



End of Life Choice Bill – Supplementary Submission

Introduction

Alzheimers New Zealand does not support the *End of Life Choice Bill*. We have concluded that our original submission was not clear enough. The purpose of this submission is to clarify our position.

Alzheimers New Zealand considers this Bill to be a weak piece of draft legislation; poor at protecting the interests of New Zealanders; and, detrimental to people's dignity and wellbeing.

These three issues are summarised below.

1. Weak draft legislation

Crucial terms in the Bill are left undefined and are wide open to interpretation (Part 1, Section 4). For example:

a) *Grievous and irremediable medical condition*

When is a condition 'grievous and irremediable'? What makes a condition grievous? The term is vague, very subjective, and with enormous scope for interpretation. Conditions which are irremediable now may well be easily treated in the future.

b) *Advanced*

At what point does a condition become 'advanced'?

c) *Irreversible decline in capability*

When is a condition deemed irreversible? Do we not all share an 'irreversible decline in capability' as we age? Who, after the middle years of life, is not in an advanced state of irreversible decline in capability?

d) *Unbearable suffering*

How do we know if someone is experiencing 'unbearable suffering'? What constitutes unbearable? Is it physical, mental, emotional, spiritual, existential or a combination of all or some of the above? Can fear for the future or a sense of hopelessness be conflated to mean 'unbearable suffering'?

e) *Cannot be relieved*

What is the timeframe envisaged for 'cannot be relieved'? At what point do we know suffering cannot be relieved? What threshold of relief is required?

f) *A manner that he/she considers tolerable*

What constitutes 'tolerable'? What is or is not tolerable is highly subjective, and may change from day to day, or even from hour to hour.

2. Poor protection for New Zealanders

Weak safeguards

a) *Lack of 'cooling off' period*

There appears to be no requirement for a mandated period of time to pass following the initial request.

The only requisite time period for reconsideration appears to be the period which elapses between the registrar being satisfied required processes have been complied with, and the medical practitioner obtaining the prescription (15 (4)). This could be very short.

It means those with low mood could easily make irreversible decisions without any reasonable opportunity for balanced consideration. Given that depression is a frequent part of people's response to facing their own death, there is considerable danger of people seeking choices which they would later rescind if rescinding was still an option and they were no longer in a depressed state.

b) *Two medical practitioners may provide poor protection*

Two medical practitioners agreeing a person meets the specified criteria for

assisted dying (sections 10 and 11) may provide few safeguards in practice. It is possible specific doctors will make provision of euthanasia a core part of their activities with little knowledge of the patient involved.

c) Pressure on vulnerable people to end their lives

Vulnerable people can easily believe they are a burden. They may encounter subtle or overt emotional, social, and economic pressure from those around them to end their lives. Alternatively, they themselves may worry they are a burden on family/whānau, care-partners and society. Subtle rather than overt pressure is not likely to be evident to attending medical professionals.

d) A new normal?

Pressure to end one's life could increase as euthanasia becomes an increasingly common occurrence. Overseas evidence shows assisted deaths in the [Netherlands have increased by 317% since 2006](#). In 1990, 1.7% of all deaths in that country were the result of euthanasia; by 2015, [the percentage was 4.5%](#).

Competency issues

The Bill defines competence as 'the ability to understand the nature of assisted dying; and the consequences for him or her of assisted dying' (section 4f), and nothing more than that. The definition is simple; however, the resulting issues are more complex:

a) Nature of tests for mental capacity

We understand absolute tests for mental capacity are either open to question or do not exist. People who appear to be mentally competent may still struggle to make good and safe decisions. Certainly, the Bill is silent on any tools which may be used to assess competence.

b) People's ability to understand (be competent) can vary over time from complete to non-existent

Ability to understand can be affected by stress, context, the way messages are delivered, fear, lack of self-confidence, underlying medical conditions,

and an array of other internal and external factors. We note that there is no requirement for the two attending medical practitioners to determine whether the person has a mental and/or physical health condition which may affect their judgement or decision-making.

Assessment of competence can also be impacted by prior assumptions, stigma and discrimination.

c) Fears about competence loss could result in premature decisions to end one's life

In the dementia area, fear of competence loss, the desire not to be a burden, and stigma and discrimination about the nature of dementia could collectively induce people with dementia to request assisted suicide. Given the Bill's vague definitions discussed earlier, this request could feasibly occur during what is commonly regarded as active life.

d) Competence definition may provide little protection for vulnerable individuals

The possibility of a small number of physicians making euthanasia their core business could result in people/ families seeking out doctors to facilitate an easy path to ending the lives of 'inconvenient' relatives. The doctors may know the patient for a very short time, make use of a low threshold for competence, and not recognise subtle coercion involved.

e) Temporarily or partially impaired individuals are also at risk

The vague definition of competence coupled with the lack of a reasonable cooling off period provides little protection for those who are temporarily or partially impaired. Such people may meet a low standard for ongoing competence despite competence being largely absent much of the time.

3. Dignity is absent from this Bill

The End of Life Choice debate is often couched in discussions about dignity and assisted dying is presented as the solution to maintaining dignity. We all face disabilities (physical, mental and/or cognitive) as we age. Instead of seeing these

things as part of life, the discussion around the Bill conflates them with a loss of dignity which is therefore undesirable, and logically must be avoided.

The subtle or overt message is that, rather than being part of life, the disabilities of age are tragic occurrences to be pitied, avoided, or nullified. Life is deemed unacceptable and assisted suicide is presented as the solution.

This is despite anecdotal evidence, academic research, dementia consumer groups, care partners and health professionals both in New Zealand and internationally showing that while some people with dementia find their lives unacceptable, this is not true for most. People with disabilities, including those with dementia, can live well with the right support and assistance:

“I can reassure you that, however it may feel at the beginning, it is still possible to live a life of quality with dementia. Not the life you had before, perhaps, but a life full of promise...” Person with dementia

If the End of Life Choice debate was truly about dignity, it would include discussion about how people live now, and social attitudes and services urgently needed to help people to live well. This is largely absent in the current discussions about the Bill.

If our society was truly serious about the dignity of people with dementia, and those with ‘grievous irremediable conditions’, it would take seriously the knowledge that with the right services and palliative care people can maintain their dignity, have their symptoms managed and live well until their death.

Conclusion

New Zealanders lives are not assisted by a weak piece of legislation with vague provisions and which is open to abuse. The urgent priority is for people living with conditions such as dementia to be able to access the support and services to enable them to live well. **Alzheimers New Zealand recommends that this Bill does not proceed.**