9 April 2008

Committee Secretary
Senate Legal and Constitutional Affairs Committee
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Email: legcon.sen@aph.gov.au

Dear Committee Secretary

Please find attached Catholic Health Australia's (CHA's) Submission into the Senate Select Committee's Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008.

Catholic Health Australia's view is that it is never permissible to end a person's life through the action of euthanasia. This submission argues for increased access to palliative care services. Australia should, as a matter of priority, ensure that a humane, dignified alternative to euthanasia is always available.

If you require any further information please contact me on 02 6260 5980 or email: richardg@cha.org.au.

Yours sincerely

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CATHOLIC HEALTH
AUSTRALIA

INQUIRY INTO THE RIGHTS OF THE TERMINALLY ILL (EUTHANASIA LAWS REPEAL) BILL 2008

APRIL 2008

SUBMISSION TO THE SENATE STANDING COMMITTEE ON LEGAL AND CONSTITUTIONAL AFFAIRS

1. Preamble

End of life care has always been a part of Catholic health and aged care. This ministry to the sick, frail and dying is complex, where health care is viewed as more than a scientific pursuit. It is an endeavour to care for the whole person, often beyond the limits of science.

Catholic Health Australia (CHA) is the largest non-government provider grouping of health, community and aged care services in Australia, nationally representing Catholic health care sponsors, systems, facilities, and related organisations and services.

CHA seeks to promote the goal of a health care system that values respect for human dignity, is person-centred, has a special concern for the poor, the common good, the appropriate stewardship of resources, and delivers social justice.

The Catholic health, community and aged care ministry is defined by interrelated foundational principles (see Attachment 1). The most relevant and important to this submission being dignity of the human person and respect for human life. CHA considers that each person has an intrinsic value and inalienable right to life and everyone has a right to essential comprehensive health care. CHA also consider that from conception to natural death, each person has inherent dignity and a right to life consistent with that dignity. It is from this foundational base that CHA makes this submission and strongly opposes the legalisation of euthanasia.

The CHA Sector Snapshot	
9,286 beds in 75 health care facilities - publicly (21) and privately (54) funded hospitals and	5,555 Community Aged Care packages (CACP)
7 teaching hospitals	594 Extended Aged Care at Home packages (EACH)
8 dedicated hospices and palliative care services	5,571 Home and Community Care programs (HACC)
Expanding day centres and respite centres 19,000 residential aged care beds	Rural and regional aged care facilities and services
6,253 retirement and independent living units and serviced apartments	Approximately 35,000 people working in the sector

It is CHA's view that it is a moral imperative that the Government and Parliament must provide adequate resources to relieve suffering rather than contemplate considering repealing of the Euthanasia Laws Act 1997.

Catholic health and aged care services place great emphasis on the provision of palliative care as an integral part of their mission. Palliative care is provided in a number of settings ranging including in the hospital, residential aged care facility and in the community (ie patient's own home). In addition, the Catholic health sector includes eight dedicated hospices and palliative care services.

2. The argument against euthanasia laws

It could be argued that euthanasia laws and the adoption of laws such as the *Groningen Protocol* in the Netherlands[1]:

- fails to distinguish with clinical precision where death is certain and those who could continue to live
- allows society and carers to escape from an unwanted burden of care
- places the onus on doctors to decide what is an acceptable quality of life according to questionable criteria
- reduces the social moral framework within which doctors make life and death decisions, without recourse to external critique
- provides a purely procedural response to the problem of measuring subjective suffering[2].

Legalising euthanasia would have huge implications for medical practice, and must be scrutinised with intellectual rigour. It could be argued that euthanasia does not give patients more autonomy but in fact further increases the authority of doctors over life and death[3]. In addition, the existence of euthanasia laws may comprise the autonomy of those who seek alternative treatments, such as palliative care and the capacity of physicians to refuse patient requests for euthanasia. It is the very complexity of this ethical territory that stops governments from being able to formulate legislation to adequately govern end-of-life decisions. There is a need for further research to better understand the ethical dilemmas faced by doctors in terminal care decision making.

3. Palliative care as the alternative

CHA believe that ethical care involves negotiation with the patient (or representative) to select the life-affirming treatment that best suits the patient's wishes and interests. Palliative care practice emphasises the holistic approach to patient care, embracing the individual's physical, psychological, spiritual and social needs. Over the past decade, developments have been made in all these areas to enhance and support the care of patients and their families.[4]

CHA believe that dying is a unique experience for each person, that person's family and others, and is part of the human journey. It comprises physical, psychological, social, spiritual and cultural elements.

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[1] See Attachment 2 : Groningen Protocol

[2] Ending the Life of a Newborn: The Groningen Protocol: Hilde Lindemann; Marian Verkerk; The Hastings Centre Report: http://www.medscape.com/viewarticle/569471, accessed 3 April, 2008

[3] Keown, John: Euthanasia, Ethics and Public Policy: An Argument Against Legalisation: Book Review, British Medical Journal http://www.bmj.com/cgi/content/full/326/7400/1218, accessed 3 April, 2008

4 Palliative Care Australia: http://www.palliativecare.org.au/Default.aspx?tabid=1221, accessed 8 April, 2008

Being committed to holistic health care delivery means that palliative care services are person and family centred and are provided for people with a life limiting illness or living with a condition which has no prospect of cure. The emphasis of care is on quality of life, for patients and their families. CHA believe that such services are intrinsic to health care and form part of the fabric of social obligation since “a society unable to accept its suffering members and incapable of helping to share their suffering and to bear it inwardly through ‘com-passion’ is a cruel and inhuman society”.[5].

4. *Demand for Palliative Care Services*

Palliative care is a growing area both in terms of the numbers of patients requiring palliative care and in the breadth of areas which fall under its banner. Palliative care will be needed by the growing number of cancer patients in Australia together with meeting the needs of a growing number of patients with other life limiting illnesses (eg advanced respiratory, cardiac or neurological conditions, HIV-AIDS). Palliative care can also enhance the wellbeing of people in aged-care facilities who, approaching death, risk being inappropriately transferred to an acute-care hospital and dying away from the place they regard as home.[6] Further, palliative care is certainly not restricted to people in older age, it is also needed by young adults, adolescents and children.[7]

Palliative Care Australia estimates that terminal illness affects at least 1 million Australians each year - including the families and friends. A person with a diagnosis of a terminal illness has a limited time to be on waiting lists for services. There is currently poor integration of services and alignment of resources across the healthcare system. It is known that in the future one in three Australian men and one in four women will develop a malignant cancer by the age of 75[8]. It is also known that cancer kills more Australians than any other single cause[9] and opinion polls have found cancer to be the nation’s greatest individual disease concern[10].

The burden of cancer in Australia is rising, with 88,398 new cases and 36,319 cancer deaths in 2001, compared with 65,966 new cases and 30,928 deaths in 1991. Cancer currently accounts for 31 per cent of male deaths and 26 per cent of female deaths in Australia and the loss of an estimated 257,000 potential life years[11].

In 2003–04 there were almost 25,000 hospital separations for which the care type was palliative care, or about 0.4% of total separations in that year. About three-quarters of these separations were from public hospitals. The average length of stay for a palliative care episode was 12.8 days in public hospitals and 10.7 days in private hospitals. Just

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[5] Pope Benedict XVI’s recent encyclical "Spes Salvi"(No. 38); Zenit Publications: http://www.zenit.org/article-22086?l=english, accessed 18 March, 2008

[6] Maddocks, I., Palliative Care in the 21st Century, *Medical Journal of Australia*, 2003; 179 (6 Suppl):S4-S5.

[7] Commonwealth Department of Health and Ageing, *National Palliative Care Strategy: A National Framework for Palliative Care Service Development,* October 2000, p4.

[8] Australian Institute of Health and Welfare, Cancer in Australia 2001, 2004.

[9] Australian Bureau of Statistics, Cancer in Australia: a snapshot, 2004.

[10] Roy Morgan polling, Health concerns in Australia, 2001

[11] op cit Australian Institute of Health and Welfare, Cancer in Australia 2001, 2004

over half (52%) of the palliative care episodes ended with the patient dying, but a substantial portion (38%) were completed by discharge from the hospital, generally to the patient's own home[12]. CHA believe there is a need to extend community based palliative care services in order to manage this growing demand for community based services.

Nationally consistent information about community-based palliative care provision, as distinct from hospital care, is not available. A trial palliative care agency data collection was conducted by AIHW in 2005 and received data from 180 palliative care agencies. Of these, 59% (107 agencies) reported that they mostly provided care in community-based settings, 28% (51 agencies) mostly in admitted patient settings and the remaining 12% (22 agencies) in both settings.13.

CHA is of the opinion that Private Health Insurance inadequately covers palliative care for the setting in which the privately insured patient is located, particularly home palliative care services. Many private health insurance funds have arrangements with providers that encourage rapid discharge of patients. While these arrangements may be suitable for those patients who are going to get better, they are inadequate for those with terminal illness.

CHA believes that this lack of expansion of services, in both community care and the private sector, at the same time as there is increased demand for palliative care services, provides an underlying driver for some sections of the community to begin to contemplate euthanasia as an acceptable alternative.

5. Funding of Palliative Care Services

There are currently three Commonwealth sources of funding for palliative care services:[14]

- Palliative Care in the Community – $62.8 million (2006–2010) to improve the standard of palliative care in the community;
- Australian Health Care Agreements – $188 million (2003– 2008) to the states and territories for palliative care, and $13.2 million to the Australian Government to support national initiatives; and
- Local Palliative Care Grants – $34 million (2005–2011) to help health-related services provide better support to people needing palliative care and their families.

The Australian Labor Party (ALP) in it's pre-election policy platform[15] outlined the following in relation to palliative care:

> *Labor believes that every person should have access to quality palliative care. People should be able to decide where they wish to die and to choose the extent*

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[12] AIHW 2005b.

[13] AIHW forthcoming

14Department of Health and Ageing: Palliative Care section: http://www.health.gov.au/internet/main/Publishing.nsf/Content/Palliative+Care-1, accessed 3 April 2008

[15] www.alp.org.au., accessed 3 April, 2008

> *of active treatment they want to prolong life as a terminal illness progresses. People have a right to relief from pain and suffering, but there is a need for legal guidelines and safeguards to prevent abuse or wrongful actions. Labor supports legislative measures to give each person a right to determine, in advance, the sort of medical treatment he or she wishes to receive, or not receive, in the event that their medical condition prevents them from expressing that wish.*

Labor's willingness to adequately fund it's election commitment in the area of palliative care will not be known until the Budget for 2008-2009 is brought down. CHA takes the view that a significant increase in spending in the area of palliative care services is warranted in order to alleviate the strains within the system.

6. Areas for Policy Reform

Palliative Care Australia assert that in relation to health services people with a terminal illness often face an inability to access appropriate care, compounded by:

- no real choice in care locations – with funding, systems, medicines and equipment access an issue;
- an absence of an integrated health system that is resourced to provide seamless services for the dying, across community, hospital, aged care facilities, respite and specialist palliative care services;
- shortage of appropriately trained doctors, nurses, and other health professionals, enabled with the right incentives and service provision models to really deliver quality care – regardless of whether they are in metropolitan, rural or remote Australia;
- insufficient respite services and availability of health professionals, with the incentive and resources to make home visits, present barriers to quality home-based care;
- lack of coordinated community networks that normally result in increased resilience and reduce the impact of loss, grief and bereavement.

CHA contends that if the following issues were addressed by Government there would be significant reduction in the stress that is currently being placed on palliative care services across the country:

- immediate access for a terminally ill patient to the MBS and PBS safety nets upon the diagnosis of a terminal condition by a recognised medical practitioner;
- better access to non-PBS items: currently a number of high cost drugs which are used to support palliative care patients are not available through the PBS, so that patients who could otherwise continue in care at home have to be admitted to a public hospital to access those drugs;
- palliative care services in the acute, residential and community care sectors are adequately resourced with flexible pools of funding to enable innovative and person-centred care;
- adequate respite and carer support, with equitable distribution of services through application of a planning formula which assesses need relative to population death rates;

- reform to the Patient Assistance travel schemes to provide a more appropriate level of subsidy for people living in rural and remote areas who need to travel for medical treatment. The schemes should aim to cover the costs of accommodation and travel, and not just provide a partial subsidy as at present.
- additional vocational training places are available in palliative care medicine as well as in related nursing and allied health disciplines;
- private health insurers to work with health and community providers to provide meaningful choice options for Australians living with a terminal illness to improve choice and reduce impact on the public health system.

A greater understanding and awareness of palliative care could also help the community and medical practitioners to adjust to acceptance of death as a natural part of human life and not a failure of the medical system, and a recognition that a high quality of life can be achieved even when death will be the inevitable outcome of the disease or illness. According to the NSW Cancer Council, nearly half of all cancer patients requiring palliative care are not being referred to palliative care because of confusion about what palliative care is. "There is a misconception that palliative care is for people at death's door. In fact, it's about helping those with an advanced illness improve their quality of life".[16]

7. International trends

The Luxembourg parliament voted by a slim margin (26 votes to 30) to legalise euthanasia and assisted suicide on February 19, 2008, becoming the third country in the European Union to do so[17]. The Netherlands became the first country in the European Union to legalise euthanasia in 2002, with Belgium following that example in 2003[18].

In the Netherlands, a protocol, known as the *Groningen Protocol*[19], for cases in which a decision is made to actively end the life of a newborn, was developed in 2005. This protocol details how infants and newborns for whom such end-of-life decisions might be made can be divided into three categories. First, there are infants with no chance of survival. These infants have severe underlying disease, such as lung and kidney hypoplasia. Infants in the second group have a very poor prognosis and are dependent on intensive care. Finally, there are infants with a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering. This group includes patients who are not dependent on intensive medical treatment but for whom a very poor quality of life, associated with sustained suffering, is predicted – such as severe forms of spina bifida.

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[16] Associate Professor Afaf Girgis, Director of the Cancer Council's Centre for Health Research and Psycho-oncology (CheRP) in press release 24 June 2004, "*Palliative Care: Improving life not just preparing for death*" , The Cancer Council New South Wales.

[17] http://www.reuters.com/article/worldNews/idUSL2011983320080220,accessed 3 April, 2008

[18] http://www.lifesitenews.com/ldn/2008/feb/08022002.html, accessed 3 April, 2008

[19] The Groningen Protocol — Euthanasia in Severely Ill Newborns: Eduard Verhagen, M.D., J.D., and Pieter J.J. Sauer, M.D., Ph.D. The New England Journal of Medicine :http://content.nejm.org/cgi/content/full/352/10/959, accessed 3 April, 2008

8. Conclusion

Ministry to the sick, frail and dying is complex. Catholic health and aged care view health care as an endeavour to care for the whole person, alleviating not only suffering but also offering respect to personal dignity and maintaining quality of living.

Catholic Health Australia’s view is that it is never permissible to end a person’s life through the action of euthanasia. Euthanasia must be distinguished from other care decisions which sometimes risk, or have the effect of, shortening life but which are not intended to hasten death. Australia should, as a matter of priority, ensure that the humane, dignified alternative of palliative care, is more readily available.

ATTACHMENT 1

FOUNDATIONAL PRINCIPLES OF CATHOLIC HEALTH AUSTRALIA

Dignity: Each person has an intrinsic value and inalienable right to life. Everyone has a right to essential comprehensive health care.

Respect for Human Life: From the moment of conception to natural death, each person has inherent dignity and a right to life consistent with that dignity.

UNDERPINS:

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- ***Human Equality***: Equality of all persons comes from their essential dignity. While differences are part of God’s plan, social and cultural discrimination in fundamental rights are not part of God’s design.

- ***Service:*** Health care is a social good. It is a service, not a commodity used for maximising profit.

- ***Common Good:*** Social conditions should allow people to reach their full human potential and to realise their human dignity. Equitable access to care, developing research and training, and conducting professional inquiry into the social, ethical and cultural aspects of health, builds social conditions and communities that respect human life and allow people to realise their potential.

- ***Association:*** Every person is both sacred and special. How we organise society – in economics, politics, law and policy – directly affects human dignity and the capacity of individuals to grow in community.

- ***Preference for the Poor:*** Priority must be given to the needs and opportunities of the poor and disadvantaged. This encompasses economic, cultural and individual notions of poverty and disadvantage.

- ***Stewardship:*** Health resources should be prudently developed, maintained and shared in the interests of the community as a whole and balanced with resources needed for essential human services.

- ***Subsidiarity:*** The identified needs of individuals and the community are best addressed at the level where responses and resources are available, appropriate and effective.

ATTACHMENT 2

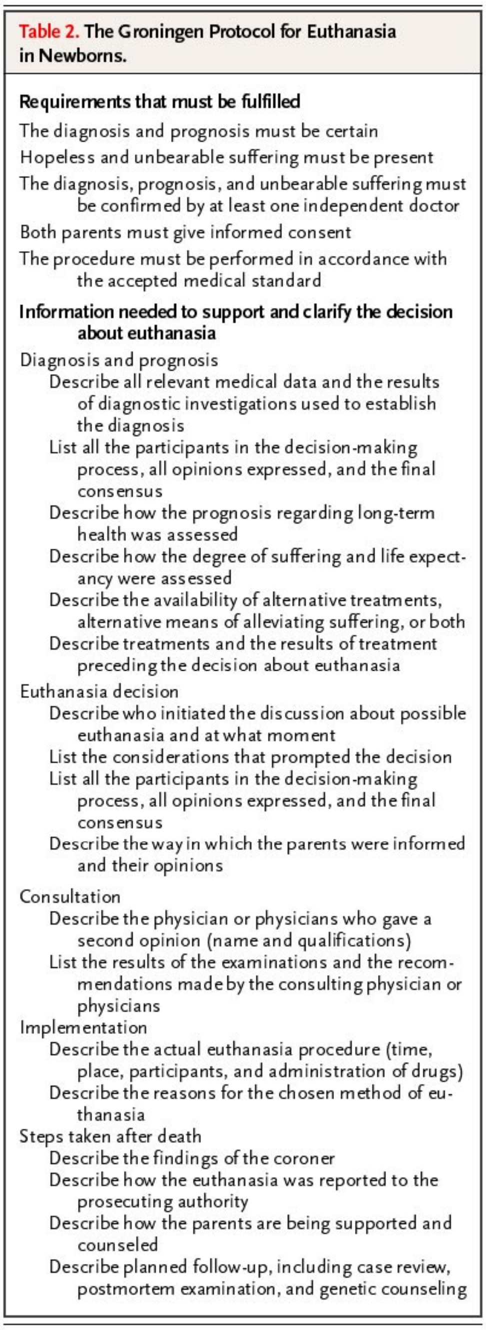

Table 2. The Groningen Protocol for Euthanasia in Newborns.

Requirements that must be fulfilled

- The diagnosis and prognosis must be certain
- Hopeless and unbearable suffering must be present
- The diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor
- Both parents must give informed consent
- The procedure must be performed in accordance with the accepted medical standard

Information needed to support and clarify the decision about euthanasia

- Diagnosis and prognosis
  - Describe all relevant medical data and the results of diagnostic investigations used to establish the diagnosis
  - List all the participants in the decision-making process, all opinions expressed, and the final consensus
  - Describe how the prognosis regarding long-term health was assessed
  - Describe how the degree of suffering and life expectancy were assessed
  - Describe the availability of alternative treatments, alternative means of alleviating suffering, or both
  - Describe treatments and the results of treatment preceding the decision about euthanasia
- Euthanasia decision
  - Describe who initiated the discussion about possible euthanasia and at what moment
  - List the considerations that prompted the decision
  - List all the participants in the decision-making process, all opinions expressed, and the final consensus
  - Describe the way in which the parents were informed and their opinions
- Consultation
  - Describe the physician or physicians who gave a second opinion (name and qualifications)
  - List the results of the examinations and the recommendations made by the consulting physician or physicians
- Implementation
  - Describe the actual euthanasia procedure (time, place, participants, and administration of drugs)
  - Describe the reasons for the chosen method of euthanasia
- Steps taken after death
  - Describe the findings of the coroner
  - Describe how the euthanasia was reported to the prosecuting authority
  - Describe how the parents are being supported and counseled
  - Describe planned follow-up, including case review, postmortem examination, and genetic counseling

Source: The Groningen Protocol — Euthanasia in Severely Ill Newborns: Eduard Verhagen, M.D., J.D., and Pieter J.J. Sauer, M.D., Ph.D. The New England Journal of Medicine :http://content.nejm.org/cgi/content/full/352/10/959, accessed 3 April, 2008