Mercy Health

Submission to Senate Inquiry into Palliative Care in Australia

March 2012

Mercy Health welcomes this Senate Inquiry into Palliative Care in Australia. This document presents Mercy Health’s comments and recommendations to the Inquiry.

Mercy Health is a Catholic community provider of care founded and wholly owned by the Sisters of Mercy Melbourne Congregation. We offer acute and sub acute hospital care, aged care, mental health programs, specialist women’s health, early parenting, palliative, home and community care, and health worker training and development.

Our palliative care services provide palliative care including symptom management, psychosocial care and end of life care for patients living at home or in aged care facilities. Our services include a holistic multidisciplinary team approach. In Victoria we care for people in metropolitan and semi-rural areas in the western region of Melbourne. We cover two of the ten fastest growing municipalities in Australia. The catchment also consists of culturally and linguistically diverse communities with sixty different languages spoken. Mercy Palliative Care is responding to the unmet needs of patients with non malignant disease including 30% of all referrals coming from patients in Aged Care Facilities.

In NSW, we provide inpatient, community and rural outreach palliative care services within the Murrumbidgee Local Health Districts of Southern NSW. This area has a higher proportion of the population which is indigenous.

Mercy Health has made comments regarding those areas raised in the terms of reference and also recommendations for the areas that have specific relevance to the palliative care services it provides.

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a. Access to appropriate palliative care

i. People living in rural and regional areas

People living in rural and regional areas are disadvantaged when it comes to accessing palliative care, as they are with many other health services.

In rural and regional areas there is a lack of medical consultancy and specialist medical support. Due to workforce shortages in these areas there is often a reliance on overseas trained medical practitioners who may have little knowledge of medications available for palliative care patients in Australia. There is limited support available from primary care services as well as a lack of access to appropriate equipment which could allow a patient to remain in their own home. Significant travel may be necessary to access medical support which can be a distressing experience for those suffering a terminal illness, with optimal care compromised.

Palliative care workforce challenges which are exacerbated the greater the distance from a metropolitan area include a lack of;

- allied health support – particularly social work services
- access to after hours support
- trained volunteers to provide support in the community setting, and volunteers coordinators to provide training, ongoing education and support these volunteers
- education opportunities to enable them to make informed decision about patient care
- nurse practitioners in palliative care
- incentives to attract palliative care medical specialist to rural and regional areas
- health professional’s knowledge and understanding of palliative care and choices/support available.

The palliative care workforce in rural and regional areas also experience professional isolation and increased education costs due to necessary travel expenses. All of these workforce challenges have an impact on the palliative care that people living in rural and regional areas can access.

Resource shortages experienced by those in rural and regional areas include;

- no local Centrelink office at which to apply for allowances or request an early release of superannuation to pay palliative care expenses
- limited access to palliative care medications
- limited number of hospice facilities and designated palliative care beds at which a person can receive palliative care
- few outreach services and those in place unable to meet demand
- lack of bereavement support
- waiting lists for available services
- inequitable palliative care provision.

Mercy Health has also found that there is a low level of awareness and understanding of palliative care service provision to those in rural areas, with a lack of knowledge how to access palliative care information/services.

ii. Indigenous people

There is a need for palliative care health care professionals to engage with Aboriginal Health workers and Aboriginal Health Centres. Together they should meet with community Elders to develop relationships and an understanding of palliative care and support services available. This would further enhance the care staff's understanding of the spiritual and cultural traditions of the Indigenous community, which has been demonstrated through previous endeavours.

To ensure successful palliative care delivery to indigenous people, it is necessary to consider;

- indigenous person may be transient – need to ensure ongoing palliative care is maintained
- possible previous negative experiences with health services and fear of 'the system'
- access to health care provision and diagnosis may have been delayed
- indigenous clients may feel hesitation in allowing staff to visit homes due to varying living conditions and behaviour of other family members
- fear that they will have to be admitted to hospital
- financial circumstances may prevent access to prescribed medications
- inability to attend appointments due to lack of reliable transport
- ensuring brochures and resources are appropriate and specific to people group
- indigenous persons may wish to 'return to country' to die.

iii. Culturally and Linguistically Diverse background

Often patients from Culturally and Linguistically Diverse (CALD) backgrounds experience social isolation, have a fear of using the health system, and lack understanding as to what is provided as part of palliative care. This is particularly common within refugee populations.

Providing palliative care in a timely manner for those from CALD backgrounds requires health professions and carers to understand the cultural barriers they may be facing to ensure appropriate care is provided

Interpreter funding models should consider the specific needs of the community where services are located.

iv. People with disabilities

Those providing care to people with disabilities often lack knowledge regarding the palliative care services that can be accessed. There is limited cross over of information between health and disability services. The co-morbidities that this group of people experience need to be taken into consideration when providing palliative care.

v. Children and adolescents

Children and adolescents requiring palliative care may have endured significant time receiving treatment in the acute care setting. Health professions have a difficult time ‘letting go’ and referring to palliative care services. This may result in a breakdown in communication between acute and palliative care services.

The lack of allied health services taking part in the care needs to be addressed, as does the lack of understanding of the issues that are part of providing palliative care to children and adolescents.

Additional education of adult palliative care providers about child and adolescent palliative care should be facilitated.

Families of those young people who are receiving palliative care face many additional challenges and would welcome further support. These challenges include additional costs for medication, travel to health services, taking extending leave from their employment, all while still providing care to their other children in the family home.

b. Funding arrangements for palliative care provision

Mercy Health would support a national approach to the distribution of palliative care funds to ensure all palliative care patients have the same opportunities to access care and medications which would improve their quality of life, and reduce the debilitation effects of pain and other symptoms associated with malignant conditions.

Mercy Health’s experience is that episode funding is not an appropriate way to fund a speciality which provides services across both the acute and non-acute sector. Specifically, palliative care provided in the acute setting is not recognised in the current funding model.

The current funding arrangements do not fit with the National Standards for the Provision of Palliative Care and the meeting of these through the National Standards Assessment Program (NSAP).

In addition, the following issues relating to the palliative care funding model require addressing;

- recognition of the cost of education provision
- incentives for the provision of medical specialists in rural and regional areas
- adequate reimbursement of General Practitioners for home visits and incentives for attending multi-disciplinary meetings
- funding for the required skill mix, which increasingly requires allied health professionals
- funding for palliative care specialist services to maintain their current standards
- patient’s ability to afford non PBS medications used in the palliative care setting
- NSW funding (activity based) is not inclusive of coordination of service provision with stakeholders, nor does it consider the service provision to other acute inpatient services – it remains limited to direct patient contact

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

Significant palliative care resources have been developed with Commonwealth Government funding although there is a need for greater promotion of these across the health sector, in addition to ongoing evaluation of their usefulness.

Caresearch (www.caresearch.com.au) should be promoted as the main repository of palliative care resources, and financial support provided to implement resources which would improve palliative care experiences for patients and their families.

Mercy Health would support the development of a national palliative care database to allow improved benchmarking and standardisation of service provision

There is a need to consider the increased number of patients with chronic diseases, including the provision of bariatric care, who will require palliative care, and resource the sector to appropriately meet this demand.

d. Effectiveness of palliative care arrangements

As there is no standardisation of palliative care services across Australia, the provision of palliative care services to Albury/Wodonga creates issues for Mercy Health with different models for each state. A nationally consistent approach would address these issues e.g. referral processes and criteria.

Like many journeys within the health sector, accessing palliative care can be fraught with confusion regarding service provision.

Specialist palliative care staff are not always available within the residential aged care setting. The quality of palliative care that residents receive is often dependent on the individual skill set of staff providing care at the time. A greater alignment of the aged care and palliative care sector, and a national approach to providing palliative care within residential aged care facilities should be considered to ensure all residents have appropriate access to palliative care regardless of their geographic location.

There is an expectation that specialist palliative care services will provide education to aged care facility staff, but no financial support is provided to facilitate this. Mercy Health would recommend additional funding for this vital area of staff education.

There is a need for further coordination between medical units that manage chronically ill patients and palliative care services for those with non malignant conditions, as is currently the case with tumour groups for malignant disease.

With the implementation of Medicare Locals progressing, there is a need to ensure formal links with specialist palliative care services are established and maintained.

Accreditation should be mandatory for palliative care services and for these services to align themselves with the National Palliative Care Standards.

e. Palliative Care workforce

Formal recognition should be given to the valuable contribution of volunteers to the palliative care workforce. Volunteers represent 60% of the Mercy Health's palliative care workforce. The Victorian model of volunteer training includes a standardised, state wide approach using the *Palliative Care Volunteer Training Resource Kit*. This kit has been sold for use nationally and internationally. Formal standards for volunteers also exist in Victoria as the *Palliative Care Volunteer Standards*, which were developed by Volunteering Victoria.

Due to increasing demand for General Practitioners (GP) services within the community, in many areas there is a limited number of GP's available, and even less who have the appropriate skills and knowledge to provide palliative care.

Difficulties are experienced in accessing Palliative Care Consultants after hours for medical back up and support to nursing staff.

Mercy Health is preparing for future palliative care workforce demand by implementing a specialised graduate nurse program offered at Werribee Mercy Hospital and Mercy Palliative Care. This specialised program allows graduates to gain on the job experience in both inpatient and community palliative care and has contributed to the introduction of a younger workforce. Consideration should be given to joint appointments between health services to allow for palliative care skills to be spread across the sector.

Please refer back to item a.i., for further comments from Mercy Health on the palliative care workforce.

i. Meeting the needs of the ageing population

The Australian population is ageing, with proportion of the population over 65 years expected to double to around 25 per cent over the next 40 years.

While people will wish to remain in their own home for as long as possible, the reality is that with the expected decline in informal carers and family support, coupled with the high acuity care needs of the frail elderly, many will spend the final part of their lives in residential aged care(RAC) facilities.

All residents in RAC facilities will require general palliative care. Specialist palliative care services will also be required for a small number. Many of these residents are likely to have suffering from multiple, often disabling chronic diseases which need to be considered as part of the palliative care provided, to ensure people receive adequate pain management and are treated with dignity in their final days.

Investment in initiatives to improve palliative care in residential aged care facilities should include the inclusion of hospice beds in RAC facilities as well as education and training around guidelines and standards for providing palliative care.

ii. Workforce education and training

Facing challenges such as those described earlier, there is need to develop new workforce models that include a multidisciplinary approach to the provision of palliative care. Participation in the Program of Experience in the Palliative Approach

(PEPA) has been successful in Victoria and for Mercy Health Albury in facilitating the general health workforce to gain experience in palliative care. There is potential for participants to consider a career in palliative care, but it essentially improves the palliative approach they can offer their patients, which is especially important for those in residential aged care facilities.

Mercy Health would recommend that palliative care be a core component of the training and continuing professional education of doctors, nurses, social workers, chaplains and other health professionals. For doctors and nurses, this should include palliative care as part of the undergraduate curriculum.

We also call for continued funding of workforce education and training needs. Provision should also be made for scholarships that encourage post graduate studies.

f. Standards for Providing Quality Care to All Australians

Mercy Health would support a review of the national standard.

Continued support for the National Standards Assessment Program (NSAP) including ongoing funding for project development this area. The palliative care standards provide a palliative care specific framework for quality improvement.

g. Advance Care Planning

i. Communicating about end-of-life care

Advance Care Planning should be a continual process across the disease trajectory, with palliative care needs been considered in these discussions.

ii. Law and Policy

There is a need for a nationally consistent approach to legislation and policy concerning Advance Care Planning. These should clearly articulate the difference between care planning after diagnosis of a terminal illness, and those made in preparation of being unable to express ones wishes due to injury or illness. The palliative care sector should be involved in the policy development to ensure the specific needs of palliative care and included.

iii. Personal Electronic Health Records

The inclusion of Advance Care Planning in Personal Electronic Health Records would support this process by starting the conversation early in a person’s illness. It would also ensure that a person’s wishes are accurately recorded and that all health professionals involved in providing care are aware of these directives, which is particularly critical when one is no longer able to speak for themselves.

h. Research, Information and Data

Mercy Health was fortunate to be a recipient of funding from the Department of Health and Ageing in the Local Palliative Care Grants Program Round 5. This funding was for the project *Enhancing staff skills in providing palliative care for persons experiencing dementia and/or mental health issues in later life.* As part of the project the booklet *Affirming Life – what is a palliative approach? A guide for family and friends with loved ones in Aged Care* was produced, and Mercy Health hosted a Palliative Care Conference in late 2011, as the closing event for the project.

The Palliative Care Outcomes Collaborative (PCOC) continues to provide services with useful patient outcome data to identify issues for improvement at a service level as well as benchmarking with other like services and the ability to trend patient outcomes which may lead to improved palliative care nation wide. This should be strongly recommended, if not mandated, nationwide.

Mercy Health calls on the Government to make a greater investment in innovative and collaborative research which can be translated into improved palliative care services for patients and their families.