



**Aged & Community
Services • Australia**

Submission

to

Senate Community Affairs Committee

Inquiry into

Palliative Care in Australia

March 2012

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Introduction

Aged and Community Services Australia (ACSA) is the national peak body for aged and community care providers representing over 1100 faith based, charitable and community-based organisations providing residential and community care services, housing and supported accommodation for almost 1 million older people, younger people with a disability and their carers.

Around 50,000 older Australians each year approach death or die in aged care homes¹. This figure is expected to increase significantly as the profile of Australia's population continues to age, with the number of people aged 85 and older projected to increase from 0.4 million currently to 1.8 million by 2050².

As a consequence, end of life care and palliative care is a core issue and a matter of fundamental concern for residential and community age care providers. The sector's capacity to respond effectively to people's needs at end of life is critical to the welfare of older Australians. Accordingly, ACSA welcomes the Senate's focus on palliative care and values the opportunity to make a submission to the inquiry.

This submission is structured around the inquiry's Terms of Reference, and concludes with an assessment which seeks to provide policy recommendations for the inquiry's consideration aimed at improving end of life and palliative care for older Australians by recognising and improving the role that aged care services can play.

The recommendations in this submission also complement those in the Productivity Commission's Report *Caring for Older Australians* which presented an integrated and comprehensive package of reforms to ensure the sustainable provision of quality care and support services for older Australians.

2. Background

2.1 The scope of palliative care

ACSA supports a scope for palliative and end of life care which spans generalist community-based services that are offered through primary care and aged care services, as well as the traditional specialist palliative care services provided mainly in hospices.³

As provided for in the World Health Organization's definition of palliative care⁴, both specialist and generalist palliative care services should embrace an approach to care which:

- provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process and intends neither to hasten nor postpone death;

¹ *Caring for Older Australians* Productivity Commission Vol 2 p226 (June 2011)

² *Australia to 2050: Future Challenges* Australian Government (2010)

³ *National Palliative Care Strategy* Australian Health Ministers (2010)

⁴ *WHO Definition of Palliative Care* World Health Organisation (2008)

- integrates the psychological and spiritual aspects of care, and offers support to help people live as actively as possible until death;
- uses team based approaches to enhance quality of life and to address the needs of those being cared for and their families, including bereavement counselling ; and
- is also applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.

A wider scope for palliative care reflects the changing epidemiology of disease due to the ageing of the population. It also reflects the premise that most people who are dying will not need to be directly cared for by specialist palliative care practitioners.^{5 6}

As populations age, the pattern of conditions that people suffer and die from change. Increasingly, more people will die of chronic diseases such as heart disease, cerebrovascular disease, respiratory disease and cancer, all of which are generally more common in older age. Many of these conditions will be associated with dementia and the ageing process. Many older people will also suffer from several conditions together that might all contribute to death.

Many older people at or near the end of life may also display mental confusion, problems with bladder and bowel control or chronic constipation, organ failure, sight and hearing difficulties and dysphasia.

The increasing prevalence of dementia⁷ poses many unique challenges for palliative and end of life care. Dementia care is palliative care, but unlike palliative care for conditions such as cancer, the process of decline takes place over an extended period and is linked to loss of cognitive abilities and (often) behaviour and personality changes which place additional requirements on care regimes and practices.

In summary, while palliative care traditionally has mainly been focused on cancer sufferers in inpatient hospices, end of life and palliative care services, and the health and aged care system overall, will need to adapt to the increased prevalence of the more complex morbidities and conditions associated with increased longevity and the ageing process.

2.2 A palliative care framework

ACSA supports the Australian Government's *Guidelines for a Palliative Approach in Residential Aged Care Services* which presents a framework that distinguishes between a palliative approach to care, specialist palliative care and end of life care.⁸ This framework is equally applicable to palliative care provided to older people in their own home⁹. The Guidelines are also consistent with the World Health Organisation's definition of the scope and purpose of palliative care.

⁵ *A Healthier Future for all Australians* National Health and Hospitals Reform Commission (2009 p. 107)

⁶ *National Palliative Care Strategy* Australian Health Ministers (2010)

⁷ *Dementia Across Australia:2011-2050* Deloitte Access Economics (2011)

⁸ *Guidelines for a Palliative Approach in Residential Aged Care* National Health and Medical Research Council (2006)

⁹ *Guidelines for a Palliative Approach for Aged Care in the Community Setting* Department of Health and Ageing (2011)

The primary purpose of a *palliative approach to care* is to improve a person's level of comfort and function (ie. their quality of life) and to address their psychological, spiritual and social needs when the person's condition is not amenable to cure and the symptoms of the condition require effective management. Providing active treatment for the condition may also still be important and may be provided concurrently with a palliative approach. Most recipients of high level aged care services, who comprise a growing proportion of residents in aged care homes, would benefit from a palliative approach to care.¹⁰

Specialist palliative care involves the participation of palliative care specialists or other qualified health care practitioners to help with the assessment and treatment of individuals with more complex symptoms, and to provide advice and information on complex symptom management issues. Specialist palliative care supplements a palliative approach to care when needed.

End of life care applies to a person's final days or weeks of life when care decisions may need to be reviewed more frequently as this is generally a period of more intensive care and support in response to terminal decline, including more intensive symptom management around pain, dyspnoea, fatigue, anxiety and depression, as well as a greater focus on emotional and spiritual comfort and support for the family.

This submission will draw on this framework for palliative care services in discussing and presenting policy options to improve palliative care services for older people.

2.3 Society's attitude towards death and dying

An additional overarching factor to consider is our society's attitude towards death and ageing. There is a commonly held perception that we do not value older people, often considering their economic value rather than their human dignity. Similarly, our society has institutionalised death, and dying and death has become increasingly hidden from our society that is obsessed with youthfulness. Reduced generational exposure to death due to falling mortality rates may have contributed to this attitude.

This underlying societal attitude has far reaching implications for how we respond to the care needs of a population which is now rapidly ageing. For example, until we reintegrate death into the cycle of life, the care of our dying is likely to remain largely superfluous to mainstream medical care that is focussed on sustaining life. This attitude also has direct implications for how we approach advance care planning which, in turn, has significant implications for how we manage end of life care.

¹⁰ The proportion of residents, both permanent and periodic short stay, with high level care needs is likely to increase as the Government responds to community pressures to give people greater choice to receive care in their own home for longer (as recommended by the Productivity Commission), and as a result of the increasing prevalence of dementia.

3. Funding arrangements for palliative care

3.1 A complex and fragmented picture

Palliative and end of life care services currently have multiple funding sources and operate under a variety of fee-for-service and salaried arrangements which cross Commonwealth and State/Territory jurisdictions and professional boundaries. The following list of funding sources provides an indication of the current complexity, but does not purport to be comprehensive.

- i. Commonwealth and State/Territory funded hospital and community health services. Under these arrangements each State/Territory health system has primary responsibility for determining the allocation of the health dollar, including the priority given to palliative care services and how they are delivered. Palliative care services can include specialist palliative care hospices, in-home palliative care services, including community nursing and allied health services, and 'palliative care beds' in hospitals.

As a result, the palliative care service arrangements are many and varied across the regions of Australia.

- ii. Fee-for-service payments under the Medical Benefits Schedule, mainly to GPs for services provided in a number of community settings.
- iii. Drugs funded under the Pharmaceutical Benefits Scheme and the public hospital system.
- iv. Commonwealth aged care funding via the Aged Care Funding Instrument (ACFI) for palliative care programs which have been directed by an authorised clinician when ongoing care will involve very intensive clinical nursing and/or complex pain management in a residential care setting.

Unlike the funding for residential care under the ACFI, funding for community aged care packages (CACPs, EACH and EACHD) does not cover a palliative care program, though the EACH packages allow for qualified nursing input.

Palliative care for community aged care package recipients is sometimes provided in cooperation with State operated out-reach or in-home palliative care services. Policies which govern the extent to which there can be co-funding and cooperation vary across Australia, including in relation to Home and Community Care services. Overall, there is reported confusion and a lack of consistency about access to these services.

- v. Funding under the Home and Community Care Program which may be used by State health agencies for community nursing care, and in some instances may also support palliative care.

- vi. Payments to palliative care service providers in respect of individuals who have relevant private insurance. There is considerable criticism as to the scope of services that can be accessed under private insurance, including allied health services.

The net result of these complicated funding arrangements is to pose difficulties for the delivery of palliative and end of life care on the preferred multidisciplinary team basis as this requires strong networking and partnerships across service providers and across the separately funded programs. Equally, the variety of arrangements makes it difficult for older people and their families to understand what services are available and how to access them, and to exercise control and choice.

Instead, this situation leads to the common criticism that current palliative care services in Australia are fragmented, variable in availability and quality, are not person centred and are difficult to understand and access. It also means that access to quality palliative care services depends on the region or State in which a person lives.

4. Access to and choice of appropriate palliative care that meets the needs of older people

The consistently expressed preference of older Australians is to die in familiar surroundings, at home or in their aged care home, and to be cared for by familiar staff¹¹. Despite this preference, only 16% of the people who die annually in Australia die at home and 10% in nursing homes. Most die in hospital (54%) and the rest (20%) die in hospices.¹²

Reasons that have been advanced to explain why people's preferences are not being met are varied. They include:

- insufficient in-home or community based palliative care services, and inconsistent policies and practices concerning individuals' access to both community aged care packages and in-home palliative care;
- the current rationing of aged care services which limits the number of people who can age at home with the support of a community care package and in-home palliative care support¹³;
- the lack in many aged care services of sufficient appropriately trained staff to pursue an effective palliative approach to care, and difficulty in accessing GPs who are skilled and knowledgeable in palliative care;
- the inability of most aged care services to access timely specialist palliative care advice and information as needed, including outside normal working hours and weekends;

¹¹ *We Need to Talk about Dying – Survey* Media Release Palliative Care Australia (2011)

¹² *National Palliative Care Strategy* Australian Health Ministers (2010)

¹³ Lifting the current restrictions on the supply of aged care services which results in the rationing of community aged care services is a major recommendation of the Productivity Commission Report *Caring for Older Australians*.

- difficulties for aged care homes in claiming palliative care funding under the ACFI because of the lack of access to GPs with palliative care knowledge and a shortage of Registered Nurses with qualifications in the specialty fields of pain management and /or palliative care.¹⁴

As a result of these circumstances, many older people are being referred to hospitals to die a less dignified death in unfamiliar surroundings and with unfamiliar faces, or spend more time in hospitals due to insufficient community-based and in-home services.

The above factors which influence access and choice for the ageing population generally also affect access and choice for special needs groups, though additional factors also apply.

In the case of rural and remote communities, isolation, remoteness and distance compounds access problems. There are increased costs for older people and their families as they often need to travel to metropolitan or regional centres for care, often incurring accommodation and travel costs, and loss of earnings for accompanying family members.

There are also additional costs for service providers related to difficulties in attracting and retaining qualified staff; the inability to achieve economies of scale; and the additional cost of service delivery generally.

Indigenous communities in rural and remote Australia also suffer from these access problems, compounded by a lack of knowledge and awareness of Indigenous cultural attitudes to death and dying. There is a general preference in Indigenous communities to remain in the family unit, often with the involvement of traditional healers. Caring for older Indigenous people who are dying in these circumstances can be challenging due to the often poor standard of accommodation and basic services in many communities, and the crossover of western and traditional approaches to medicine. These circumstances call for considerable flexibility in service delivery, preferably in partnership with the informal carers. Training and employment of more Indigenous people to deliver aged care would assist.

These additional costs and barriers for providing aged care and palliative care services in rural and remote locations, including in Indigenous communities, are widely acknowledged.

The Productivity Commission recommended a number of measures which would assist. These include taking into account the additional costs of service delivery, such as staff accommodation and wage costs, due to remoteness and distance when setting care prices for aged care and palliative care services; block funding of services to allow greater certainty and flexibility; and the use of Multi-Purpose Service models to maximise economies of scale and flexibility in health and aged care service delivery. Other measures could include dedicated programs aimed at training more locals to work in the health and aged care sectors (such as distance learning and scholarships), and to encourage greater use of tele-medicine through the National Broadband Network to enable specialist input when needed and to support training.

¹⁴ Payments for palliative care under the ACFI require a directive from a clinical nurse consultant/ specialist in palliative care with at least five years of experience or medical practitioner, and a pain assessment.

For culturally and linguistically diverse communities, an additional factor affecting access is the lack of awareness of service availability and communication barriers due to language difficulties. The availability of interpreter services and information tailored for each community would help to improve access to services for these communities.

The Productivity Commission recognised these issues as applying to aged care delivery generally and made recommendations that would also apply to the provision of palliative and end of life care in aged care settings. In particular, the Commission recommended that its proposed national network of Seniors Gateways ensure that all older people have access to appropriate information and assessment services and should also be responsible for facilitating access for people with language and cultural needs through the provision of specific 'hubs' for older people from diverse backgrounds who have limited English skills.

The Commission also recommended that care prices should take into account the costs associated with catering for people from non-English speaking backgrounds, including the cost of interpreter services and the cost of staff undertaking professional development to increase their capacity to deliver culturally appropriate care.

For people with disabilities, many of the access issues mirror those for mainstream communities, and are linked to the fragmentation of the current service structure. An added dimension in older age for people with long term disabilities is the interface between the aged care and the disability service systems, which are funded under separate arrangements. In the aged care system, and putting aside for now the adequacy of the funding levels, older Australians can be assessed to receive a program of palliative care (see further below). Eligibility for this service extends to people with disabilities who happen to have been cared for in the aged care system, but is not available for people who are cared for in the disability system.

The design of the foreshadowed National Disability Insurance Scheme will need to address this interface issue. One option is to ensure that people living with disabilities have access to the same palliative care and support available through the aged care system irrespective of which system they choose for their care and support.

Overall, there is a lack of awareness and understanding in the general population of many of the issues around dying, death and grief, and a lack of awareness of the services that are available and how they can be accessed.

The Productivity Commission's proposal for a national network of Seniors Gateways to replace the current disparate aged care information and assessment services would be a useful innovation to help improve community information about service options. Seniors Gateways should also be funded and given responsibility for raising community awareness about death and dying and preparing for later life, including the role of advance care directives.

5. Effective use of palliative, health and aged care resources

In their submissions to the recent Productivity Commission's inquiry into aged care, many participants in the aged care sector reported that the end of life care needs of older Australians are being poorly served by the current arrangements for community and residential aged care, with a general view of many that palliative care was poorly provided in many aged care homes.¹⁵ Most ACSA members would agree that, in general, there is considerable scope to improve the quality of palliative care in aged care services.

There are three key inter-related factors that act as barriers to the effective delivery of palliative and end of life care in the aged care sector:

- i. the adequacy of palliative care funding;
- ii. the skill level and knowledge of the aged care workforce in the area of palliative care; and
- iii. the ability of many aged care services to access timely specialist palliative care advice and support when more complex symptom management is required.

5.1 Adequacy of palliative care funding

Funding for the care of residents of aged care homes is currently distributed using the Aged Care Funding Instrument (ACFI), a resource allocation instrument which distributes funding according to the main areas that distinguish care needs among individual residents. Depending on an assessment of individual care needs across three domains (Activities of Daily Living; Behaviour Supplement; and Complex Health Care Supplement), funding may be provided for each individual at any one of 64 funding levels or prices. Within the Complex Health Care Supplement, a maximum allocation of \$57.18 per day may be paid in respect of an aged care resident who has a palliative care plan in place following assessment by an authorised clinician that 'ongoing care will involve very intensive clinical nursing and/or complex pain management'.¹⁶

It is likely that a number of submissions to the Inquiry will draw comparisons between the level of ACFI funding for palliative care and the funding provided for the delivery of specialist palliative care in Australia's hospices. The comparisons are stark and demand scrutiny. The admitted patient palliative care per diem rate in the Victorian health system is \$566 (marginally more for rural hospitals)¹⁷. Palliative Care Australia in their submission to the Productivity Commission's aged care inquiry indicated that the current ACFI subsidy is around one-third of the amount that specialist palliative care services receive.

But care is needed to ensure that valid and like-for-like comparisons are made. Noting that the type of palliative care services to be provided in a specialist hospice are unlikely to be comparable to the delivery of a palliative approach to care and end of life care in an aged care home, a more pertinent approach for the Inquiry would be to query the basis for the

¹⁵ *Caring for Older Australians* Productivity Commission Vol 2 p 229 (2011)

¹⁶ People being cared for under a palliative care plan would also be eligible under ACFI for assistance with activities of daily living, which involves a daily payment of up to \$93.21.

¹⁷ *Victorian Health Policy and Funding Guidelines 2011-12 Part 2: Health Operations* Department of Health Victoria

daily payment of \$57.18 in aged care homes, and its adequacy. ACSA has not been able to identify the costing basis for this price.

An assessment of the adequacy of the current price for a palliative care program needs to start by taking into account that the setting of prices under ACFI is not based on any contemporary assessment of the actual cost of delivering care in different regions of Australia. Rather, the prices were calibrated to achieve a predetermined overall Budget outcome based on historical funding levels, adjusted for a gradual increase in the acuity of residents, the increase in the number of care recipients under the provision ratio¹⁸, and the indexation of the wages component to reflect only minimum wage adjustments which bear no relationship to wage pressures in the sector.

As such, the ACFI funding levels, and the funding levels of the Resident Classification Scale (RCS)¹⁹ which preceded them, cannot be expected to reflect the impact on the cost of care of the significant changes that have occurred since the late 1980s, when the current funding base was established. These changes include changes in care practices, accreditation and space and privacy standards, additional regulatory and compliance reporting requirements, increased community expectations and, most importantly, changes in labour markets which have tightened significantly since the original funding base was established.

In summary, there is no robust data or objective analysis for assessing whether current aged care funding is appropriate to support a palliative approach to care or to support end of life care.

This issue and the pricing of aged care services more generally, was acknowledged by the Productivity Commission in its Report *Caring for Older Australians*. The Report recommended that an independent pricing authority should be established to monitor report and assess aged care costs and to transparently recommend prices, subsidies and a rate of indexation for these services, (which would be provided as an individual entitlement based on assessed care needs).

With regard to palliative care, the Productivity Commission recommended that the Australian Government should ensure that residential and community care providers receive appropriate funding for delivering palliative and end of life care as part of a person's assessed individual entitlement, and that the payment should be determined by the Government on the transparent advice of the independent body in consultation with the Independent Hospital Pricing Authority. The involvement of both bodies would ensure that there is an alignment between prices for palliative care services in both settings, and would allow aged care providers who have the capacity the opportunity also to provide specialist palliative care.

ACSA strongly supports these recommendations.

ACSA also considers that the independent pricing authority should distinguish between the cost of the delivery of a palliative approach to care for those with higher care needs and the appropriate payment or supplement for the delivery of an end of life palliative care program,

¹⁸ Under current Australian Government policies, aged care services under the *Aged Care Act 1997* are rationed to support 113 people for every 1,000 people aged 70 and over.

¹⁹ It is also noteworthy that the RCS, and the separate funding scales for hostels and nursing homes which preceded the RCS, made no specific provision for palliative care.

in accordance with the framework in the Australian Government's *Guidelines for a Palliative Approach in Residential Aged Care*.

ACSA acknowledges that an important task for the independent pricing authority will be to identify the transition point from a palliative approach to care to intensive end of life care, especially in relation to dementia care. While challenging, a process for identifying this transition is essential to ensure realistic levels of funding to support quality end of life care.

5.2 The palliative care workforce

Good quality palliative and end of life care services can only be delivered if care staff have the necessary skills and knowledge, preferably operating in multidisciplinary teams and having timely access to specialist palliative care support when needed.

ACSA is not aware of any measure or index of the skill and knowledge level of the current aged care workforce with regard to delivering a palliative approach to care and end of life care. It notes that a number of programs have been initiated to increase the overall supply and quality of nursing and personal care skills in the aged care sector, but there is a generally held view that more needs to be done to up skill the aged care workforce and to increase the supply of quality staff, including ensuring that the existence of these training opportunities is more widely known.

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 or Home and Community Care but there is a wide variation in the training provided by Registered Training Organisations, and the timeframe to complete such courses ranges from 2 weeks to 18 months. Delivering a palliative care approach is not a core subject for Home and Community Care.

Palliative care training needs to be an important component of Certificate III and IV training for care workers, including building the curriculum around the Australian Government's *Guidelines for a Palliative Approach in Residential Aged Care* and its companion document *Guidelines for a Palliative Approach for Aged Care in the Community Setting*. This could be addressed as part of the independent review, recommended by the Productivity Commission, of aged care related vocational educational and training programs courses and their delivery by Registered Training Organisations.

The aged care sector has also seen a significant decline in the number of Registered Nurses²⁰. Between 2003 and 2007 the number of Registered Nurses employed declined by 7% whereas the number of residents increased by 12.5% and acuity levels (measured as a proportion of high care residents) continued to increase – currently 71% of residents require high level care. While all aged care staff should be trained in the palliative approach to care, the skills and knowledge of appropriately trained Registered Nurses are particularly important for end of life care.

ACSA considers that the supply and skill level of the aged care workforce needs to be a priority for Health Workforce Australia and the Community Services and Health Industry Skills Council. Comprehensive and effective training programs and strategies need to be put

²⁰ *Who Cares for Older Australians* National Institute of Labour Studies (2008)

in place, with a particular focus on generalist palliative care skills as well as palliative care specialists. A starting point would be to assess the skill levels and skill gaps of the existing workforce, determine a measure of future demand against an agreed framework for palliative care delivery for older people, and review the relevance and appropriateness of the current training curricula for supporting the delivery of palliative and end of life care. This information could then provide the basis for planning and designing future training programs, including assessing the need for incentives to encourage take up.

Increasing the supply of nurse practitioner palliative care specialists should be a priority to provide support for generalist palliative care delivered in the community and in aged care homes. The Hunter Collaborative Palliative Dementia Care Framework and the Palliative Aged Care Link Nurses in Victoria provide good demonstrations of how a nurse led program can support palliative care in the community.

There are also issues related to community perceptions about working with the aged (the majority of whom require a palliative approach to care) that impact on the ability to provide a professional health and aged care workforce. The quality of the relationship between the aged and health professionals has been compromised by negative stereotypes of caring for older people, 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. Universities will need to address these cultural factors to make it more attractive to pursue a career in aged and palliative care, and to encourage the networking of services and multidisciplinary approaches. Strategies are required to include compulsory palliative and aged care units into the undergraduate curriculum, and opportunities to undertake clinical placement in these areas.

As well as increased emphasis on training and staff development, attention needs to be given to the sector's capacity to attract and retain quality staff in a competitive labour market. The aged care sector has a reputation for being a low wage sector. Nurses in other parts of the health system attract significantly higher wages, and personal care workers in the aged care sector are amongst the lowest paid in the community. Their position at the bottom of the ladder has been further cemented by the recent Fair Work Australia decision to significantly increase wages for employees under the Social and Community Services (SACS) Award, and the promise by the Australian Government to fund their share of the increased wages.²¹

As a consequence, staff turnover is a key concern for the aged care sector. Surveys²² indicate that a quarter of personal care workers and one in five nurses have to be replaced each year. This is detrimental to the delivery of a palliative approach to care and aged care generally, especially for people living with dementia, as familiarity with regular and respected carers is essential to good care outcomes.

Also, the cost associated with the need to replace staff leads to inefficiency and a significant opportunity cost, including wasted training efforts.

The Productivity Commission was mindful of the importance of competitive wages to the future capacity of the sector to deliver quality aged and palliative care services. It

²¹ Most employees in the aged care sector relate to the Aged Care Award.

²² *Who Cares for Older Australians?* National Institute of Labour Studies (2008)

recommended that the independent body established to recommend prices for the delivery of aged care services should, when assessing and recommending prices, take into account the need to pay fair and competitive wages to nursing and other care staff, and the appropriate mix of skills and staffing levels for the delivery of those services.

ACSA strongly supports this recommendation, and highlights that prices which take into account fair and competitive wages must incorporate a flow-on to Aged Care Award employees of the recent SACS Award increases, a sector with which the aged care sector directly competes for staff.

5.3 Informal carers and volunteers

As is widely acknowledged, the requirements for the successful delivery of aged care services extend beyond the formal workforce to include informal carers. Most recently, in its report on *Caring for Older Australians*, the Productivity Commission concluded as follows²³:

‘Informal carers provide the majority of direct care to older Australians and often play a key role in the coordination of formal care services. Their role is not only fundamental to those they care for, but for the functioning of the aged care system as a whole.’

The successful delivery of end of life care and a palliative approach to aged care is no less dependent on the availability of informal carers, especially to support the delivery of in-home care.²⁴

Accordingly, ACSA strongly supports the Productivity Commission’s recommendations for providing effective and more accessible support for informal carers, including carer education and training, emergency respite, carer counselling and peer group support and carer advocacy services. In particular, Seniors Gateways should be resourced and required to undertake assessments of the capacity of informal carers to provide ongoing support and, as appropriate, to approve entitlements for planned respite and other essential support services.

Carers Support Centres should also be created, partly by bringing together existing specialist carer support programs, to provide more comprehensive and easily accessible carer support services.

Volunteer pastoral carers also have a vital role in supporting people who are dying, and their families, with the spiritual dimensions of end of life care. Organizing and managing an effective pastoral care program, including the recruitment, training and retention of volunteers, is costly for service providers. This was acknowledged by the Productivity Commission when it recommended that funding for services which engage volunteers in service delivery should take into account the costs associated with volunteer administration, regulation, training and support.

²³ *Caring for Older Australians* Productivity Commission Vol 2 p325 (2011)

²⁴ It is reported in the Australian Institute of Health and Welfare report *Aged Care Packages in the Community 2009-10: A Statistical Overview* (2011) that 94% of EACHD recipients had informal carers.

5.4 Timely access to specialist palliative care advice and information

While there is a general view that there is considerable scope to improve palliative care services in aged care homes and in the community, there are also examples of aged care services providing high quality palliative care services.

ACSA members report that this is more likely to be the case in situations where strong local networks exist between palliative care specialists and generalist palliative care providers in the community and in aged care homes. Examples where such networks have been developed include the in-home palliative care services provided by Silver Chain and Bethesda Hospital in the Perth metropolitan area, the Palliative Aged Care Link Nurses Positions in Victoria and the Hunter Collaborative Palliative Dementia Care Framework in Newcastle.²⁵

The home-based palliative care service provided in Perth by Silver Chain is a particularly successful multidisciplinary collaborative model. The service, which is primarily funded by the WA Health Department, provides:

- in home specialist palliative care to clients living at home or in care facilities that do not have a registered nurse managing care 24 hours a day;
- a palliative nurse consultancy service to hospitals and residential facilities where client care is managed by a registered nurse 24 hours a day; and
- telephone advice to rural service providers regarding managing the palliative care needs of individual clients.

As well as responding to people's preference to die at home, it has been reported that about 60% of those who died at home had no hospital admissions during their episode of care with the service, and 28% had only one admission.²⁶

However, it must be recognised, as previously noted, that the successful provision of in-home palliative care is often dependent on the availability of a spouse or other informal caregiver to provide ongoing support. In the terminal stage, it is also 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. Hence, carer support and education programs and access to assistive technology are essential, including respite and training to administer necessary pain medications, such as syringe driver medications.

Unfortunately, examples of successful collaboration and networking are the exception rather than the rule, and often do not extend to aged care homes. This situation is often a consequence of the current division of Commonwealth/State funding responsibilities for health and aged care. There is also a widely held perception that the residential and community aged care sector is not 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.

²⁵ *Palliative Care - Aged Care Reform Series* National Aged Care Alliance (2010)

²⁶ *Palliative Care - Aged Care Reform Series* National Aged Care Alliance (2010)

As a result, as stated earlier, access to quality palliative care services can depend significantly on which State or region a person lives in.

5.5 Timely access to emergency drugs

An aspect of the current health system which can impact on the effectiveness and quality of end of life care provided in aged care homes concerns State/Territory regulations governing the holding of stocks of emergency drugs by aged care homes.

In some States, medications such as hyoscine (for terminal secretions) and midazolam (for terminal agitation) are not legislated to be held in emergency stock, and drugs such as morphine can only be held in limited quantities.

Timely access to sufficient quantities of these emergency medications (doctor prescribed) is essential for the comfort and dignity at end of life. ACSA has received feedback from some members that access in some areas to these medications can be problematic, especially outside normal working hours and on weekends and public holidays.

ACSA considers that the current regulations governing access to and the stocking of emergency palliative care drugs should be reviewed in recognition of a greater and more effective role that aged care services can provide for the care of people at end of life.

6. Efficient use of palliative and end of life resources

The fragmented nature of palliative care funding and service delivery also impacts on the efficiency of resource utilisation.

There appears to be much cost shifting between different agencies providing palliative care and gaps in services, often to the detriment of the client. For example, a resident in an aged care home who is unable to receive the complex nursing and symptom management care required at end of life is often transferred by ambulance to an acute care hospital. If aged care was funded appropriately to employ adequately skilled staff and to access specialist palliative care advice and information as needed, more people could be cared for at end of life in a community setting, in familiar surroundings and known to staff. This would result in more efficient use of resources and a better outcome for the older person and the family.

The inefficiency of the current arrangements is best illustrated by the large number of older people who are referred from aged care homes to hospitals to die (54% of people die in hospitals). It would be a better use of resources, as well as more respectful of people's preference to die in familiar place with familiar carers, if aged care providers were properly supported to provide end of life care in aged care homes or people's own homes.

End of life and palliative care for older people, their carers and families, requires a well-resourced and well integrated service delivery framework that supports specialist palliative care services, and enhances in-home and community-based palliative and end of life care

through better integration of residential and community aged care with specialist palliative care services.

Ideally, palliative care services would be the responsibility of one funding body, rather than the current complex arrangements. Current arrangements, even with the best intentions, are often coloured by concerns about the relative contribution of the different funding bodies rather than by what service delivery arrangement is best practice.

How best to achieve greater local integration and cooperation in a fragmented system is a threshold decision for the Inquiry.

One option is to refer this matter to Health Ministers and the Council of Australian Governments (COAG) for resolution in the context of the current health reforms to establish Local Health Networks and Medicare Locals to foster greater local collaboration and networking. The outcome, after lengthy consideration, is likely to be that the parties have agreed to cooperate to facilitate greater integration, supported by some sort of performance reporting.

Despite some examples of strong local networking between sectors, experience suggests, however, that the level of local collaboration is likely to continue to vary across the country unless there is a structural driver to change behaviours. An alternative approach which would provide greater certainty for the provision of specialist palliative care advice and information to residential and community aged care services is to fund Medicare Locals to provide this service using specialist nurse practitioners or nurse consultants, in collaboration with GPs who are skilled in palliative care. Medicare Locals could also have the option to purchase services from the State Health systems.

The Medicare Local specialists could also be given a role in assessing older people for eligibility for end of life funding or supplement under the ACFI.

7. The adequacy of palliative care standards

ACSA considers that the Standards for Providing Quality Palliative Care for All Australians developed by Palliative Care Australia provide a useful benchmark against which service providers can measure their quality of care. These Standards are optional in both health care and residential care settings.

Residential aged care services currently must be accredited by the Aged Care Standards and Accreditation Agency against the Aged Care Accreditation Standards, including Standard 2: Health and Personal Care which includes outcomes relating to pain management and palliative care.

Whilst ACSA is supportive of the Standards for Providing Quality Palliative Care, it does not support their incorporation into the Aged Care Standards and Accreditation Agency's processes and accreditation requirements at this time. As canvassed earlier in this submission, for reasons to do with resourcing, the availability of staff skilled in palliative care and timely access to advice and information from specialist palliative care practitioners, the

quality of palliative care across Australia is variable. As a result it would be difficult for providers to consistently achieve the standards.

In the circumstances, pending reforms which would allow a consistent improvement in palliative care service standards, ACSA considers that the standards should remain optional and be treated as standards to which providers should aspire within the limitations of current resources and arrangements.

8. Advance care planning

ACSA considers that there should be national consistency in legislation and policies governing the scope and implementation of advance care directives to ensure they are valid across all jurisdictions. Consistency of arrangements would also make the task of raising community awareness, and increasing the take up of advance care planning, much simpler.

The current system of separate State and Territory laws is resulting in confusion and unnecessary complexity for people (older people, their families, health professional and care staff) who move interstate and for care providers who operate across State and Territory borders. The difference in terminology is also confusing. National consistency would allow the integration of the best aspects of the current laws and provide a real opportunity for the development of streamlined and easy to understand legislation and policy.

ACSA considers that the roll out of e-health and the National Broadband Network presents an ideal opportunity to include advance care directives in personally controlled electronic health records. Partly as a result of the fragmented nature of the current system for caring for people approaching death, individuals' paper-based preferences are not always communicated effectively to the health professionals who care for them. Including advance care directives in personally controlled electronic health records would give individuals greater confidence that their preferences are communicated and respected.

The take up of advance care planning would also be assisted by awareness raising activities by the Seniors Gateways, and by aged care providers having staff who are trained to be able to discuss and put in place advance care directives which are kept up to date.

9. Research

The ageing of Australia's population and the consequential changes to the epidemiology of disease at end of life, including conditions and disabilities associated with the ageing process, have created a need for research into palliative and end of life care to be given a higher funding priority, especially research to support improved palliative care for the less traditional life limiting conditions which are becoming more common.

Of primary concern for the aged care sector is dementia care. The increasing prevalence of dementia in Australia poses many unique challenges for palliative care practices and service models. The challenges relate to the dying process taking place over an extended period during which time people will be subjected to a gradual decline in cognition, functional

ability and possibly behaviour, emotions and personality. Pain management and care, and encouraging the take up of advance care directives, is challenging in such circumstances.

Accordingly, ACSA considers that priority should be given by organisations such as the National Health and Medical Research Council to support research into improving palliative and end of life care for dementia sufferers, and that the results of the research should not only inform policy, but also be disseminated widely to health and aged care practitioners to inform evidence-based care practices. In particular, priority should be given to research projects that support and help translate into practice the *Guidelines for a Palliative Approach in Residential Aged Care* and the *Guidelines for a Palliative Approach in the Community Setting*.

10. Conclusion

Drawing on the information and analysis presented in this submission, ACSA considers that a future system to provide an effective and efficient palliative approach to care and end of life care for older Australians should factor in or feature the following:

- i. The number of people who approach death while in the care of residential and community aged care providers is projected to increase significantly as the population of people aged 85 and over reaches 1.8 million by 2050.
- ii. The consistently expressed preference of older people is to die in familiar surroundings, at home or in an aged care home, cared for by familiar and trusted staff. Despite this, most old people die in acute hospitals.
- iii. Most old people who are dying will not need to be directly cared for by specialist palliative care practitioners.
- iv. An appropriately resourced aged care system which has timely access to specialist palliative care advice and information is an effective and efficient means of delivering end of life care for older people in their own home or in aged care homes.
- v. The current fragmented system of palliative care delivery needs to be reformed to ensure that people's access to quality services does not depend on in which region or State/Territory a person lives in.
- vi. There is a need to significantly increase the availability of a skilled workforce to deliver a palliative approach to care and end of life care and to support informal carers and volunteer pastoral carers.
- vii. There is a need for greater community awareness of, and take up of, advance care planning and for arrangements to ensure that people's preferences at the end of their life are effectively communicated and respected.

- viii. Increased priority should be given to funding research aimed at increasing the effectiveness of palliative care delivery, especially for the care of people living with dementia.

11. Recommendations

Based on the above analysis, ACSA advances the following inter-related recommendations for reform of the current arrangements for the care of older Australians at end of life for the Committee's consideration and endorsement:

- 1 The establishment of an independent pricing authority by the Australian Government, as recommended by the Productivity Commission, to monitor, report and assess the regional costs of delivery of residential and community aged care services, based on the use of a palliative approach to care, and to transparently recommend prices, subsidies and a rate of indexation for the services.
- 2 The appropriate payment or supplement for end of life care be determined on the transparent advice of the independent pricing authority in consultation with the Independent Hospital Pricing Authority.
- 3 The independent pricing authority be required to take into account when recommending prices the need to pay fair and competitive wages to nursing and other staff, and an appropriate mix of skills and staffing levels for the delivery of the services.
- 4 Payments to individuals in respect of receiving a palliative approach to care and end of life care should form part of an individual's assessed entitlement for care and support.
- 5 The independent pricing authority take into account the additional costs of delivering services in rural and remote locations, including staff accommodation and wages, when recommending prices for palliative and aged care.
- 6 The funding arrangements for aged care and palliative care services in rural and remote locations and for special needs groups such as the homeless and Indigenous communities utilise flexible funding models, as appropriate, such as block funding and multi-purpose service models.
- 7 Medicare Locals be funded either to provide specialist palliative care advice and information for older people cared for in aged care services and training, using specialist nurse practitioners and Nurse Consultants, and in collaboration with GPs, or to purchase the services from the State/Territory health systems.

- 8 Health Workforce Australia and the Community Services and Health Industry Skills Council should be funded to undertake, in consultation with the health and aged care sectors, an urgent assessment of the current and future palliative care workforce needs, both generalist and specialists, and to recommend measures to meet the identified workforce needs, including the workforce needs of rural and remote services. The latter should include dedicated programs aimed at training more locals (including Indigenous people) to work in health and aged care, such as distance learning and scholarships.
- 9 The independent review of aged care-related vocational education and training courses recommended by the Productivity Commission should include a review of the appropriateness of course curricula and course delivery to support a palliative approach to care and end of life care in aged care services.
- 10 A regional network of Seniors Gateways, as recommended by the Productivity Commission, be established. As well as a general role of simplifying access to aged care services, the Gateways should be given responsibility for providing information and advice on palliative care services and for raising community awareness about death and dying and preparing for later life, including awareness of the role of advance care planning.
- 11 The Seniors Gateways be funded to provide information tailored to the needs of people from non-English speaking backgrounds, and that prices recommended by the independent pricing authority for a palliative approach to care and end of life care should take into account the cost of interpreter services and professional development for staff to increase their capacity to deliver culturally appropriate care.
- 12 The Seniors Gateways should be resourced and required to undertake assessments of the capacity of informal carers to provide ongoing support and, as appropriate, to approve entitlements for planned respite and other essential support services.

Carers Support Centres should also be created to provide more comprehensive and easily accessible carer support services.
- 13 Funding for services which provide a volunteer pastoral carers program should take into account the costs associated with volunteer administration, regulation, training and support.
- 14 The design of the National Disabilities Insurance Scheme takes into account the interface between the aged care and disability systems for people with long term disabilities as they age, with a view to giving people with disabilities needing access to end of life care the same access to services as available under the aged care system.
- 15 Nationally consistent policies and legislation be enacted to govern the operation of advance care planning and directives, and that advance care directives be included in personally controlled electronic health records.

- 16 Seniors Gateways be resourced to increase community awareness of advance care directives and to support their take up, especially by people with a dementia diagnosis.
- 17 The incorporation of the Standards for Providing Quality Palliative Care into the accreditation processes of the Aged Care Standards and Accreditation Agency not be supported at this time. Pending implementation of reforms to improve the capacity of aged care services providers to meet consistently the Standards, they remain optional and be treated as standards to which providers aspire within the limitations of current resources.
- 18 The current regulations governing access to, and the stocking of emergency palliative care drugs, be reviewed in recognition of a greater and more effective role that aged care services can provide for the care of people at end of life.
- 19 Priority be given by organisations such as the National Health and Medical Research Council to research projects that support and help translate into practice the *Guidelines for a Palliative Approach in Residential Aged Care* and the *Guidelines for a Palliative Approach in the Community Setting*, with a particular emphasis on research into improving palliative and end of life care for dementia sufferers.

ACSA notes that the above recommendations align with the recommendations of the Productivity Commission's Report *Caring for Older Australians*, and the recommendations of the National Aged Care Alliance in its *Blueprint for Reform of Aged Care* and its Aged Care Reform Series Paper *Palliative Care*.
