



Senate Community Affairs Committee Inquiry into Palliative Care in Australia

Aged & Community Services WA
March 2012

Senate Community Affairs Committee's Inquiry into Palliative Care



Aged & Community Services Western Australia – 15 March 2012

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Introduction:

Aged and Community Services Western Australia Inc (ACSWA) is a peak industry body representing the church and charitable, and not-for profit organisations and groups that provide residential and community care for older Western Australians. Our members provide services throughout the State in metropolitan, rural and remote locations, and collectively manage:

- 8653 residential aged care beds
- 7803 independent living units
- 51 day care centres
- 1500 community care packages and over \$61.5 million in Home and Community Care funding.

ACSWA supports the concept that all Australians should be supported to die in their place of choice with their symptoms well managed and their pain minimised. While most people would prefer to die in their own home environment, residential aged care facilities are increasingly becoming providers of palliative care, with 43% of people who are admitted as high care residents to residential facilities dying within six months of their admission, and 52% dying within one year of admission (Australian Institute of Health and Welfare, 2010. Residential aged care in Australia 2009-09: a statistical overview. Canberra AIHW.)

The Productivity Commission Inquiry into Caring for Older Australians concluded that end of life care is core aged care business and that 'not only is it likely to be less expensive than equivalent services delivered in a hospital, but more appropriate care can be provided in a homelike environment that best meets the desires of the dying'. It is therefore critical that resources are directed to residential and community aged care providers to optimise palliative and end of life care in those settings.

Our submission addresses the issues specifically concerning the aged under each of the Senate Inquiry's terms of reference.

(a) What are the factors influencing access to and choice of appropriate palliative care that meets the needs of the ageing population?

Existing palliative care services currently tend to focus more on end of life care than encompassing the wider scope of palliative care which aims to maximise quality of life for people of all ages who have a life limiting illness. End of life care is only one stage of quality palliative care provision, and is often when people are most at risk of being inappropriately referred for hospitalisation. Those who are transferred often spend their final days in designated 'palliative care beds' that are provided within acute care settings, which are often more intent on preserving life than enabling death.

Our approach to palliative care still appears to be grounded in the traditional hospice model of care in which people in their terminal phase of life (usually those with advanced cancer) went to purpose built facilities to die. However, while cancer is the core business for specialist palliative care service, it is not the leading cause of death for older people. For people aged over 65 years in Australia the leading causes of death are heart disease, cerebrovascular disease, lung cancer, chronic obstructive airways disease and dementia. Emerging trends in caring for this population indicate that specialist palliative care

practitioners do not necessarily provide the direct care for these people during their end of life care.

Patterns of mortality and morbidity are changing in older Australians; and alongside an increase in life expectancy has been an increase in the proportion of older Australians experiencing lengthy periods of frailty complicated by chronic and complex life-limiting conditions and co-morbidity. The need for specialist palliative care services is increasing with these changing health patterns. Current service capacity does not match the expected increased need for palliative care. Older people requiring palliation may therefore seek care in a residential aged care facility. Residential aged care is increasingly the place of death for older people with terminal conditions.

The residential and community aged care sector appears not to be recognised as providing a valuable healthcare service to older Australians and appears to be segregated from the overall health system in Australia, with lack of a seamless transition between the sectors. Supporting the needs of those living with a life limiting illness requires a well resourced and integrated model of care that includes hospitals, medical officers, specialist palliative care services, community and residential care services.

Our current aged care system has been described in the Productivity Commission report (Caring for Older Australians) as complex and difficult to navigate, with excessive waiting times for admission, and limited choices of care providers. Funding provided by the Commonwealth Government to the residential care sector is inadequate to deliver appropriate palliative care services, and inequitable when compared to the hospital system, where inevitably many older Australians with life-limiting conditions will spend their final days due to a shortage of other options. The maximum amount payable by the Commonwealth under existing funding arrangements for the complex care of residents requiring palliation in a residential care facility is approximately \$150 per day, in comparison to public hospitals providing palliation who receive approximately \$1100 per day. This level of funding does not enable adequate resourcing of nursing and allied health staff to provide appropriate multi-disciplinary palliative care services in the residential aged care environment. Additionally, general practitioners have demonstrated a reluctance to provide services in residential aged care, which limits access to appropriate end of life care. The Productivity Commission concluded that there is a strong case for a greater role for residential and community care providers to deliver palliative and end of life care but highlighted the 'insufficient and inadequate' funding for palliative and end of life care in the aged care system.

Community palliative care services are provided in WA by visiting specialist teams, including Silver Chain Palliative Care and Palliative Ambulatory Services. The Ambulatory Service, funded by the WA Department of Health, can provide consultancy advisory support, on-site patient reviews and consultations regarding complex palliative care needs, and staff education services to support clinical staff in various settings including residential aged care. It is however only accessible from Monday to Friday during normal working hours.

Silver Chain in WA also receives state government and Department of Veterans Affairs funding (with additional bequests and donations), for home palliative care, and is widely acknowledged as the benchmark for quality community palliative care services. It is available 24 hours a day, seven days a week. Data indicates that approximately 60% of Silver Chain's clients die at home in accordance with their wishes. However, this service is often dependent on the availability of a spouse or unpaid caregiver to provide ongoing support, and in the terminal stage of disease is often dependent on environmental factors that impact on functional ability in the home, and the provision of specialised assistive equipment to support mobility and activity of daily living functions. Nevertheless, older Australians have expressed a desire to have their palliative care needs provided in their own home.

Supporting the needs of people living with a life limiting illness, their carers and families, requires a well-resourced and well integrated service delivery model that supports specialist palliative care services, and enhances in-home support through better integration of community care with specialist palliative care services. Examples of where improvements can be made are:

- Appropriate financial incentives for General Practitioners and specialists to provide services in residential and community care settings
- Provision of aids and equipment in support of care requirements
- Improved access to an interdisciplinary palliative care team – support in direct care provision or consultancy (both residential and in Community)
- Well-integrated health care systems facilitating seamless delivery of care (services should be delivered through a continuum, with support for both service providers, clients and families).

An additional factor to consider related to palliative care and dying is our society's attitude towards death and ageing. We do not appear to value older people, often considering their economic value rather than their human dignity as more important. Similarly, our society has institutionalised death and it has become increasingly hidden from a society that is obsessed with youthfulness. Until we reintegrate death into the cycle of life, the care of our dying will remain superfluous to mainstream medical care that is focussed on sustaining life. Palliative care affirms life and regards dying as a normal process.

What are the particular issues for:

(i) People living in rural and regional areas.

Older Australians living in rural and regional areas generally have limited access to specialist palliative care services, particularly indigenous people. There are increased costs for older people receiving palliative care as they often need to travel to metropolitan or large regional centres for care, often associated with accommodation and transport costs and loss of earnings for themselves or family members related to time off work to accompany the patient; and limited access to health professionals due to rural workforce shortages in their home community to provide ongoing and local palliative care support.

Appropriate access to an interdisciplinary palliative care team across the triangle of care – inpatient, hospice or community, is a necessity for residents in rural and remote areas of Western Australia who have palliative care needs. These services would also be required to have back up services for clients and service providers to have access to services after hours and weekends. Improved access to relevant aids and equipment to support the essential services to palliative care clients and their families is often difficult to access in rural and remote areas.

For residential and community aged care providers there are issues related to diseconomies of scale that increase the cost of care in rural and regional areas that are disincentives to the provision of palliative care services in these areas. Funding needs to recognise the additional costs of care provision in rural areas.

(ii) Indigenous people.

Indigenous Australians have a culture in which they prefer to die in their own communities, and often prefer the involvement of traditional healers. This creates a dilemma for mainstream palliative care services that are based on a western medical model of care. Palliative care in the indigenous community needs to be flexible to accommodate local cultural needs, and provided in a partnership arrangement with local health workers.

Many indigenous communities are located in remote areas, where there are chronic shortages of health professionals and limited professional development opportunities.

(iii) People from culturally and linguistically diverse backgrounds.

Australia's population of older people from culturally and linguistically diverse backgrounds is expected to increase by over 40% between 2011 and 2026, when it is projected that one in every four Australians aged over 80 will be from a CALD background. This group may have a lack of knowledge and awareness of how the Australian health system, including palliative

care, operates. They may be further disadvantaged by limited proficiency in the English language, restricting access to information about available services.

The diversity of cultural and religious differences and expectations will necessitate a flexible palliative care model to accommodate the differing needs of the CALD population. Palliative care staff will require a broad understanding of appropriate religious and cultural norms related to palliative care, family dynamics and dying.

Older Australians from CALD backgrounds may have limited family support as a result of migration, and diminished support networks to enable supported palliative care in the home.

(b) What are the funding arrangements for palliative care provision in aged care, including the manner in which sub-acute funding is provided and spent?

The Productivity Commission into Caring for Older Australians highlighted the 'insufficient and inadequate' funding for palliative and end of life care in the aged care system. The palliative care model advocates for a holistic model of care aimed at supporting quality of life in the physical, psychological and spiritual domains. Existing Commonwealth funding to residential care does not support the multi-disciplinary approach required to provide appropriate palliative care. The Aged Care Funding Instrument (ACFI) used to determine the level of funding for residents requires palliative care to be provided under the directive of a Clinical Nurse Consultant or Clinical Nurse Specialist in pain or palliative care, or a medical practitioner to achieve funding under 'Complex Health Care Procedures'. Timely access to such health professionals is limited in residential aged care.

Additionally, primary health care services provided from State Government funded health services are often inaccessible to residents in aged care facilities, as it is expected that aged care providers who are funded by the Commonwealth must provide the range of Specified Care and Services outlined in the Aged Care Act 1997, which includes the 'establishment and supervision of a complex pain management or palliative care program, including monitoring and managing any side effects'. Given that the maximum daily funding available for a palliative care resident in an aged care facility is approximately \$150, in comparison to a palliative care client in an acute hospital who is funded at approximately \$1100 per day, it is inconceivable that there is equity in the care provided.

There has been a shift in the staffing and skill mix in aged care, with a decrease in the number of registered nurses and allied health staff, and an increase in unregistered care staff who now make up the bulk of the workforce in aged care. Reasons cited for this change includes difficulty recruiting professional staff as aged care is perceived as having low status among the health professional workforce, and the lack of wage parity between acute and aged care nursing which contributes to the challenges in attracting and retaining professional staff who are necessary to provide specialised and holistic palliative care.

(c) How efficient is the use of palliative, health and aged care resources?

The lack of coordination between Commonwealth funded aged care services, State Government health care, including outreach, primary and acute/tertiary health services, and local Government services such as Home and Community Care, results in an inefficient and cumbersome health experience for residents requiring palliative care. Legislative jurisdictions also impact on a nationally consistent approach to providing health care because of differences in regulations relating to who is able to administer medicines (such as Schedule 8 drugs) and the use of syringe drivers to manage pain, and indeed, access to certain drugs that are funded under the Pharmaceutical Benefits Scheme and public hospital system. Quality end of life care is realised when all health care services work together in a seamless manner to provide coordinated care that is not confined by funding and jurisdictional boundaries.

As previously discussed, funding arrangements for the provision of aged care services, including palliative care, is inequitable between Commonwealth and State funded services. There appears to be much cost shifting between different agencies providing palliative care because of this inequity, often to the detriment of the client. For example, a resident in an aged care facility who is unable to receive the complex nursing care required during end of

life care, may need to be transferred to an acute care hospital to receive such care. If residential aged care was funded appropriately to employ adequately skilled staff this would enable the integration of complex end of life care in the aged care setting, where the needs of the client are known to staff. This would result in a better outcome for the resident and improved use of financial resources.

The provision of home palliative care in WA has resulted in fewer people dying in a hospital setting, with 60% of clients using this service dying at home.

(d) How effective are palliative care arrangements, including hospital care, residential aged or community care facilities?

A more recent initiative in WA, an ambulatory outreach palliative care service that offers services in residential aged care facilities is a useful resource that will improve end of life care. It also provides a useful upskilling function to improve the palliative care skills of staff in the residential care facility. However, it is limited to a Monday to Friday service and is not available out of hours.

Older Australians have expressed a desire to reside in their own homes as they age, and receive care as required in their community. WA has a number of specialist community palliative care service providers with a focus on end of life care and symptom management. Such services can support palliative clients to remain in their own home, but usually require the ongoing support of a spouse or unpaid caregiver. There are cost effective benefits to enabling individuals to remain in their home, but there is additional caregiver stress in these arrangements. Appropriate home care can improve patient outcomes and reduce the potential for admission to hospital for acute episodes of care, but their needs to be an expansion of services to provide respite for caregivers.

A number of research studies have reported that palliative care provided in acute care settings may be less than ideal as hospitals are more focussed on health improvement and less on the psychological, spiritual and social needs of the life limited patient and their family.

(e) Can you comment on the composition of the palliative care workforce?

Ideally, a multidisciplinary team consisting of doctors (specialists and GPs), pharmacists, nurse practitioners, nurses, physiotherapists, occupational therapists, dieticians, social workers, counsellors, chaplains, personal care workers and volunteers would constitute the palliative care workforce. These multidisciplinary teams should be able to offer palliative care in a variety of settings, including hospice, residential aged care, community and hospital settings. There are opportunities to enhance the role of nurse practitioners in the provision of palliative care.

Including:

(i) Its ability to meet the needs of the ageing population.

Public hospitals appear to have strict criteria regarding admission and discharge, length of stay etc which results in challenges for residents with a life-limiting illness to receive care at times other than when their condition is critical. For this reason it is imperative to have alternative options, such as community and residential care services that can provide palliative care. The provision of palliative care within the aged care sector would be a logical extension of service, and is in fact viewed as 'core business' by the Productivity Commission Inquiry into Caring for Older Australians. However, aged care is experiencing difficulty in attracting and retaining a workforce related to a number of issues. It is plagued by image issues that are perpetrated by media stories that highlight isolated incidents of poor quality care that reinforce and stereotype aged care as low status and contribute to poor morale amongst aged care workers. There is a lack of wage parity between those in the aged care sector and those in other health care settings that is a significant issue in attracting and retaining staff.

With a predicted growth of 300% in the aged care workforce requirements between 2003 and 2021, competitive pressures for labour, and workforce losses in the health industry being

generated by the ageing of the industry workforce, it is imperative to develop strategies to ensure an appropriate workforce to meet the needs of an ageing population with increased palliative care needs. It is unlikely that without significant reform of the aged care sector, the expansion of palliative care services within this sector is limited, despite it appearing to be the most logical provider of such services.

Western Australia has seen extreme labour shortages in recent years, related to the mining resource boom, which has severely impacted the aged care sector. Economic modelling indicates that if economic growth is maintained at the average rate as occurred between 2003 and 2009, WA would require an additional 400,000 workers over the next 10 years, resulting in a shortfall of 150,000 workers in WA by 2017. The aged care sector in WA has experienced significant competition in attracting and retaining staff in a robust economic climate when the resources sector offers higher remuneration and perceived better working conditions. ACSWA believes that an urgent review of the migration program is required to extend the scope of the workforce to include suitable short-term skilled and non-skilled workers who can provide services in areas of critical labour supply in WA, particularly rural and remote areas. This includes a reclassification of aged care workers, whose ANZSCO skill level 3 falls below the minimum skill level requirement criteria for participation in the Regional Sponsored Migration Scheme, although occupations such as pet groomers, crutching contractors and animal attendants qualify for this program.

The Productivity Commission's Inquiry into Caring for Older Australians recognised the need to pay competitive wages in the aged care sector, and recommended that in future funding arrangements there was a need to take this into consideration when establishing prices for the delivery of aged care services.

(ii) The adequacy of workforce education and training arrangements.

There are issues related to the perception of working with the aged (the majority of those requiring palliative care) that will impact on the ability to provide a professional healthcare workforce for this sector. The quality of the relationship between the aged and health professionals has been compromised by negative stereotypes of caring for our elderly, whose health problems stimulate little medical interest and are seen as less technical amongst our university educated health professionals who are trained in a curative medical model of care. Tertiary educational institutions will need to address some of these factors to make it more attractive to pursue a career in aged and palliative care. Strategies to include compulsory palliative and aged care units into the undergraduate curriculum, and opportunities to undertake clinical placement in these areas, is recommended. There are also opportunities to enhance the role of nurse practitioners in palliative care.

Personal care workers are increasingly providing a role in palliative care in both the aged care residential and community home support palliative care sector. The workers usually have a minimum Certificate III in Aged care but there is a broad range in the variability of the training provided by registered training organisations, and the timeframe to complete such courses ranges from 2 weeks to 18 months. Palliative care is not a core unit in Certificate III training. ACSWA has lobbied for a review of the quality of some Certificate III training courses to ensure that all graduates enter the workforce with the appropriate skills required.

The Productivity Commission Inquiry into Caring for Older Australians acknowledged that although some aged care facilities provided excellent end of life and palliative care, this was not always the case. It identified that a lack of knowledge and skills among the aged care workforce in the area of palliative and end of life care was a key area of concern to them and concluded that it should be a basic competency of aged care worker training, with upskilling of registered nurses in palliative care provision.

(f) How would you describe the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians?

The Standards for Providing Quality Palliative Care provide a useful benchmark against which a range of organisations can measure their quality of care. These Standards are optional. Most healthcare organisations that include palliative care amongst their services must attain mandatory accreditation against a set of industry standards, and it is anticipated that organisations providing palliative care incorporate the palliative care standards into their overall quality management system, against which they are formally assessed. Residential aged care services must be accredited against the Aged Care Accreditation Standards, a set of Standards that includes a range of health and personal care Standards, including palliative care.

A national reference group was convened by Palliative Care Australia in 2011 to consider the optional implementation of the Standards for Providing Quality Palliative Care into residential aged care. The group was supportive of this plan, but considered that if it was perceived to be the industry benchmark by the Aged Care Accreditation Agency that it may be viewed as a 'minimum requirement' for residential aged care providers to achieve. This is unrealistic due to the inequity of funding and the skill levels of the workforce in residential aged care when compared to specialist palliative care services. The palliative care standards are applicable to residential aged care and can be achieved at the 'primary care' level. However, it should remain an optional and aspirational resource to demonstrate the provision of quality of palliative care in residential aged care facilities.

(g) Advance care planning.

(i) What avenues are there for individuals and carers to communicate with health care professionals about end-of-life care?

In WA the Advance Health Directive was introduced in 2010; this is a legally binding document that enables individuals to document decisions about their future treatment, and is effective at the time the individual can no longer make reasonable judgments about treatment decisions.

The Enduring Power of Guardianship enables a person to give authority to another person (the enduring guardian) to make personal, lifestyle and treatment decisions on their behalf if they are unable to do so in the future.

Residential aged care providers usually obtain details about the resident's end of life wishes at the time of admission, as this is seen as an expectation to demonstrate compliance with the Aged Care Accreditation Standards, against which all providers must comply. This information may not necessarily have been formally documented by the incoming resident in an Advance Health Directive, which creates a dilemma for the aged care provider as to the legality of complying with the resident's end of life wishes when they are not documented in a legally binding Advance Health Directive. There are also issues related to advance care planning for people without legal decision-making capacity, such as those with dementia.

There is a challenge currently for health professionals in ensuring the individual's end of life decisions are known and communicated to relevant personnel as there is no formal lodgement facility for Advance Health Directives to accommodate this.

There appears to be a low level of understanding in the community about Advance Health Directives, and reluctance by treating health professionals to initiate discussion about these matters. The WA Health Department recently funded a project "Talking about end of life" to improve the skills of residential aged care staff at all levels to facilitate decision making regarding the provision of palliative care and advance care planning for residents and their families. This is yet to be evaluated.

(ii) Should there be national consistency in law and policy supporting advance care plans? What are the consequences of there not being consistency?

National consistency is definitely required in laws and policy supporting advance care plans/directives as health professionals involved in end of life decisions cannot always be cognisant of their legal obligations that may be applicable in the jurisdiction in which the advance care plan/directive was made as there are currently differences in requirements between States and Territories. Additionally there is no centralised repository where health professionals can identify whether the individual has identified their end of life decisions. Ideally, this could be achieved with the roll out of the personal electronic health record.

(iii) What scope is there for including advance care plans in personal electronic health records?

As above.

(h) What are your views on the availability and funding of research, information and data about palliative care needs in Australia?

From a residential and community aged care perspective most of the information provided about palliative care is distributed by the Department of Health and Ageing and accessed through websites such as CareSeach, which is an online resource of palliative care information and evidence, and The Palliative Approach Toolkit, which formed part of a project '*Implementation of a comprehensive evidence-based palliative approach in residential aged care*' that was funded by the federal government's Department of Health and Ageing under the Encouraging Better Practice in Aged Care (EBPAC) Program. Guidelines have been developed for a palliative care approach for residential aged care (2009 edition).

Conclusion

Patterns of mortality and morbidity are changing in older Australians; and alongside an increase in life expectancy has been an increase in the proportion of older Australians experiencing lengthy periods of frailty complicated by chronic and complex life-limiting conditions and co-morbidity. The need for palliative care services is increasing with these changing health patterns.

ACSWA supports the concept that all Australians should be supported to die in their place of choice with their symptoms well managed and their pain minimised. While most people would prefer to die in their own home environment, residential aged care facilities are increasingly becoming providers of palliative care.

It is critical that adequate resources are directed to residential and community aged care providers to optimise palliative and end of life care in those settings, and funding must recognise the additional costs of care provision in rural areas.