19 March 2012

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir/Madam,

Re: Senate Inquiry into Palliative Care in Australia

The Life, Marriage and Family Centre is an agency of the Catholic Archdiocese of Sydney and has been established to extend the research, policy, educational and pastoral activities the Church undertakes with respect to life, marriage and family issues.

The Catholic Church has a great and ongoing tradition of caring for the ill and dying and for their families. Across Australia Catholic providers operate over 19,000 residential aged care beds, together with eight dedicated hospices and palliative care services, and provide around half of all palliative care for the dying.[1]

Although Catholic practitioners, associations and institutions active in the field of palliative care will provide more detailed submissions to this inquiry, we wish to offer a brief explanation of the key principles and concerns we urge the Committee to take into account in making its recommendations. These relate specifically to terms of reference (a), **the provision of palliative care in Australia**, and (g), **advance care planning**.

The provision of palliative care in Australia

Palliative medicine cares for the whole person as they live their final stages of life. It improves the quality of life of patients and families who face life-threatening illness from diagnosis to the end of life and bereavement. Palliative care affirms life and regards dying as a normal process; provides relief from pain and other distressing symptoms; neither hastens nor postpones death; integrates the physical, social, psychological, emotional and spiritual aspects of patient care; and helps people to live as actively as possible until death.[2]

The ethos of palliative care – its affirmation that a life, even in its end stages, is good and worthy of being cherished and cared for – is fundamentally different from a fear-based outlook which sees any kind of limitation or dependency at the end of life as being demeaning to human dignity.

Dying is an intensely personal experience, but it is also a journey that no one should have to undertake alone. To be cared for when one is dying and to receive the support necessary to live the last days, weeks, months or years of one's life as well as possible, while accepting death and dying, is one of the deepest entitlements of our humanity. Palliative care carries a special significance for Catholics and Christians who *"see in the dying person, as in no other, the face of the suffering and dying Christ calling out for love"*.[3]

Every Australian has the right to receive good palliative care and we have as a nation, the capacity to provide palliative care to all Australians who are terminally ill. Sadly, however, there are still people in our community who are not dying well. Too often this is because they are unable to access the care they require, or sometimes because of a lack of awareness and understanding of what palliative care is able to offer.

As a nation, we must address both the questions of access to palliative care, and the education and awareness of patients, their families and those who care for them.

Regrettably, negative attitudes towards the terminally ill are apparent in our society, particularly in the ongoing debate about euthanasia and assisted suicide. Dying people should never be regarded as 'unproductive' or 'burdens', but as human persons – men and women with inherent dignity, who are worthy of care, reverence and love. Prevailing negative attitudes and pressures make it all the more imperative to promote the value of palliative care and foster positive attitudes of respect for life and for the natural and deeply human experience of dying.

Advance care planning

Instruments for advance care planning, if regarded as providing guidance, rather than being legally binding, and if based on sound principles of human dignity and respect for human life, may be helpful in alleviating fears of possible over-treatment at the end of one's life. Catholic medical ethics and the palliative care movement readily recognise that there is a time for aggressive treatments and a time to accept our human condition and prepare for death as a natural event.

However, the fundamental ethical principle is that treatments should only be withdrawn if they are therapeutically futile, overly burdensome or not reasonably available without disproportionate hardship.[4]

Advance care planning is a very sensitive and complex area. It is particularly troubling that some Australian jurisdictions have chosen to make advance care planning instruments or 'directives' enforceable by law. It is ethically unacceptable to legally bind a patient in anticipation of a future event or illness, or otherwise seek to remove the proper and ethical exercise of therapeutic judgment by those persons to whose care that patient is entrusted. Indeed, it would be completely unethical and immoral to seek to bind someone involved in the provision of health care to act in a way which was against their conscience.

There are deeply problematic aspects to advance care planning instruments. These instruments ask patients to anticipate which treatments they would or would not wish to

receive in the event of various scenarios, including nutrition and hydration. Food and water are in reality ordinary, human care, rather than medical treatment, although their provision may sometimes require the assistance of technology.[5] Advance care planning instruments encourage patients to refuse in advance particular medical or 'life-prolonging treatment' if they reach a certain stage of their illness.

This kind of approach to advance care planning is deeply concerning, because it has the potential to legally bind a person who at the time they made the directive had no way of knowing with certainty what they might feel, wish or experience at a future stage of their illness.

Any national framework for advance care planning which would have the effect of legally binding a patient or his or her carers, rather than simply providing guidance, is ethically unacceptable and must be rejected. In particular, such binding directives risk violating the right to freedom of conscience and belief of those involved in health care.

The dying and the terminally ill are persons of great worth, value and vulnerability. Our palliative care system and advance care planning provisions must reflect their dignity and their right to be cared for, encouraged and supported to the end. No one should have to die alone and every person's last weeks, days and hours should be regarded as precious. This time should be neither cut short through inadequate treatment nor prolonged by futile or burdensome over-treatment as a result of advance care directives. Our approach to the dying should be guided by the authentic ethic of palliative care which respects and treats the whole person as a unique individual in a unique situation.

Thank you for the opportunity to make a submission on this important matter.

Yours sincerely,

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[1] Catholic Health Australia, Palliative Care Policy 2010. http://www.cha.org.au/site.php?id=899.
[2] http://www.who.int/cancer/palliative/en/
[3] *Charter for Health Care Workers*, 132. Pontifical Council for Pastoral Assistance to Health Care Workers, Vatican City, 1995.
[4] Catholic Health Australia, Code of Ethical Standards, 2001.
[5] See *Briefing note on the obligation to provide nutrition and hydration*. Catholic Health Australia. www.cha.org.au/site.php?id=228.