June 30, 2015

Re: Legal and Social Committee Inquiry into End-of-Life Choices

Dear Ms Topic,

Please accept the following submission from Lives Worth Living (LWL) to the End-of-Life Inquiry of the Victorian Parliament.

Please note that LWL wishes the submission to be publicly available for reading.

I look forward to having an opportunity to speak before the Committee in support of this submission.

Yours faithfully,

Daniel Pask
LIVES WORTH LIVING.
Who We Are

Lives Worth Living (LWL) is a network of senior disability rights advocates with concerns about euthanasia and eugenics. We are not a religious group or a pro-life lobby group. Our submission to this enquiry is based secular human rights. We are all people with disability.

LWL supports the National Disability Insurance Scheme (NDIS) and the difference it will make to the lives of people with disability. However, some disabilities, such as dementia, whose onset is typically seen close to what is considered the end of life, are currently not well supported by the NDIS. This lack of support may lead to extra costs being incurred by governments to provide treatment and care. Consequently, a risk to people with dementia, their lives being considered too costly to sustain, exists. NDIS support cuts out at the age of 65, leaving ageing people with disabilities vulnerable.

We believe that legislation must closely attend to the UN Convention on the Rights of People with Disabilities, which has been ratified by Australia.

LWL believes that there is a need for more considered national work on a range of issues at the health/disability interface and to harmonise these to avoid the risk of different human rights outcomes based on where people live and how they experience disability. This work should include the adoption of a National Position on Eugenics and Biotechnology by all Australian First Ministers, including in the State of Victoria, covering issues which ensue from Article 10 of the UN Convention\(^1\), which assumes particular importance at the end of life.

International Experience

While acknowledging that the terms of this inquiry cover issues broader than euthanasia and assisted suicide, LWL must point to overseas evidence from Dr. Theo Boer, of the Netherlands where euthanasia has been legal since 2002. Speaking at an international euthanasia and assisted suicide symposium held in Australia recently, Dr Boer pointed out that since 2007, there has been an annual rise in cases of up to 15%, with such numbers being increasingly inclusive of dementia patients. Boer observes that euthanasia is becoming the default way to die for many despite the availability of high-quality palliative care. LWL believes this is a path down which Victoria ought not to travel.

LWL has grave concerns based on the evidence of international experience in Belgium and the Netherlands and that legislation intended to apply only to those who are terminally ill, via a process of legal interpretation, testing by individuals and human error, comes to apply to an alarming range of people, with or without their explicit consent.

LWL believes bills to legalise euthanasia or assisted suicide directly contravene the rights of people with disabilities, as enshrined in Article 10. People with disabilities at the end of life are especially

\(^1\) Article 10 - Right to life: States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.
vulnerable to notions that we are burdensome, and susceptible to discrimination and abuse by family members, members of the medical profession, carers and others.

**Concerns About Terminology and Types of Disabling Impairments**

LWL expresses great concern with the use of terminology such as “terminal” in bills and legislation pertaining to end-of-life issues. Some impairments causing disability also have the effect of lowering the life-span that a person might otherwise be expected to enjoy, while not directly leading to or causing death itself. LWL is concerned that bills or legislation may be applied to persons whose actions they were never intended to determine, with potentially tragic consequences.

Some people with communication disorders experience great difficulty in making their end-of-life wishes known, placing their trust in selected family members or others with the ability to assist them to communicate. Erroneous assumptions are often made about quality of life of people with communication difficulties, without their express wishes being known or even sought. This places such people in a very vulnerable position, and urgent work is needed to ensure their well-being throughout their life-spans.

Greater work must be done to ensure Victorians with disabilities are able to physically access health facilities. Inaccessibility may lead to common complaints unrelated to disability, such as breast cancer go untreated until such conditions become terminal. The lack of accessible health facilities, and other barriers are forms of discrimination that may pressure people to consider options such as euthanasia or assisted suicide if they were made legally available.

Improving and maintaining access to palliative care facilities catering especially for people with disabilities would reduce the pressure on people to choose other options for the end of their lives, such as euthanasia or assisted suicide, should they become legally available.

**Concerns Regarding Palliative Care and Advance Care Directives**

LWL urges caution when promoting advance care directives and other similar documents to ensure the level and type of care people receive at the end of their lives. This, broadly, is because people have limited ability to accurately predict their emotional and behavioural reactions to future situations. Advance directives are promoted as an answer to the perceived problem of suffering and loss of autonomy. This fear, expressed especially about disability, also relates to the end of life.

Research shows that people’s attitudes only remain stable for a maximum of two years, and so, if an illness or disability preventing communication were to occur after two years of signing an advance care directive, it is likely that the preferences expressed therein will not be the person’s current wish.

Attitudes and preferences are mostly constructed “online”, and not from a stable set of values and priorities, which would help ensure quality decisions regarding the end of life. As with opinion polls, preferences regarding life-sustaining treatments can be altered by the way that questions soliciting

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preferences are framed, for example by including information about survival rates. This phenomenon may have tragic consequences.

Perceptions about patients’ the “will to live” fluctuate dramatically and frequently, in correlation to changes in their physical and emotional well-being. Will to live is not based on relatively stable assessment of medical conditions or overall happiness, but is very related to immediate sense of distress and discomfort. Many disabling impairments are episodic in nature, and thereby finding an optimum time to offer or make an advanced care directive, let alone euthanasia or assisted suicide, is fraught with difficulty. What may be unbearable one day, may become tolerable the next, yet people tend to imagine that events such as illness or disability will have a worse effect than when actually experienced. So this suggests that people would underestimate their desire for life-saving treatment in case of disability, or illness where the initial diagnosis is terminal.

People make advanced care directives based on vague or inaccurate information regarding the effects of disabilities or illness. This wrong information may stem from errors in media reports, family and friends’ experiences of disability, or via transfer of health-care professionals’ attitudes about disability, old age and so on. It is vital that measures be taken to ensure people making decisions regarding end of life care because they face the prospect of disability, or have an illness which may lead to progressive levels of disability, are provided accurate, up-to-date information. Review of instructions in advance care directives should be mandatory at intervals that take individuals’ attitudinal change into account.

It is very important to acknowledge that people making advance care directives fear not only their own potential inability to make quality decisions during treatment or following disability, based on inaccurate predictions of their wants, conditions’ effects and the like. They also have much to fear from the irrationality of others to whom they have entrusted their care, such as relatives, medical professionals and workers in institutions where they may be living. Great difficulty arises when people have communication disorders or difficulties to begin with, relying on selected individuals to convey their end-of-life wishes. Such people, and indeed others with different types of disability, become very vulnerable, and would be imperilled should euthanasia ever be legalised in Victoria.

Loneliness, depression and isolation

Efforts to alleviate sheer loneliness and isolation, prevalent among people reaching the end of life, and exacerbated by disability, must continue in order to prevent people from depression and despair. While these were once accepted as “safeguards” against being accepted for euthanasia or assisted suicide, a series of cases overseas demonstrates that they have now become acceptable reasons for being euthanized. LWL calls on the Victorian government to establish more tailored psychological services for people with disabilities, in order to prevent and treat depression and related conditions, especially at the end of life.

Conclusion

The above submission outlines a number of deeply concerning aspects of End-of-Life care as it pertains to people with disabilities. LWL believes that it is critical that the disability community is heard on this issue. In particular we stress the point that the Victorian Parliament strongly resist bills to legalise either euthanasia or assisted suicide while people with disabilities continue to face discrimination from a wide variety of sources, including the medical profession. We should not be
faced with questions regarding dying with “dignity” while conditions make it so difficult for people with disabilities to live in a dignified way. Many members of LWL have personal anecdotes to tell which are very enlightening with regards to the issues that face people with disabilities at times in their lives that bring concerns about the end of life into sharp relief. We would be happy to supply these via a representative attending a hearing in Melbourne to give testimony, in order to elaborate on LWL’s submission.