



PalliativeCare
AUSTRALIA

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

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 2017² – approximately 35% of all Australians who die each year do so in residential aged care.⁵

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 frame⁸ 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, 2011⁹

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.

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 families¹³ 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 Committee¹⁴

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.

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

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 performance²⁴. 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

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 Taskforce³¹

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 through 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.

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, 2018³⁵

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 Committee³⁸

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, 2018⁴¹

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

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 2018⁴⁵

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.

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 Report⁵¹

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 identified⁵³ 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 Taskforce⁵⁴ 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 Health⁵⁶

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, 2011⁵⁷

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