From:	
To:	LSIC
Subject:	Submission to Parliamentary Inquiry into End of Life Choices
Date:	Monday, 31 August 2015 4:27:49 PM
Attachments:	Inquiry_End_Life_Choices_v2.4.pdf ATT00001.htm Inquiry_End_Life_Choices_v2.4.docx ATT00002.htm One in 10 dementia carers think about killing a loved one study.pdf ATT00003.htm

---

Dear Lilian

Re: Submission to Parliamentary Inquiry into End of Life Choices

Please find enclosed my submission to the above Inquiry. I have provided it in both PDF and Word versions, and have provided Appendix A as a separate PDF attachment.

Any queries please don't hesitate to get in touch.

With kind regards

Liz Burton

PARLIAMENT OF VICTORIA

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES (Legislation and References)

END OF LIFE CHOICES INQUIRY

SUBMISSION FROM LIZ BURTON

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

The Committee is invited to take into account during its deliberations the matters delineated below relating to items 2 and 3 of its Terms of Reference together with comments on the Inquiry process regarding public consultation.

1. COMMENTS ON PUBLIC CONSULTATION PROCESS

1.1 Consultation process and scope

It is considered that the current process to review end of life choices including the invitation to the public for submissions would have benefited from one or more consultation reports outlining the arguments for and against the proposition to allow such choices.

For example the Victorian Law Reform Commission in its review of Succession Laws in 2013 prepared a number of consultation papers that allowed prospective respondents to inform themselves of the issues concerning the law of succession. This meant that respondents could assist the Commission with providing an informed response.

In the case of the End of Life Choices Inquiry the absence of consultation reports is considered contentious as it enables emotive responses to an emotive proposition rather than responses based on consideration of the major issues and implications to a departure from the current law. Soliciting responses that are made without the benefit of an informed assessment of the key issues may result in suboptimal outcomes by the Parliamentary Inquiry.

1.1.1 Recommendation

Accordingly it is recommended that the Committee either:

(a) refers the review process to the Victorian Law Reform Commission for consideration and recommendation; or

(b) prepares consultation papers outlining the full range of issues associated with a significant changes to the law and refers them to the public for a further round of consultation before the Committee prepares its final report and recommendations.

1.2 Responses from the public may not reflect ethnic diversity

It is important to note that Victoria has an extensive ethnic diversity in its population mix but that the names of submitters as reflected on the Submissions page of the Committee's website does not appear to reflect the extent of ethnic diversity. Concern

is expressed that their views are not taken into account by the Committee in a process seeking submissions from people who are aware of the Inquiry.

1.2.1 Recommendation

Accordingly it is recommended that Members of Parliament be mandated to undertake full consultation with their electorates on this topic and to provide written input to the Committee. Consultation with electorates needs to be through an invitation to those on the State electoral roll to a formal meeting on the topic.

1.3 Committee Inquiry website

It is recommended that the Committee's website on the Inquiry include provision for individuals to provide their email address to receive updates on the subject concerning the Committee's progress on deliberations and current status of any Bill.

2. INTRODUCTION

In considering whether or not to recommend the introduction of end of life choices, an evaluation is needed of the benefits to individuals from legislative provision to allow termination of life, in relation to documented evidence of abuse of such provision whereby individuals' lives are ended without their consent for self interest.

Consideration is needed as to whether society at large benefits from an increase in cases of abuse by people taking advantage of such provisions for personal gain or whether it is considered that medical intervention is sufficient for the vast majority of treatments.

3. ITEM 2 OF COMMITTEE'S TERMS OF REFERENCE:

REVIEW OF CURRENT FRAMEWORK OF LEGISLATION, PROPOSED LEGISLATION AND OTHER RELEVANT REPORTS AND MATERIALS

3.1 Magnitude of the legislative changes contemplated regarding introduction of end of life choices

Current State laws prohibit the wilful ending of human life either through the assistance of other people such as medical professionals or by the individual undertaking self-administration. This has been in place since the founding of Australia in 1788. The magnitude of the legislative changes and therefore of social change contemplated by this review of the current legislative framework to enable end of life choices cannot be underestimated.

3.2 Influence of lobby groups and superficial polling

Concern is expressed over the influence exerted on State government by various lobby groups advocating the introduction of end of life legislation and over superficial polling that may suggest strong support. The basis of this concern relates to the lack of consideration of the full range of issues that would impact on individuals as a direct consequence of the introduction of legislation enabling end of life procedures.

It is essential that philosophical principles are applied to the Committee's deliberations to avoid expediency and the influence of specific groups whose lobbying is based on a silo approach, simplifying the issues and insinuating themselves as representing the majority view on the subject.

3.3 Collateral damage

Dying with dignity is a term often used by advocates for introducing end of life choices for humans but consideration needs to be given to collateral damage that may be facilitated through changes to laws currently protecting individuals from forced termination of their lives. Forced termination can take the form of subtle coercion from family or through corrupted formal assessment pathways.

Consideration needs to be given to unintended consequences and to collateral damage to sections of the community who are vulnerable and/or who are formally under the guardianship of individuals who may benefit from their estate.

3.4 Protection for individuals under formal guardianship provisions

Protection needs to be included in the case of persons who are under formal guardianship provisions, irrespective of whether or not they are under State Guardianship provisions, to ensure that they cannot be subjected to end of life legislation. Individuals under guardianship provisions fall into three main categories: (a) those who have always had diminished responsibility and have never been capable of self determination; (b) those who were capable of self determination but who later became incapable; and (c) those who are temporarily under guardianship (for example individuals who were otherwise well but are temporarily incapacitated from a medical event such as stroke) and who are expected to recover.

There is considerable disquiet in the community about the potential for exploitation of assisted suicide/voluntary euthanasia laws particularly in the case of older citizens and the vulnerable. Various forms of elder abuse are extensively documented as an ongoing feature of the Australian community and these include:

- Financial elder abuse (example: State Trustees website on financial elder abuse at https://www.statetrustees.com.au/community/financial-elder-abuse/) and
- A spectrum of mistreatment including neglect, inadequate care and various forms of physical and emotional abuse demonstrating evidence of the potential for exploitation of end of life choices benefiting not the affected individual but their relatives and/or parties such as formal guardians who stand to benefit (example: Victorian Department of Health Elder Abuse Prevention and Response Guidelines for action 2012-14 at http://www.health.vic.gov.au/agedcare/downloads/pdf/eap_guidelines.pdf).

Any changes to existing laws need to ensure that they do not facilitate collateral damage in the form of providing the opportunity for:

- pressure from family members on the elderly and vulnerable to agree to end their life under end of life choice so as to remove the burden of duty of care from their relatives; and/or
- applying end of life legislation to release the estate of affected individuals to beneficiaries earlier than might otherwise be the case; and/or
- formal guardians to exploit end of life legislation that allows them to act on behalf of the affected individual to end their life in circumstances where they would not want it ended and where the guardian stands to benefit; and/or

- corruption and bribery of professionals to approve end of life in circumstances where the individual would not want it ended and where those representing or acting on their behalf would benefit.

3.4.1 Recommendation:

It is essential to address these issues through the establishment of:
(a) international best practice formal procedures; and
(b) associated criminal charges in relevant laws against perpetrators.

In relation to (a) it is recommended that individuals who reject participation in end of life legislation have a process available to them to formally register themselves with the State as non participants. This process should use a similar system to the passport application process requiring: (a) an official form, (b) full documentation of their identity, (c) a photo at the time of the request, (d) specified categories of witnesses to their request and (e) lodgement of the form with the relevant Government department (recommended as being the Attorney General's Department).

3.5 Recognition of self-seeking motives to end lives of others

Self-seeking motives to end the lives of others are a recognised element in the introduction of laws allowing assisted suicide or self administered suicide and attempts to avoid such deaths are built into the legal framework in countries where such laws have been enacted. Measures to attempt to ensure that the individual is making the decision without coercion include preventing assisted suicide by making it illegal for doctors to both prescribe and hand over a lethal drug (Germany and Switzerland), although both of these countries allow assisted suicide under certain circumstances.

In Oregon, USA assisted suicide was legislated in 1997 and allows for terminally ill, mentally competent patients with less than six months to live to request a prescription for life-ending medication. Since then, Washington state and Vermont have enacted legislation based on the Oregon model.

3.6 Increase in human life span and diseases affecting the elderly

As life spans increase, illnesses affecting independence such as varying forms of dementia and impacts from stroke and chronic diseases affect higher proportions of the population. Families, carers and the health system are impacted and the literature has documented extensively the issues associated with elder abuse. See Appendix A for recent article from Sydney Morning Herald entitled "One in 10 dementia carers think about killing a loved one: study".[1]

It is essential that any legislation allowing human lives to be terminated is based on the considered and documented determination of the individual and does not allow the decision to be made by other parties. This includes cases where the individual is comatose or otherwise mentally incapable. This

The legal system does not have the funding to monitor and prosecute all cases where individuals' lives have been terminated without their consent and it is argued that

[1] "One in 10 dementia carers think about killing a loved one: study". Sydney Morning Herald, July 22, 2015

society overall does not benefit from a system that allows lives to be terminated without the voluntary consent of the individual.

Accordingly it is considered that any end of life legislation must be based on voluntary participation and consent and not decided by other parties on behalf of the individual, under any circumstances.

3.6.1 Recommendation

That any introduction of end of life choices legislation be restricted to the Oregon, USA model allowing terminally ill, mentally competent patients with less than six months to live, to request a prescription for life-ending medication.

3.6.2 Further recommendation

The Committee's attention is drawn to Submission 588 "Doctors opposed to euthanasia" regarding the clinical and legal issues experienced in jurisdictions where end of life choices have been enacted.

3.7 Mandatory minimum sentencing

A corollary of any end of life legislation needs to be laws prescribing mandatory minimum sentencing for people who end the lives of others using end of life legal provisions as a pretext.

3.7.1 Recommendation

That the Committee includes consideration of recommending laws prescribing mandatory minimum sentencing for people involved in terminating the lives of others for self seeking motives, whether directly or indirectly.

4. ITEM 3 OF COMMITTEE'S TERMS OF REFERENCE:

CONSIDER WHAT TYPE OF LEGISLATIVE CHANGE MAY BE REQUIRED INCLUDING AN EXAMINATION OF ANY FEDERAL LAWS THAT MAY IMPACT SUCH LEGISLATION

4.1 Implications regarding Victorian Wills Act 1997 and the Administration and Probate Act 1958

In the history of legislation concerning wills and the Administration and Probate Act, voluntary euthanasia has never been permitted by the State. Accordingly wills are considered after death. Laws allowing voluntary euthanasia have been enacted in a number of countries and in Australia, consideration was given by the Tasmanian Government through the introduction of a Bill by the Greens but was defeated. With the possibility of the introduction of such laws in Victoria, it is considered that this form of death, the date of which is determined by the individual, has implications for wills and their administration.

Individuals who determine the date of their own death ought to be able to settle their will in advance of their death. In particular, if they have grounds to believe that their will might be contested, they ought to be able to apply to the Court for a hearing to have the case considered and determined before their death.

The advantage of this procedure is that the individual who made the will would have the opportunity for a hearing at Court and to address the case made by person/s contesting it. The outcome would need to be binding on all parties.

4.1.1 Recommendation

It is recommended that as a corollary to the introduction of any legislation allowing end of life choices that the Victorian Wills Act 1997 and the Administration and Probate Act 1958 be amended to allow end of life participants to have their wills administered and their estate disbursed in advance of their death.

The Sydney Morning Herald

Appendix A

One in 10 dementia carers think about killing a loved one: study

Amy Corderoy
Published: July 22, 2015 - 4:58PM

"It's tiring, it's exhausting, it's never-ending. It just got to the point that I was just thinking it would be so much easier if it was all over," says Sandra* of the nearly 15 years she spent caring for her father at home.

He had Alzheimer's disease, and in the whole time he lived with her she had only one night away from him.

Sandra is among the many carers who hide what they feel is an unspeakable secret: they have wished their loved one were no longer living.

The first-ever study into the phenomenon has found high levels of distress among carers, with some actively contemplating killing the very person they are dedicating their life to.

Alzheimer's Australia says not enough is being done for the 70 per cent of people with the condition who live in the community and their carers, with a huge shortage of carers looming for people suffering from the common condition.

Study leader Siobhan O'Dwyer from Griffith University's Menzies Health Institute Queensland, said carers were under incredible pressure and often had no one to speak to about their feelings.

"I think this really reflects how trapped people are in this role, how isolated they are and the lack of support for these roles," she said.

The study, published in the journal *Aging and Mental Health*, found that almost 20 per cent of the carers interviewed had verbally or physically abused the person they were caring for, while the same number had wished their family member dead. Another two of the group's 21 participants had actively thought about how they might kill their loved one.

"None of them had actually shared these experiences or thoughts before they talked to us," Dr O'Dwyer said. "Most people tell us, particularly in the context of dementia, that once the person is diagnosed other family members drop away, friends don't stay involved… we need GPs and social workers and psychologists to be asking these questions and actually listening to the answers they are given."

She said while it was largely women in her study who reported thinking about the death of their loved one, the majority of murder-suicides committed among older people were committed by men.

"What we think that means is that women might report more thoughts, but men might be more likely to just go ahead and act," she said. "If we wait for these men to tell us it might be too

late."

She said violence by carers typically occurred in response to a crisis, without the usual behaviour and thought patterns associated with domestic violence perpetrators.

Carol Bennett, the chief executive of Alzheimer's Australia, said the results were very concerning.

"We know there is a significant issue with elder abuse," she said. "Managing some of the symptoms of dementia can become very complex, particularly as the condition progresses."

Ms Bennett said organisations such as hers were overwhelmed with requests for support and resources in the community, with 1.2 million Australians already caring for someone with dementia.

"We know there is going to be a shortage of 150,000 paid and unpaid carers by 2029," she said.

Sandra said she can understand why people might begin to think about killing the person they were caring for.

While for many years she had lots of good days, it was towards the end, when her father refused to eat, that she began to feel like it would be better if he died.

"Even being a nurse, I didn't realise how hard it would be [on myself] for someone to just refuse to eat. He would just clamp his mouth shut and no amount of coaxing would work.

"It was pretty awful. I felt helpless, and it was almost like on some level he was trying his best not to be here."

Sandra says more in-home respite care that allows a person to be looked after without disturbing their routine is vital for carers.

"It's 24-7, and there is little relief," she said.

* name changed.

This story was found at: ***http://www.smh.com.au/national/health/one-in-10-dementia-carers-think-about-killing-a-loved-one-study-20150722-gii5fw.html***