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Palliative
Care
Australia

3 December 2008

Ms Christine McDonald
Committee Secretary
Senate Finance and Public Administration Committee
Parliament House
Canberra ACT 2600
by email: fpa.sen@aph.gov.au

Dear Christine

Inquiry into Residential and Community Aged Care in Australia

Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.

Palliative Care Australia appreciates the opportunity to make this submission to the inquiry into the funding, planning, allocation, capital and equity of residential and community aged care in Australia.

This submission does not seek to address each of the inquiry's terms of reference.

Instead, this submission focuses on a key issue that is impairing the efficient and cost effective performance of the aged care system in relation to residents and clients living with terminal conditions. Our submission highlights suggestions for changes to achieve better outcomes and as background also includes reference to PCA's positions statements on *Residential Aged Care and End of Life* and *Primary Care and End of Life*.

We advise that there are significant opportunities enabled through recognition that end of life care is a part of, and not an uncomfortable afterthought to, the normal scope of practice of aged care in Australia. We urge the committee to include these issues in its considerations.

Palliative Care Australia would welcome the opportunity to discuss these issues in more depth with committee members.

Yours sincerely

Donna Daniell
Chief Executive Officer

Palliative Care Australia submission to Senate Finance and Public Administration Committee Inquiry into Residential and Community Aged Care in Australia

1. Introduction

The significance of our ageing population to aged care, and to the demand on such services for end of life care, is substantial and will increase with the expected increases in the proportion of the population aged over 65 years. In 2007, 13% of Australia's population was aged 65 years and over and 1.6% was over 85 years. It is predicted that our ageing population will increase significantly from 23% to 25% over 65 years and 4.9% to 7.3% over 85 years in 2056, and 25% to 28% over 65 years and 5.8% to 9.3% over 85 years in 2101. [1]

In 2008, there are currently 227,300 people with dementia, with the number expected to be 731,000 by 2050 unless there is a medical breakthrough.[2] Between 2000 and 2050, the number of people with dementia in Australia is expected to increase by 327%,[3] while the total population increases by less than 40%.[4]

It is time for planning to deliver care to the person residing in their care setting, in contrast to the current arrangements that see transfers between residential, respite, community and acute care settings. Many of these transfers are avoidable is the barriers to funding pools and systems changes were addressed.

Further, it must be recognised that Residential aged care facilities are increasingly the place of shorter duration of stays with populations having more acute care needs as they approach their end of life. The inability of residential aged care facilities to deliver this care results in access that is often less than delivered in home based or community care. Accordingly, end of life care[1] should be recognised as part of the normal scope of practice of both residential and community aged care services.

2. Needs-based approach to end of life care

The provision of quality end of life care for all is most efficiently and effectively achieved in accordance with a *needs-based service delivery model* that acknowledges that patients have different needs that may change over time. There needs to be strong networks between residential aged care facilities and primary and specialist care providers, as well as support care providers[2] and the community.

In 2005, PCA endorsed a population needs-based approach to end of life care service development

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[1] Australian Bureau of Statistics, *Population Projections, Australia, 2006 to 2101*. (Cat No. 3222.0)

[2] Access Economics (2006) *Dementia in the Asia Pacific Region: The Epidemic is Here*, Alzheimer's Australia, Canberra

[3] Access Economics (2005) *Dementia Estimates and Projections: Australian States and Territories*, Alzheimer's Australia, Canberra.

[4] Australian Bureau of Statistics, *Population Projections Australia*, 2003, Canberra

The following definitions of end of life, end of life care and palliative care are used throughout this position paper. Source: Palliative Care Australia *Palliative and End of Life Care – Glossary of Terms. Edition 1, 2008* (http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%2008%20LR.PDF).
End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.
End of life care: End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.
Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

[2] Support care providers include assistants in nursing and personal care staff in aged care homes, volunteers, charitable organisations, complementary therapists (for example, massage therapists, music therapists and aromatherapists), pastoral carers, and others who provide a supporting role in the care of a patient living with an eventually fatal condition and their family and carers. Source: Palliative Care Australia *Palliative and End of Life Care – Glossary of Terms. Edition 1, 2008*

which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources[3]. PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and involves the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*[4] define the standard of care that all Australians should be able to expect in different care settings. For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups whose care needs can be categorised as:

- complex, or
- intermediate, or
- appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible. The implementation of needs-based end of life care should be informed by standardised referral criteria that outline the requirements for upward and downward referral relevant to aged care, primary health care and specialist palliative care.

There needs to be full integration of the National Palliative Care Standards with the Aged Care Accreditation Standards.

This needs to be supported by a national roll-out/education campaign to enhance the recognition of specialist palliative care and its role in supporting needs-based end of life care, through direct, indirect or consultant care.

The National Standards Assessment Program (NSAP) aims to support the move towards best practice in palliative care, as established in the *Standards for Providing Quality Palliative Care for All Australians*. The NSAP is a robust national quality assurance program that streamlines self assessment and peer review activities by building on mutual recognition with existing accreditation mechanisms.

Through this program, PCA is developing resources that will support and enhance the ability of services to improve the quality of care within their existing quality improvement processes and accreditation cycles.

The NSAP is funded by the Australian Government Department of Health and Ageing. It supports the policy goals set out in the National Palliative Care Program and the National Palliative Care Strategy.

The NSAP is a three and a half year program, running from 2007 – 2010, that has been planned in phases to ensure broad-based consultation, coordinated resource development, maximum participation, and sector engagement.

Following the pilot, the program will be rolled out nationally to all specialist palliative care services. Phase two of the program will involve the development of self assessment modules for residential aged care and acute care settings.

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[3] PCA 2005. *A Guide to Palliative Service Development: A population based approach*. PCA, Canberra http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf

[4] PCA 2005. *Standards for providing quality palliative care for all Australians* http://www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf

3. End of life care and aged care

Access to, and the quality of, end of life care is diverse and inconsistent in both residential and community aged care. Some aged care services enjoy ready access to primary care physicians well skilled in palliative care, and to specialist palliative care physicians.

Some residential aged care facilities, particularly high care facilities, do have effective systems in place to limit hospitalisations by providing care in-place.

Overall, though, more needs to be done to make residential aged care facilities culturally sensitive to the care needs of people with terminal conditions.

Supporting all aged care services to work towards providing quality end-of-life care will require additional resources to enable aged care facilities to provide appropriate palliation, pain and symptom relief.

This will include: appropriate access to general practitioners, to palliative care specialists under agreed and consistent referral and access criteria, and to nurses who can administer opioids. It will also include access to PBS-subsidised palliative medicines for residents of aged care facilities, and the structuring and resourcing of specialist palliative care services so that they are able to provide care and consistent support for primary health care providers in the residential aged care setting.

Palliative Care Australia is pleased to see the inclusion of palliative care indicators in the new funding mechanisms for residential aged care facilities.

The Aged Care Funding Instrument (ACFI) is based on an assessment of residents’ care needs. Importantly, it includes complex health care elements which constitute palliative care funding indicators in residential aged care and works to facilitate the enhanced provision of palliative care in residential aged care facilities.

It is too early to get a picture of how well this is working. Palliative Care Australia understands that information gathered through this funding process will be compiled to provide an additional source of data about the provision of palliative care, hopefully leading to a greater understanding of end of life care in residential aged care.

There are barriers, including inadequate pain relief and symptom management, in residential aged care facilities preventing people being able to receive quality end of life care.

Palliative Care Australia is calling for the introduction of systems for coordinating the management of pain and symptom relief for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents’ care needs are met in a timely and ongoing manner.

By limiting hospitalisations to cases of genuine need for acute care, this will have positive effects on hospital costs in Australia.

The *Guidelines for a Palliative Approach in Residential Aged Care,* were launched in 2004 and distributed to every aged care home in Australia to help aged care team members to apply a palliative approach in residential aged care facilities. An Enhanced Version was issued in May 2006 after approval by the National Health and Medical Research Council.[5]

Palliative Care Australia has been involved in substantial projects implementing these Guidelines, including a Resource Kit, assisting the development of training resources for Certificate III and Certificate IV competency units in a palliative approach, ongoing production of the Residential Aged Care Palliative Approach Network (RACPAN) Newsletter, and working with the Australian General Practice Network and Divisions of General Practice on the Engaging GPs' Support for the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care project.

Guidelines for a Palliative Approach for Aged Care in the Community Setting are currently being developed. These 'ComPAC' guidelines aim to promote good practice in end of life care for elderly people living in the community.

6. Advance care planning

Quality end of life care is realised when it meets the person's needs and upholds their care preferences.

Advance care planning offers everyone, and especially people living with a terminal condition, their families and significant others the opportunity to take control of decisions which affect their care.

Advance care planning provides a mechanism to improve the quality of end of life care for people. It enables the coordination of their desired access to resources and services, to match their anticipated care needs.

All Australians, including those receiving residential or community-based aged care services, should be supported to consider and provided the opportunity to specify the type of care they would like to receive at the end of life. Continual reassessment of current circumstances and likely future scenarios are part of this consideration. Specialist palliative care providers have expertise to support all involved in advance care planning.

4. Workforce issues

End of life care should be acknowledged as a basic competency for aged care workers (regardless of the setting in which they work) and included in the core curricula of aged care worker education and as an element of ongoing training.

Measures must be introduced to address workforce shortages in aged care, and thereby their impact on aged care services' capacity to provide quality end of life care.

In particular, aged care services, both residential aged care facilities and community services, need to develop and implement workforce and service development plans that acknowledge their end of life care responsibilities as part of needs-based service provision. This is likely to require increased levels of staffing with practitioners who can prescribe and administer pain and symptom management drugs.

Health and aged care workers across all levels of the health and aged care systems should be skilled and educated to engage in end of life care discussions and advance care planning with patients and their families, significant others and carers.

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[5] The National Palliative Care Program, Australian Government Department of Health and Ageing. *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines). Enhanced Version approved by National Health and Medical Research Council May 2006 http://www.nhmrc.gov.au/publications/synopses/_files/pc29.pdf

5. PCA recommendations

Palliative Care Australia calls for:

i. End of life care to be acknowledged as a basic competency for aged care workers (regardless of the setting in which they work) and included in the core curricula of aged care worker education and as an element of ongoing training and quality improvement.

ii. The development and implementation of nationally standardised referral criteria for patients with palliative care needs that promote needs-based service provision, supported by a national roll-out/education activities.

iii. Aged care services, including residential aged care facilities, to develop and implement workforce and service development plans that acknowledge their end of life care responsibilities as part of needs-based service provision. This is likely to require increased levels of staffing with practitioners who can prescribe and administer pain and symptom management drugs.

iv. The introduction of systems for remove the barriers, coordinating the management of pain and symptom relief for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents' care needs are met in a timely and ongoing manner.

v. Full integration of the National Palliative Care Standards with the Aged Care Accreditation Standards.

vi. The implementation of measures to address workforce shortages in aged care, and thereby their impact on aged care facilities' capacity to provide quality end of life care.

vii. Increased recognition of specialist palliative care and its role in supporting primary care provision of needs-based end of life care, through direct, indirect or consultant care.

viii. Development and implementation of initiatives to increase community awareness of end of life planning options and community capacity to discuss and plan for death and dying

6. Conclusion

The current experience of end of life care in Australia is disparate and inconsistent and we cannot, in good faith, promise patients at the end of their life access to care that is customised to preferences and reliably delivers good symptom control. Our health and aged care systems can do better.

Attachments:

- PCA Interim Position Statements
    - Residential Aged Care and End of Life
    - Primary Care and End of Life

RESIDENTIAL AGED CARE AND END OF LIFE

Interim Position Statement

Palliative Care Australia

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.[6]

Palliative Care Australia believes

- The provision of quality end of life care for all is most efficiently and effectively achieved in accordance with a *needs-based service delivery model* that acknowledges that patients have different needs that may change over time. There needs to be strong networks between residential aged care facilities and primary and specialist care providers, as well as support care providers[7] and the community.
- End of life care should be recognised as part of the normal scope of practice of residential aged care, recognising that aged care facilities are home for many people at the end of life.
- End of life care should be considered a *core competency* for aged care workers.
- Aged care services must develop and implement workforce and service development plans that acknowledge their end of life care responsibilities.
- The implementation of needs-based end of life care should be informed by *standardised referral criteria* that outline the requirements for upward and downward referral relevant to aged care, primary health care and specialist palliative care.
- More needs to be done to make residential aged care facilities culturally sensitive to the care needs of people with terminal conditions.
- There are barriers, including inadequate pain relief and symptom management, in residential aged care facilities preventing people being able to receive quality end of life care.

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[6] The following definitions of end of life, end of life care and palliative care are used throughout this position paper. Source: Palliative Care Australia *Palliative and End of Life Care – Glossary of Terms. Edition 1, 2008* (http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%2008%20LR.PDF).
End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.
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Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

[7] Support care providers include assistants in nursing and personal care staff in aged care homes, volunteers, charitable organisations, complementary therapists (for example, massage therapists, music therapists and aromatherapists), pastoral carers, and others who provide a supporting role in the care of a patient living with an eventually fatal condition and their family and carers. Source: Palliative Care Australia *Palliative and End of Life Care – Glossary of Terms. Edition 1, 2008*

Palliative Care Australia calls for

- End of life care to be acknowledged as a basic competency for aged care workers (regardless of the setting in which they work) and included in the *core curricula of aged care worker education* and as an element of ongoing training.

- The development and implementation of *nationally standardised referral criteria* for patients with palliative care needs that promote needs-based service provision, supported by a national roll-out/education campaign.

- Aged care services, including residential aged care facilities, to develop and implement *workforce and service development plans* that acknowledge their end of life care responsibilities as part of needs-based service provision. This is likely to require increased levels of staffing with practitioners who can prescribe and administer pain and symptom management drugs.

- The introduction of *systems for coordinating the management of pain and symptom relief* for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents' care needs are met in a timely and ongoing manner.

- Full integration of the National Palliative Care Standards with the Aged Care Accreditation Standards.

- The implementation of measures to *address workforce shortages* in aged care, and thereby their impact on aged care facilities' capacity to provide quality end of life care.

- Increased recognition of specialist palliative care and its role in supporting primary care provision of needs-based end of life care, through direct, indirect or consultant care.

Background

The significance of our ageing population to aged care, and to the demand on such services for end of life care, is substantial and will increase with the expected increases in the proportion of the population aged over 65 years. In 1999, 12% of our population was over 65 years of age and 2% was over 80 years. It is predicted that by 2016, 16% will be over 65 years and 4% will be over 80 years, increasing by 2041 to 25% over 65 years and 8.3% over 80 years.[8] For dementia alone the "epidemic" affecting an estimated 162,000 people in 2002 is expected to affect over half a million Australians by 2040.[9]

Residential aged care facilities are increasingly the place of death for people with terminal conditions, unless residents are transferred to acute care facilities.

In 2005, PCA endorsed a population needs-based approach to end of life care service development which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources[10]. PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and involves the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*[11] define the standard of care that all Australians should be able to expect in different care settings. For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups whose care needs can be categorised as:

- complex, or

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[8] J. Abbey. 'The reality for aged and community care and end of life'. Presentation to *A Matter of Life and Death: Confronting the new reality*, Canberra 13 March 2008

[9] ibid

[10] PCA 2005. *A Guide to Palliative Service Development: A population based approach*. PCA, Canberra http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf

[11] PCA 2005. *Standards for providing quality palliative care for all Australians* http://www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf

- intermediate, or
- appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible.

Access to, and the quality of, palliative care is diverse and inconsistent in residential aged care. Some aged care facilities enjoy ready access to primary care physicians well skilled in palliative care and to specialist palliative care physicians. Some facilities, particularly high care facilities, have systems in place to limit hospitalisations by providing care in-place.

Supporting aged care facilities to work towards providing quality end-of-life care will require aged care facilities to be additionally resourced to provide appropriate palliation, pain and symptom relief.

This will include: appropriate access to general practitioners, to palliative care specialists under agreed and consistent referral and access criteria, and to nurses who can administer opioids. It will also include access to PBS-subsidised palliative medicines for residents of aged care facilities, and the structuring and resourcing of specialist palliative care services so that they are able to provide care and consistent support for primary health care providers in the residential aged care setting.

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PCA has been involved in substantial projects implementing the *Guidelines*, including a Resource Kit, assisting the development of training resources for Certificate III and Certificate IV competency units in a palliative approach, ongoing production of the Residential Aged Care Palliative Approach Network (RACPAN) Newsletter, and working with the Australian General Practice Network and Divisions of General Practice on the *Engaging GPs' Support for the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care* project.

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[12] The National Palliative Care Program, Australian Government Department of Health and Ageing. *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines). Enhanced Version approved by National Health and Medical Research Council May 2006 http://www.nhmrc.gov.au/publications/synopses/_files/pc29.pdf

PRIMARY HEALTH CARE AND END OF LIFE

Interim Position Statement

Palliative Care Australia

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.[13]

Palliative Care Australia believes

- The provision of quality end of life care for all is most efficiently and effectively achieved in accordance with a *needs-based service delivery model* that acknowledges that patients have different needs that may change over time.

- Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people.

- End of life care is, and should be, part of the normal scope of practice of all primary health care professionals.

- End of life care should be considered a *core competency* for all primary health care workers.

- Health service *workforce and service development plans* should be developed in collaboration with other care providers to support needs-based service provision.

- The implementation of needs-based end of life care should be informed by *standardised referral criteria* that outline the requirements for upward and downward referral relevant to aged care, primary health care and specialist palliative care.

- Discussion and reform towards a *primary health care system that enables broader access to quality end of life care* through increased capacity of primary health care providers should be actively supported.

- More needs to be done to make primary health care culturally sensitive to the care needs of people with terminal conditions.

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[13] The following definitions of end of life, end of life care and palliative care are used throughout this position paper. Source: Palliative Care Australia *Palliative and End of Life Care – Glossary of Terms Edition 1, 2008* (http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%2008%20LR.PDF).
End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.
End of life care: End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.
Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goals is quality of life.

- There are barriers, including inadequate pain relief and symptom management, preventing people being able to receive quality end of life care.

Palliative Care Australia calls for

- End of life care to be acknowledged as a basic core competency for primary health care workers and included in the core curricula of health worker education and as an element of ongoing training.

- The implementation of needs-based end of life care for patients with palliative care needs should be informed by *nationally agreed criteria* for access and referral to, and discharge from, specialist palliative care services. The nationally agreed criteria should promote needs-based service provision, and be supported by a national roll-out/education campaign.

- Health services should be supported in developing and implementing *workforce and service development plans* that acknowledge the end of life care responsibilities of primary care providers as part of needs-based service provision.

- *Recognition of specialist palliative care* and its role in supporting primary health care provision of needs-based end of life care, through direct, indirect or consultative care.

- The introduction of research and data collection methods to help improve the quality of care by primary health care professionals in serving the end of life population.

Background

The capacity of the current health system to provide access to quality care at the end of life for all Australians who may require it is questionable.[14] As the Australian population continues to age and an increasing number of Australians live out the final stages of their life with chronic, complex conditions, both the total population, and the proportion of the Australian population requiring end of life care annually, is expected to increase. This underlines the necessity of developing an approach to end of life care that prioritises quality care and promotes broad access through the efficient use of resources.

Needs-based service provision

In 2005, PCA endorsed a population needs-based approach to end of life care service development which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources[15]. PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and involves the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*[16] define the standard of care that all Australians should be able to expect in different care settings. For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups whose care needs can be categorised as:

- complex, or
- intermediate, or
- appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible.

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[14] PCA 2008 *End of life care is everyone's affair - tackling the challenge of end of life.* Palliative Care Australia submission to the National Health and Hospitals Reform Commission, PCA, Canberra

[15] PCA 2005. *A Guide to Palliative Service Development: A population based approach*. PCA, Canberra http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf

[16] PCA 2005. *Standards for providing quality palliative care for all Australians* http://www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf

At the centre of the needs-based approach to care provision is an acknowledgement of heterogeneous care needs at the end of life and a recognition that the end of life needs of many patients are appropriately met by primary care providers (generalist, and other specialist and support care), with specialist palliative care providers contributing direct, indirect care or consultation advice as required.[17]

The role of primary care providers is outlined within this needs-based framework. Primary care providers include the patients' primary generalist providers who are normally the first contact medical, nursing or allied health professional. The primary generalist provider has an ongoing role in the care of patients with an eventually fatal condition. Primary specialist providers include all other specialists that have first contact with patients.[18]. In general, the substantive work for both these groups is not palliative care.

The largest subgroup includes those patients who do not require access to specialist care as their needs may be met through their own resources or with the support of primary care providers.[19] (PCA, 2005).

The second largest subgroup of patients may experience sporadic exacerbations of pain or other physical symptoms or may experience complex social or emotional distress. This temporary increase in their level of need may require access to specialist palliative care services for consultation and advice, however the needs of this population group can be met by their primary care provider working in consultation with a specialist palliative care provider.

The smallest subgroup of patients are those who have ongoing complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers.

Primary care providers need to manage the care of their patients with a terminal condition, and to work in consultation with specialist palliative care providers to meet the needs of patients whose end of life care needs may be more complex (PCA, 2005). This necessarily requires primary care providers to have adequate skills, training and education and established relationships with specialist palliative care providers.

End of life care as a core education requirement for primary care providers

A key element in providing quality needs-based end of life care is ensuring that those involved in the provision of end of life care, whether as primary or specialist palliative care providers, are equipped with the skills and resources to perform their roles effectively.

The role of primary care providers includes assessment, triage, clinical management, referral specialist palliative care providers where appropriate, and care coordination using a palliative approach for patients with end of life care needs.[20] Primary care providers thus require, as a core skill, the capacity to perform this role effectively.

In recent years the end of life care educational requirements of primary care providers have been increasingly acknowledged, most notably by the Palliative Care Curriculum for Undergraduates (PCC4U) Project, and projects designed to promote competency in end of life care among currently practising primary care workers in the aged care sector. The reach of these projects to date has been, understandably, limited. Notably, however, the PCC4U Project represents both a recognition of the necessity of undergraduate education in end of life care for all primary health care professionals, as well as steps towards achieving this goal. This project has been explicit in outlining the palliative care capabilities required by primary care health providers:

- effective communication in the context of an individual's responses to loss and grief, existential challenges, uncertainty and changing goals of care

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[17] PCA 2008 *Palliative and End of Life Care - Glossary of Terms – Edition 1 2008*, PCA, Canberra
[18] ibid
[19] PCA 2005. *A Guide to Palliative Service Development: A population based approach*. PCA, Canberra http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf.
[20] PCA 2005. *A Guide to Palliative Service Development: A population based approach*. PCA, Canberra http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf.

- appreciation of and respect for the diverse human and clinical responses of each individual throughout their illness trajectory
- understanding of principles for assessment and management of clinical and supportive care needs
- the capacity for reflection and self evaluation of one's professional and personal experiences and their cumulative impact on one's self and others.[21]

Development of nationally agreed referral and discharge criteria

As noted above, the needs-based approach to end of life care offers a framework based on resource efficiency and delivery of quality care. At least in part, this is contingent on effective assessment and referral practices on behalf of primary care providers to ensure that individual patient's care needs are met in a timely manner. In this sense a key component of effective needs-based service provision is the development of protocols that establish referral and assessment criteria.

The necessity of establishing nationally agreed referral and discharge criteria to ensure responsive, evidence-based care that meets patients' needs has been underlined by research demonstrating disparity and uncertainty over when referral to a specialist palliative care provider is required and warranted. Auret, Bulsara and Joske[22], for example, studied Australasian hæmatologists' referral patterns to palliative care, finding variation between providers in when referral occurred. Further, they found widespread referral practices that do not support needs-based service provision. Johnson et al[23] assessed cancer specialists' (including hæmatologists') palliative care referral practices. They concluded that "measures are needed to encourage ongoing needs-based assessments, especially of emotional, cultural and spiritual issues."

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[21] Palliative Care Curriculum for Undergraduates Project Team (2005) *Principles for including palliative care in undergraduate curricula*. Canberra: Australian Government Department of Health and Ageing

[22] Auret, K., Bulsara, C. and Joske, D. (2003) "Australasian haematologists' referral patterns to palliative care: lack of consensus on when and why" *Intern Med Journal* 33(12): 549-51

[23] Johnson, C.E., Girgis, A., Paul, C.L. and Currow, D.C. (2008) "Cancer specialists' palliative care referral practices and perceptions: results of a national survey" *Palliat Med* 22(1): 51-7