Statement of Dr Jane Fischer

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Date: 29 May 2019

1. This statement made by me accurately sets out the evidence that I am prepared to give
to the Royal Commission into Aged Care Quality and Safety. This statement is true and
correct to the best of my knowledge and belief.

2. I currently hold the voluntary position of Board Chair for Palliative Care Australia and have
done so since 2017. I have been a Board member since 2012.

3. I make this statement on behalf of Palliative Care Australia and I am authorised to do so.

4. This statement presents the policy and system-issues on behalf of Palliative Care
Australia (PCA), informed by consultation with member organisations, clinicians, key
stakeholders and those with a lived experience of palliative care. I also draw upon my
experience as a palliative care specialist to inform my views.

Professional background

5. I am a medical practitioner and palliative medical specialist MBBS FAcHPM.

6. I am currently employed as the CEO/Medical Director at Calvary Health Care Bethlehem
(CHCB) in Melbourne and have been in this role since 2007. CHCB is part of Calvary, a
National Not for Profit organisation providing public and private hospital services, Aged,
Retirement and community services. CHCB is a publically funded Specialist Palliative
Care Service with a state-wide role caring for those with Progressive Neurological
Disease. CHCB provides multidisciplinary care across inpatient, clinic, day centre and
community settings in people’s homes or residential care facilities.

7. Prior to working at CHCB I gained extensive experience as a clinician in rural, remote and
metropolitan settings in both Western Australia and Victoria.

8. I was on the Board of Palliative Care Victoria for nine years and was Chair for six years. I
have been on a number of state based advisory committees and am currently the Chair
of the Victorian Palliative Medical Training Advisory Committee.
9. In November 2018 as Chair of Palliative Care Australia I co-Chaired a palliative care roundtable on behalf of the Australian Government Minister for Health, The Honourable Greg Hunt MP.

Palliative Care Australia Limited

10. Palliative Care Australia (PCA) is the national peak body for palliative care in Australia, providing leadership on palliative care policy and community engagement. PCA launched in 1998, developing from the Australian Association for Hospice and Palliative Care Incorporated which started in 1991.

11. 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 by improving access to, and promoting the need for, quality palliative care.

12. PCA member organisations are located in each state and territory, and we are supported by affiliate members the Australian and New Zealand Society of Palliative Medicines (ANZSPM), Palliative Care Nurses Australia (PCNA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ).

13. The work of PCA is guided by a skills-based Board, underpinned by a Strategic Direction (2019-2021) which identifies focus areas towards our Vision of quality palliative care for all - to promote palliative care as a human right for all Australians, to inform the community to contribute to the call for palliative care, and to lead the palliative care sector by being a viable and effective peak palliative care organisation.

14. Much of PCA’s work to promote issues is done through developing policy and contributing to national policy debates, guided by its National Policy Advisory Committee. PCA has a number of position statements, provides submissions to government, develops reports and has established a register of consumers and carers with a lived experience of palliative care to foster opportunities for representatives to engage in policy, service delivery and reform activities on a national level.

15. Sector development is also a core focus of PCA’s work, underpinned by the Palliative Care Service Development Guidelines which outlines the range of palliative care services that should be available, and the workforce and system capabilities required to deliver an effective network of palliative care services using a population-based and geographic approach to service planning.

16. In addition, the National Palliative Care Standards developed by PCA are now in the 5th edition, and clearly articulate and promote a vision for compassionate and appropriate specialist palliative care, recognising the importance of care that is person-centred and age-appropriate. These standards are supported by the Palliative Care Self-Assessment (PaCSA) online portal, enabling specialist palliative care services to self-assess against these voluntary standards, develop a quality improvement action plan and provide evidence against the National Safety and Quality Health Service Standards.
17. The work of PCA is also aligned with the priorities set out in the National Palliative Care Strategy 2018 endorsed by all Australian Health Ministers, which represents the commitment of the Commonwealth, state and territory governments to ensuring the highest possible level of palliative care is available to all people.

18. PCA’s future focused Palliative Care 2030 – working towards the future of quality palliative care for all complements the objectives of the National Palliative Care Strategy, and outlines guiding principles to assist the health, disability and aged care sectors, governments and the general community, to plan and prepare for the future.

19. PCA believes the community needs to be more engaged with palliative care, dying, grief and bereavement and undertakes community awareness activities including the Dying to Talk initiative and National Palliative Care Week. In addition, PCA develops and provides resources for people living with a life-limiting illness, their carers and families, as well as the National Service Directory of specialist palliative care services.

**Please explain the importance of palliative care in the aged care system?**

20. 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.¹

21. PCA supports the WHO definition and maintains that palliative care is person and family-centred care with the primary goal to optimise the quality of life, as palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.²

22. PCA also supports the adoption of the WHO definition by governments at all levels in Australia as an active WHO Member State. Within the health, aged care and disability care systems, palliative care should not mean different things, as the range of definitions and understandings prevent the development at the highest levels across jurisdictions and the Commonwealth of an integrated approach to the care of Australians living with a life-limiting illness.

23. Palliative care is also 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

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² Palliative Care Australia (2018) Palliative Care 2030 – working towards the future of quality palliative care for all, PCA, Canberra.
and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.³

24. The WHO have recently identified that there are a number of significant barriers which must be overcome to address the unmet need for palliative care, including national health policies and systems that do not often include palliative care at all, limited or non-existent training on palliative care for health professionals, and a lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer patients and health systems.⁴ These barriers extend to Australia where a number of structural and policy-based issues are contributing to the lack of understanding and attention given to palliative care in the aged care system.

25. Fundamentally it is essential to distinguish that ‘palliative care’ or a ‘palliative approach’ is broader than ‘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.

26. Palliative care involves three equally important domains including:⁵

- early intervention to prevent or relieve distressing physical symptoms (such as breathing difficulties, pain, nausea, vomiting and delirium);
- the provision of psychological and spiritual support to reduce suffering and distress as people and their families cope with a life-limiting illness and in their bereavement; and
- social support to address problems related to the person’s social and living circumstances, access to carers and their functional independence.

27. Many people living with a life-limiting illness have needs that may be straightforward and predictable, effectively met through their existing health and aged care professionals and the broader team involved in their care.⁶ 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.

28. Not all people living with a life-limiting illness will require specialist palliative care, however some people may develop more complex and persistent, or intermediate and fluctuating, needs that require support through the secondary provision of specialist palliative care.⁷ Specialist palliative care comprises of multidisciplinary teams with specialised skills,

³ WHA, Resolution WHA67.19, Strengthening of palliative care as a component of comprehensive care throughout the life course, May 24, 2014.
⁵ Palliative Care Australia 2018, Background Report to the Palliative Care Service Development Guidelines, prepared by Aspex Consulting, Melbourne.
⁶ ibid
⁷ Op. Cit (2)
competencies, experience and training in palliative care, and is one component of broader palliative care service delivery.8

29. General practitioners and aged care staff need 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.

30. A compounding factor in this is that palliative care is often focused on dying and narrowed to ‘end of life’, particularly within aged care policy and systems. This should not be the case as palliative care is most effective when considered early in the course of an illness, which not only improves quality of life but also reduces unnecessary hospitalisations and use of healthcare services.9

31. Although originally associated primarily with a diagnosis of cancer, palliative care is appropriate for anyone with a life-limiting illness including chronic conditions such as dementia, congestive heart failures, renal disease and chronic obstructive pulmonary disease (COPD), and degenerative diseases such as motor neurone disease. Individuals may benefit from palliative care from diagnosis, concurrently with life-sustaining or curative treatment, until death.10

32. To assist in understanding the importance of palliative care within the provision of aged care, the causes of death are relevant to the extent to which deaths might be expected (such as dying due to COPD) or unexpected (such as dying due to a traffic accident).11 In Australia the leading causes of death in 2017 were ischaemic heart disease, dementia, cerebrovascular disease and chronic lower respiratory diseases,12 all of which are life-limiting illnesses that could be considered as expected deaths.

33. 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%) 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

34. This all demonstrates that aged care has a significant role to play in the delivery of palliative care for older Australians now and into the future. Policy and system barriers should be addressed to ensure the delivery of accessible and high-quality palliative care within aged care settings. This will enable older Australians to receive the compassionate care they deserve focused on quality of life whilst living with a life-limiting illness, and will

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8 World Health Organisation (2018) Fact sheet: Palliative Care [accessed online], Palliative Care Australia 2018
11 Op. Cit. (5)
enable better support of them, their families and carers during the dying and bereavement process.

What are the elements of appropriate palliative care in aged care services? In your answer please consider whether or not appropriate palliative care includes adapting the care to the individual needs and identity of the person receiving care. If it does include such adaptations, please give at least one example of how palliative care can be adapted for the individual needs of the person receiving care.

What is the relationship between palliative care and person-centred care in the aged care system?

35. Palliative care is holistic, person and family-centred care that is responsive to the clinical, physical, emotional, and psychological needs of a person and their family. It is based on effective communication, shared decision-making and personal autonomy.

36. Good palliative care in aged care includes a collaborative decision-making approach that encompasses the life experiences and preferences of the individual, family, and the expertise of all clinicians and support providers involved, while also recognising that agreed goals of care may change overtime.

37. There are a number of common elements of palliative care provision within aged care that aged care services and staff, in conjunction with other health professionals including general practitioners, should be able to provide. These align with the National Palliative Care Standards, which recognise that palliative care is not one size fits all and must be tailored to the individual:

- Attitudes and supports that affirms life and regards dying as a normal process and a human experience, not just a biological or medical event;
- Understanding the local and wider communities and the populations care is being provided for;
- Employment of qualified staff who receive appropriate and regular training to fulfil their roles safely and competently;
- Timely initial and ongoing person-centered assessment by appropriately trained clinical staff focused on physical, psychological, cultural, social and spiritual need;

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15 Op. Cit (2)
16 Palliative Care Australia 2018, Palliative Care Service Development Guidelines
17 Palliative Care Australia 2018, National Palliative Care Standards 5th edn, PCA, Canberra
18 Ibid
• Care is based on current and comprehensive clinical assessment, delivered in accordance with the person’s expressed values, goals of care and preferences as evidenced in their care plan, and informed by the best available evidence;

• Care enables a person to live as well as possible to the end of their life, where palliative care should be within discussions on quality of life and considered an integral part of the growing focus on wellness and reablement in aged care;

• Care plans are documented in clinical records and incorporate management of emergency and out-of-hours support, including a person’s preference for transfer and level of intervention, which are communicated to all involved in the delivery of care;

• Assistance for the older person and their family to come together and talk about sensitive issues and planning for care;

• Where an individual is not able to participate in care planning or decision-making, a substitute decision-maker or legal guardian is identified in accordance with the person’s goals and preferences and relevant legislation and/or policies;

• Staff actively pre-empt distress to the best of their ability and when it occurs, the response to it is timely, appropriate and effective, with actions documented;

• Access to medicines, consumables, qualified staff and processes to adequately manage pain, vomiting, shortness of breath and other symptoms common as a person is dying; ¹⁹

• All staff need to be able to recognise a change in a person’s condition or deterioration, and there are protocols and procedures in place for the escalation of care or need, including within a residential facility or home care service;

• Staff are able to recognise complexities that may not reasonably be met by the current services and seek advice or referral to specialist palliative care; ²⁰

• Provision of resources such as equipment are needed to aid care at home or to support care in an aged care facility;

• There are policies and procedures in place that support and promote continuity of care across settings and throughout the course of the person’s illness;

¹⁹ Op. Cit (5)
²⁰ Palliative Care Needs Assessment Guidance, National Clinical Programme for Palliative Care, Clinical Strategy and Programmes Division, 2014
WIT.0159.0001.0008

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• Providing support for people to meet cultural obligations, emotional, social and spiritual concerns;

• Value and appreciate the role of carers and provide support by understanding the level of care that they are willing and able to give, their need for information, a clear plan for out-of-hours concerns or unexpected events, education on how to safely assist with care, and referral to respite care services and other carer support services such as the Carer Gateway;

• Support for family members and carers in preparing for death and 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. Grief and bereavement support should be extended to staff, and other residents within residential aged care; and

• Staff are supported in coping with the daily demands of working with people living with a life-limiting illness, their family and carers, and are encouraged to participate in opportunities that build resilience.

It is important to also acknowledge that Australia has a diverse population. Person-centred palliative care within aged care must be culturally safe and responsive, supporting each person’s beliefs, values, and traditions.

**Are older people, either in the residential or home care setting, regularly transferred to a hospital or hospice for palliative care? If yes, why does this occur?**

38. In some instances, it is appropriate that older people are transferred to hospital if their symptoms are such that they can no longer be managed in their home or residential aged care facility. However, this should be considered within the context of understanding the role and scope of palliative care that aged care services and general practitioners should be providing, and the issues related to the current narrowing of palliative care support in aged care to the last weeks or days of life.

39. Based on my own clinical experience and information provided to PCA from member organisations, health and aged care professionals and community members, the following factors contribute to older people being transferred from aged care settings:

- Issues surrounding recognition and response to clinical deterioration, including when someone is dying, may lead to appropriate or inappropriate transfer. Predicting prognosis and the timing of dying can be difficult, where it may be difficult to distinguish clinical deterioration that is reversible (i.e. the person is ‘sick’) from deterioration that is part of the normal dying process;21

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21 Op. Cit (11)
• Limited timely access to required health professionals (including GPs, RNs, specialist providers) and/or medicines;

• Resident/consumer choice to be transferred to hospital, which may or may not be indicated in their advance care planning documentation, and recognising that people may (and have the right to) change their preferences at any time, particularly when confronted with the reality of deterioration or dying, or if a person thinks hospital is where they have to go to die;

• Family members may advocate for hospital transfer particularly if there hasn’t been good communication about prognosis and what to expect, or if they are concerned about the quality of care being received;

• Lack of awareness of legal issues that are relevant to medical decisions made at the end of life can impact on staff confidence in making decisions, including those surrounding medications, substitute-decision making, withholding or withdrawing treatment, providing emergency treatment and Advance Care Directives;

• Limited advance care planning and/or Advance Care Directives that identify treatment and intervention preferences and the person’s preferred place of death. Planning and discussions, should occur well before the end of life and not be commenced in the last weeks or days of life where the focus should be on providing comfort to both the dying person and their family and carers;

• Families disagreeing with a person’s Advance Care Directive stating their preferred place of death;

• Provider policies that do not take into account palliative situations or advance care planning. For example, PCA has been told of aged care providers who have a policy of requiring hospital transfer in certain circumstances, which may not align with a person’s advance care plan; and

• Lack of support for carers to care for a person within the home, including:
  - delayed access to home care services or services provided at a level lower than they have been assessed as requiring;
  - issues with state-funded service eligibility, including community-based specialist palliative care and the Commonwealth funded services;
  - limited or unsuitable respite services and/or a deterioration in the carers own health needs or circumstances.

40. The extent of transfers specifically from aged care settings to hospital or ‘hospice’ ‘for palliative care’ is difficult to quantify. The fragmented and incomplete nature of palliative care data is well recognised across health and social care settings.22

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

42. Additional issues making it difficult to identify a true picture of transfer to hospital from aged care for the purpose of palliative care include:

- Reporting on use of hospital inpatient services is based on the ‘care type’ which does not specifically relate to the supply or use of designated specialist palliative care services;

- It is not possible to clearly identify people receiving palliative care services within residential care, as data derived from payments for ‘palliative care’ via the Aged Care Funding Instrument (ACFI) does not reflect either the number of residents who needed palliative care, nor the number who received palliative care;

- There is no data collected about palliative care need or provision within the home care programs;

- The use of the term ‘hospice’ itself can be problematic as the term is not universally used in Australia and can mean different models or service types in different jurisdictions. For example in Queensland the term ‘hospice’ refers to a style of care rather than something that takes place in a specific building. In other jurisdictions the term specialist palliative care or community specialist palliative care may be used to refer to inpatient services or home based services, rather than the term ‘hospice’. Further the AIHW reports on public or private acute hospital with an identified ‘hospice care unit’ delivering specialist palliative care services, either as a free-standing facility or wards within hospital;

- Most states and territories also operate outpatient and other community-based specialist palliative care services, including hospital-in-the-home (HITH)

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23 Australian Institute of Health and Welfare 2019 Palliative care services in Australia [web report: last updated 22 May 2019]
24 Ibid
26 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]
27 Op Cit. (5)
28 Op. Cit. (24)
29 Palliative Care Queensland PCQ Hospice Service Network [viewed online]
30 Ibid
programs, under which people are provided with hospital-type care and are categorised as an admitted patient, but receive this care in their home;\textsuperscript{31} and

- Providers may not record transfers of residents to hospitals, meaning that some of the deaths reported in residential aged care actually occur in hospitals.\textsuperscript{32}

43. 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.

On average, how long before death are older people transferred to a hospital or hospice for palliative care?

44. Data for residential aged care facilities suggests that about four in five residents (81\%) who 'exit' from an aged care facility do so due to death.\textsuperscript{33} What is known is that people in their last year of life demonstrate intense use of acute hospital services including unplanned emergency admissions,\textsuperscript{34} with an average of nearly eight admissions per person in this period.\textsuperscript{35}

45. However, data sources do not readily 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.\textsuperscript{36, 37}

46. The bigger issue here is that people are being transferred to a hospital or 'hospice' for the purpose of dying. Dying should be seen as a normal part of life, and the very nature of aged care service provision requires that the aged care sector, at the policy, systems, education, provider and staff levels, acknowledges the need to provide palliative care.

47. It is acknowledged that acute medical care in Australia prioritises treating illness and preserving life, which does not necessarily respect the needs of people living with a life-limiting illness, and can impose additional unnecessary pain and distress without necessarily delivering desirable outcomes.\textsuperscript{38}

48. Issues surrounding clinically non-beneficial treatment are important to raise here. Non-beneficial treatment (also referred to as futile or potentially inappropriate treatment) is

\begin{itemize}
  \item \textsuperscript{31} ibid
  \item \textsuperscript{32} Op. Cit. (5)
  \item \textsuperscript{33} ibid
  \item \textsuperscript{34} NSW Agency for Clinical Innovation, \textit{Diagnostic Report To inform the model for palliative care and end of life care service provision – February 2014}
  \item \textsuperscript{35} Australian Institute of Health and Welfare 2016. \textit{Australia's Health 2016: 6.18 End-of-life care Australia's health services}} no. 15. Cat. no. AUS 199. Canberra: AHW.
  \item \textsuperscript{36} Op. Cit (15)
  \item \textsuperscript{37} Australian Institute of Health and Welfare 2016. \textit{Australia's Health 2016: 6.18 End-of-life care Australia's health services no. 15. Cat. no. AUS 199. Canberra: AIHW}
  \item \textsuperscript{38} Australian Medical Association 2015. \textit{Position Statement: Palliative Approach in Residential Aged Care} [accessed online].
\end{itemize}
used to describe treatment which is of no benefit, cannot achieve its purpose, or is not in the person’s best interest. Many studies have identified widespread non-beneficial treatment for people at the end-of-life, including inappropriate transfers, admission to intensive care units, intervention contrary to what is set out in their Advance Care Directives or documented resuscitation orders, and administration of medicines, including antibiotics, to a person who is dying.

49. PCA is notified of many instances where an older person dies en route to hospital, within the emergency department, or shortly after entering acute care. This is supported by a 2018 study that reviewed 109 residential aged care residents who attended and died in hospital from July 2013 to June 2014, reporting that the mean hospital stay to death was 5.2 days, and that 7% of residents either died in the emergency department or were dead-on-arrival.

50. The fact that 35% of all older Australians die in aged care facilities highlights the pressing need for aged care providers to providing quality palliative care for older Australians allowing them to live and die in the place of their choosing.

Who makes the decision that an older person be transferred to a hospital or hospice for palliative care?

51. This is dependent on a number of factors which may be unique to each aged care service based on their model of care, availability of clinical staff, lack of timely access to GPs, medication access issues and the appropriate staff to administer medicines. Most commonly it will be a RN, GP, locum GP or team leader in charge.

52. What should primarily guide decisions is the persons preferred place of care and preferred place of death and, the distinction between the person’s ‘dying phase’ and ‘death’. While 50% of Australians die in a hospital, the reality is that ‘much of the dying phase occurs within the home’.

53. People’s preferences for care during the dying phase and death have implications for the planning and provision of palliative care, engagement with specialist palliative care and transfer to other care settings, including from home to residential aged care, or from community-based care to acute settings.

54. Having choice and control over where death occurs is important, however many factors may shape or change people’s preferences about where they wish to die. Preferences expressed may change as the illness progresses, and changes in family circumstances,
such as the loss of potential carers, may reduce the perceived ability to manage dying at home.\textsuperscript{45}

55. If an aged care recipient with capacity states that they do not want to go to hospital for emergency treatment, or refuses treatment, their request should be respected, even if they require life-sustaining treatment.\textsuperscript{46} Health professionals within aged care settings who are responsible for making the decision to transfer an older person to a hospital need to be aware of the legal frameworks regarding capacity and respecting consumer choice.

**Are people with advanced dementia regularly transferred from home care or residential care to a hospital or hospice for palliative care?**

56. There is no robust data available on the number of people with advanced dementia that are transferred to hospital or 'hospice' for palliative care, due to many of the abovementioned reasons with respect to data collection, where almost half of hospital episodes for people living with dementia do not have dementia recorded as a diagnosis\textsuperscript{47}.

57. The proportion of people with a diagnosis of dementia in comparison to patients with cancer, using specialist palliative care services is low (73.2\% versus 2.9\%)\textsuperscript{48}, as many people with dementia struggle to get access to appropriate palliative care that responds to their needs and respects their wishes. Dementia is a complex life-limiting illness, and this has many implications regarding appropriate or inappropriate transfer to tertiary settings.

58. Appropriate assessment by specialist palliative care services to address symptoms that may be masking behavioural and/or psychological issues such as agitation, discomfort and fearfulness could minimise the need for hospital transfer, in alignment with the person's goals of care. This acknowledges that Dementia Australia and others highlight that people living with dementia struggle to access palliative care or receive care in a timely fashion, are given inappropriate life-sustaining or invasive procedures, and receive inadequate pain management.\textsuperscript{49}

**Where an approved aged care provider provides palliative care services, which members of staff of that approved provider should be involved in that care?**

59. Palliative care describes 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. All

\textsuperscript{45} Op. Cit (5)  
\textsuperscript{46} ELDAC Toolkit *End of life law in Australia: An overview for the aged care sector legal toolkit*  
\textsuperscript{47} Australian Institute of Health and Welfare 2013. *Dementia care in hospitals: costs and strategies* [accessed online: last updated 10 Oct 2017]  
\textsuperscript{48} Palliative Care Outcomes Collaboration 2019, *Patient outcomes in palliative care – national report July – December 2018* [accessed online]  
\textsuperscript{49} Dementia Australia and Palliative Care Australia, 2018 *Policy Statement Palliative care and dementia* [viewed online]. Harris D, *Forget me not: palliative care for people with dementia* in Postgraduate Medical Journal 2007 June; 83 (980): 362-366
staff should play a role in delivering palliative care in aged care services, guided and supported in doing so by the Aged Care Quality Standards.

60. The delivery of palliative care in aged care ensures improved allocation of scarce health and aged care resources whilst building an upskilled and responsive aged care sector that values its staff whilst providing opportunities for career development and advancement.

61. Treating residents and consumers with dignity and respect supports their personhood and provides an environment which enables them to make choices about their care that are paramount in palliative care. Goals of care should be established and reviewed regularly with the person and their family and these will then direct the care the person receives and from whom.

62. Example of how all staff play a role on delivering palliative care includes

- Personal care workers (PCW) play an important role in providing palliative care as they:
  
  o are the people who spend the most time with a resident or consumer and therefore knows them best;
  
  o get to know the person and their preferences;
  
  o identify changes as they occur, and report and document the changes so that timely interventions can be put in place; and
  
  o support residents and consumers to participate in activities they enjoy to support their quality of life

- Activity officers:
  
  o support residents and consumers to participate in activities they enjoy to support their quality of life.

- Catering staff:
  
  o tailor meals to preferences and dietary needs; and
  
  o ensure food is appetising and visually appealing to encourage people with limited appetite to eat, and to maximise enjoyment.

- Registered nurses and allied health staff:
  
  o conduct thorough and timely assessments;
  
  o develop comprehensive care plans to guide the person's care;
  
  o address the changing needs of the person; and
  
  o identify the need for medical and specialist intervention, refer and follow up.
Aged care service managers:
- develop a culture which enables and celebrates the work of staff in providing appropriate palliative care to their residents and consumers; and
- ensure staff receive the support and training they need to provide quality and compassionate care.

Are people who are not staff members of approved aged care providers often involved in the provision of palliative care within aged care services?

63. There are a range of people who work in collaboration with aged care in the provision of palliative care to aged care recipients. This may include general practitioners, visiting allied health professionals, pharmacists, spiritual care workers, and at times, specialists such as geriatricians, oncologists, cardiologists, and neurologists.

64. Allied health professionals such as occupational therapists, physiotherapists, speech therapists and social workers play an essential role, including support to manage physical symptoms, nutrition, communication and mobility in order to maintain function and independence, and sharing information relevant to disease progression to a person living with a life-limiting illness, their families and carers, and aged care staff.

65. Pharmacists play an important role in the provision of medicines and medication management in aged care. Medicines play a critical role in the quality of life of people receiving aged care services in aged care facilities and in their own homes. Pharmacists undertake medication management reviews, dispense and deliver medication and provide dose administration aids and medication charts for the safe administration of medications.

66. Specialist palliative care services can provide services directly to people living with a life-limiting illness or provide palliative care consultancy services to other health professionals. These consultancy services, sometimes referred to as consultative support services, allow other health professionals to seek expert advice on the prognosis and management of people who are not under the full-time care of specialist palliative medicine physicians.

67. The provision of specialist palliative care services to recipients of aged care services varies within jurisdictions, and may occur via

- inpatient care in ‘designated’ palliative care beds that are used to provide palliative care under the clinical supervision of a specialist palliative medicine physician;
- inpatient care in other beds to people receiving disease-modifying or other types of care in acute beds, subacute beds and other types of beds. The provision of

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50 Op. Cit (5)
51 The Pharmacy Guild of Australia, 2018, Community pharmacy and aged care [accessed online]
52 Op. Cit (5)
palliative care in these settings may involve direct care by specialist palliative care physicians or the involvement of specialist palliative care consultancy services;

- outpatient (ambulatory) services in outpatient clinics, specialist rooms or residential facilities;
- community-based specialist palliative care services separate to hospital-based specialist palliative care, provided by non-government providers; and
- outreach specialist palliative care services, including palliative care nurse practitioner-led and telehealth models that work directly with aged care services.

68. Volunteers also significantly contribute to palliative care provision within residential aged care as well as in a person's home. These may include trained palliative care volunteers whose availability can increase the capacity of services to meet the support needs of people living with a life-limiting illness, their families and carers, and pastoral care volunteers that provide spiritual and emotional support.

Are there obstacles to accessing palliative care within the current aged care system? If yes, what are they?

If any, what are they key differences between palliative care in residential aged care and home care?

69. For the purpose of this response, accessing palliative care within the current aged care system is taken to mean care that is, or should be provided to people living with a life-limiting illness by existing health and aged care professionals involved in their care, noting that this is not referring to specialist palliative care unless stated otherwise.

70. The Aged Care Workforce Strategy Taskforce also noted that all health professionals 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 – acute hospitals, aged care facilities, general practice, specialist clinics, community health services, allied health services, community aged care services, and other settings in which people may be living.

71. PCA submits that there are a number of structural and policy-based obstacles that contribute to the lack of understanding and attention given to palliative care within aged care, across either or both residential services and home care services. These obstacles 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.

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53 Op. Cit (5)
54 ibid
55 Op. Cit (5)
72. This has been influenced in part by the narrow view of palliative care in Commonwealth funded aged care programs and policy to the 'end of life' or the dying phase. For example:

- 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'.

- The 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'. This narrows the understanding of palliative care in residential aged care to that of medication and symptom control.

- 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, 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'.

- 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. This data influences government policy, noting there were about 239,600 permanent residents in Australia (2016–17) with completed ACFI appraisals, and about one in 50 of these residents (4,509) had an ACFI appraisal indicating the 'need' for palliative care.

73. 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', highlights how the existing paradigm results in palliative care being seen as 'out of scope' within aged care policy and decisions. This review noted that access to palliative care was 'raised numerous times by consumers, carers and providers

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56 Aged Care Sector Committee, Aged Care Roadmap 2016 [Accessed online]
57 Federal Register of Legislation, Quality of Care Principles 2014, Part 3, 3 (item 3.8) [Registered 16 January 2019]
59 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'.
60 AIHW (2018) Palliative care services in Australia, Characteristics of residential aged care residents needing palliative care [web only report: Oct 2018]
during the review, but was not considered by the reviewers as it does not align specifically with the terms of reference'.

Another obstacle is that the Aged Care Quality Standards which provide a legislative base for minimum requirements in aged care that are focussed on outcomes for consumers rather than processes for providers, do not include a standard or any requirements that refer to palliative care, beyond end of life. These Standards are 'intended to provide a structured approach to the management of quality and represent clear statements of expected performance'. They define what good care should look like, and what the consumer can expect.

- 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'.

- 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'.

Further, the Guidance and Resources for Providers to support the Aged Care Quality Standards primarily refers to palliative care in such a way as to imply it is something delivered by 'others' rather than part of the care that needs to be 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'.

As far back as 2012 the Senate Inquiry into Palliative Care in Australia Report raised concern with the lack of a standard within aged care saying "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.".

There are significant obstacles for people living with a life-limiting illness to access aged care services that enable them to remain within their home if this is their preference,
including inconsistent assessments for the 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.

78. 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."70 However, PCA have been informed that 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, leaving the consumer and their carer or family, without the services that are required to meet their individual needs.

79. 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."71

80. People living with a life-limiting illness will have different levels of need, which may vary over time. If they require additional support or services to address increasing complexity, the wait times to receive a HCP are unacceptable. The long wait times for HCP usually means:

- Periods of hospitalisation are extended as people are unable to receive support at home as their needs increase;
- They move to residential aged care when this is not what they wanted and where they could otherwise have been supported at home; or
- The person dies prior to receiving the care they were assessed as requiring.

81. Some of the obstacles to accessing services experienced in aged care are ‘overlap’ issues with health care. As the Aged Care Workforce Strategy Taskforce72 notes, there are also obstacles or impediments to those accessing ‘aged care’ services to also access ‘health care’ services, which creates confusion over who has responsibility for managing care needs, contributing to ineffective management and poor coordination, while also placing tremendous stress on the aged care workforce to manage complex medical care needs beyond their scope of practice, without adequate support.

82. Funding interface issues and a lack of consistency about what state or territory government will fund or provide between, and within individual jurisdictions, is impacting

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71 Ibid
72 Op.Cit (30)
on a person receiving Commonwealth funded aged care services who also requires access to specialist palliative care services.

83. For example, PCA is advised of many instances when a person in receipt of both home based aged care services and specialist palliative care services requires additional assistance with personal care, however the My Aged Care and/or Regional Assessment Service assessors involved determine this is the responsibility of the specialist service and do not approve personal care. At the same time, the state-funded specialist palliative care service were either not available, not resourced or not able to provide services to people if they are also receiving aged care services. In the end the result is either:

- the person requires personal care to be undertaken by a carer or family member which may not be their wishes or appropriate for the person or their carer;
- the person is left without personal care for periods of time, often the case for single-person situations where there is not a family available;
- the person or family funds additional services to come into the home if they can afford it or if this is available; and
- in some instances, PCA are aware that for the want of assistance to have basic personal care provided such as showering and toileting, people have required entry into residential aged care.

84. The Productivity Commission Inquiry report into Human Services acknowledges that “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”. 73

85. There is increasing focus at a government and regulatory level in Australia regarding opioid prescribing for chronic non-cancer pain.74 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. All Australians receiving palliative care must be able to access necessary medicines, including opioids, to manage pain and other symptoms.75

86. The obstacles surrounding appropriate and timely access to medicines for palliative care provision within aged care include:

- Staff being able to recognise deterioration and symptom onset and act upon them;

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74 Therapeutic Goods Administration 2018. Consultation: Prescription strong (Schedule 8) opioid use and misuse in Australia – options for a regulatory response [accessed online]
75 Palliative Care Australia 2019. Sustainable access to prescription opioids for use in palliative care [accessed online]
• Timely access to prescribers who are familiar with contemporary medication regimes, including anticipatory prescribing;
• Lack of appropriate stocks of anticipatory medicines stored on site using an imprest system to address breakthrough symptoms;
• Lack of qualified staff available 24/7 who are able to administer the medications without delay;
• Contracting arrangements with pharmacy, which can lead to varying delivery timeframes of the next day or longer;
• Not including anticipatory medicine requirements within early goals of care and care planning discussions and documentation; and
• Within the home, there are additional barriers to medicines access, including safe storage and monitoring of schedule 8 medicines, impacted by different jurisdictional legislations regarding administration.\textsuperscript{76}

87. PCA has been advised that in some instances family members have been asked to get a private prescription and have this filled at a community pharmacy, then return with the medicine to the facility, or where a community pharmacist is required to open the pharmacy to dispense the medicine and deliver it to the facility after-hours.

88. 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.

89. It must be acknowledged at the policy and systems level, as well as by providers and the aged care workforce, that the majority of palliative care provided to older Australians accessing aged care services will be done by aged care staff.

90. However support from general practitioners is critical. PCA have been advised that aged care providers increasingly report difficulty in arranging GP support both to residential facilities, and to older people living in the community,\textsuperscript{77} as a recent report revealed close to a third of doctors plan to not take on new patients, to reduce the number of visits, or to stop completely over the next two years.\textsuperscript{78}

91. Reasons for a decrease in GP engagement have been identified as:\textsuperscript{79, 80}
• shortage of GPs in some locations;
• interoperability of software systems and health records;

\textsuperscript{76} Brisbane South Palliative Care Collaborative and NPS MedicineWise, 2018, \textit{Guidelines for the handling of palliative care medicines in community services}
\textsuperscript{77} Palliative Care Victoria, Palliative Care Consortia Aged Care Projects Survey results, 2018
\textsuperscript{78} Australian Medical Association 2017, \textit{AMA Aged Care Survey Report} [accessed online]
\textsuperscript{79} ibid
\textsuperscript{80} Op. Cit (5)
• current GP remuneration levels and funding models;
• the time required to visit facilities or homes;
• limited operating hours of primary care services and after-hours requirements;
• no suitably qualified staff within aged care to carry out clinical handover;
• inadequate equipment within the setting; and
• lack of knowledge and/or confidence about the management aspects of palliative medicines such as legal obligations and opioid prescribing.

92. GPs play a critical role in supporting people to die within the community, through providing palliative care directly, in association with community nurses and aged care services, and being involved as partners in care delivery with community-based specialist palliative care teams.\(^{51}\)

93. Further compounding obstacles to supporting palliative care within aged care include lack of access to after-hours support for aged care staff if this is required, which includes both GPs’ and specialist palliative care services, and lack of access to appropriate equipment and medical supplies which can be important to delivering good palliative care through maximising independence and quality of life. This can be limited due to cost, particularly in the home care setting, as the CHSP program limits funding available per consumer to $500 per year (with provider discretion to increase the cap to $1,000 if assessed as necessary),\(^{82}\) and HCP funds needs to stretch to cover all care needs. This often means that necessary equipment cannot be afforded or is not prioritised.

**How can these obstacles be overcome?**

94. These obstacles can be overcome through the following:

94.1. Palliative care must be seen as core business for aged care no matter the setting, and not rely upon specialist palliative care services providing care that can and should (and in some cases is) delivered by aged care.

94.2. Support the adoption of the WHO definition of palliative care by governments at all levels in Australia as an active WHO Member State.

94.3. Palliative care not ‘end of life’ should inform policy, funding and system development, and include consultation across portfolios and sectors.

94.4. Targeted data collection, and better data linkage across data sets 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.

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\(^{51}\) Op. Cit (5)
\(^{82}\) Op. Cit (70)
94.5. The Aged Care Quality Standards need to direct providers in their responsibility in delivering palliative care and providers should be evaluated against these requirements by observing the outcomes for their consumers.

94.6. Clarifying roles and responsibilities across Commonwealth and state / territory funded services to ensure equitable access to specialist palliative care support for older people receiving aged care services.

94.7. When required, specialist palliative care teams should be enabled to support aged care services, through streamlined assessment, appropriate and early planning, clear referral pathways and different modes of support dependent on population-based planning.

94.8. Organised and pro-active care planning centred on the goals, preferences and needs of the resident or consumer, and including responding to crisis situations.

94.9. 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.

94.10. 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 facilitate advance care planning within aged care services.

94.11. Consider the relevant recommendations made in the Senate Inquiry into Palliative Care in Australia Report.

94.12. Consider the goals within the recently released National Palliative Care Strategy 2018 included ‘Goal 7 – Accountability’ with ‘Priority 7.5 indicators for quality palliative care are reflected in the accreditation processes of all aged care settings’.

Are these obstacles different in rural, regional or remote areas compared to urban areas? If yes, how do the obstacles differ and why does this occur?

95. It is well documented that people living in rural, regional and remote Australia experience obstacles resulting in poorer health outcomes including higher levels of disease, shorter life-expectancy, and poorer access to and use of all health services.

96. These same obstacles extend to palliative care within aged care, including lack of access to GPs, allied health and specialist services, and difficulties in recruiting and retaining appropriately trained and skilled staff.

97. This means that people living in rural and remote Australia are afforded significantly less choice when it comes to the services they can access and therefore are not always able to have their preferences met in how they live (and die) with a life-limiting illness. This can

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83 Department of Health, National Palliative Care Strategy 2018
84 Australian Institute of Health and Welfare Rural and remote health web report last updated 29 May 2017 [accessed online]
be exacerbated by some aged care services in rural and remote areas only providing HCP levels 1 (for people with basic care needs) and 2 (for people with low-level care needs) and not providing the higher level packages level 3 (for people with intermediate care needs) or level 4 (high-level care needs) even if the person has been assigned a high level package.

98. For older people living in rural and remote Australia, a specific obstacle at the end of their life is receiving appropriate palliative care, and dying, on country. Further, returning a person to country after they have died can be costly to a family and be hard to organise logistically. This can have an intense and lasting impact on the family of the person who has died and the wider rural or remote community.

99. In many rural and remote communities, there is also an absence of available or accessible health professionals trained in psychosocial care to offer bereavement follow up, an integral component of palliative care. 85

What is the relationship between advance care planning and palliative care?

Please explain the importance of advance care planning in the context of the aged care system.

100. Advance care planning is a process whereby the older person can communicate their preferences to others about their future care. The process may be a series of conversations involving family or others. The advance care planning conversations may lead to the development of an Advance Care Directive which documents what is important to the person and can help guide care if the person is unable to make decisions for themselves.

101. Advance care planning is important for everyone but especially for people receiving aged care services. Many people receiving aged care services have dementia or other life limiting illnesses and over time may be less capable of communicating their medical and care preferences. Ensuring everyone involved in a person's care are 'on the same page' and understand what is important to the person should they be unable to communicate their preference, can be achieved through advance care planning. A written Advance Care Plan or an Advance Care Directive increases the likelihood that the person's preferences will be known and followed. 86

102. Importantly, aged care staff have a fundamental role to play in preparing for these discussions, and in ensuring residents and consumers are provided with opportunities to consider and express their goals, values and beliefs.

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86 Palliative Care Australia and Advance Care Planning Australia Policy Statement Advance Care Planning and Advance Care Directives, April 2018
Normalising discussions of death and dying in the community can also mean that family and friends have an understanding of people’s preferences over time independently of a particular diagnosis and before ‘requiring’ these discussions to take place.

How does having a cognitive impairment of reduced decision-making capacity affect the ability of people to make choices about their palliative care?

What can be done to improve the ability of people with cognitive impairments or reduced decision-making capacity to make choices about their palliative care?

Capacity is assumed under law unless there is evidence to the contrary. People with a cognitive impairment are usually able to communicate preference in some areas even when cognitive impairment has progressed, so they should always be supported to be as involved as possible in discussions about their care, including palliative care.

Working with people with cognitive impairment takes skill and training and requires strategies tailored to the person’s individual abilities. This requires focussing on the person’s strengths and being creative in enabling them to communicate preference. This typically involves keeping questions clear and simple and working with the person in a quiet environment with minimal distractions.

Commencing advance care planning discussions early in disease progression is particularly important when someone is diagnosed with a cognitive impairment.

Many people may have already appointed a substitute decision maker who has the authority to make decisions on the person’s behalf should they lose the capacity to do so. Therefore, aged care providers and others involved in a person’s care should ensure they determine who has the authority to make decisions.

Do you consider the skills and availability of the aged care workforce to be a barrier to people accessing palliative care within the aged care system?

How can the aged care workforce be improved to facilitate better access to high-quality palliative care services, both in residential aged care facilities and home care?

Yes, the skills and availability of the aged care workforce are a barrier, to providing palliative care within the aged care system, as well as supporting access to specialist palliative care if required. The ability to deliver palliative care within aged care services also requires the right number of staff and the right mix of skills to meet the needs of the residents and consumers for whom they care.

However, this needs to be considered within the context of the structural and policy-based issues that are contributing to the lack of understanding and attention given to the...
importance of palliative care in the aged care system, which is subsequently impacting on the skills and availability of the aged care workforce to provide palliative care.

110. The following information is provided acknowledging that the Aged Care Workforce Strategy Taskforce has recognised that the work of caring for people in aged care is undervalued leading to staff turnover and lack of consistency in staffing, and has developed a strategy designed to position the industry moving forward.\textsuperscript{69}

111. 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.

112. 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 meaning that most people working in aged care have received no formal training in palliative care.

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

114. Ideally support for the workforce should go beyond just the completion of entry level palliative care training, and should encompass ongoing training with mentoring and

\textsuperscript{69} Aged Care Workforce Strategy Taskforce, A Matter of Care Australia’s Aged Care Workforce Strategy June 2018
support to ensure skills and confidence are well embedded. Some of this mentoring may come from specialist palliative care services.

**Are there any successful workforce models for delivering palliative care services in aged care? If yes, what are they and what makes them successful?**

**Are there any successful examples for delivering palliative care services in the aged care system? If yes, what are they and what makes them successful?**

115. 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, where aged care services should be able to provide for the needs of people living with a life-limiting illness.

116. For the purpose of answering this question, the focus is on models of collaboration between aged care services and specialist palliative care services, as quality palliative care occurs when strong networks exist between a person’s health and aged care professionals across all settings.

117. Like the provision of palliative care is not one size fits all, how specialist services and aged care providers work collaboratively will also not necessarily be one particular model, as this should be based on local need and population-based planning. Examples can include a specialist palliative care services employing specific staff, usually nurse practitioners, who provide in-reach support, palliative care needs rounds and education to aged care staff, shared-care models also involving GPs, or aged care providers employing health professionals with palliative care specialisations or more senior roles such as clinical nurse consultants to act as a liaison.

118. These models have in common a focus on clinical review, capacity building, ongoing quality improvement strategies, education and mentoring of staff. Unfortunately many of these have been established as pilot programs with one-off or short term funds meaning they are not always able to be sustained when the funding ends.

119. The challenge for the specialist palliative care sector is that there are only 226 specialist palliative care physicians and 3,457 palliative care nurses in Australia. It is therefore important that the aged care sector are resourced and skilled to enable them to provide quality palliative care, and recognise when appropriate and timely referral to specialist palliative care is required, in addition to a significant investment in the specialist palliative care workforce.

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80 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).
Is bereavement support important in palliative care? If yes, why?

Are you aware of bereavement support being offered by aged care providers? Either in the residential or home care setting? If yes, please describe the features of the support offered.

120. Grief and bereavement is an important and integral aspect of palliative care for family members as well as aged care staff and other residents and consumers. Awareness of grief and bereavement of all staff, including non-clinical staff, is important as often long-term and close relationships are formed with residents and their families.

121. Grief is a normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. 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. Grief can be experienced across many domains including emotional, cognitive, behavioural, physical and spiritual. The experience of grief can vary widely, with some people experiencing complicated grief or grief that lasts for a prolonged period.

122. All providers of palliative care services (including aged care services) need to have the capacity to assess where family members and carers sit along a continuum of need for bereavement support services and refer accordingly. Support for those experiencing grief can be obtained from many professional and informal sources, and it is vital to align bereavement support services with people’s needs.

123. Several Australian states (including Tasmania and Victoria) distinguish between ‘universal’ strategies (that should be available to support all bereaved people) and ‘targeted’ (or specialist) strategies (that should be available to support people at risk of, or experiencing, complicated grief).

124. 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. However some aged care providers have introduced different models of bereavement support, from contacting family members after a resident or consumer has died to offer support and referral to services if required, to holding ‘get-togethers’ for family members who have lost someone within the service.

125. Upskilling the aged care workforce in this area would not only assist in supporting the families and carers of the person who has died, but would also foster an environment of support and resilience for other residents and the staff themselves.

126. In conclusion, the structural and policy-based obstacles that contribute to the lack of understanding and attention given to palliative care within aged care must be addressed. These current obstacles as outlined are impacting on individuals, families, aged care staff,

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91 Ibid
and the broader community’s experiences and perceptions of aged care (particularly residential aged care), death and dying.

127. PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers by improving access to, and promoting the need for, quality palliative care.

128. This is a goal shared with the aged care sector, to improve the quality and safety of person-centred care provided to older Australians.

Signed: Jane Fischer
Date: 29 May 2019

Witness: Victor Harcourt
Date: 29 May 2019