ACSA
Aged & Community Services Australia

JOINT SELECT COMMITTEE ON PALLIATIVE CARE IN WESTERN AUSTRALIA

INQUIRY INTO PALLIATIVE CARE IN WESTERN AUSTRALIA

Submission

10 July 2020

ABOUT ACSA

Aged & Community Services Australia (ACSA) is the leading aged care peak body supporting over 700 church, charitable and community-based, not-for-profit organisations. Not-for-profit organisations provide care and accommodation services to about one million older Australians.[1]

ACSA represents, leads and supports its members to achieve excellence in providing quality affordable housing and community and residential care services for older Australians.

Aged care providers make a significant $17.6 billion economic contribution to Australia, representing 1.1% of GDP by producing outputs, employing people and through buying goods and services. The direct economic component is akin to the contribution made by the residential building construction and sheep, grains, beef and dairy cattle industries.[2]

ACSA members are important to the community and the people they serve, and are passionate about the quality and value of the services they provide, irrespective of their size, service mix or location.

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[1] Australian Government, Department of Health, Report on the Operation of the *Aged Care Act 1997*, December 2016.
[2] Deloitte Access Economics, Australia's aged care sector: economic contribution and future directions, Aged Care Guild, June 2016, page 24.

INTRODUCTION

Palliative care is a core part of everyday service delivery for many aged care and community care providers. Yet as discovered by the Joint Select Committee on End of Life Choices in its 2018 report *My Life, My Choice,* there is a "marked lack of consistency in the use of the palliative care" that make the extent and nature of palliative care difficult to define clearly.[3]

This in turn creates challenges for policy-makers in defining and then funding program areas to deliver quality palliative care. These challenges, particularly in relation to the delivery of palliative care in the aged care setting, are also compounded by the complexity of the interface between the Commonwealth-funded aged care system and the state-government administered health system.

This submission incorporates the experiences of ACSA members in relation to WA government-funded palliative care services, and also outlines some of the challenges faced by ACSA members in delivering palliative care to West Australians within the current system and funding environment.

PALLIATIVE CARE DELIVERED BY AGED CARE AND COMMUNITY SERVICE PROVIDERS

Aged care providers typically provide palliative care in the course of service delivery to their residents, if they are a residential aged care provider, or to their clients if they provide in-home care services to people living in the community.

Recent developments in thinking around palliative care have seen it move from being a series of treatments in the final days and weeks of life to a more holistic approach taken to help and support people to live as actively as possible until death and be available to anyone who has a life-limiting condition.[4]

In the residential aged care setting in particular, we know that people are living longer and entering aged care homes later in life and for shorter time periods. In contrast to 10 or 20 years ago, the typical aged care resident is older, more frail and is more likely to be experiencing chronic life-limiting health conditions.[5]

In this context, palliative care services provided by aged and community care providers include, but are not limited to:

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[3] *My Life, My Choice – The Report of the Joint Select Committee on End of Life Choices,* August 2018, p. 57.

[4] Ibid, p. 63.

[5] See Australian Government, Department of Health, Report on the Operation of the Aged Care Act 1997, 2018-19, published November 2019, https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997.

- Support for people to complete activities of daily living such as personal hygiene needs, taking meals and cleaning;
- Clinical care including medication management, pain management, wound care, nutrition management and other specialised nursing needs;
- Transport services including attending medical appointments or social activities;
- Carer or family support, including respite services; and
- Emotional and pastoral/spiritual support.

ACCESSING SPECIALIST PALLIATIVE CARE SERVICES AND OTHER RELATED SERVICES

Because they provide care to people toward the end of their life, aged and community care providers are natural users of Specialist Palliative Care Services, particularly those that fall into the 'community care' section of the Specialist Palliative Care Services funded by WA Health.

Aged care providers also call upon the expertise of General Practitioners, pharmacists, geriatricians and other medical condition specialists such as oncologists when creating and revising care plans and end-of-life treatment plans for clients living with life-limiting conditions. This can occur at any time during a client's life as well as during the phase referred to as the 'terminal phase' when a person's death is weeks, days or hours away.

KEY CHALLENGES FACED BY AGED CARE PROVIDERS WHEN IT COMES TO PALLIATIVE CARE

Many aged care providers in Western Australia and across the country deliver high quality palliative care embedded within their service delivery models in recognition of the importance of palliative care principles to the wellbeing and quality of life of older people with life limiting conditions.

However, there remain some challenges to the consistent incorporation of palliative care within the scope of the day-to-day service delivery of all aged care providers. This ability to deliver holistic, comprehensive and person-centred palliative care to clients is key to ensuring an older person's last days and hours can occur in accordance with their wishes.

Unfortunately, sometimes aged care residents require transfer to hospital because their palliative care needs are greater than can be met at the aged care home, or because the resident and/or families request it. This may result in disruption, discomfort and/or distress for the resident and their family at the end of a person's life.

People receiving regular aged care services at home can also require hospitalisation when they would prefer to be cared for in their own home because of a lack of available services to support them to palliate in their own home.

When this happens it results in a poor outcome for individuals and additional costs to the health care system that could have been avoided had the individual been able to palliate at an aged care home or in their own home in accordance with their wishes.[6]

INADEQUATE FUNDING

Although there are some federal funding initiatives that exist to support aged care providers in the delivery of palliative care, these situations can still occur because at a more broad program level, aged care providers are not consistently funded or supported to deliver a holistic approach to palliative care that responds to their clients' clinical needs as well as their personal preferences when it comes to end of life choices.

The most recent financial performance survey conducted on the aged care industry found that some 60% of aged care providers reported an operational loss.[7] Worryingly, this figure rises to 74% in rural and remote locations, pointing to ongoing inequities experienced by people living outside metropolitan areas.[8]

In this constrained funding environment, delivering a comprehensive suite of best practice palliative care choices can be a challenge for many aged care providers.

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[6] See *My Life, My Choice – The Report of the Joint Select Committee on End of Life Choices,* August 2018, p. 68.

[7] *Aged Care Financial Performance Study*, Six months ended 31 December 2019, StewartBrown, January 2020, p. 6.

[8] Ibid.

In this funding context, not all providers have the capacity to make significant investments in continuously upskilling staff and the home's infrastructure to deliver quality palliative care, particularly during the 'end of life phase'.

INCONSISTENT ACCESS TO SPECIALIST PALLIATIVE CARE SERVICES

In some areas there is a lack of availability of the required clinical and medical staff with skills to deliver appropriate palliative care to a person during their final days and hours.

Specialist palliative care outreach services that bring palliative care expertise into the aged care setting represent a positive and effective model for upskilling aged care workers and helping older people to achieve their end of life wishes in situ through direct care provision.

In most Australian states, health authorities fund multi-disciplinary teams of palliative care specialists to deliver outreach services to local aged care providers to assist them to improve their palliative care practice, upskill their staff and to deliver direct assistance to treating teams during the 'terminal phase' of their clients on an as-needs basis.

The West Australian Government, through WA Health, funds specialist palliative care services in an inpatient, community care or consultancy basis. The 'community care' model allows West Australians to receive expert palliative care in their home, whether that be in the community or in residential aged care.

These specialist palliative care services are offered by a specialist multi-disciplinary team with qualifications and training in palliative care, and "support, advise, educate and mentor" existing care teams "to provide end of life and palliative care and/or to provide direct care to people with complex palliative care needs".[9]

However, as was identified by the Joint Select Committee on End of Life Choices in its 2018 report, coverage and access to these services across the state is patchy, particularly in rural and remote areas.[10]

The report notes that:

"*Four of the WA Country Health Service regions only have access to consultative specialist palliative care. Without access to inpatient or community specialist palliative care, patients do not have the same level of choice as patients in the other parts of the state."*[11]

Inequities of access and health service coverage for Australians living outside metropolitan areas is a country-wide problem that all states and territories continue to grapple with.

However the lack of access to the kind of palliative care expertise that could help a person in a regional, rural or remote area spend their final days and hours in relative comfort and without pain or distress is of particular concern to ACSA, as we advocate for universal access to health system coverage regardless of location, socio-economic or cultural background.

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[9] *My Life, My Choice – The Report of the Joint Select Committee on End of Life Choices,* August 2018, p. 65.

[10] Ibid, p.71.

[11] *My Life, My Choice – The Report of the Joint Select Committee on End of Life Choices,* August 2018, p. 65.

RECOMMENDATIONS

While aged care providers are not and never will be a substitute for higher level acute care settings that some people will require during the terminal phase, there are several key ways through which providers could be better supported to cater to the end of life wishes of their residents and clients:

1. Adequate funding provision through the Aged Care Funding Instrument or other mechanism to ensure aged care providers are resourced and equipped to embed best practice palliative care principles within their day-to-day service delivery;
2. Improving access to external specialist palliative care services through a more consistent and seamless aged care/health system interface; and
3. Improving awareness and understanding of the practice of palliative care within the aged care and health systems, as well as the general population more broadly.

Adequate funding provision for upskilling of the aged care workforce in the principles and practice of palliative care.

ACSA recognises that funding for aged care is largely a Commonwealth responsibility. However, it is impossible to consider the challenges of palliative care delivery to older people devoid of the context of the funding constraints within which aged care providers operate.

Aged care providers need to be funded through a mechanism that recognises the importance of palliative care and adequately funds providers to embed it within their service delivery models, including through ear-marked training to upskill staff where required.

The efficacy of state-run and state-funded specialist care services that intersect with the aged care system relies on the ability of aged care providers to be able to deliver the clinical care required during a person's end-of-life phase.

Thus without a stable and sustainable funding base, aged care providers will not be able to consistently act as the skilled, responsive partner to state-run palliative care services in delivering best practice end-of-life care to West Australians.

Improve access and availability of Specialist Palliative Care Services.

Greater availability and access to palliative care specialists would also assist to strengthen whole-of-system capacity to support older people's end of life wishes.

This is particularly important if we are to move the general perception and understanding of palliative care within both the aged care and healthcare sectors from one of being solely focussed on the 'terminal phase' to a more holistic approach that aims to improve the quality of life of all people with a life-limiting condition.

As the Joint Select Committee on End of Life Choices found in its 2018 report, the availability of Specialist Palliative Care Services is not uniform in its breadth and depth across all regions of Western Australia.

People living in regional, rural and remote areas continue to be disadvantaged by inequitable access to the sorts of services that could help them have the end-of-life experience of their choosing.

ACSA recommends greater investment in all types of Specialist Palliative Care Services to achieve consistent coverage for all West Australians, regardless of where they live and what setting they reside in toward the end of their life (e.g. whether they be in hospital, at home or in residential aged care).

Improve awareness and understanding of the practice of palliative care within the aged care and health systems, as well as the population more broadly.

The practice of palliative care need not be limited to the relief of symptoms during the final days and hours of a person's life, or the 'terminal phase'. Palliative care can and should be introduced early in the course of a life-limiting illness or condition to help improve a person's quality of life as well as their physical and emotional wellbeing.

However, as noted by the Joint Select Committee on End of Life Choices,

"*there remains a misconception that palliative care is just for the final days and weeks of life… Many patients and their families are reluctant to involve palliative care in their treatment out of the mistaken fear and misunderstanding of what it represents."*[12]

For people living in residential aged care this is compounded by the requirement of the Aged Care Funding Instrument (ACFI) of them to be in the end of life phase of their illness in order for the palliative care funding to be claimed for their care.

In order to address this misconception, often held by both families, patients as well as medical, health and care practitioners, ACSA recommends investment in a broad-based awareness campaign to improve public knowledge and understanding of what palliative care is and how it can help them, their loved ones or their patients.

The campaign would have a dual purpose and be focussed on two audiences.

Firstly, it would aim to improve the understanding and awareness about the principles and practice of palliative care among health care practitioners such as GPs, nurses, and pharmacists, as well as aged care workers, community care workers and allied health professionals such as social workers.

Secondly, it would aim to improve general community understanding about how palliative care can help improve quality of life much earlier following diagnosis of a life-limiting condition than most people believe.

By targeting both practitioners and users of palliative care, such a campaign would help to improve the end-of-life experience for West Australians with life-limiting conditions, as well as their families and those who care for them.

[12] *My Life, My Choice – The Report of the Joint Select Committee on End of Life Choices,* August 2018, p. 63.