SUBMISSION TO THE

CARING FOR OLDER AUSTRALIANS
PRODUCTIVITY COMMISSION INQUIRY

July 2010

Palliative Care

Palliative care is 'specialist health care and practical support' for those people living with a life-threatening illness. It involves early identification and impeccable assessment and treatment of pain and suffering. Improved access to palliative care services is essential to enable people living with a life-threatening illness and their families to make the most of each day and to experience comfort and support at the end of life in the place of their choosing.

Why Palliative Care is a Critical Issue for the Inquiry

- As a community we ignore, deny, fear and avoid the issue of death and dying. It is imperative that this is addressed as a key issue, particularly for older Australians given its prevalence and inevitability.
- Optimal palliative care improves the quality of life for people living with a life threatening illness and should be available to all Australians and their families, when and where they need it.
- The number of Australians aged over 65 years is expected to increase by 50 per cent over the next 10–15 years and includes a fourfold increase of the population aged 85+ over the next 40 years[1]. This will increase dramatically the need for optimal palliative care able to be provided by all relevant health and aged care services.
- A failure to provide optimal palliative care impacts on the wider community through preventable admissions to acute services which are likely to reduce the cost-effective use of health resources.

Future Imperatives

Delivering the right palliative care at the right time and in the right place is a challenge the health system, including aged care services, must meet. Seamless coordinated palliative care is required as the population ages and deaths from chronic illnesses increase.

The focus of aged care reform must encompass healthy ageing and social inclusion, supportive, restorative and rehabilitative care, and optimal palliative care.

The Inquiry must also consider the needs of people with disabilities under 65 years of age who receive aged care services due to the unavailability of other suitable services to provide the level of care they require. People aged less than 65 years with disabilities or chronic diseases (for example, degenerative neurological conditions) must have access to optimal palliative care services, wherever possible within service/care contexts that promote their quality of life.

A major sustained national public awareness campaign (similar to Beyond Blue) is required to increase community awareness and capacity in relation to issues of death and dying, and to visibly promote the right to optimal palliative care at all care sites.

Status Quo Must Change

There is international recognition that many older people currently experience less than optimal care towards (and at) the end of life. The particular challenges posed for older adults by a combination of physical co-morbidities, cognitive changes, and reduced social support are not always fully recognised and/or met by aged care services.[2] The World Health Organisation has called for 'better palliative care for older people'[3] to address this.

Studies indicate most people would prefer to die at home[4]. With an increasing ageing population and the increased likelihood that many elderly will live alone, there is an urgency to provide increased resources within the community setting to support this population to live at home as long as possible and to die at home if this is their wish. This not only supports client choice but is likely to reduce hospital and residential aged care admissions and associated costs.

By 2020, half of all deaths in Australia are predicted to occur in residential aged care facilities[5]. Of those admitted to an aged care facility in Australia, 62% die within the first year[6]. Death in this setting is a common experience; however, there is evidence that aged care facilities are unable to offer appropriate palliative care[7].

What happens in aged care affects the broader health system. If appropriate aged care services with staff skilled and comfortable in providing palliative care are not available, there is a high risk of avoidable hospital admissions, increased length of stay in hospitals, more admissions to residential aged care facilities and issues with staff retention and stress within aged care services[8],[9].

The Australian National Health and Hospitals Reform Commission)[10], Palliative Care Australia's *Health System Reform and Care at the End of Life: Guidance Document*[11] and the new *National Palliative Care Strategy*[12] have also put the spotlight on optimal palliative care as the responsibility of the whole-of-health, including the aged care system.

KEY CHALLENGES

1. WORKFORCE
2. SERVICE SYSTEM DESIGN & INTEGRATION
3. QUALITY AND FUNDING
4. SUPPORT FOR CARERS
5. CARE PLANNING

1 WORKFORCE

The changing availability and composition of the workforce presents the most crucial challenge in managing the needs of an ageing population. Aged care services already face an ageing workforce, high rates of staff turnover and poor capacity to attract and retain staff due to higher pay rates in the acute sector. These challenges will be compounded by forecast major general workforce shortages over the coming decades.

The National Health and Hospital Reform Commission stressed that strategies to increase the competence of the aged care workforce in the area of holistic end of life and palliative care is urgently required[13].

Suggested Solutions

- A palliative approach[a] should be considered a core *competency* for all who work in aged care and be incorporated as mandatory in their education, ongoing training and competency base. Promotion of the Palliative Care Curriculum for Undergraduates (PCC4U)[14] would support this. Currently there are no nationally agreed minimal educational requirements, practice codes or competency standards for assistants in nursing and other unlicensed workers in aged care. A national framework for assistants in nursing and unlicensed workers is required to ensure an appropriately skilled workforce can undertake tasks that support nursing care. Their education must include a palliative approach as a core competency[15],[16].
- Staffing levels and skill sets are currently inadequate for optimal palliative care in residential aged care settings. There is an urgent need to address workforce shortages and set standards that regulate workloads, skill sets and professional pathways and thus improve recruitment, retention and care. This will require improved funding for aged care and recognition that this is valued work.
- The Program of Experience in the Palliative Approach (PEPA)[17] program and palliative care scholarships have been valuable initiatives and these should be extended. To date, this has enabled aged care staff to spend quality time within palliative care services. We recommend also developing *reverse PEPA* opportunities enabling experienced palliative care professionals to provide education and guidance within aged care services for a period of time. This will encourage cultural change necessary for sustainable optimal palliative care.
- Clinical leadership and linking models need to be further developed and resourced. These have the potential to provide improved structural solutions to workforce challenges. Examples include:

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[a] A palliative approach aims to improve the quality of life for individuals with a life-threatening illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, social and spiritual needs. Underlying this philosophy is a positive approach and open attitude towards death and dying. A palliative approach is not confined to the end stages of an illness.
Ref: Commonwealth of Australia, 2004, Guidelines for a Palliative Approach in Residential Aged Care, p 3

  - Aged Care Nurse Practitioners – they play a valuable role in educating, encouraging and supporting staff, as well as liaising with general practitioners, allied health professionals, pharmacists and specialist palliative care practitioners, etc. Evidence indicates the introduction of such roles `increases service-users satisfaction, improves outcomes (timely access, assessment and client interventions), reduces the prescription of pharmaceuticals, decreases readmission to acute care and reduces costs'.[18]
  - Link nurse models[19] whereby an appropriately educated and resourced aged care nurse leads the palliative care delivery in that service. This person links with their closest specialist palliative care service for consultation, education and support. The Program of Experience in the Palliative Approach (PEPA) program could assist with the education of these nurses.
- Access to appropriate pain and symptom control often required at the end of life is not always able to be provided by low care residential aged care facilities, due to limited storage of medications and access to nurses who can dispense Schedule 8 drugs.

Mr Ball was in a low level aged care facility nearing the end of his life from chronic pulmonary disease. He suddenly became severely short of breath and agitated. Palliative care staff had suggested medications to be on hand in case of just such an emergency; however, as the medication could not be stored at the facility or administered due to lack of registered nurses he was admitted to hospital by ambulance.

There is also an urgent need to strengthen emergency access 24/7 to palliative care medications in the community. Solutions could be achieved through clinical leadership and linking models (covering multiple services) as well as greater support from specialist palliative care services, hospital emergency departments and local pharmacies.

- Specialist palliative care services need substantial investment if they are to provide adequate levels of ongoing education, direct care and consultancy to primary aged care providers to cope with the needs of the ageing population.
- The Home and Community Care (HACC) Program requires review to ensure palliative care is no longer a `no- growth' area in this current ageing environment. HACC services such as district nursing, personal carers and home care services provide much of the community care required for palliative care clients. The 'no-growth' restriction and limited HACC funds results in less than appropriate levels of care for palliative care clients.

2 SERVICE SYSTEM DESIGN & INTEGRATION

Given the major structural workforce challenges ahead, solutions will not reside within the aged care sector alone but will depend on a broader systems framework that stretches across the traditional boundaries of primary care, aged care, palliative care, acute care and care for people with disabilities.

Current examples of this broader boundary-crossing approach include:

- National Transitional Care Aged Care Program
- Victorian Hospital Admission Risk Program
- Residential Aged Care Clinical In Reach Pilots from hospitals into residential aged care facilities (such as those provided by Melbourne Health, Northern Health and Southern Health in Victoria)
- Provision of consultancy and education to aged care services by specialist palliative care services.

Rather than being at the innovative fringe of the health system (in terms of funding and scope) such initiatives need to be seen as essential design and capability elements of an effectively functioning and integrated health system.

Further research and development in this area, building on the experience to date, should inform structural and strategic approaches that address current and future workforce challenges that are likely to be most keenly felt in aged care but will have far-reaching implications across the whole health system. They need to be resourced and further developed accordingly.

Service Capability and System Configuration

The recently developed *Victorian Palliative Care Service Delivery Framework* (SDF)[20] articulates a service capability framework and system configuration underpinned by principles and program objectives. *The Capability Framework* delineates the roles, levels of capability and service accessibility expected of various types of palliative care service. It considers workforce availability, education, training, research, quality and infrastructure. The *System Configuration* identifies how the service system would be structured and considers processes and approaches to service linking and integration.

There would be merit in using a similar service capability and system configuration approach more comprehensively across the health and aged care system, having regard to workforce challenges and areas where the system needs strengthening and improving. There is a need to build into the service system design and capability appropriately resourced strategies and processes that will facilitate service innovation and integration so that the whole health and aged care system functions effectively.

State and federal governments need to coordinate and collaborate in developing integrated services that meet the palliative care needs of older people wherever they are.

E- Health plus broader IT system integration and access would facilitate effective communication between primary, acute, palliative, aged care and other relevant providers.

3 QUALITY AND FUNDING

The National Health and Hospital Reform Commission recommended a needs-based approach that acknowledges that patients have different needs that may change over time and that ensures people can access the right care in the right setting[21]. This is particularly true as a person's dependency increases as they live with a life threatening illness or approach the end of their life. A whole of health sector approach to the delivery of optimal palliative care is required.

Suggested Solutions - Quality

- *Health System Reform and Care at the End of Life: A Guidance Document*[22], the Palliative Care National Standards Assessment Program[23] , the new *National Palliative Care Strategy*[24] and *National Palliative Care Standards*[25] should be considered alongside aged care reform so as to ensure optimal palliative care is available to all older Australians.
- The National Palliative Care Standards should be reflected in the Residential Aged Care Standards, HACC Standards and all hospital standards. Related key performance measures should be implemented, monitored and reported on.
- The National Health and Medical Research Council endorsed *Guidelines for a Palliative Approach in Residential Aged Care*[26] and the soon to be released Commonwealth *Guidelines for a Palliative Approach for Aged Care in the Community Setting* [27] should be mandated to guide palliative aged care practice and be accompanied by appropriately resourced education programs (which recognise the level of staff turnover and the cost of backfilling staff).
- Multipurpose facilities appear to be unaware of the Guidelines for a Palliative Approach in Residential Aged Care. This should be corrected and ongoing education provided.
- All General Practitioners visiting Residential Aged Care Facilities must be made aware of the *Guidelines for a Palliative Approach in Residential Aged Care* and work within them.
- Alzheimer's Australia recently released a report predicting the number of Australians with dementia will quadruple to more than 1.1 million by 2050. Dementia is a fatal disease and as yet there is no cure.[28]In Australia deaths from dementia related illness have increased 138 percent since 1999[29]. It is projected that nearly one third of our population will be either dying from dementia or dying with dementia in the future. There is a need to include advanced dementia within the quality framework for contemporary palliative care.
- Greater investment is required in strategic and collaborative research to provide evidence-based protocols and care pathways for optimal palliative

care, particularly given the complex co-morbidities among the 85+ population. There also need to be appropriately resourced strategies to ensure that the evidence base is reflected in workforce education and care delivery.

Suggested Solutions - Funding

- The continuing use of the Commonwealth Own Purpose Outlays Index (COPO) means that funding for aged care services continues to decline in real terms and is at the point where sustainable quality care is at serious risk. It is unrealistic to expect high quality care to be maintained under these funding arrangements, which also exacerbate workforce recruitment and retention.
- Funding arrangements must appropriately reflect the cost of meeting resident and carer needs at this time of increased intensity of care. The Aged Care Funding Instrument (ACFI) used in residential care does not provide adequate funding for optimal palliative care. Allied health care services such as physiotherapy, speech therapy, social work and occupational therapy are not funded appropriately and therefore psychosocial, spiritual, loss and bereavement needs are often not met.
    - There is no funding for bereavement support within aged care services with families left unsupported after the death of a loved one. This can lead to preventable distress of families, complicated grief and subsequent need for health services.

4 SUPPORT FOR CARERS

Strategies for caring for older Australians must recognise the vital role played by carers, family members and volunteers who provide care for people often until they die.

Suggested Solutions:

- The availability of respite services is inadequate to meet current let alone future needs. Appropriate levels of inpatient and in home respite are crucial to prevent avoidable patient and carer distress and hospital admissions.
    - A funded process of engagement with Aboriginal, established and newly emerging ethno-specific and multicultural organisations is vital to ensuring that older people from diverse backgrounds have access to culturally safe palliative care services, including culturally relevant information, professional support, respite, and access to a flexible funding pool to meet the needs of carers.
- The promotion of consistent needs assessment through the development and implementation of a national validated End of Life Needs Assessment Tool and Family Care Plan is required.
- There is a need to develop greater pools of skilled palliative care volunteers for access by residential aged care facilities, community care and acute

care. These volunteers provide respite, practical support and emotional comfort. National standards for recruitment, training and, supervision and support of these volunteers is urgently required. Adaption of Victoria's Palliative Care Volunteer Standards[30] and Palliative Care Victoria's Palliative Care Volunteer Training Resource Kit[31] could assist in this.

5 CARE PLANNING

Multidisciplinary care planning which includes *Care Pathways* and *Advance Care Planning* is essential if palliative care is to meet the wishes of older Australians and is to be well planned and coordinated. This empowers the person, clarifies wishes with their carers and assists in ensuring people are cared for appropriately in the setting of their choice whilst avoiding unnecessary and unpleasant treatments. This also supports effective use of health resources.

Mr Jones suffered from chronic pulmonary disease, epilepsy and dementia. His end of life wishes included being kept comfortable within his home environment (now the RACF) as long as possible.

A step-by-step plan was formulated with the palliative care consultant, the aged care staff and the family. The plan proved effective on several occasions when Mr Jones suffered a major seizure and distressing symptoms of dyspnoea. Both the family and the aged care team expressed satisfaction that his symptom control could be managed well by the aged care nurse, and that he was spared a distressing and disorientating hospitalisation.

Suggested Solutions

- The *Health System Reform and Care at the End of Life: A Guidance Document* recently released by the National End of Life Framework Forum provides guidance on facilitating person-centred care planning, end of life care pathways and advance care planning.

- National evidence-based guidelines on end of life care pathways are needed for specific chronic diseases, as well as for people with complex co-morbidities.

- A national approach to the development and introduction of a suite of user friendly nationally mandated advance care planning templates (which are suitable and transferable across all care settings) should be developed and readily available. This must be accompanied by appropriately tailored education programs for members of the community and the broad healthcare workforce, to ensure effective implementation and sustainability.

Palliative Care Victoria Inc. is an independent not-for-profit peak body representing palliative care providers, consumers and their families and those with an interest in palliative care in Victoria.

Established in1981, Palliative Care Victoria's mission is to promote optimal palliative care for all, when and where they need it.

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