) or Medical Research Futures Fund (MRFF) grants.

Embrace and plan for future technologies

There are a range of new and emerging technologies and digital infrastructure that will impact the delivery of palliative care within aged care in the future. This technology may be used to better monitor people living with a life-limiting illness and frailer, older Australians with multiple conditions, facilitate assessment and referral pathways, streamline transfers and information exchange, assist in directing resources to where they are most beneficial and reduce social isolation and support care givers. Examples of beneficial technologies include:

- smartphone apps;
- wearable devices;
- real-time technology for remote monitoring;
- facial recognition software;
- virtual reality and holograms;
- accessible online programs, resources and education;
- telehealth including videoconferencing and telemedicine.

Further, investment in improved information and communications technologies (ICT) with interoperability to link all aspects of a person's 'journey' no matter what system, who pays or where they access it, including acute, community, aged care, primary care and specialist care is essential. This should underpin robust data collection, analysis and availability, including quality related information, patient reported outcome and experience measures and population needs assessment.

> *"In creating increased opportunities to age in place—without loss of independence—technology supports positive ageing. It even challenges the traditional concept of 'aged care'."*
>
> **– A Technology Roadmap for the Australian Aged Care Sector**[105]

To ensure all Australians benefit from these emerging technologies, equity of access must be a guiding principle. A person's geographic location nor requirement to pay a contribution to access these technologies, should result in inequities and discrimination in access.

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[104] National Palliative Care Strategy 2018

[105] A Technology Roadmap for the Australian Aged Care Sector, June 2017, AGED CARE INDUSTRY IT COUNCIL

"The benefits of the digital economy cannot be shared equally when some members of the community are still facing real barriers to online participation. Digital inclusion is based on the premise that everyone should be able to make full use of digital technologies – to manage their health and wellbeing, access education and services, organise their finances, and connect with friends, family and the world beyond."

– Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2018

✓ **PCA RECOMMENDS**

- Establish National Minimum Data Sets (NMDS) for palliative care which includes both health and aged care.
- Introduce a Palliative Care 'Field of Research' with the addition of funding specific to palliative care within aged care research.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

- Understanding
- Capability
- Collaboration
- Data and evidence

Best practice and innovative models

Australia needs to create an environment that fosters the development of best practice models of palliative care in aged care underpinned by evidence, population-based planning, consistent data collection and supported by a strong specialist palliative care workforce.[106]

Aged Care Quality Standards

The Aged Care Quality Standards, implemented on 1 July 2019, provide a legislative base for minimum requirements in aged care.

> *'...Standards are intended to provide a structured approach to the management of quality and represent clear statements of expected performance'.*
>
> **– Quality of Care Principles 2014**[107]

Organisations providing Commonwealth subsidised aged care services are required to comply with the Aged Care Quality Standards and will have their performance assessed against the Standards. These Standards focus on outcomes for consumers and reflect the level of care and services the community can expect from organisations that provide Commonwealth subsidised aged care services. They define what good care should look like, and what the consumer can expect.[108]

The *Quality of Care Principles 2014* also document the services and supports residential aged care providers are required to provide to care recipients who need them. This includes 'nursing services' described in part as 'services may include, but are not limited to, the following: (a) establishment and supervision of a complex pain management or palliative care program, including monitoring and managing any side effects'.[109] There is no reference to palliative care in the *Quality of Care Principles 2014* for home care services.

Nearly 245,000 older people died in the financial years 2012–13 and 2013–14. The majority of those (80 per cent) had used at least one aged care program.[110] These numbers clearly indicate that more needs to be done to support residents, consumers, families and aged care providers by ensuring palliative care is a core service offered in facilities and in community care.

Yet the new Aged Care Quality Standards do not include reference to the provision of palliative care as an outcome for consumers nor requirement for providers. Nor does palliative care appear in the glossary of the *Guidance and Resources for Providers to support the Aged Care Quality Standards*.[111] This is a missed opportunity and a backward step as palliative care was an expected outcome in the previous residential aged care accreditation standards.[112]

In order to drive improvement in the provision of palliative care in aged care, it is imperative that palliative care be recognised as core business for aged care. Palliative care therefore must be included within the organisational requirements within 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'.[113]

Requirements under standards 2 and 3 of the Aged Care Quality Standards make reference to 'end of life'.[114] However, as outlined above, there is a major difference between the provision of palliative care and just care at the 'end of life'.

As the Standards only refer to 'end of life', this severely restricts the care consumers may receive as this focuses providers on a period of time rather than the longer term benefits consumers may receive from palliative care. The *Guidance and Resources for Providers to support the Aged Care Quality Standards* refers to palliative care in such a way as to imply it is something delivered by 'others' rather than something that should be part of the care delivered by the aged care provider. In the 'examples of actions and evidence' section in Standard 2 under 'workforce and others' it says 'members of the workforce know how to access people with the relevant knowledge or qualifications to provide information to consumers on end of life planning or palliative care if the consumer wishes to include these in their care and services plan', and in the 'reflective questions' section of Standard 3 says 'how does the organisation work with others outside the service (such as palliative care specialists) to improve the consumer's end of life care?'[115]

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[106] Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.

[107] Quality of Care Principles 2014 11 (1) - Compilation No. 5 Compilation date: 15 March 2019

[108] Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards*, May 2019

[109] Quality of Care Principles 2014, Part 3, 3, item 3.8 - Compilation No. 5 Compilation date: 15 March 2019

[110] Australian Institute of Health and Welfare 2018. *Cause of death patterns and people's use of aged care: A Pathway in Aged Care analysis of 2012–14 death statistics*. Cat. no. AGE 83. Canberra: AIHW

[111] Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards,* May 2019

[112] Accreditation Standards Fact Sheet on Aged Care Quality and Safety Commission website https://www.agedcarequality.gov.au/sites/default/files/media/accreditation_standards_fact_sheet_updated.pdf and Quality of Care Principles 2014, Part 2, 2, item 2.9 Palliative Care – The comfort and dignity of terminally ill care recipients is maintained. (compilation No. 4 date 1 January 2019)

[113] Department of Health, *National Palliative Care Strategy 2018*

[114] Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards,* May 2019

[115] Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards,* May 2019

While ever the Aged Care Quality Standards fail to include palliative care as a requirement, it will never become embedded in practice and could be viewed as an optional extra allowing providers to overlook it to the detriment of consumers living with a life-limiting illness. The Standards provide an opportunity to support providers and drive improvements in the quality of care for people living with a life-limiting illness receiving aged care services.

Best practice in advance care planning

Aged care staff have a fundamental role to play in preparing for and facilitating advance care planning discussions, and in ensuring residents and consumers are provided with opportunities to consider and express their preferences, values and beliefs. Aged care staff need to be supported with the skills needed to undertake these conversations.

Research has shown that advance care planning is related to an earlier start of palliative care, with a significantly earlier initiation of palliative care when staff had spoken with the resident about their care preference.[116] Advance care planning has also been found to increase compliance with patient's wishes for care and a reduction in unwanted interventions, increased use of palliative care and prevention of hospitalisation.[117] Advance care planning should therefore be considered integral to aged care and palliative care.

Mechanisms are thereby needed to support general discussion and/or advance care planning including policies, standards and remuneration to health professionals. Advance care planning documents need to be embedded within interoperable systems such as My Health Record, eHealth solutions and patient and aged care resident and consumer records so that all relevant healthcare professionals and other nominated people are able to access them as needed, especially in emergency situations.[118] However, advance care planning is an individual choice and while it should be encouraged, must not be made mandatory.

In some states, medical treatment orders are developed in the form of a Goals of Care document. This uses shared decision making to bring together a discussion about the person's own preferences and values (either expressed in a written Advance Care Planning document, or verbally) within the boundaries of what is medically possible.[119]

Dignity of risk

While duty of care and having systems in place to limit risks is vitally important, balancing this with a person's human right to decision-making and having their choices enacted is essential, especially for older Australians in their last years of life. PCA has previously suggested that the language used in the aged care context should be reviewed, where terms such as 'quality' should not be used as a substitute for 'safety' and 'accreditation'. The interchangeable use of these words further complicates an already complex area and increases the potential for misunderstanding of the objectives of accreditation.

Consumers, families and carers should be supported to change advance care plans, care plans or treatment decisions if circumstances change. They should be provided with the resources and time to understand their right to request or decline treatment or care, even if it is life-prolonging, where unless required by law, doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope or benefit or improve the person's quality of life.

Where appropriate, substitute decision makers should be identified and actively involved in discussing the consumer's needs and wishes, and all consumers, in particular those without family advocates, must be able to access independent advocacy support to ensure that any aspect of their care is upheld.

'…I think that residential aged care should have the goal that it's a place where people can at least enjoy their last few months or years before they die. They know they're going to die. We know they're going to die. And what currently happens is most of us sit around waiting for them to die, and if they die quickly then it's a good job done. Everyone sort of thinks that's a good thing, and it's clearly not, and it wouldn't be acceptable in a paediatric palliative care-type service and it's not acceptable anywhere else.'

– Professor Joseph Ibrahim[120]

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116. M ten Koppel, B D Onwuteaka-Philipsen et al, *Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European counties* in Palliative Medicine 2019, 1-13.
117. Palliative Care Australia 2018, *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne.
118. Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.
119. Introducing Goals of Patient Care in Residential Aged Care Facilities to Decrease Hospitalization: A Cluster Randomized Controlled Trial Martin R.S., Hayes B.J., Hutchinson A., Tacey M., Yates P., Lim W.K. (2019) Journal of the American Medical Directors Association.
120. Professor Joseph Ibrahim Witness Testimony Royal Commission into Quality and Safety (Sydney, 16 MAY 2019, DAY 21)

Creating an environment for innovation

Specialist palliative care services have a significant role to play providing leadership and capacity building for primary care and aged care.

This requires the commitment of Commonwealth and state and territory governments as well as creative use of new technologies. Specialist palliative care doesn't always need to deliver the care but help to ensure others are equipped to deliver palliative care and be able to recognise and refer appropriately when specialist expertise is required.

For too long the provision of palliative care in aged care has often relied on the commitment of well-intentioned individuals working together, often across sectors, to find creative solutions to meet the needs of their residents and consumers. Whilst this is to be commended, and is a demonstration of the good work that happens in aged care, such 'work arounds' rely too much on individual personalities and can mean solutions can fall apart if personnel change. In other situations new services receive only short term, one off funding meaning innovative programs are often unable to be sustained.

It is important that creative new service models that are established are not reliant on individuals and local good will, but rather are sustainably built into existing systems to ensure gains made are not lost. Whilst there are a number of new service models being trialled, the diversity of the Australian population and geography means that no single model will work universally. It is important therefore that work is done to ensure the new models are able to be adapted to provide equitable access across Australia given the limited specialist palliative care workforce.[121]

EXAMPLE

58 year old man with renal failure had lived in town for several years so he could access dialysis. He was also under the care of the Corrections service. He developed multiple co-morbidities and could no longer sustain haemodialysis. His health was declining and the specialist palliative care team discussed his options with him, his family and the corrections service. He was aware of his prognosis and trajectory. It was significant for him to die on country over 500 kilometres away. He was fortunate as his local community had a small aged care facility with 2 palliative care beds. The corrections service supported his return to country. He was flown to the community by the RDFS and admitted to the facility. The usual prognosis after ceasing dialysis is 7 – 14 days. He beat these milestones living for 3 weeks in community which was a great outcome for him and his family allowing them quality time together.

The impact on bereavement of being able to return someone to country to be together with family and for family to be able to carry out their cultural duty is significant.

EXAMPLE

An older lady with a life-limiting illness was a long term nursing home resident. Staff advocated very well for her. She had poor symptom control and her GP wasn't managing her symptoms very well. The lady didn't want to go to hospital, but the staff encouraged her to agree to transfer to hospital to see if her symptoms could be better managed. She was in hospital for a week then transferred back to the facility. Whilst slightly better, her symptoms were still not very well managed on return. Staff referred to the local comprehensive (specialist) palliative care service who provided phone advice to the staff and GP. The lady's care and symptom control improved as a result. The lady died in the aged care facility where she wanted to be.

This was an example where the nursing home staff did a great job of advocating on behalf of the resident:

- identified the need for transfer to hospital to find a way to better manage symptoms
- worked with resident to encourage and support her to get improved symptom management by agreeing to go to hospital
- identified need for and arranged specialist palliative care involvement
- enabled lady to die in location of her choice.

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[121] AIHW (2018) *Palliative care services in Australia – palliative care workforce* [web only report – last updated 17/10/18]. Data from 2016 - 226 specialist palliative care physicians (0.7% of medical specialists and 0.7 clinical FTE per 100,000 population) and 3,457 palliative care nurses (1.1% of all employed nurses or 11.2 clinical FTE per 100,000).

EXAMPLE

A 65 year old man with Parkinson's disease, wanted to be on country but his symptoms were difficult to manage in remote community. Working together, family and local services managed to get him back home for several days. The community aged care worker visited a couple of times each day. After a few days at home it was arranged for him to stay at the local community aged care service building with staff and family working together to care for him for the 48 hours before he died. This allowed him to die on country and ensured his family would not need to vacate their home (in Indigenous communities if someone dies in the home it will sometimes be permanently vacated).

This is an example where services worked creatively to meet the needs of the individual and allowed him to die on country. However in this instance the creative work around resulted in significant overtime for staff who supported him in the last 48 hours which did drain local resources available for others.

EXAMPLE

A Yugoslavian gentleman, living in a small aged care facility was divorced with no contact with his children. He remained in contact with relatives in Yugoslavia. The only thing we wanted was to return to Yugoslavia to die. Staff from the facility undertook fundraising to raise the funds for him to return to Yugoslavia with a nurse escort. He died two months after returning to his home town - happy to be home.

PCA RECOMMENDS

» Palliative care must be included and clearly articulated in the Aged Care Quality Standards.

» Develop and fund innovative models of care to ensure older people have equitable access to palliative care and specialist palliative care.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

» Understanding

» Capability

» Data and evidence

» Accountability

Funding models

The aged care system is continuing to undergo reform so that it more effectively and efficiently supports older people to live in their homes and communities for as long as possible, and enables people to make informed decisions about their care, while remaining sustainable for taxpayers and service providers.[122]

Older people can access a range of Commonwealth funded aged care services from entry level Commonwealth Home Support Program (CHSP), four levels of Home Care Packages (HCPs) for people with more complex needs, to residential aged care for those unable to be supported in the community.

Funding in the community

Lack of clarity about eligibility for CHSP, delayed access to HCP and limited available funding represent significant barriers for people living with a life-limiting illness to access necessary services and choose where they received care as they near the end of their life. Despite support for an increase in the take up of advance care planning, the current aged care system works against people pro-actively planning ahead.

For people living with a life-limiting illness and a short prognosis, the wait times to receive a home care package often means that:

» the person has passed away prior to receiving the care they were assessed as requiring;

» periods of hospitalisation are extended due to the lack of support for them to return home;

» people move to residential aged care who could otherwise be supported in the community.

Additional funding must be allocated to address the length of time people are waiting for access to an HCP at the level for which they have been assessed.

Accessing aged care services is a complex, multi-step process which requires good English language skills, high levels of literacy and patience to navigate. It is therefore not uncommon for First Australians and people from Culturally and Linguistically Diverse backgrounds to experience a range of challenges in navigating the aged care system. The My Aged Care website is not user friendly and contact with the call centre can leave consumers frustrated.

EXAMPLE

An 88 year old lady with a life limiting haematological cancer who lives alone rang My Aged Care to request an Aged Care Assessment Team assessment for eligibility for a Home Care Package. She was “given the third degree” of questions by call centre staff regarding what services she needed help with “right at this moment”. She tried to explain to them that she required an assessment because she knew she was deteriorating and wanted to have a plan for more support in place when she required it, to stay at home for as long as possible. This lady reported she “ended up in tears” and said “I give up”.

In 2015, the Aged Care Sector Statement of Principles was developed by the Aged Care Sector Committee in conjunction with the Australian Government to guide future changes in the aged care system. It said ‘consumers will have access to the care they need when and where they need it…’.[123] Yet too often people living with a life-limiting illness are still denied timely access to services.

People are prioritised for an HCP based on their assessed need. However, care level and priority for home care service are not necessarily linked. For example a level 4 consumer will not always have a ‘high’ priority for home care service, they may need a high level of care, but not be considered to be at immediate risk for a range of reasons.[124]

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.

Despite published guidance material[125] to inform assessor recommendations concerning priority, there is a lack of transparency in how the waiting list and priority allocation works in reality making it difficult for consumers and those making referrals to know if, when or whom may be allocated high priority. Anecdotal feedback indicates the ‘likelihood of being assessed as being high priority relates more to the availability or ongoing support of a carer than the other criteria’.[126]

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[122] Aged Care Financing Authority, *Annual Report on the Funding and Financing of the Aged Care Industry* – 2019 [viewed online]

[123] Aged Care Sector Committee, *Aged Care Sector Statement of Principles* 2015 pg 7

[124] Department of Health, My Aged Care *Guidance on Priority for Home Care Services* Version 1.0 https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf viewed 4 April 2019

[125] Department of Health, My Aged Care *Guidance on Priority for Home Care Services* Version 1.0 https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf viewed 4 April 2019

[126] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

EXAMPLE

A gentleman with a glioblastoma and right hemiparesis requiring his wife's assistance with feeding, personal care, supervision to transfer and walk, was also dependent on her for all cleaning, meal preparation, shopping, and transport.

His wife has a condition were she suffers severe migraines and is confined to bed for days with dizziness, vomiting. When assessed by the Aged Care Assessment Team for a Home Care Package he was assigned a 'medium' priority rating rather than approved as 'high priority' which would have allowed him access to his home care package sooner. He was advised he was unable to be assessed as high priority because his carer was not saying she was no longer able to continue in the carer role.

If as a society we want person-centred care for older people living with a life-limiting illness and want to facilitate their participation in planning their care, they need to be provided with clear, accurate information about when and what level of service they will be able to access.

It is essential therefore that the national prioritisation system be more transparent, that there is greater consistency in how priority is assessed and clearer communication with consumers so they know when they will receive service.

The length of time people wait for access to an HCP at their level of approval is inappropriate.

> *'…the waiting times to which older Australians have been subjected in between being assessed as needing home care packages and actually receiving funding for care are severe and unacceptable. This has caused great suffering and continues to do so. The long waiting lists are cruel, unfair, disrespectful and discriminatory against older Australians.'*
>
> **– Dr T McEvoy QC**[127]

Often people who are waiting for an HCP to be assigned are offered access to CHSP in the interim. However, CHSP is only designed to provide entry level support, which is well below the support most people living with a life-limiting illness and a short prognosis require. Yet, even when the services provided by CHSP would not be considered suitable, the *Guidance on Priority for Home Care Services* says 'if the client does not want to accept other interim services or informal / formal supports they should not be considered high priority' for a Home Care Package.[128]

EXAMPLE

An 86 year old lady with colorectal cancer and multiple co-morbidities including osteoarthritis limiting her mobility and unstable atrial fibrillation, lived alone in a regional area. She was assessed as eligible for a level 3 HCP with a medium priority rating. She agreed to be referred for interim CHSP services and was referred for Meals on Wheels and Transport. However she was refused service by the community transport provider because she required assistance in and out of the vehicle. She passed away before being assigned a home care package.

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 First Australians 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.

> *'The evidence indicates that while many consumers prefer to remain living in their own home, the value of support packages are inadequate to provide this opportunity for those with high care needs.'*
>
> **– Legislated Review of Aged Care 2017** [129]

Whilst the Legislated Review of Aged Care 2017 recommended 'that the government introduce a level 5 home care package to allow people with higher care needs to stay at home longer',[130] 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[131] 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. As the number of people who are expected to die each year is known, cost modelling for such a supplement would be relatively easy to carry out.

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127. Dr T McEvoy, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety 22 March 2019 P-1097
128. Department of Health, My Aged Care Guidance on Priority for Home Care Services Version 1.0 https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf [viewed online 4 April 2019]
129. Department of Health, Legislated Review of Aged Care 2017 page 8
130. Department of Health, Legislated Review of Aged Care 2017 page 13
131. 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

Funding in residential aged care

People living within residential aged care facilities who may be nearing the end of their life should be supported appropriately, and while residential aged care is not seen as a hospital they are increasingly expected to meet hospital type outcomes, particularly as they relate to end of life care.

The current funding model in residential aged care, the ACFI, does not adequately recognise additional costs associated with palliative care. The ACFI only recognises and funds 'palliative care' at the 'end of life' where the definition of end of life referenced is the last week or days of life, with ACFI 12 (item 14) enabling a 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.*'[132]

'Palliative care funding in the Aged Care Funding Instrument …. doesn't work well.. … We think that much more needs to be done to support residential aged care providers and to bring in palliative care services that other people in the community receive to support people to have a good death.'

– Patricia Sparrow, Chief Executive Officer, Aged and Community Services Australia [133]

'It can be very difficult for (providers) to show that someone is palliative. So in some instances providers have said by the time we've actually got through that process and proved the person is palliative, the person has passed away'.

– Patricia Sparrow, Chief Executive Officer, Aged and Community Services Australia[134]

The Government has recognised that a new approach is needed which provides funding that more closely matches consumer need. A new residential aged care funding model, the Australian National – Aged Care Classification (AN-ACC) has been developed which attempts to better match funding to need.[135] However, the AN-ACC takes a narrow view of palliative care and does not allow people to be assessed as eligible for the only palliative care classification after admission. The work done to develop the AN-ACC only included a very small cohort of residents who met the criteria for Class 1 'admit for palliative care'.

To meet the criteria for 'Class 1 admit for palliative care' requires having a palliative care plan developed by a palliative care team nurse or physician and/or appropriate medical practitioner on admission to the care home; a life expectancy of three months or less; and, a score of 40 or less on the Australia-modified Karnofsky Performance Status (AKPS)'. A person with a life expectancy of three months or less, with a palliative care plan in place may not need to be in bed for 50 per cent of the time but may still require ongoing clinical assessment, symptom management and support. By including this AKPS measure (score of 40 or less) as a requirement for assignment to Class 1 will exclude people who require the additional funding to support their palliative care needs. It perpetuates the inaccurate view that people nearing the end of their life tend to be in bed rather than focussing on measures that enhance their quality of life and funding those interventions appropriately.

PCA has recommended to the Department of Health that a micro study be undertaken to ensure the new funding model adequately addresses palliative care needs.

Medicare Benefits Schedule

The Medicare Benefits Schedule (MBS) should allow for longer consultations which are necessary for palliative care nurse practitioners and palliative care specialists for inpatient case conferencing and family meetings. Advance care planning and Goals of Care discussions are not one-off as the medical opinion as well as the person's preferences may change as the person's condition change as they move towards the end of their life. It is important that these discussions occur so the person's preferences and values are known and the person has the option of documenting their preferences to guide health professionals supporting their care should they be unable to communicate or lose capacity. This also requires access to MBS rebates for long-term and primary care management provided by Nurse Practitioners and an MBS item for longer Nurse Practitioner attendances to support the delivery of complex and comprehensive care.[136] [137]

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132. Australian Government, Department of Health (2016) *Aged Care Funding Instrument User Guide* [accessed online]
133. P Sparrow, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 19 February 2019, P-432
134. P Sparrow, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety, 19 February 2019, P-440
135. Department of Health, *Proposal for a new residential aged care funding model,* [viewed online https://consultations.health.gov.au/aged-care-division/proposed-new-residential-aged-care-funding-model/]
136. Palliative Care Australia, submission on the Report from the Nurse Practitioner Reference Group to the Medicare Benefits Schedule (MBS) Review Taskforce 6 June 2019
137. Palliative Care Australia, submission on the Report from the Specialist and Consultant Physician Consultation Clinical Committee to the MBS Taskforce 1 July 2019

Respite care

Caring for someone living with a life-limiting illness or at the end of life can be a rewarding experience, and needs to be appropriately supported through available and appropriate respite care. If this is not available there is the potential to increase strain on the carer by creating more problems to be coped with after the respite period, such as a decline in the care recipient's condition, decreased likelihood of accessing respite in future and implications related to grief and bereavement. It is also important to note that the provision of respite care alone is not a panacea, where there is a need to develop a package of services that may benefit the carer in their role of supporting a person receiving palliative care.

Unfortunately, the current aged care system is not suitable for supporting the respite needs of the individuals with palliative care needs and carers. In general, those receiving HCPs can, on paper, receive respite care. However, in reality the delay in getting access to HCPs is often time prohibitive and people either die or are too unwell to use it. If they do receive an HCP, package funds are often required to address other care needs and the need for respite is not prioritised. The system for allocating respite bed days to residential care providers places the supply of respite beds with the independent facilities, and as the cost of supplying a respite bed is greater than a non-respite bed, PCA believes this has a negative effect on respite bed availability. Demand for accessing respite services is high, and access to emergency respite is very limited. PCA has received advice that planned respite wait lists are untenable, for example in one jurisdiction a person receiving palliative care was unable to receive respite for six months or more.

Emergency access to respite care is extremely difficult to arrange, and what is available often requires at least two weeks 'notice' in these time sensitive 'emergency' situations. These time delays are compounded by unclear and varying application processes across locations. As a result, when a carer is unable to provide care, it is not unusual for a hospital admission or entry into residential care to be arranged earlier than otherwise required and not in alignment with the wishes of both the person and their family/carer.

The emotional cost of the current assessment and process of accessing respite care is often bewildering and confusing for carers who, by the very nature of requiring access to respite care, are often already extremely tired, stressed or burnt out, compounded by feelings of guilt and loss when their loved one enters respite care. Carers deserve adequate funding to provide timely respite that is high-quality, responsive, culturally appropriate, addresses the needs of the person they care for, respects their individuality, is delivered with respect and compassion, and promotes a good quality of life.

✓ PCA RECOMMENDS

» The operation of the National Prioritisation System for HCPs be more transparent.

» Require greater consistency in how priority for HCPs is assessed.

» Simplify all communication with consumers about assessment, approval and assignment of their HCP.

» Additional funding be allocated to reduce the length of time people are waiting for an HCP at the level for which they have been assessed.

» A palliative care supplement be made available for people in receipt of any level of home care package living with a life-limiting illness whose needs exceed the value of their package funding.

» Undertake a micro study to ensure the new residential funding model (Australian National – Aged Care Classification AN-ACC) adequately addresses palliative care needs.

» The MBS Review Taskforce consider how relevant MBS items can be better aligned with contemporary palliative care clinical evidence and practice, including the roles of general practitioners, nurse practitioners, allied health and community-based specialist palliative care providers.

» The Australian Government should provide adequate funding to ensure timely access to high quality respite care.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

» Collaboration

» Investment

» Data and evidence

Grief and bereavement

Grief is a normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Grief can be experienced across many domains including emotional, cognitive, behavioural, physical and spiritual. Personal and social circumstances may place some family members and/or carers at increased risk of experiencing problems in the lead up to and aftermath of a person's death.[138]

It is important that there is support for family members and carers in preparing for death and in understanding the process of dying, as well as bereavement support at designated timeframes after a death in a way that is appropriate for their age, culture and social situation.

> *'… perhaps being offered some pre-counselling around chemotherapy, around palliative care before those services are needed would have been really helpful, I think. Just – if you can have some idea of what might happen or what might you expect and how that might impact you, that would have made it so much easier. It's really shocking when a doctor says to you, "We think we should get the palliative team to come and speak to your nana at home", and that was, really, the first I had ever had any contact with that on a personal level. And I think some pre-counselling would have been helpful'.*
>
> **–Nicole Dunn**[139]

All providers of palliative care (including general practitioners and aged care staff) should have the capability to assess where family members and carers sit along a continuum of need for bereavement support, and refer if required.[140]

Bereavement and its effects on staff and other residents is often under-recognised and under-acknowledged in aged care. Only a limited number of aged care services provide bereavement support or access to pastoral care programs and there is no structured approach more broadly within the sector.[141]

With 35 per cent of all deaths in Australia occurring in residential aged care there is a need to ensure all staff are aware of issues around grief and bereavement, as often long-term and close relationships are formed with residents and their families.[142] The same is true in home care. Grief and bereavement support should therefore be extended to staff, and other residents and consumers within aged care. 'Often there is no time for debriefing when a resident or consumer dies – with the next resident admitted immediately'.[143] Upskilling the workforce in this area would not only assist in supporting the families and carers of the person who has died, but also foster an environment of support for other residents, consumers and the staff themselves, an important component of self-care and staff retention.

Despite the lack of funding available for grief and bereavement support, some aged care providers have introduced different models of support, from contacting family members at agreed intervals after a resident or consumer has died to offer support and referral to services if required, to holding events to commemorate and support family members who had someone die while receiving the service. Aged care providers should be supported and funded to be able to routinely provide grief and bereavement support.

✓ **PCA RECOMMENDS**

» Aged care providers should be supported, resourced and funded to provide grief and bereavement support, including for staff.

Implementing this recommendation aligns with and advances the following goals of the National Palliative Care Strategy 2018:

» Understanding
» Capability
» Access and choice
» Investment

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[138] Palliative Care Australia, *Palliative Care Service Development Guidelines* – January 2018

[139] Nicole Dunn, Transcript of Proceedings, The Royal Commission into Aged Care Quality and Safety 30 July 2019 P-3979-80

[140] Palliative Care Australia 2018, *Palliative Care 2030 – working towards the future of quality palliative care for all*, PCA, Canberra.

[141] Thompson C, Morris D and Williams K (2017) *Bereavement support and prolonged grief: Issues for residential aged care* (Issues Brief). Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

[142] Palliative Care Australia, Economic Research Note 4, *The Economic Benefits of Palliative Care and End-of-Life Care in Residential Aged Care*, 2017

[143] Palliative Care Australia, consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

Access to medicines

Timely access to appropriate medicines is a core tenant of good palliative care. The World Health Assembly (WHA) endorsed palliative care as a human right under article 12 of the International Convention on Economic, Social and Cultural Rights (ICESCR), specifically stating that: ‘access to palliative care and to essential medicines… including opioid analgesics … contributes to the realisation of the right to the enjoyment of the highest attainable standard of health and well-being’.[144]

Access to palliative care medicines for pain and other symptom management can be problematic in aged care.

> *‘Too often, people are transferred back and forth between hospitals and aged care facilities, as aged care facilities lack palliative care expertise and qualified staff to administer pain relief’.*
>
> **–Productivity Commission Inquiry report into Human Services[145]**

Planning for medicine requirements including daytime and anticipatory management, stock on hand and staff required to deliver medicines, as well as direct clinical support through various modes, may pre-empt after-hours needs for many people, leaving only a small proportion of people with unanticipated or unmet after-hours medicine needs. [146]

Limited staff skill and availability can be a barrier to appropriate access to necessary medicines in aged care. If staff are not trained or confident in identifying deterioration and symptom onset they will be unable to identify when symptom relief may be needed. If timely access to prescribers is limited or prescribers are not familiar with contemporary medication regimes, including anticipatory prescribing, access to medications may be delayed or not forthcoming. If aged care services do not store appropriate stocks of anticipatory medicines on site using an imprest system, breakthrough symptoms may not be adequately addressed. Contractual arrangements with dispensing services may result in delayed delivery of prescribed medications. If suitably qualified staff are not on site to administer prescribed regular or breakthrough medication, residents may be left with poorly managed symptoms.

Residents often have to wait until the next shift change, an appropriate health professional to be called out, or be transferred to hospital, for the purpose of receiving a medicine that could and should have been provided within the facility.

A number of case studies presented at hearings of the Royal Commission into Aged Care Quality and Safety have included instances where poor symptom management has occurred as a result of issues associated with access to medicines.[147]

Many older Australian accessing aged care services and requiring palliative care wish to remain at home for as long as possible. To help them achieve this, they need rapid access to medicines for pain and other symptom management 24 hours a day, which may need to be managed by the persons family or carer(s), including the provision of subcutaneous medicines. However, within the home, there are additional barriers to medicines access, including safe storage and monitoring of schedule 8 medicines, impacted by different jurisdictional legislation regarding administration.[148] Support for carers is needed to ensure they understand medication requirements and are comfortable in administering needed medications. The caring@home project funded by the Department of Health has developed resources for organisations, health professionals and carers to support carers to help manage breakthrough symptoms safely using subcutaneous medicines for terminally ill person in their care.[149]

Using several medicines concurrently — polypharmacy — can be appropriate but may also be problematic as it can place older people at risk of harm, including from adverse drug reactions, and is associated with poor clinical outcomes, including nutritional deficiencies, falls, frailty, impaired cognition, more frequent hospitalisation, and premature mortality. The prevalence of polypharmacy among older Australians is relatively high,[150] with polypharmacy considered the norm in palliative care.[151]

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144. World Health Assembly, Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course, WHA Res 67.19, 67th session, 9th plen mtg, Agenda Item 15.5, A67/VR/9 (24 May 2014) 2
145. Productivity Commission (2017) Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report No. 85, Canberra.
146. Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.
147. For example: The Royal Commission into Aged Care Quality and Safety Transcript of Proceedings 27 June 2019 evidence concerning Mr Paranthoiene’s care and Transcript of Proceedings 23 May 2019 evidence concerning Mrs DE’s care.
148. Brisbane South Palliative Care Collaborative and NPS MedicineWise, 2018, *Guidelines for the handling of palliative care medicines in community services*
149. What is caring@home? Factsheet, caring@home website [viewed online 31 July 2019] https://www.caringathomeproject.com.au/Portals/13/Documents/caringathome-FactSheet-2019.pdf
150. A Page et al *Polypharmacy among older Australians, 2006–2017: a population-based study* in Medical Journal Australia 211 (2) July 2019
151. Government of South Australia , SA Health, *SA Palliative Care Community Pharmacy Update* Issue 16 - August 2013 [viewed online]

Pharmacists play an important role in the provision of medicines and medication management in aged care. Pharmacists undertake medication management reviews, dispense and deliver medication and provide dose administration aids and medication charts for the safe administration of medications.[152] [153] Medication reviews can assist in limiting poor outcomes as a result of polypharmacy, with multidisciplinary interventions generally observed to be effective at reducing polypharmacy and inappropriate medication use and the involvement of pharmacists and nurses appears to be a mechanism to enhance deprescribing.[154]

Opioids are often prescribed for pain control for people receiving palliative care. Opioids are categorised as Controlled Drugs which are strictly regulated by state and territory health departments. However, due to jurisdictional differences this can be confusing for doctors which can cause delays for older people in accessing the medications they need.[155]

A number of new service models are emerging as ways to improve access to medicines in aged care. A new unit of clinical pharmacists within the Aged Care Quality and Safety Commission will work directly with residential aged care providers to educate them around best practice use of medicines. The Government is also supporting a Canberra trial to embed a part-time pharmacist in all 27 residential care facilities to ensure the quality use of medicines.[156]

There is increasing focus at a government and regulatory level in Australia regarding opioid prescribing for chronic non-cancer pain.[157] In an effort to reduce inappropriate prescribing that can lead to harm from misuse and abuse of opioids, palliative care patients are being placed at risk of unintended harm through reduced or ceased opioid prescribing. 'Good palliative care does require the use of high-dose opioids, and that's what patients deserve'.[158] All Australians receiving palliative care, including those receiving aged care services, must be able to access necessary medicines, including opioids, to manage pain and other symptoms.[159,160]

✓ PCA RECOMMENDS

- Anticipatory prescribing for people with palliative care needs should be accommodated by establishing imprest systems in residential aged care.
- Education and ongoing support in handling, storing, administering and disposing of medicines safely to be available to carers and family of older people living at home with a life-limiting illness.

Implementing these recommendations aligns with and advances the following goals of the National Palliative Care Strategy 2018:

- Capability
- Access and choice
- Collaboration

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152. The Pharmacy Guild of Australia, 2018, *Community pharmacy and aged care* [accessed online]
153. Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.
154. G Peterson et al *Practice pharmacists and the opportunity to support general practitioners in deprescribing in the older person* in Journal of Pharmacy Practice and Research (2018) 48, 183–185
155. The Pharmacy Guild of Australia, 2012 Submission to the Senate Inquiry on Palliative Care in Australia
156. Department of Health, More Choices for a Longer Life – reducing the misuse of medicines in residential aged care webpage last updated 2 April 2019
157. Therapeutic Goods Administration 2018. *Consultation: Prescription strong (Schedule 8) opioid use and misuse in Australia – options for a regulatory response* [accessed online]
158. Dr Harry Nesplon, RACGP President from *Opioid crackdown: doctors wary of prescribing for end-of-life care* interview on ABD radio 3 June 2019.
159. Palliative Care Australia 2019. *Sustainable access to prescription opioids for use in palliative care* [accessed online]
160. Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.

Appendix 1: Issues Overview: palliative care within aged care – prepared for the Royal Commission into Aged Care Quality and Safety

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care in Australia, providing leadership on palliative care policy and community engagement. Working closely with consumers, Member Organisations and the palliative care and broader health, aged care and disability care workforces, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

> *Though not specifically referred to in the Royal Commission's Terms of Reference a hearing focussed on palliative care would provide the opportunity to inquire into and better understand the role of palliative care in aged care, and adequately examine the quality of care. A hearing would allow the voices of consumers, aged care and palliative care providers to highlight current gaps as well as showcase innovative models of care to improve the experience of aged care consumers.*

There are a number of structural and policy-based issues that contribute to the lack of understanding and attention given to palliative care in aged care. These impact on individuals, families, aged care staff and the broader community's experiences and perceptions of aged care (particularly residential aged care), death and dying, as well as the rates of avoidable or unnecessary hospital admissions, increased costs across systems and sectors, and grief and bereavement support.

This overview highlights five key structural and policy-based issues that must be addressed if the needs of older Australians living with a life-limiting illness are to be adequately met by the aged care sector. Focusing on these key issues in no way implies that other issues raised through the Royal Commission are not of value or importance.

Addressing these structural issues should lead to multi-faceted sustainable improvements in the sector, where aged care services and individual staff members should be supported to see and celebrate their respective roles within palliative care provision given:

- In 2017, over 1 in 7 Australians were aged 65 and over.[1]
- The population of those aged 65 years and older is increasing rapidly, where by 2031 this age group is expected to be about 5.7 million (19% of the population). [2]
- The leading causes of death for older Australians aged 65 and over were all non-malignant life-limiting illnesses that may have benefited from palliative care from diagnosis (in order of % of deaths): coronary heart disease, dementia and Alzheimer disease, cerebrovascular disease, and chronic obstructive pulmonary disease.[3]
- 80% of older Australians that die use at least one aged care program.[4]
- There were 160,909 deaths in Australia in 2017[2] – approximately 35% of all Australians who die each year do so in residential aged care.[5]

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[1] AIHW (2018) *Older Australia at a glance* [web report: released 10/09/ 2018]

[2] Palliative Care Australia (2018) *Palliative Care 2030 – working towards the future of quality palliative care for all,* PCA, Canberra.

[3] Australian Bureau of Statistics (2018) 3303.0 - *Causes of Death, Australia, 2017 Quality Declaration* [web report: released 26/09/2018]

[4] AIHA (2018) *Cause of death patterns and people's use of aged care: A Pathway in Aged Care analysis of 2012–14 death statistics*. Cat. no. AGE 83. Canberra

[5] Productivity Commission (2017) *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services,* Report No. 85, Canberra.

PCA will also be providing a submission detailing the impacts of these structural and policy-based issues, on the provision of quality care to older Australians within the aged care and palliative care systems, which result in part from a significant lack of understanding about palliative care.[6]

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 not just about dying or 'end of life'. Palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.[7]

Palliative care tends to be erroneously associated only with 'end of life'. A focus on care at the end of life only represents a specific time frame[8] and often narrows the focus to the dying phase allowing opportunities for earlier support to be overlooked in aged care.

> *"...older people suffer unnecessarily, owing to widespread underassessment and under treatment of their problems and lack of access to palliative care...The concept that palliative care is relevant only to the last few weeks of life (when no other treatment is beneficial) is outdated."*
> *– World Health Organisation, 2011*[9]

The medical management and coordination of care may be undertaken by a wide range of professionals across many organisations and settings, as people will have different levels of need for palliative care, which may vary over time and increase or decrease in complexity. Palliative care may be ongoing, delivered concurrently with other treatments and is focused on helping people live their lives as fully and comfortably as possible until death and to help families cope during the time of illness and in their bereavement.[10]

Although originally associated primarily with the diagnosis of cancer, it is appropriate for anyone with life-limiting illnesses including chronic conditions such as Chronic Obstructive Pulmonary Disease, Chronic Heart Failure, and dementia, and degenerative diseases such as Motor Neurone Disease, where individuals may benefit from palliative care from diagnosis till death.[11]

Those with complex and persistent needs, or at various points during intermediate and fluctuating need, may require care by specialist palliative care providers. However many people living with life-limiting illnesses needs are straight forward and predictable, which are able to be well managed and supported by other health professionals, including those working within aged care. The capability of the aged care and broader health workforce to manage straightforward and predictable needs is a key factor influencing demand for specialist palliative care services, where there are only 226 specialist palliative care physicians and 3,457 palliative care nurses nationally.[12]

Quality palliative care occurs when strong networks exist between specialist palliative care providers and 'generalist' palliative care providers – which includes GPs and those working within aged care at all levels.

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[6] Australian Government Department of Health (2019) *National Palliative Care Strategy 2018* [accessed online]
[7] Op.Cit (2).
[8] ASSQHC (2015) *National Consensus Statement Essential Elements for Safe High Quality End of Life Care*. ACSQHC, Sydney [Accessed online]
[9] World Health Organisation (2011) *Palliative care for older people: better practices*, WHO Regional Office for Europe, Denmark [Accessed online]
[10] Op.Cit (8)
[11] Op.Cit (6)
[12] AIHW (2018) *Palliative care services in Australia – palliative care workforce* [web only report – last updated 17/10/18]. Data from 2016 - 226 specialist palliative care physicians (0.7% of medical specialists and 0.7 clinical FTE per 100,000 population) and 3,457 palliative care nurses (1.1% of all employed nurses or 11.2 clinical FTE per 100,000).

Carers and families[13] also play a significant role in the support and care of people living with a life-limiting illness and as such need to be considered as partners in care. The impact of supporting and caring for someone with a life-limiting illness needs to be acknowledged, where carers need support to assist them in providing care in a manner that also promotes their health, wellbeing and personal aspirations.

The issue of palliative care in aged care has been raised by a number of witnesses before the Royal Commission. In order for the Commission to be fully informed about the quality of care provided in aged care, it must explore:

- how palliative care is viewed within aged care,
- policy and structural impediments to aged care embracing palliative care as core business; and
- interjurisdictional issues that create barriers to people receiving aged care services and specialist palliative care services.

> *"The committee considers that at times it is forgotten that disease does not discriminate. Although longevity increases the incidence of incurable illnesses such as dementia, incurable and life-limiting illnesses can be suffered by anyone, from the very youngest to the very oldest members of community. Funding mechanisms should reflect this fact, and ensure care is delivered in accordance with the WHO definition of palliative care." – Senate Community Affairs Reference Committee*[14]

The following issues overview outlines five structural and policy-based issues, where detailed case study examples will be provided in the PCA submission. It is important to note that while PCA has limited the scope of this overview, there are other specific issues related to the provision of palliative care within aged care including:

- care for people who are Aboriginal or Torres Strait Islander,
- care for people who are living with dementia,
- timely access to medicines,
- access to specialist palliative care within rural and remote Australia,
- advance care planning, and
- appropriate grief and bereavement support for carers and families, staff within aged care, and residents of residential aged care facilities.

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[13] Family includes people identified by the person as family. Carers may include family members and other members of their community (such as close friends and neighbours) who the person agrees to being involved in their care.

[14] Australia. Parliament. Senate. Community Affairs References Committee & Siewert, Rachel 2012, *Palliative care in Australia*, (3.79) Community Affairs References Committee, Canberra, ACT [Accessed online]

1. ‘Palliative care’ should inform structures and policy not just ‘end of life care’

The understanding of palliative care in aged care has been influenced in part by the narrow view of palliative care in Commonwealth funded aged care programs and policy, or the lack of recognition of palliative care within aged care service provision. Examples include, but are not limited to:

- The legislated **Quality of Care Principles 2014** stipulates the services and supports residential aged care providers must provide to care recipients who need them, and includes ‘nursing services’ described in part as ‘*services may include, but are not limited to, the following: (a) establishment and supervision of a complex pain management or palliative care program, including monitoring and managing any side effects*.’[15] This single reference to palliative care in these Principles narrows the understanding of palliative care in residential aged care to that of medication and symptom control.

- The Aged Care Sector Committee’s **Aged Care Roadmap** released in 2016 does not mention palliative care or dying. This is despite the responsibility of this key document to ‘set out the path to a system where people are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life’.[16]

- The **Legislated Review of Aged Care 2017** which ‘considered the impact and effectiveness of the changes to aged care and made recommendations for future reform to the aged care system’,[17] access to palliative care was ‘raised numerous times by consumers, carers and providers during the review, but it was not considered by the reviewers as it does not align specifically with the terms of reference’.[18]

- The **Aged Care Funding Instrument (ACFI)** only recognises and funds ‘palliative care’ at the ‘end of life’ where the definition of end of life referenced is the ‘last week or days of life’.[19]

- The Australian Institute of Health and Welfare **Palliative care services in Australia report** (palliative care in residential aged care section) represents ACFI appraisal data in a way that equates ‘appraisal’ for funding as ‘need’ for palliative care.[20] This data influences government policy, noting there were about 239,600 permanent residents in Australia (2016–17) with completed ACFI appraisals, and about 1 in 50 of these residents (4,509) had an ACFI appraisal indicating the ‘need’ for palliative care.[21]

- The **Aged Care Quality Standards**[22] which provide a legislative base for minimum requirements in aged care do not include a standard or any requirements that refer to palliative care.

> *“Palliative care is unarguably one of the most important services delivered by the aged care industry and vital to protecting the quality of life of older Australians as their lives draw to an end.”[23] – COTA, 2017*

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[15] Federal Register of Legislation, *Quality of Care Principles 2014,* Part 3, 3 (item 3.8) [Registered 16 January 2019]

[16] Aged Care Sector Committee, *Aged Care Roadmap 2016* [Accessed online]

[17] Australian Government Department of Health (2017) *Legislated Review of Aged Care 2017* [Accessed online]

[18] Op.Cit (16)

[19] Australian Government Department of Health (2016) *Aged Care Funding Instrument User Guide* [accessed online]

[20] Note: As of 2018 this report states ‘In practice, it is possible to receive palliative care in residential aged care without having received an ACFI assessment indicating the need for palliative care. Also note that the data available to the AIHW cannot confirm the extent or nature of palliative care actually provided for those who were assessed and funded for palliative care’.

[21] AIHW (2018) *Palliative care services in Australia, Characteristics of residential aged care residents needing palliative care* [web only report: Oct 2018]

[22] Aged Care Quality and Safety Commission (2019) *Guidance and Resources for Providers to support the Aged Care Quality Standards* [Accessed online]

[23] COTA, ‘Extending Choice And Control Over Palliative Care In Aged Care’ (Media Release), 22 May 2017 [Accessed online]

2. The Aged Care Quality Standards do not include the provision of palliative care as an outcome for consumers or requirement for providers

Organisations providing Commonwealth subsidised aged care services are required to comply with and have performance assessed against the Aged Care Quality Standards (Standards) from 1 July 2019. These "…*standards for quality of care and quality of life for the provision of aged care"* are intended to provide a structured approach to the management of quality and represent clear statements of expected performance[24]. These 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 Aged Care Quality Standards clearly define what good care should look like… make it easier to check that people receive good care… It's about them [your provider] caring for you and your individual needs"[25] - Guidance and Resources for Consumers*

As stated, narrowing the focus to 'end-of-life' is not representative of palliative care, and does not allow the full opportunity for support primarily focused on quality of life to be provided:

- Standard 2 '*Ongoing assessment and planning with consumers*' includes requirement 'b) Assessment and planning identifies and addresses the consumer's current needs, goals and preferences, including advance care planning and end of life planning if the consumer wishes'.[26]
- Standard 3 *'Personal care and clinical care'* includes the requirement 'c) The needs, goals and preferences of consumers nearing the end of life are recognised and addressed, their comfort maximised and their dignity preserved'.[27]

The **Guidance and Resources for Providers to support the Aged Care Quality Standards** refers to palliative care in such a way as to imply it is something delivered by 'others' rather than part of the care delivered by the aged care provider, for example, '*members of the workforce know how to access people with the relevant knowledge or qualifications to provide information to consumers on end of life planning or palliative care if the consumer wishes to include these in their care and services plan'*.[28]

The lack of acknowledgment of palliative care provision within aged care in the Standards is despite the **Senate Inquiry into Palliative Care in Australia Report** noting in 2012 the concern with the lack of a standard within aged care where *"The committee is concerned by the level of variance in the standard and quality of palliative care. The committee considers there could be merit in the introduction of a mandatory national standard linked to accreditation that would cover the provision of palliative care".*[29]

These Standards provide an opportunity to support those working within the aged care sector and drive improvements in the quality of care for people living with a life-limiting illness receiving aged care services. The Standards should align with the Government's recently released **National Palliative Care Strategy 2018** which includes Priority 7.5 "indicators for quality palliative care are reflected in the accreditation processes of all care settings".[30]

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[24] Federal Register of Legislation, *Quality of Care Amendment (Single Quality Framework) Principles 2018* [Registered 10 Oct 2018]

[25] Aged Care Quality and Safety Commission, *Guidance and Resources for Consumers - What the new Aged Care Quality Standards mean for you* [webpage – last updated 2 April 2019]

[26] Ibid

[27] Ibid

[28] Ibid – Standard 2, 'examples of actions and evidence' section, under 'workforce and others'

[29] Op.Cit (14):(2.37)

[30] Op.Cit (6) Goal 7 – Accountability, Priority 7.5

3. CHSP and HCP ‘versus’ palliative care - impact on the choice to stay at home

Currently access to Commonwealth funded home care supports are hampered due to poor understanding of palliative care, inconsistent assessment for Commonwealth Home Support Program (CHSP) and Home Care Packages (HCP), waiting times for HCPs and interface issues with state/territory funded specialist palliative care services. This overview highlights key structural issues relevant to CHSP and HCP for people living with a life-limiting illness in accessing aged care services and community-based specialist palliative care. PCA will provide case studies detailing the issues in the submission.

> *“Older Australians have increasingly complex care needs that frequently require multidisciplinary services drawn from across the aged care and health care systems. However, funding and jurisdictional boundaries and professional silos can impact on access to care and the care experience for the older person and increase costs for older people and governments” – Aged Care Workforce Strategy Taskforce* [31]

My Aged Care as the main entry point to the aged care system was designed to make it easier for older people to access information and have their needs assessed and be supported to find and access services.[32] However, ambiguity and inconsistency in the operation of My Aged Care screening and assessment services is particularly impacting on people living with a life-limiting illness.

The **CHSP Program Manual** states “*CHSP clients are able to receive palliative care services from their local health system in addition to their home support services.”*[33] However, My Aged Care staff undertaking screening, Regional Assessment Service (RAS) and Aged Care Assessment Team (ACAT) assessors often dispute whether a CHSP service should be provided, particularly if a specialist palliative care service is already involved.

People will have different levels of need for palliative care, which may vary over time, increasing or decreasing in complexity, and may or may not require specialist palliative care. It is not clear why an individual and their family/carer should not be able to be adequately supported by a CHSP level service, especially with personal care such as showering, to remain in the home if this is what they wish, while continuing to be adequately managed though their general practice and/or state or territory funded community-based specialist palliative care service.

The CHSP Program Manual, like the Standards, also refers to palliative care in such a way as to imply it is something delivered by ‘others’ rather than part of the care delivered by the aged care provider or that specialist palliative care is largely responsible, where “*…as with any palliative care arrangement, the palliative care team would coordinate the skills and disciplines of many service providers to ensure appropriate care services. This would include working with the client’s CHSP service providers.”*[34]

Not all of the issues lie within aged care as State and territory governments are responsible for the provision and delivery of community-based specialist palliative care services. Unfortunately there is also lack of consistency about what services jurisdiction’s fund, particularly for those eligible to receive Commonwealth funded aged care services, or indeed disability services.

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[31] Aged Care Workforce Strategy Taskforce (2018) *A matter of care: Australia's aged care workforce strategy* [accessed online]

[32] Australian Government, My Aged Care, *Ageing and Aged Care webpage* [viewed 24 April 2019]

[33] Australian Government Department of Health (2018) *Commonwealth Home Support Programme Program Manual 2018* [accessed online]

[34] Ibid

" …there is currently overlap in the roles of the different levels of government, which has led to uncertainty and buck passing over how stewardship is shared and service provision is coordinated across different settings…[consumers] may miss out on specialist palliative care because it is unclear whether it is the Australian Government's responsibility as steward of the aged care system, or the role of State and Territory Governments as providers of specialist palliative care…" – Productivity Commission, 2018[35]

If a person's needs change and they require additional support, then a HCP may be required to facilitate remaining at home if this is still wanted. Information on My Aged Care is not a true representation of the issues regarding accessing HCP services at the 'end-of-life' where "*If you are caring for someone who is nearing the end of their life, there is help and support available during this difficult time…There are a number of aged care services that may help a person nearing the end of their life to stay in the comfort of their own home. These services include: nursing care – a qualified nurse comes to your home…personal care – help with bathing or showering…health support – there are a number of services…*"[36]

For a person living with a life limiting illness, the wait times to receive a HCP usually means periods of hospitalisation are extended as their needs increase are not able to be supported at home and/or the person has died prior to receiving the care they were assessed as requiring, and/or they move to residential aged care when this is not what they wanted and could have been supported at home.

Waiting periods aside, there is often the assumption that a person with a life-limiting illness whose needs escalate will automatically require a level 4 package, or entry into residential care. This is in part due to the lack of clarity and consistency regarding what palliative care 'aged care' will or can provide, and what state/territory funded specialist palliative care services can or will provide. Any review or consideration of new models or funding levels must include consideration of the issues raised throughout this brief, and consultation across portfolios and sectors.

In addition, access to aids and equipment can be hampered by lack of clarity around Commonwealth and state/territory responsibilities. This ongoing issue for older people has become more complex as funding for equipment services has been impacted by the National Disability Insurance Scheme, where '*clearer funding and program responsibilities across State and Territory and Commonwealth jurisdictions should be created as a priority to improve consumer understanding regarding eligibility*'.[37]

A hearing focussed on palliative care would provide the opportunity to inquire into and better understand the issues related to older Australians living with a life-limiting illness and their family and/or carer to remain within their home if this is what they would prefer.

"…the most important consideration in service delivery reform at present is to increase the capacity to support palliative care in the home (including residential aged care), or specialised hospice facilities where that is the preference, and reduce unnecessary (and often unwanted) transfer into the hospital system. This is likely to have the effect of saving money. Most important however, is that it will provide a better experience to patients and those around them." - Senate Community Affairs Reference Committee[38]

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[35] Op.Cit (5)

[36] Australian Government, My Aged Care, *End-of-life care at home webpage* [Last reviewed: 15 May, 2018].

[37] National Aged Care Alliance (2018) Position Paper *Assistive Technology for Older Australians* [accessed online]

[38] Op.Cit (14): (7.31)

4. Palliative care is not appropriately recognised for funding in residential care

Noting work has recently been undertaken to investigate alternative approaches for residential aged care funding, a hearing focusing on palliative care would allow the Commission to inquire into the implications that stem from how palliative care is recognised and described in current and proposed funding models in residential aged care.

Currently the Aged Care Funding Instrument (ACFI) is the resource allocation instrument used to determine levels of care funding in residential aged care. Per the **Aged Care Funding Instrument User Guide**[39] ACFI recognises and funds 'palliative care' at the 'end of life' where the definition of end of life referenced is the last week or days of life, with ACFI 12 (item 14) enabling a 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.'*

Note the language used here of 'very intensive' and 'complex' care is at odds with the statement on the first page of the same User Guide, where '*the ACFI questions provide basic information that is related to fundamental care need areas, it is not a comprehensive assessment package. Comprehensive assessment considers a broader range of care needs than is required in the ACFI. Comprehensive assessment is used for the purposes of ensuring care recipients receive quality and safe care that appropriately meets their care needs."*

Palliative care is not the last weeks of days of life. Note the **National Consensus Statement: essential elements for safe and high-quality end-of-life care**[40] definition of 'end of life care' is also broader than that referred to in the ACFI:

> *"People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:*
>
> - *advanced, progressive, incurable conditions*
> - *general frailty and co-existing conditions that mean that they are expected to die within 12 months*
> - *existing conditions, if they are at risk of dying from a sudden acute crisis in their condition*
> - *life-threatening acute conditions caused by sudden catastrophic events."*

> *"The ACFI specifies that funding specifically for palliative care is only allowable 'in the last week or days' of a resident's life. This limit is strictly adhered to in Australian Government decisions, which has pursued Administrative Appeals Tribunal cases against aged care facilities that sought funding to provide palliative care for too long." - Productivity Commission, 2018*[41]

Aside from the definitional issues, the following also exist in relation to the ACFI and palliative care:

- The basic residential care subsidy amount is paid to the provider for each eligible permanent resident based on their classification under the ACFI. Whilst calculated on an individual basis it is not individually allocated.

- To receive funding for 'palliative care' a provider requires a directive from a clinical nurse consultant or clinical nurse specialist in pain or palliative care or from a medical practitioner and a pain

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[39] Australian Government Department of Health (2016) *Aged Care Funding Instrument User Guide* [Accessed online]

[40] Australian Commission on Safety and Quality in Health Care (2015) *National Consensus Statement: essential elements for safe and high-quality end-of-life care.* [Accessed online]

[41] *Op.Cit (5)*

assessment. Given the funding is only available in the 'last week or days of life' it can be difficult to obtain the necessary documentation and lodge the funding application within the necessary timeframe particularly in regional and rural areas.

- Any data derived from payments for 'palliative care' via the ACFI does not reflect either the number of residents who needed palliative care, nor the number who received palliative care. Any such data only represents the number of residents who were assessed as meeting the funding criteria and for whom a claim was submitted.
- Funding can be recouped by the Government if it is considered that 'palliative care' has been provided for too long, constituting a financial risk for providers.[42]

The Department of Health has recently released a consultation paper outlining the proposed new funding model, the Australian National – Aged Care classification (AN-ACC) which allows in part for 'a variable price per day for the costs of individualised care for each resident based on their AN-ACC casemix class'.[43] As it currently stands, the AN-ACC includes Class 1 'admit for palliative care'. This class is only available on admission and residents are unable to be reassessed into this funding class at a later time, rather, *"residents who become palliative while in residential care are reassessed as per any other change in care requirements*".[44] With $4.6 million committed for a trial of the AN-ACC to commence in the second half of 2019, PCA will be providing a submission to the consultation paper, as there is concern that the proposed model may only exacerbate the views in aged care policy and funding models.

5. The aged care workforce needs support to make palliative care core business

There is a lack of adequate systemic support for the aged care workforce to appropriately deliver quality palliative care to older Australians living with a life-limiting illness who are receiving aged care services.

> *"To support the workforce, a social change and workforce recruitment campaign is needed to reframe attitudes to care, ageing and dying and to promote the value of the aged care workforce"*
>
> *- Aged Care Workforce Strategy Taskforce 2018*[45]

Given many of the issues identified in general within the recent work of the Aged Care Workforce Strategy Taskforce, PCA highlight in this issue overview the following points that will be explored in more detail in the broader submission:

- The work of caring for people in aged care is undervalued leading to staff turnover and lack of consistency in staffing.[46]
- There currently does not exist robust evidenced based tools to appropriately quantify the best mix of staff required in residential aged care[47,48], that includes having the right number and mix of staff to ensure that a predictable standard of care is provided at all hours.

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[42] Leading Aged Services Australia, 2017, LASA submission to the National Palliative Care Strategy Consultation.
[43] Australian Government Department of Health, *Proposal for a new residential aged care funding model - consultation paper* March 2019
[44] Ibid
[45] Op.Cit(30)
[46] Ibid
[47] COTA (2018) *Position Paper Keep fixing Australia's aged care system…taking the next steps in tandem with the Royal Commission* [accessed online]
[48] Australian Healthcare and Hospitals Association, Submission to the Royal Commission 25 March 2019 pg 22

- Employment conditions and job security also impact on staff retention, where rates of pay in the aged care sector are often not as high as those offered in different settings'.[49]
- Undergraduate and vocational education and training (VET), including nursing and Certificate III in Individual Support and Certificate IV in Ageing Support, do not include palliative care as core units.[50]
- It is not known how many aged care providers include palliative care on their mandatory training calendars.

> *"The level of palliative knowledge within the aged care sector varies considerably between, and within, facilities as well as states" - Evaluation of the National Palliative Care Strategy Final Report*[51]

As has been identified, lack of timely access and coordination between aged care providers and health services impacts the ability for aged care recipients living with a life-limiting illness to have their palliative care needs met. This includes access to primary care services where increasingly aged care providers report difficulty in arranging GP visits to residential aged care facilities, and similarly not all GPs will do home visits to older people living in the community.[52] This has been identified[53] as a result of a shortage of GPs in some locations, interoperability of software systems and health records, current GP remuneration levels and funding models, the time required, limited operating hours of primary care services and after-hours requirements, no suitably qualified staff within aged care to carry out clinical handover, and inadequate equipment within the setting. The result is often people being transferred to an emergency department when their care may have been able to be appropriately managed within the home or residential facility.

As the Aged Care Workforce Strategy Taskforce[54] notes, the impediments to those accessing 'aged care' services to also access 'health care' services creates confusion over who has responsibility for managing care needs, contributing to ineffective management of complex care needs and poor coordination, placing tremendous stress on the aged care workforce to manage complex medical care needs beyond their scope of practice, without adequate support from medical specialists.

Further, bereavement and its effects on staff and other residents is often under-recognised and under-acknowledged in aged care, with no structured approach to bereavement support either through pastoral care programs or more broadly within the sector.[55]

> *"In 2015, the Department undertook a feasibility study...This study found that there is a need for an enhanced knowledge base for palliative care in aged care generally, to improve palliative care practice in this setting." – Australian Government Department of Health*[56]

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[49] Op.Cit (30)

[50] ibid.

[51] Urbis, *Evaluation of the National Palliative Care Strategy 2010 Final Report*, September 2016 [Accessed online]

[52] Palliative Care Victoria (2018) *Palliative Care Consortia Aged Care Projects Survey results* [Accessed online]

[53] Australian Medical Association (2018) *2017 AMA Aged Care Survey Report* [Accessed online]

[54] Op.Cit (30)

[55] Ibid

[56] Australian Government Department of Health, 'Palliative Care Guidelines for the Aged Care Sector' Webpage [last updated 23 October 2017]

Conclusion

There are a number of structural and policy-based issues that contribute to the lack of understanding and attention paid to palliative care in aged care. Palliative care should be recognised as an essential component of quality aged care provision, where there are examples of innovative programs around the country that could guide reform in this area.

Fundamentally however, without the aged care system, including policy, assessment services, and the workforce having an understanding of 'palliative care' there will remain structural and workforce impediments to:

- the appropriate identification of all of a person's needs,
- individuals and their families and carers being informed of all of their care and support options, as well as having sufficient understanding to navigate systems, and direct their care as is their right,
- ensuring adequate and timely care planning, which should include goal of care discussions that also anticipate future care preferences and need,
- multidisciplinary care and support coordination across sectors and funding – including primary care, aged care and community-based specialist palliative care, and
- Commonwealth and state and territory services working together to ensure no one living with a life-limiting illness falls between the gaps in service provision.

> *"Palliative care is an important public health issue due to population ageing, the increasing number of older people in most societies and insufficient attention to their complex needs...Palliative care services urgently need to be developed to meet the complex needs of older people. These services need to be available for people with diseases other than cancer and offered based on need rather than diagnosis or prognosis" – World Health Organisation, 2011*[57]

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[57] World Health Organisation (2011) *Palliative care for older people: better practices*, WHO Regional Office for Europe, Denmark [Accessed online]

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