

SUBMISSION TO THE LEGAL AND SOCIAL ISSUES LEGISLATION COMMITTEE

INQUIRY INTO END OF LIFE CHOICES

Mercy Health's submission to the Inquiry into End of Life Choices is made with specific reference to point 3, *practices being utilised in the medical community including palliative care*. It has been reviewed by the Mercy Health Ethics Committee.

Mercy Health is a Catholic organisation grounded in a 2,000-year tradition of caring for others. Founded by the Sisters of Mercy, Mercy Health employs over 6,000 people who provide acute and subacute hospital care, aged care, mental health programs, specialist women's and babies' health, early parenting education and support, palliative care, home and community care, and health worker training and development. Mercy Health employs people from many cultures and backgrounds who, irrespective of their beliefs, share a common bond to care for those in need.

Mercy Health operates large community based and inpatient palliative care services in the western metropolitan region of Melbourne, as well as smaller regional services in Albury and Young in Southern New South Wales. Mercy Health has been committed to providing palliative care services since 1985.

Mercy Palliative Care provides care for people with a terminal illness and supports their loved ones within their own homes. Our primary service in Victoria provides services to local government areas of Brimbank, Hobson's Bay, Maribyrnong, Melbourne, Moonee Valley, Wyndham and the Shire of Melton. In doing so, it is also recognised as one of Australia's largest providers of expert palliative care services in residential aged care homes.

Its dedicated team includes specialist palliative care physicians, nurses, counsellors, family support volunteers, music therapist, pastoral care and bereavement support. The service is free of charge and available 24 hours per day, seven days per week. Our service provides palliative care to 500 people at any one time with 2,000 referrals received each year.

In addition, our Gabrielle Jennings Centre for Palliative Care, located within Werribee Mercy Hospital, is a purpose built 12-bed unit comprising eight single rooms and two bedrooms. Care is provided for patients requiring symptom control, end of life care and respite when beds are available. There are lounge and kitchen facilities for use by patients and their visitors. Relatives are able to stay overnight if they desire.

Staff comprise experienced palliative care nurses, palliative care physicians and a registrar working in conjunction with a multidisciplinary team. The Unit operates at 95 per cent occupancy.

This submission is informed by our experience as both a palliative care provider as well as a provider of aged care, with 22 residential aged care homes in Victoria, New South Wales, Queensland and Western Australia. In addition, as the operator of a tertiary

women's hospital, Mercy Hospital for Women, we also have significant experience in the provision of palliative care to neonates and women experiencing terminal gynaecological disease.

The World Health Organisation (WHO) defines palliative care as, "an approach that improves the quality of life of patients and their families facing the problems 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."

The WHO recognises palliative care as a human right. At Mercy Health we believe that palliative care should be available to all when needed, not solely based on diagnosis or prognosis. It can occur well before a person enters the end stage of their illness. It can and should occur in concert with curative treatments, e.g. radiation, chemotherapy.

We also believe that palliative care should be available to those living with chronic conditions which are not necessarily immediately life threatening. These include Alzheimer's and other dementias, cardiovascular diseases, chronic obstructive pulmonary diseases, HIV/AIDS, Parkinson's disease, kidney failure, motor neurone disease etc.

While palliative care is accepted as best practice for end of life care, many people do not have their symptoms and pain adequately managed and their human dignity honoured as they approach the end of their lives. We sadly have witnessed instances where people are referred for palliative care too late or not at all.

In Australia and many other parts of the world the demand for palliative care services is increasing due to the ageing of the population and increases in the prevalence of cancer and other chronic diseases that accompany the ageing process. The number of people who die each year in Australia will almost double in the next quarter of a century. As the number of people dying each year increases, pressure to improve the quality of dying is also likely to grow.¹

Within Western society, there is a lack of desire to speak openly about dying and health professionals are not immune to this². There is also a concerning lack of knowledge regarding what is legal.

A report published in February 2014 paints a disturbing picture.³ It found that 41 per cent of care professionals had received no training on assessment of pain in people who had dementia. Further, 13 per cent of care professionals did not think adequate pain control (if it might also hasten death) was a legal choice for people in Australia and 14 per cent were unsure. Twenty-nine percent did not believe that people had the right to refuse

¹ Swerissen, H and Duckett, S., 2014, Dying Well. Grattan Institute

² Australian Commission on Safety and Quality in Healthcare, Safety and quality of end-of-life care in acute hospitals, 2013

³ Alzheimer's Australia 2014, End of Life Care for People with Dementia

food or fluids or were unsure and 38 per cent had not received any training on the legal rights of a person with dementia at end-of-life. This begs the question how many people suffering dementia are being denied a good death and as such, effective palliative care. Whilst this study was undertaken within a dementia cohort, our experiences within acute and community based health service provision would suggest these findings could be easily applied across many healthcare settings and disease cohorts.

In the Grattan Institute publication⁴, a good death is described as one that “gives people dignity, choice and support to address their physical, personal, social and spiritual needs.” It could also be termed, “a good life to the very end.”⁵ That is, giving people dignity, choice and support to address their physical, personal, social and spiritual needs is a lifelong necessity.

The publication goes on to say that three reforms are required for a good death:

1. More public discussion about the limits of healthcare as death approaches and what we want for end of life.
2. We need to plan better to ensure that our preferences for the end of life are met.
3. Services for those dying of chronic illness need to focus less on institutional care and more on people’s wishes to die at home and in homelike settings.

As life becomes short by either terminal illness or ageing, the health workforce needs to be better equipped to ask patients, clients and their families “what is important to you?” Within our aged care facilities, we aim to give each resident the best day possible every day. It is the same with palliative care. Every life is a story and we need to take the time to listen to each person’s story and ask, “What do you want the story’s ending to look like?”

Advance care planning is a vital part of this process. It has been shown to improve end of life care for patients and reduces stress, anxiety and depression in surviving loved ones.⁶ Advance care planning is a critical component of patient centred care. It empowers individuals to make choices based upon what matters to them. Planning is pertinent to both the acute and residential aged care sector. However, its implementation has been sporadic.

The Victorian Auditor General’s report into palliative care, released in April 2015 found *“Advance care planning has been an accepted model of practice for many years. Despite this, use of advance care planning is low and shows no signs of growth. It is disappointing that greater progress has not been made as advance care planning is a central pillar of effective palliative care”*⁷.

⁴ Swerissen Op Cit

⁵ Gawande, Atul, 2014, Being Mortal: Illness, Medicine and What it Means in the End

⁶ Advance care planning: have the conversation A strategy for Victorian health services 2014–2018

⁷ Victorian Auditor General’s Report April 2014 Palliative Care

The report also found that, *“Demand for home-based care is increasing and some metropolitan community palliative care services have struggled to meet this demand, resulting in waiting lists to access services. This can place additional stress on patients and carers, and can mean that some people who have chosen to die at home cannot spend their last days there. Department of Health and Human Services (DHHS) has committed to better forecasting demand for services and to work with palliative care services to better understand how to support carer needs and respond to unmet demand.*

More also needs to be done to support carers and families. While there has been progress in some areas, improving respite provision and access to psychosocial support remain major priorities. Notably, 'support for carers' and 'engaging with the community' were two key priorities of DHHS's Strategic Directions that have not been met.

*Going forward, it is imperative that DHHS sets clear expectations for service delivery across the state and provides sufficient and appropriate funding to health services and community organisations”.*⁸

In considering end of life choices, people need to be assured that a dignified, supportive and pain controlled death can be achieved. However, this requires better access to advance care planning and dedicated palliative care services. Until this is addressed there will be artificial, as well as real barriers, to making effective and appropriate end of life choices.

Discussion on end of life choices should not be linked to discussion on the legalisation of euthanasia. Such a link in many ways trivialises discussions on end of life choices. This and its associated ethical and moral issues have no place in the discussion of effective end of life care. *“Concerns about voluntary euthanasia and assisted dying often clouds discussion about end of life care. This makes it more difficult to address much more common situations of withdrawing treatment and increasing pain relief. Preparation to anticipate these choices and planning for how we want to die is critical for dying well”.*⁹

Mercy Health submits that the Committee should consider the following:

- **Are the resources and funding being provided adequate to ensure equitable access to palliative care for all Victorians in need?**

Are community palliative care services accessible to those who need them? Our own experience demonstrates a need to expand services to be able to care for more people across a range of disease profiles. However, without appropriate funding this cannot be achieved, (this includes in-home respite care which involves an overnight carer being available at the patient’s home for the last days of their lives).

⁸ Victorian Auditor General’s Report April 2014 Palliative Care

⁹ Swerissen Op Cit

- **Are the loved ones of those who are dying provided with adequate support?**

Mercy Health provides grief counselling for anyone experiencing bereavement following a death as part of its palliative care services. We also recognise that managing a terminal illness can significantly impact on people's financial resources. As a result, two years ago the Mercy Health Foundation established an endowment fund named the Urgent Need Appeal. Family members who become carers have limited leave entitlements and are often faced with difficult decisions, such as leaving their employment or seeking unpaid leave so they can continue to care for their loved one. Other financial stresses include the cost of medication, medical fees, travel and increased utility costs for heating, cooling or using additional equipment. Many patients at end of life stage are more sensitive to the cooler or warmer weather because of their condition. High temperatures in summer and low temperatures in winter can make breathing difficult and uncomfortable for someone who is dying. Providing this sort of financial assistance is a largely unmet need in Australia.

With regard to the cost of medication, several palliative care medications are not on the Pharmaceutical Benefits Scheme and therefore access is limited to those who can afford to pay.

- **Health professionals require further education and support in the area of palliative care.** As recently as 8 July 2015, this was evidenced in an article in *The Age* written by Associate Professor Neil Orford, Director of Intensive Care at University Hospital Geelong and Director of Critical Care Services at St John of God Hospital Geelong. The article describes his experience with his elderly father in an intensive care unit.

*"I have learnt it is easy not to get good end-of-life care. Although there is growing recognition at all levels of the health system that it is better to provide end-of-life care that focuses on people rather than just disease, it is still easy not to die well. It is easy not to know you are in the last part of your life. It is easy not to be asked what you value in life, or to be offered care that puts this first."*¹⁰

While the level of palliative care training has undoubtedly improved for students undertaking undergraduate training, our experience suggests that continuing education is required for both specialist and general practitioners (GPs). In particular, GPs need to develop their knowledge and skills in palliative care and gain greater confidence in prescribing medication.

- As a national provider of residential aged care, Mercy Health believes that the **development of a standard education package for residential aged care workers on end of life care is critical.** As the Australian Commission on Safety and Quality in Health Care (ACSQH) states, "A fundamental first step in providing safe and high quality end-of-life care is to recognise those patients who would be likely to benefit from such

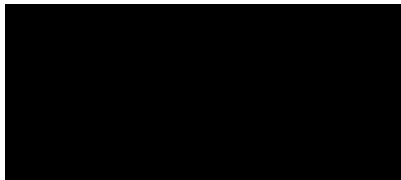
¹⁰ *The Age* Wednesday 8 July 2015

care”.¹¹ Such training should include case studies to educate staff on the triggers which may indicate that end of life care should be commenced.

- Recently, the ACSQH published a **consensus statement on palliative care**.¹² It describes the elements that are essential for delivering safe and high quality end-of-life care in acute hospitals.

While it is aligned with the National Safety and Quality Health Service (NSQHS) Standards, it provides recommended, rather than mandatory, practice. **Mercy Health would support this becoming a component of the NSQHS Standards.**

- Finally, the **public requires support and education in advance care planning and palliative care options**. They need to be informed about care choices at the end of life so that they can advocate for themselves and their loved ones ensuring the care they receive reflects the ending they desire for their own stories.



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¹¹ Ibid

¹² Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015