Submission to the

Inquiry into End of Life Choices

by Senator Joe Bullock, Senator for Western Australia

I commend the Legislative Council of Victoria for establishing this important inquiry into end of life choices. As a relatively new legislator myself, I am conscious of the trust placed in us by the community to ensure that the laws and the processes of government are directed to the well-being of the community as a whole, and particularly of those who are vulnerable or in special need because of their circumstances.

All of us will face death one day. We are fortunate to be living in a relatively wealthy society that, with advances in medical and allied health sciences, including the multidisciplinary specialties of palliative care, can provide us with appropriate comfort and care as we deal with this final part of our lives on earth.

In this submission I will briefly comment on palliative care and end of life choices; euthanasia; and advanced care planning.

Palliative care and end of life choices

The World Health Organisation defines palliative care as follows:

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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. Palliative care:*
>
> - *provides relief from pain and other distressing symptoms;*
> - *affirms life and regards dying as a normal process;*
> - *intends neither to hasten or postpone death;*
> - *integrates the psychological and spiritual aspects of patient care;*
> - *offers a support system to help patients live as actively as possible until death;*
> - *offers a support system to help the family cope during the patients illness and in their own bereavement;*
> - *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*

- *will enhance quality of life, and may also positively influence the course of illness;*

- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*[i]

This definition has been adopted by Palliative Care Australia.[ii] Palliative Care Australia is an incorporated body whose members are the eight state and territory palliative care associations, including Palliative Care Victoria, as well as the Australian and New Zealand Society of Palliative Medicine. The membership of those associations includes palliative care service providers, clinicians, allied health professionals, academics, consumers and members of the general community.[iii]

All the elements of this definition are important in considering the provision of palliative care in Victoria.

Palliative care is not limited to pain control. It also addresses other distressing symptoms, including physical symptoms such as nausea and incontinence, as well as psychological, social and spiritual matters.

Palliative care takes into account the patient's family as well as the patient. It focuses on the need to provide support systems both to "*to help patients live as actively as possible until death*" and "*to help the family cope during the patient's illness and in their own bereavement*".

The last bullet point in the definition makes it clear that palliative care is not limited to the relief of symptoms only after all therapeutic interventions have failed but should be initiated in conjunction with therapeutic interventions.

Recommendation 1:

In considering the provision of palliative care in Victoria all the elements of palliative care as defined by the World Health Organisation should be taken into account to ensure a broad and comprehensive approach to the funding and provision of palliative care.

To neither hasten nor postpone death: Euthanasia has no part in end of life care

One essential tenet of palliative care is to intend "*neither to hasten nor postpone death*".[iv]

Death is, of course, inevitable for all human beings.

Palliative care recognises that there is a point in the progression of many illnesses when therapeutic interventions are no longer justified as the burdens they impose are not proportionate to the likelihood of benefit to the patient in terms of prolonged life or cure from the illness.

The WHO definition does acknowledge that, while directed primarily at improving the quality of life, palliative care may also "*positively influence the course of illness*".

For example, contrary to popular belief that the use of morphine to control pain is likely to hasten death, "*Research findings suggest that aggressive pain management at the end of life does not necessarily shorten life, but rather pain management may be life-prolonging by decreasing the systemic effects of uncontrolled pain that can compromise vital organ function*".[v]

Palliative care aims at helping "*patients live as actively as possible until death*". It rejects the notion that hastening death through active measures such as a lethal injection or sedation combined with dehydration is an appropriate response to end of life issues.

In considering the provision of palliative care, and end of life care in Victoria, it should be very clear that proposals for the provision of euthanasia and assisted suicide are outside the scope of palliative care and contrary to its philosophy and practice. Attempts to blur the distinction between palliative care and euthanasia should be exposed and rejected.

For example, the use of palliative sedation – where various degrees of unconsciousness are induced in order to deal with refractory symptoms – should be distinguished from an intentional ending of a patient's life by permanent sedation combined with cessation of hydration and nutrition.[vi]

> ***Recommendation 2:***
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> ***In considering the provision of palliative care in Victoria the tenet of palliative care "to intend neither to hasten nor postpone death" should be understood as excluding all forms of euthanasia and assisted suicide. Palliative care <u>does not include</u> any measures which are intended to hasten death or directly end the life of the patient, including permanent sedation with cessation of hydration and nutrition.***

Legislators have no right to legalise patient killing

Proposals to legalise any form of assisted suicide or euthanasia necessarily involve the threshold question of whether our election to Parliament gives us the right to sanction the killing of other human beings (putting aside circumstances such as self-defence or the defence of the nation). This is not a difficult question. The answer is simple: We do not have the right to sanction the killing of our fellow human beings.

Recommendation 3:

Any proposals for legalising assisted suicide or euthanasia should be firmly rejected as beyond the right of legislators: there is no right to make a fundamentally wrong law.

Advanced care planning

Advanced care planning can play an important role in ensuring that patient's preferences for treatment and care are respected even after they become incompetent in communicating these preferences.

However, It is important to acknowledge the inherent difficulties of advanced care plans and avoid legislation or policy practice that interprets preferences expressed in such plans as binding directives which would prevent medical practitioners and other health care providers from acting in accord with good medical practice and in the patient's best interests.

The Law Reform Commission of Western Australia pointed out the deficiencies of an advanced health directive: *"[T]he fundamental difficulty [is] that it prescribes a form of medical treatment without knowing the precise circumstances which would exist when the directive is required to be used. Therefore it is likely to be either too specific, failing to cover all circumstances, or too general, causing interpretative problems*."[vii]

This and other problems with advanced health directives are confirmed in the landmark paper examining the extensive experience with such directives in the United States by Angela Fagerlin and Carl E.Schneider.[viii]

> *[P]eople 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 … [D]rafters 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.*
>
> *… [L]iving wills seem not to increase the accuracy with which surrogates identify patients' preferences. And the reasons we surveyed when we explained why living wills do not affect patients' care suggest that these problems are insurmountable.*[ix]

Consent to medical treatment is not held to be legally valid unless an appropriately qualified medical practitioner has explained to the patient the nature and purpose of the treatment, as well as any risks or side effects, and what alternatives are available. It is simply not

possible to ensure that a person completing an advanced health directive is adequately informed before signing it.

Fagerlin and Schneider write:

> *Nor do people reliably know enough about illnesses and treatments to make prospective life-or-death decisions about them … For such information, people must rely on doctors. But doctors convey that information wretchedly even to competent patients making contemporaneous decisions.*
>
> *Living wills can be executed without even consulting a doctor, and when doctors are consulted, the conversations are ordinarily short, vague, and tendentious. In the Tulsky study, for example, doctors only described either 'dire scenarios . . . in which few people, terminally ill or otherwise, would want treatment' or 'situations in which patients could recover with proper treatment.*[x]

Section 103 of Queensland's *Powers of Attorney Act 1998* usefully provides that a health professional is protected from liability for departing from a direction given in an advance health directive:

> *(a) if a health provider has reasonable grounds to believe that a direction is uncertain;*
>
> *(b) if a health provider has reasonable grounds to believe that a direction is inconsistent with good medical practice; or*
>
> *(c) if a health provider has reasonable grounds to believe that circumstances, including advances in medical science, have changed to the extent that the terms of the direction are inappropriate.*

These are all appropriate conditions for a protection for liability and help ensure that advanced health directives, which can be a useful guide to a person's preferences for health care treatment, are not inappropriately applied in ways that could be contrary to the person's actual intentions or that violate good medical practice.

Provisions in Western Australian law[xi] contain a useful requirement for health providers to consider certain matters before putting an advanced health directive into effect in order to determine:

> *if circumstances exist or have arisen that —*
>
> > *(a) the maker of that directive would not have reasonably anticipated at the time of making the directive; and*
> >
> > *(b) would have caused a reasonable person in the maker's position to have changed his or her mind about the treatment decision.*

These matters include:

> *(a) the maker's age at the time the directive was made and at the time the treatment decision would otherwise operate;*
>
> *(b) the period that has elapsed between those times;*
>
> *(c) whether the maker reviewed the treatment decision at any time during that period and, if so, the period that has elapsed between the time of the last such review and the time at which the treatment decision would otherwise operate;*
>
> *(d) the nature of the condition for which the maker needs treatment, the nature of that treatment and the consequences of providing and not providing that treatment.*

Victoria should consider incorporating similar elements in its law.

> ***Recommendation 4:***
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> ***Victoria's Medical Treatment Act 1988 should be reviewed in the light of the established problems with binding advanced directives and modified to make such directives advisory rather than absolutely binding.***

Choosing where to die

For some of us death will come suddenly and we will simply have no choice about where to die. For many of us we will have more warning of our impending death and time to prepare and make decisions about where we would prefer to be when we die, and during the last days of our lives leading up to death. Increasingly people in these circumstances are expressing a preference for dying at home, in familiar surroundings, provided this can be achieved without an undue burden on their family and loved ones.

The recent report from the Victorian Auditor General on Palliative Care 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.*[xii]
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> *In 2012–13, 67 per cent of people who died in the care of a Victorian community palliative care service recorded their preferred place of death. The majority indicated they would prefer to die at home, however, only half were able to do so.*

As the health care profession gets better at discussing death, and models of health care allow patients to have a greater role in decision-making, it is likely that there will be growing demand for palliative care to be managed in the home.

In its Strategic Directions, DHHS committed to modelling demand for palliative care and developing a business case to support the sector to cope with a growth in service need. This has not yet occurred. However, it did recently hold a forum to discuss options for a new policy framework to succeed the Strategic Directions. DHHS' early feedback from palliative care representatives suggests that the sector is ready to aim higher and is interested in exploring how to measure the impact of its activities by focusing more on reporting patient outcomes. An example would be to report on how much time patients were able to spend in their place of choice prior to dying, rather than just recording the percentage of patients who actually died in a specific place. The modelling and new policy will be critical to help the sector better manage and coordinate existing resources, and to build the case for gradually expanding services and attracting more skilled professionals to palliative care.

Given that some community palliative care services are struggling to accommodate people within appropriate time frames, it is timely for DHHS to review the funding model, which has remained largely unchanged for 10 years. [xiii]

Naturally improvements in home based palliative care will require adequate funding.

Recommendation 5:

The recommendation of the Victorian Auditor General that there be a review of the funding model for palliative care services in Victoria, particularly with a view to enhancing home based palliative care to enable all those who would prefer to spend their last days at home to do so, should be strongly supported.

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i. http://www.who.int/cancer/palliative/definition/en/

ii. *Palliative and end of life care: Glossary of terms*, Palliative Care Australia, 2008, p. 11, http://www.palliativecare.org.au/Portals/46/docs/publications/PCA%20Glossary.pdf

iii. http://www.palliativecare.org.au/

iv. http://www.who.int/cancer/palliative/definition/en/

v. Mularski, R.A. et al. "Pain Management Within the Palliative and End-of-Life Care Experience in the ICU", *Chest*, 2009,135:1360-1369, p. 1364, http://chestjournal.chestpubs.org/content/135/5/1360.full.pdf+html

vi. Ibid. p. 1365

vii Medical Treatment for the Dying: Discussion Paper, p.13 at: http://www.health.wa.gov.au/publications/documents/Medical%20Treatment%20for%20the%20Dying%20Discussion%20Paper%20May%202005.pdf

viii Fagerlin A and Schneider CF, ""Enough: the failure of the living will" ", *Hasting Centre Report* , March-April 2004, p. 30-42 http://www.thehastingscenter.org/Pdf/Publications/Hcr_Mar_Apr_2004_Enough.Pdf

ix. Ibid., p. 38

x. Ibid., p. 33 citing J.A. Tulsky et al., "Opening the Black Box: How Do Physicians Communicate about Advance Directives?" *Annals of Internal Medicine* 129 (1998): 441-444.

xi. *Guardianship and Administration Act 1990,* s 110S(3)-(4)

xii. Victorian Auditor-General, *Palliative Care*, Apr 2015, p. vii, http://www.audit.vic.gov.au/publications/20150415-Palliative-care/20150415-Palliative-care.pdf

xiii. Ibid. p.17-18