Senate Standing Committee on Community Affairs
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Australia

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Submission from **Catholic Women’s League Australia Inc.**
to the
Senate Community Affairs Committee
Inquiry into the provision of Palliative Care in Australia.

I. Introduction

Catholic Women’s League Australia Inc. (CWLA) is the national peak body representing the League's seven member organisations located throughout Australia. We are a Non-Government Organisation (NGO) and have consultative (Roster) status with the Economic and Social Council of the United Nations. We are also a member organisation of the World Union of Catholic Women’s Organisations (WUCWO).

One of CWLA’s four principle aims is to influence legislative and administrative bodies at all levels of government in order to preserve the dignity of the human person. We recognise that palliative care is an important practical expression of respect for the dignity of every human life and are grateful for the opportunity to contribute to this important inquiry.

"You matter because you are you.
You matter to the last moment of your life,
and we will do all we can, not only to help you die peacefully,
but also to live until you die."
Dame Cicely Saunders

II. Factors influencing access to and choice of appropriate palliative care that meets the needs of the population:

There has been a massive increase in the number of Australians accessing palliative care in hospitals. Over the 10-year period from 1999–00 to 2008–09, the number of palliative care separations in admitted patient care (in a hospice, a dedicated palliative care ward or in other admitted patient beds in a hospital) increased by 56%. (*Trends in Palliative Care in Australian Hospitals,* Australian Institute of Health and Welfare, Canberra, Oct 2011.) While this is an extremely positive development, this finding should also alert us to the ever expanding need for palliative care as Australia's population continues to age and grow. Greater funding and more options will clearly be needed in the future.

CWLA strongly endorses the principle that, where ever possible, every effort is made to ensure that palliative care is available to all Australians. Here, however, we wish to draw the Committee's attention to one particular area where people's need for palliative care is often overlooked.

Perinatal palliative care assists women and their partners who receive a life limiting diagnosis for the child during pregnancy. Some of our members have recently been involved in discussions with healthcare professionals and parents who have been in this very difficult situation. Although overseas experience and research suggests that parents who have received a diagnosis of a life limiting condition in their child benefit greatly from palliative care and support at that time, there is little experience, research and provision for such care in Australia.

CWLA recommends that the Committee considers opportunities to develop perinatal palliative care in Australia.

III. The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities.

Of all deaths in Australia in 2008–09, just over half occurred in an admitted patient setting within a hospital. Thankfully, a greater proportion of these people now receive palliative care during the hospital stay that ended with their death, than ten years ago (from 21% to 34% during the period from 1999–00 to 2008–09). Today, a further 20% of all deaths also occur in hospices.

However most Australians, when asked where they would prefer to die, still nominate their home as their preference. Unfortunately, only 16% of people will be able to die at home, and 10% in their nursing home. There is still much to be done to maximise the possibility that this final wish is fulfilled.

There would also be important secondary effects of increasing opportunities for people to die at home or in a residential aged care facility. Martin Laverty, the CEO of Catholic Health Australia, the largest single grouping of non-government health, aged and community care services in Australia explains:

> Some older people are going to hospitals to receive palliative care when they could be better cared for at home or in an aged care service. A public hospital bed can cost taxpayers up to three to four times more per day to operate than an aged care bed, where very often older people would be better off.
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> Increasing funding for residential aged care facilities, where palliative care can be delivered more appropriately for many older people, should be a priority for all Governments, as part of a strategy to improve both quality of care for people in the final stages of their lives and to take pressure of public hospital beds. ("Action on Palliative Care Provision Long Overdue," *Media Release,* Catholic Health Australia, Oct 20, 2011.)

CWLA recommends that resources for home or community based palliative care, as well as the provision of palliative care in residential aged care facilities, be increased. In these settings there would appear to be an important role for trained volunteers to work alongside professionals.

IV. Advance care planning

CWLA supports, in principle, the practice of advance care planning. It is important to ensure that people we trust are able to make decisions for us if the time comes when we are unable to make decisions about our own care. It is sensible to let these people know our values and our wishes for future medical treatment, to help guide their decision making.

Community education which encourages people to think about and discuss their future health care preferences with family, friends and healthcare professionals should be encouraged. People should also be encouraged to consider whether there is a need to legally appoint a representative to make health decisions on their behalf.

Written 'advanced care directives' however, can be problematic. These plans are likely to be inflexible, difficult to interpret and where they have legal status, ('living wills' have been given statutory status in Queensland and to a limited extent in ACT and South Australia) may prevent health care professionals from changing patient care to suit changes in the circumstances. Such directives may also suggest wordings that refuse care that should be provided, or insist on inappropriate treatment.

Overseas experience with 'living wills' has shown that they have failed to deliver hoped for outcomes. A landmark article by Fagerlin and Schneider published in the international bioethics journal *Hastings Centre Report* notes that: "In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned." They explain:

> First, despite the millions of dollars lavished on propaganda, most people do not have living wills. And they often have considered and considerable reasons for their choice. Second, people who sign living wills have generally not thought through its instructions in a way we should want for life-and-death decisions. Nor can we expect people to make thoughtful and stable decisions about so complex a question so far in the future. Third, drafters of living wills have failed to offer people the means to articulate their preferences accurately. And the fault lies primarily not with the drafters; it lies with the inherent impossibility of living wills' task. Fourth, living wills too often do not reach the people actually making decisions for incompetent patients. This is the most remediable of the five problems, but it is remediable only with unsustainable effort and unjustifiable expense. Fifth, living wills seem not to increase the accuracy with which surrogates identify patients' preferences. (Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30-42, 38)

Written expressions of future health care preferences do have a place, but they should usually seek to guide rather than direct decision making. If a health care representative has been appointed, written wishes should be flexible enough to allow the representative to respect the person's values as he or she adjusts to new situations on the advice of health care professionals. An example of a program along these lines is *A Guide For People Considering Their Future Care* by Catholic Health Australia and approved by the Australian Catholic Bishops. It includes a 'model statement for future health care', which contains some suggestions about the kinds of things someone might like to think about, and perhaps to record, to guide future medical treatment. (http://www.cha.org.au/site.php?id=223)

Advance care plans should not bind family members, representatives or health care professionals to act against their conscience. In this regard, the proper focus of advance care planning should be ongoing conversation and review.

Additionally, no one should be legally, or otherwise, compelled to engage in advance care planning. Many people trust their families and their health care professionals to know and do what is best for them. In some cultures and ethnic groups, this is the normal way in which health care decisions are made and this process should be respected.

For these reasons, **CWLA cautions against a national approach to advance care planning that emphasises, or even legislates for, advance care directives. These considerations also count against the inclusion of *overly directive* advance care plans in personal health records.**

Thank you again for the opportunity to contribute to inquiry. We wish the Committee well in its deliberations.

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