Aged Care Association Australia

Submission to the

Senate Community Affairs Committee inquiry into the provision of palliative care in Australia

27 March 2012

Introduction

Aged Care Association Australia (ACAA) welcomes the inquiry by the Senate Community Affairs Committee into the provision of palliative care in Australia, including:

- (a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:
    - (i) people living in rural and regional areas
    - (ii) indigenous people
    - (iii) people from culturally and linguistically diverse backgrounds
    - (iv) people with disabilities, and
    - (v) children and adolescents;
- (b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;
- (c) the efficient use of palliative, health and aged care resources;
- (d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;
- (e) the composition of the palliative care workforce, including:
    - (i) its ability to meet the needs of the ageing population, and
    - (ii) the adequacy of workforce education and training arrangements;
- (f) 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;
- (g) advance care planning, including:
    - (i) avenues for individuals and carers to communicate with health care professionals about end-of-life care
    - (ii) national consistency in law and policy supporting advance care plans, and
    - (iii) scope for including advance care plans in personal electronic health records; and
- (h) the availability and funding of research, information and data about palliative care needs in Australia.

For older people, death commonly occurs while receiving aged care, both residential and community, unless the residents are transferred to acute care facilities. However, there are barriers, including inadequate pain relief and symptom management, in aged care – both residential and community – preventing people being able to receive quality, seamless end of life care for their complex health needs, in the setting of their choice.

The increasing acuity of recipients of care in residential and community contexts is stretching workforce capacity to manage effectively and safely in what is rapidly becoming a sub-acute treatment service.

What is needed to ensure that people can really decide where they wish to die with dignity?

Accordingly, it is both a short-term and a long-term strategic planning need for resourcing to support aged care facilities to work towards providing quality care for people approaching the end of their lives, including appropriate palliation, pain and symptom relief.

a) Factors influencing access to and choice of appropriate palliative care that meets the needs of the population

The recent Productivity Commission report *Caring for Older Australians* defines aged care as [1]:

A range of services required by older persons (generally 65 years and over (or 50 years and over for Indigenous Australians)) with a reduced degree of functional capacity (physical or cognitive) and who are consequently dependent for an extended period of time on help with basic ADLs. Aged care is frequently provided in combination with basic medical services (such as help with wound dressing, pain management, medication, health monitoring), prevention, reablement or palliative care services.

The World Health Organisation's definition of palliative care states[2]:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

ACAA believes that all of this applies in aged care, both residential and community-based.

Most, but by no means all, people with palliative care needs in Australia are elderly. The peak umbrella group for the broad aged care sector, the National Aged Care Alliance, has produced a Vision Statement which looks forward to the aged care system of the future where:

> There will be a range of readily available support and care services linked seamlessly into the broader health system. These include easily accessible primary health care services; transition care after any acute health episode so no-one has a long term aged care assessment while acutely unwell; restorative and rehabilitative services to provide the greatest opportunity of getting back to full function after acute care; support and care services for people living with

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[1] Productivity Commission 2011, *Caring for Older Australians*, Report no. 53, Final Inquiry Report, Canberra, p XVI

[2] World Health Organisation (WHO), http://www.who.int/cancer/palliative/definition/en/

dementia; and palliative and end of life care.[3]

In this submission we will set out briefly some of the challenges and opportunities around achieving this. We look forward to the opportunity to meet with the committee.

It is the responsibility of the Australian community to ensure that people's choices of care, and place of care, are respected and supported.

Aged Care providers seek to ensure that good quality palliative care services and care are available to their residents and clients. Circumstances including difficulty of access to appropriate clinical support, difficulties in the medication regime, and recognition of the real costs of providing such quality palliative care services and care, do not always make this possible.

Recommendation

ACAA recommends that the Senate Community Affairs Committee endorse the need for quality palliative care services to be provided in aged care, with the necessary changes to government support systems.

b) Funding arrangements for palliative care provision

The Productivity Commission identified "insufficient and inadequate funding" for palliative care as a weakness of the current system[4].

To a significant degree, aged care is already a palliative care service. Increasingly, aged care, both residential and community, is where people with terminal conditions are spending most of their last months, if not the last days.

Because of inadequate resourcing, the aged care system struggles to cope with these palliative care needs, with Commonwealth Government funding through the Aged Care Funding Instrument (ACFI) not adequately supporting palliative care needs.

In particular, some real weaknesses persist with the Aged Care Funding Instrument (ACFI) not being relevant to what is actually occurring around resident needs for palliative care.

Despite increasing trends for hospitals to discharge terminally ill patients to aged care if they are aged over 55 years, ACFI does not adequately cover the frequency and skill intensity of care and treatment needed for palliation to be effective.

Even with an ACFI of HHH or HNH such residents are not well funded as having complex care needs. The current ACFI subsidy is around one third of the amount that specialist palliative care services receive in state and territory jurisdictions. An additional ACFI supplement is therefore needed.

These weaknesses need to be resolved in readiness for a rapidly ageing population which will place greater demands on aged care residential and community services.

The Government's health reform agenda provides $1.6 billion over 4 years for "sub-acute beds" which the Commonwealth Government says can mean places in the community, or in residential

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[3] National Aged Care Alliance, *Leading the Way: Our Vision for Support and Care of Older Australians*, 2009, p. 5, available at www.naca.asn.au

[4] Productivity Commission, op.cit, p. XXV

aged care. This is a potentially important means of ensuring that aged care can play an active role in providing seamless care services to older people with sub-acute care needs. The problem is having this recognised and supported by the States and Territories who are recipients of this funding.

Recommendation

ACAA recommends that the Senate Community Affairs Committee recognise and support the need for aged care funding to include adequate funding for the provision of quality palliative care.

c) Efficient use of palliative, health and aged care resources

There are currently no additional funds within the residential aged care budget to supplement palliation services. The burden of increased demand will therefore be borne by the aged care sector and will take funds away from already cash-strapped services. The aged care sector cannot provide service of equivalent quality to the acute sector if funding is vastly different. The real cost of palliative care in the aged sector must be identified to ensure funding is realistic and adequate.

Despite increasing trends for hospitals to discharge terminally ill patients to aged care if they are aged over 55 years, ACFI does not adequately cover the frequency and skill intensity of care and treatment needed for palliation to be effective.

The inability to manage preventable pain in the home or in residential aged care facilities, combined with difficulties in accessing medication and community care services, contribute to the current overloading of hospital services.

The use of morphine and other opioid medications is common in palliative care, as well as in the management of pain more generally, for example for people with chronic pain of all types. These ‘drugs of dependence’ are listed on Schedule 8 of the *Poisons Standard* published by the National Drugs and Poisons Schedule Committee[5] and are thus commonly known as Schedule 8 (or S8) drugs.

Unfortunately, the current health care system is largely designed to provide short-term, episodic care for mainly acute illness. The key challenge for better integration of palliative care within the broad health care sector is: where does palliative care sit in the current health ‘divides’ between acute care, sub-acute care, chronic care, primary care, specialist care, community care, and residential aged care?

The national health reform agenda can help redress this, enhancing the ability of general practice to provide quality palliative care services for patients with terminal conditions.

The proposed Medicare Locals could play a vital leadership role in developing more integrated health services, including developing and implementing the necessary referral criteria and the enhanced workforce education that will be necessary, if a truly integrated, multidisciplinary model for palliative care is to be developed.

Exactly how this is to happen is still very problematic. The Department of Health and Ageing

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[5] Available online at www.comlaw.gov.au/ComLaw/Legislation/LegislativeInstrument1.nsf/0/393335F04039C0CBCA257608007EB106/$file/PoisonsStandard2009SUSDP24.pdf

discussion paper on governance and functions of Medicare Locals[6] does not even attempt to tackle how GP, specialist and allied health professional service referrals and multidisciplinary team work will be managed, financed, and coordinated to achieve better integration of care services for people with terminal conditions, or indeed needing aged care.

The final report of the National Health and Hospitals Reform Commission (NHHRC) in June 2009 recognised the importance of palliative care and made a number of recommendations to improve palliative care services in a range of settings[7]. These recommendations, together with the Government responses in May 2010[8] were:

NHHRC recommendations 54 is to build the capacity and competence of primary health care services, including Comprehensive Primary Health Care Centres and Services, to provide generalist palliative care support for their dying patients. This will require greater educational support and improved collaboration and networking with specialist palliative care service providers.

The Government response is that the Government supports this recommendation. Medicare Locals will work to improve coordination and integration between primary health care and other local health services. Palliative care will be an important part of the Government's $1.6 billion investment in 1,316 new sub-acute beds and the $122 million in 286 new sub-acute beds in Multi-Purpose Services in rural and remote areas.

NHHRC recommendation 55 is to strengthen access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on people living in residential aged care facilities.

The Government response is that the Government agrees with this recommendation. Palliative care will be an important part of the Government's $1.6 billion investment in 1,316 new sub-acute beds and the $122 million in 286 new sub-acute beds in Multi-Purpose Services in rural and remote areas. This could be made available to residential aged care facilities, subject to state decisions.

NHHRC recommendation 56 is for additional investment in specialist palliative care services be directed to support more availability of these services to people at home in the community.

The Government response is that the Government agrees with this recommendation. Palliative care will be an important part of the Government's $1.6 billion investment in 1,316 new sub-acute beds. These funds may be used for services in the community.

NHHRC recommendation 57 is that advance care planning be funded and implemented nationally, commencing with all residential aged care services, and then being extended to other relevant groups in the population. This will require a national approach to education and training of health professionals including greater awareness and education among health professionals of

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[6] Department of Health and Ageing Oct 2010. *Medicare Locals – Discussion Paper on Governance and Functions*, http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/MsedicareLocalsDiscussionPaper

[7] Commonwealth of Australia, *A Healthier Future For all Australians: Final Report of the National Health and Hospital Reform Commission* – June 2009, Australian Government, Canberra, 2009, available online at http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/publications?OpenDocument&ct=National Health and Hospitals Reform Commission

[8] Commonwealth of Australia, *A National Health and Hospitals Network for Australia's Future – Delivering better health and better hospitals*, Australian Government, Canberra, May 2010 available online at http://www.health.gov.au/internet/yourhealth/publishing.nsf/Content/report-redbook/$File/HRT_report3.pdf.

the common law right of people to make decisions on their medical treatment, and their right to decline treatment. We note that, in some states and territories, this is complemented by supporting legislation that relates more specifically to end of life and advance care planning decisions.

The Government response is that the Government supports this recommendation. The Australian Health Ministers' Conference agreed to undertake targeted consultation for the Draft National Framework for Advance Care Directives on 22 April 2010.

Recommendation 66 is that care for people in remote and rural locations necessarily involves bringing care to the person or the person to the care. To achieve this, we recommend:

- networks of primary health care services, including Aboriginal and Torres Strait Islander Community Controlled Services, within naturally defined regions;
- expansion of specialist outreach services – for example, medical specialists, midwives, allied health, pharmacy and dental/oral health services;
- telehealth services including practitioner-to-practitioner consultations, practitioner-to-specialist consultations, teleradiology and other specialties and services;
- referral and advice networks for remote and rural practitioners that support and improve the quality of care, such as maternity care, chronic and complex disease care planning and review, chronic wound management, <u>and palliative care</u> {my emphasis};

and

- 'on-call' 24-hour telephone and internet consultations and advice, and retrieval services for urgent consultations staffed by remote medical practitioners.

Further, we recommend that funding mechanisms be developed to support all these elements.

The Government response is that the Government supports this recommendation. Medicare Locals will play a key role better linking people to care in remote and rural areas, including:

- ensuring local primary health care services are better integrated and more responsive to local needs;
- planning, administering and purchasing after hours services for the local area;
- working with Local Hospital Networks to bring together primary and acute care practitioners and services, to ensure seamless transition by patients between services.

The Commonwealth Government has recognised in the 2010 Council of Australian Governments (COAG) agreements[9] and the National Health and Hospitals Network initiative[10] that effective care in all settings needs to be accompanied by increased investment in a range of related sub-acute services, including palliative care.

Part of the unfinished agenda of the COAG health reform process is the place and funding of community care, including the place of palliative care within that mix. This is vital to achieving enhanced palliative care services and outcomes.

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[9] Council of Australian Governments, *National Health and Hospitals Network Agreement*, April 2010.

[10] Commonwealth of Australia May 2010, op cit.

Accordingly, ACAA submits that it is both a short-term and a long-term strategic planning need for resourcing to support aged care facilities to work towards providing quality care for people with terminal conditions in both residential and community-care settings, including appropriate palliation, pain and symptom relief.

Currently, the Aged Care Funding Instrument (ACFI) does not adequately support resident needs for palliative care. In particular, ACFI does not adequately cover the frequency and skill intensity of care and treatment needed for palliation to be effective.

The Productivity Commission recommended that:

9.4 The Australian Government should replace the current system of discrete care packages across community and residential care with a single integrated, and flexible, system of care entitlements (the Aged Care System). The system would have the following features:

- *it would cover services including residential care, community care (domestic, personal, nursing), reablement, planned respite, home modification, palliative care, high level aids and equipment, and care coordination.*[11]

10.3 The Australian Government should ensure that residential and community care providers receive appropriate payments for delivering palliative and end-of-life care. These payments should form part of the assessed entitlement determined by the Gateway assessment process. The appropriate payment for palliative and end-of-life care should be determined by the Government on the transparent advice of the Australian Aged Care Commission and in consultation with the National Hospital Pricing Authority.[12]

d) Effectiveness of a range of palliative care arrangements

Traditionally, most people with palliative care needs have died in hospital. For a range of reasons, including increasing life spans at the end of life, people's wishes, and cost effectiveness, this is no longer appropriate.

The Productivity Commission found that the "palliative and end-of-life care needs of older Australians are not being adequately met under the current arrangements," and that "a greater role by residential and community care providers in delivering these services will provide more appropriate care and be less expensive than services delivered in a hospital."[13]

In particular, the Productivity Commission is critical of the dysfunctionality of many aspects of the current system, and makes recommendations for reform of the system, which would achieve "better palliative and end-of-life care through an assessed entitlement from the (proposed) Gateway"[14].

ACAA agrees that implementation of the Productivity Commission's proposed reforms would enable aged care providers "to offer a range of other services in their facilities, such as … palliative pain management and end-of-life care, subject to meeting the relevant quality and safety requirements and reaching agreement on prices and other terms and conditions"[15].

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[11] ibid, recommendation 9.4, p. LXIX
[12] ibid, recommendation 10.3, p. LXXI
[13] ibid, p. LXXXVII
[14] ibid, p. LV
[15] ibid

e) Composition of the palliative care workforce

Aged care facilities have difficulties in attracting appropriately trained clinical staff (medical and nursing) for palliative care for both resourcing and structural reasons.

Shortages of adequately skilled health workers across all care settings are central to current limitations to access quality palliative care. Limited access to appropriately qualified staff has been associated with sub-optimal pain relief in both residential aged care facilities and home care situations, and thus to unnecessary and unwanted hospitalisations. Inadequate links to and resourcing of specialist palliative care services compound the difficulties in ensuring that care needs are met.

In 2008, the consultancy firm PricewaterhouseCoopers undertook an evaluation of a tool designed to assist general practitioners to provide palliative care to their patients in residential aged care facilities. The report identifies a number of barriers to GPs practising a palliative care approach for patients in residential aged care, including GPs' time pressures and work demands, inadequately trained residential aged care staff, and poor remuneration. The *Guidelines for a Palliative Approach in Residential Aged Care for General Practitioners* themselves were not identified as an enabler to providing palliative care, suggesting that the Guidelines may not be a preferred approach for engaging with GPs.[16]

In 2009, National Prescribing Service and Palliative Care Australia conducted an important analysis of quality use of medicines (QUM) in palliative and end-of-life care. Priority areas identified include a lack of understanding of palliative and end-of-life care, the need to develop guidance for prescribers on 'deprescribing' – the withdrawal of 'curative' medicines in the palliative stage, the education and training of RACF staff in the use of medicines at end of life, greater potential to use Advance Care Directives to articulate choices regarding medicine use at end of life.[17]

An internal paper of the ACT Home Based Palliative Care (HBPC) service finds that the role of GPs in the ongoing care of patients admitted to HBPC varies enormously. The role ranges from the GP retaining full medical management of the patient's care to the GP requesting full control be handed over to HBPC with the specialist attached to the service picking up all medical care.[18]

A recent UK report finds that the important role that primary care professionals play as providers of palliative care is widely recognised, but the processes, resources and skills to provide effective care are often lacking. In consequence, many patients lack access to well-coordinated, comprehensive community-based palliative care that can effectively address their psychosocial and physical needs. One specific consequence is that about 50% of patients do not die where they would choose, with stark disparity between those who wish to die at home and those who do so.[19]

ACAA stands ready to work with all stakeholders to bring effective changes to this situation. In

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[16] PricewaterhouseCoopers. *Evaluation of the Impact of the Guidelines for a Palliative Approach in Residential Aged Care for General Practitioners and Barriers for GP Participation*. January 2009.

[17] National Prescribing Service Limited and Palliative Care Australia. *Achieving quality use of medicines in the community for palliative and end of life care.* Sept 2009 available at http://www.palliativecare.org.au/Portals/46/Policy/QUM%20in%20palliative%20care%20-%20report%20-%20September%202009.pdf.

[18] Skeels, Andrew. *Home based palliative care*. Unpublished discussion paper of the ACT Home Based Palliative Care (HBPC) service, Clare Holland House, Canberra, Jan 2010.

[19] Dale et al. "A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality." *Qual Saf Health Care* 2009 18: 174-180. Downloaded from qshc.bmj.com on January 31, 2010. Published by group.bmj.com

particular, referral pathways to and from specialist palliative care services (both hospice and home-based), and other health services need to be made easier.

f) Adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians

Palliative Care Australia's *Standards for Providing Quality Palliative Care to All Australians*[20] are an important endeavour to ensure that palliative care standards are accepted and implemented.

It is important for all relevant standards and guidelines to recognise that quality palliative care – specialist and generalist – can be provided in aged care settings, but that this needs to be accompanied by changes to both resourcing and regulations governing access to and use of palliative medicines.

Recommendation

ACAA recommends that the Senate Community Affairs Committee endorse the need for Palliative Care Australia's *Standards for Providing Quality Palliative Care to All Australians* need to incorporate meaningful standards which can be applied in both residential and community-based aged care, including a recognition that palliative care can be provided by generalist practitioners, as well as specialists.

g) Advance care planning

Advance care plans provide a mechanism to better meet people's needs. They offer terminally ill patients the opportunity to be empowered to take control of the conditions of their care. Further, advance care plans, in stipulating the preferred condition for care of the patient, provide a mechanism for limiting unnecessary and unwanted hospitalisations to provide unwanted care or interventions.

Greater uptake of advance care plans by recipients of aged care – both residential and community – would greatly assist the ability of aged care service providers to provide care which accords with each client's wishes.

Improving people's awareness – and uptake - of advance care planning is the key to enhancing and recognising consumers' wishes in palliative care situations. It is important for relatives and carers to be aware of patient wishes, and for those wishes to be respected.

Recommendation 57 from the final report of the National Health and Hospitals Reform Commission[21] was that advance care planning be funded and implemented nationally, commencing with all residential aged care services, and then being extended to other relevant groups in the population. This will require a national approach to education, training and resourcing of care professionals including greater awareness and education among health professionals of the common law right of people to make decisions on their medical treatment, and their right to decline treatment. We note that, in some states and territories, this is

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[20] Palliative Care Australia 2005, Standards for providing quality palliative care for all Australians (4th edition), available at http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf

[21] Commonwealth of Australia, *A Healthier Future For all Australians*: *Final Report of the National Health and Hospital Reform Commission – June 2009*, Australian Government, Canberra, 2009

complemented by supporting legislation that relates more specifically to end of life and advance care planning decisions.

ACAA believes that it is imperative that this aspect of the national health reform agenda be implemented.

The Government's 'framework' is a good start, but needs to go much further. There will be little practical effect unless undergraduate clinical (medical and nursing) training schools ensure that students appreciate that advance care plans are legal instruments which, provided they are properly executed, represent the wishes of the individual and that those wishes need to be respected.

ACAA, as the representative of key service providers, also notes that an effective e-health system, incorporating coordinated care including aged care, will be an important component of effective enhancement of the important role of advance care planning in Australia.

h) Availability and funding of research, information and data about palliative care needs in Australia

Research into palliative care needs in Australia have been constrained by the previously prevailing paradigm that palliative care was a specialist discipline that occurred in specialist care environments. It is important that this paradigm be changed and that research be funded and directed towards appropriate care in more generalist settings, including aged care.

In particular, there has been no adequate assessment of the real cost of palliative care to the aged care sector.