



## Submission on End of Life Choice Bill

### Executive Summary

- 1) **Alzheimers New Zealand neither supports nor opposes medically assisted dying.** Our submission addresses concerns about both the Bill as drafted, and the end of life context for people with dementia more generally.
- 2) Over 62,000 people have dementia and this number is forecast to triple by 2050. Family and friends are also affected by the diagnosis. Those affected by dementia must have a strong voice in the Select Committee's deliberations.
- 3) If the legislation is to proceed, shortcomings in two areas must be resolved. First, crucial concepts in the Bill are left undefined. Second, inadequate safeguards may put vulnerable people at risk.
- 4) Any legislation also needs to ensure all groups can exercise their human rights. Alzheimers New Zealand firmly believes that people with dementia must be able to enjoy equal recognition before the law together with all other New Zealand citizens. As drafted, it is difficult to envisage how the provisions of the Bill could be accessed by those with dementia, cognitive impairments or similar disabilities. Once such groups are left out, then it is highly likely this Bill contravenes the UN Convention on Rights of Persons with Disabilities.
- 5) Alzheimers New Zealand also believes *all* people are important, whatever their life stage and whatever their health status. The End of Life Choice Bill seeks to compassionately address unbearable pain and suffering via assisted dying. However, our country is also seeking to compassionately address unbearable pain and suffering and reduce suicide rates by reviewing mental health services and providing more and better assistance

for those at risk. There appears to be a significant contradiction here with one group's lives potentially being valued more highly than the other.

- 6) It is highly likely that many of the problems this Bill is seeking to address will be solved by ensuring we have quality end of life care. Alzheimers NZ firmly believes that if adequate services and resources were available most, though not all, people with dementia would not feel that medically-assisted dying was a preferable option (legal or not).

## **Our Organisation**

Alzheimers NZ ([www.alzheimers.org.nz](http://www.alzheimers.org.nz)) was established in 1986 and is the lead organisation at a national level representing people living with dementia. Our mission of achieving a dementia-friendly New Zealand means we focus on:

- Raising awareness of dementia and its impacts and supporting people with dementia to live well;
- Providing practical solutions to help build a dementia-friendly New Zealand;
- Providing information and resources that contribute to more informed decision-making by people living with dementia, and by policymakers;
- Building capability, readiness and resources within the dementia sector;
- Advocating for high quality services, including the need for more Government support to address the challenges posed by the rapid increase in the number of Kiwis with dementia (dementia is one of the biggest healthcare challenges facing New Zealand); and
- Promoting research about the prevention, treatment and cure for dementia, and the care and support of people affected by the condition.

## **Our Submission**

Thank you for the opportunity to comment on the End of Life Choice Bill. Alzheimers New Zealand believes that people living with dementia should have a strong voice as part of the Select Committee's deliberations.<sup>1</sup>

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<sup>1</sup> Use of 14-point font is part of helping to make the information in this submission accessible for people with a diagnosis of dementia

More than 62,000 people in our country currently have dementia and this number is set to triple by 2050. These numbers do not include the many family and friends who are also significantly affected.

*The Lancet* describes dementia as *the greatest global challenge for health and social care in the 21st century*.<sup>2</sup> It can affect anyone but is more prevalent as we age. Symptoms commonly include changes in memory, thinking, behaviour, personality, emotions, and the ability to perform everyday tasks. Dementia is progressive, terminal, and is individual; what people can do, remember, and understand may change from day to day. The needs and views of people affected by dementia are highly relevant to any legislation on assisted dying.

Those in favour of medically-assisted dying often cite people with dementia as amongst those who could take advantage of a change in legislation because they deteriorate slowly over many months or years and often have other complex health conditions. Those opposed to medically-assisted dying raise concerns about the vulnerability of people with dementia to making decisions in the early stages in response to real or imagined pressures, and that they may change their minds later. Both sides cite ethical, moral, spiritual, and existential concerns.

Unsurprisingly, people living with dementia hold a diversity of views.

Therefore, as an organisation, **we neither support nor oppose assisted dying**. People we have consulted see medically assisted dying as a complex issue with no easy answers. In addition, there has been no New Zealand research on the attitudes of people with dementia, their informal care partners, the public or health professionals specifically about medically-assisted dying for people with dementia.

While we neither support nor oppose medically assisted dying, we do have concerns about both the Bill as drafted, and the end of life context for people with dementia more generally. These issues and other concerns addressed in our submission are listed below:

- a) There are shortcomings in the draft legislation needing attention, if it does proceed;

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<sup>2</sup> [The Lancet Commission on Dementia Prevention](#) (2017)

- b) The legislation as written may breach our international human rights obligations;
- c) People with dementia must be able to enjoy equal recognition before the law together with all other New Zealand citizens;
- d) Better end of life care would solve many of the problems this legislation seeks to resolve; and
- e) People with dementia have a right to the type, quality, and volume of services to help them to live well.

A final issue concerns the context of the Bill. Alzheimers New Zealand believes *all* people are important, whatever their life stage and whatever their health status. The End of Life Choice Bill seeks to compassionately address unbearable pain and suffering via assisted dying. However, our country is also seeking to compassionately address unbearable pain and suffering and reduce suicide rates by reviewing mental health services and providing more and better assistance for those at risk. There appears to be a significant contradiction here with one group's lives potentially being valued more highly than the other.

### **Shortcomings in the Draft Legislation**

If the legislation is to proceed, shortcomings in two areas must be resolved. First, crucial concepts in the Bill are left undefined. Second, inadequate safeguards may put vulnerable people at risk.

### ***Definitions***

A number of words used in the Bill have a crucial impact on how it is interpreted and applied. Part 1, Section 4 of the Bill on eligibility for assisted dying requires individuals seeking such assistance to [italics added]:

- (a) Be 18 years or over
- (b) Meet the citizenship or residency criteria
- (c) (ii) Suffer from a *grievous and irremediable medical condition*
- (d) Be in an *advanced state of irreversible decline in capability*
- (e) Be experiencing *unbearable suffering which cannot be relieved in a manner that he/she considers tolerable*
- (f) *Have the ability to understand:*

- i. *The nature of assisted dying*
- ii. *The consequences for him / her of assisted dying*

The italicised terms in section 4 all have an impact on the interpretation of the Bill and are crucial for defining who is eligible for assisted dying and who is not. *None* of these essential terms are defined in the Bill:

- ***Grievous and irremediable medical condition*** – When is a condition grievous and irremediable? Is dementia a grievous condition? What makes a condition grievous?
- ***Advanced*** – At what point does a condition become advanced? Is habitually forgetting things an advanced condition or does someone need to be unable to care for themselves? Is someone unable to care for themselves necessarily in an advanced state of irreversible decline?
- ***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?
- ***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?
- ***Cannot be relieved*** – What is the timeframe envisaged? At what point do we know suffering cannot be relieved?
- ***A manner that he/ she considers tolerable*** - What constitutes *tolerable*? Is tolerability likely to change over time?

#### **Recommendation:**

Alzheimers NZ acknowledges the subjective nature of the terms: ***Grievous and irremediable medical condition; Advanced; Irreversible decline in capability; Unbearable suffering; Cannot be relieved; and A manner that he/ she considers tolerable.*** Despite the subjectivity, we recommend that these terms are clarified.

## ***Safeguards***

The safeguards built into this Bill appear to be weak. The need for two medical practitioners to agree the person meets the criteria for assisted dying (sections 10 and 11) may provide few safeguards in practice. We could have the situation where specific doctors make helping with medically assisted dying a core part of their activities with little knowledge of the patient.

A second problem is the risk that vulnerable people could sense they were a burden, emotionally, socially and economically and consequently might feel they need to end their lives so as not to be a burden on family/whānau, care-partners and society.

This pressure could increase as assisted dying becomes more of a 'norm' due to increasing numbers dying in this manner. There is evidence numbers are likely to increase, for example the number of assisted deaths in the Netherlands has increased by 317% since 2006.<sup>3</sup> In 1990, 1.7% of all deaths in that country were the result of euthanasia; by 2015, the percentage was 4.5%.<sup>4</sup>

Different countries apply different safeguards in different situations. Human euthanasia is legal in the Netherlands, Belgium, Colombia, Luxembourg and Canada. Assisted suicide is legal in Switzerland, Germany, Japan, and in the US states of Washington, Oregon, Colorado, Vermont, Montana, Washington DC, and California. Cancer is the most common (over 70%) reason for medically-assisted dying in these areas, and the safeguards used tend to be better suited to cancer than to dementia.

Safeguards used overseas include:

- i. The person seeking medically-assisted dying is certified as mentally competent and capable of making and communicating health care decisions for him/herself;
- ii. There is a "cooling off" period between diagnosis and a person being "permitted" medically-assisted dying;
- iii. The person makes the initial request for medically-assisted dying and then repeats this request over some period, for example three months later;

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<sup>3</sup> [European Institute of Bioethics 2017](#)

<sup>4</sup> [End-of-Life Decisions in the Netherlands over 25 Years](#) (2017)

- iv. The General Practitioner or other person who approves the request certifies that the person is not subject to any pressure to make that decision;
- v. The person seeking medically-assisted dying is advised by experts on the likely prognosis for their condition;
- vi. The person is fully advised of the potential of living wills and advance care planning to address their concerns;
- vii. The person advises their carers and family/whānau of their request;
- viii. The person and their family/whānau are fully informed of the range of medical and social supports, for example palliative care, that is available for them;
- ix. In some areas the person must be within a short period, usually six months, of death; and
- x. The person is physically and mentally capable of self-administering the aid-in-dying drug.

The New Zealand Bill includes (i), (iv), (v), possibly (vi), and possibly (viii).

### **Recommendations:**

**Alzheimers NZ recommends in the event Parliament decides to support End of Life Choice Bill, that:**

- **The legislation includes a “cooling off” period;**
- **The legislation is more specific about the potential of living wills and advance care planning to address concerns about end of life; and**
- **The person and their family/whānau is fully informed of the range of medical and social support, for example palliative care, that is available for them.**

### **Human Rights**

Any legislation needs to ensure all groups can access their human rights.

Alzheimers New Zealand is concerned that, as written, people with dementia would struggle to exercise their human rights under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

International human rights law requires that all people are born with the same set of rights and with the same freedom for self-determination.<sup>5</sup> This means *all* people, including people affected by dementia must be able to seek medically assisted dying if it becomes law.

The problem with the Bill is it is highly unlikely that a person with dementia who meets the criteria in 4 (c), (d) and (e), will also meet the criteria in (f). A person with dementia deemed to be suffering from a *grievous and irremediable medical condition*, and deemed to be in *advanced state of irreversible decline in capability*, and deemed to be experiencing *unbearable suffering which cannot be relieved in a manner that he/she considers tolerable* has probably also reached the stage where he /she no longer has *the ability to understand the nature of assisted dying or the consequences for him / her of assisted dying*.

We acknowledge that there are difficulties here, however, all New Zealand legislation must be consistent with the UNCRPD. Convention clauses which may be relevant to this legislation include:

- a) Freedom for people to make their own choices (Preamble)
- b) Freedom from discrimination (Preamble and Article 5)
- c) Equal recognition before the law (Article 12)
- d) Freedom from .... inhuman or degrading treatment (Article 15)
- e) Freedom from exploitation, violence and abuse (Article 16)
- f) Enjoyment of the highest standard of health care and, access to the *same range, quality, and standard of ... health care and programmes as provided to other persons* (Article 25) [emphasis Alzheimers NZ].

In summary, member states are required to *refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities act in conformity with the present convention* (Article 4) [emphasis Alzheimers NZ].

### **Recommendation:**

**Alzheimers New Zealand recommends that in the event Parliament decides to support End of Life Choice Bill, the legislation is consistent with our international human rights commitments, particularly the provisions of the**

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<sup>5</sup> Office for Disability Issues

## **United Nations Convention on the Rights of People with Disabilities (UNCRPD).**

### **Enabling People with Dementia to Enjoy Equal Recognition Before the Law**

Alzheimers NZ strongly believes that people affected by dementia have the same rights as any other citizen. Therefore, if the Parliament decides to support the End of Life Choice Bill, then people with dementia must have the same rights as any other citizen. However, safeguards must be included to protect vulnerable people who use the assisted dying provision.

Alzheimers New Zealand endorses the requirement for the person seeking medically assisted dying to be mentally competent at the time of decision-making, as is required in all countries permitting assisted dying (part 1, 4(f)). This would mean the word 'advanced' (Part 1, 4 9d) being interpreted to enable earlier decision making by people with dementia.

However, this does not solve the problem. Having to decide while still competent may mean people receive medically assisted dying earlier than they wish, because waiting risks competency loss. When competency is gone, then people are either left impotent or may experience medically assisted dying when they no longer wish it to occur.

Other countries have responded in different ways. The Netherlands, Luxembourg, and Belgium all explicitly accept dementia as grounds for medically-assisted dying. The Netherlands has the longest history, and numbers of dementia deaths assisted are small, but increasing. In 2015, 109 euthanasia requests from competent patients in the early stages of dementia were granted; 141 were granted in 2016.<sup>6</sup>

Rules around assisted dying / euthanasia for people with dementia vary in latitude between the three countries. At one end, the Netherlands will accept euthanasia / assisted dying advance directives from people who are not necessarily either terminally ill nor at the end of their lives. A physician can comply with an advanced euthanasia request made by a formerly competent patient if the "criteria of due care" are met. These criteria include:

- a) Voluntary and carefully considered request;

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<sup>6</sup> [European Institute of Bioethics 2017](#)

- b) Unbearable suffering with no prospect of improvement;
- c) Patient is informed of their situation and further prognosis;
- d) No reasonable alternative available;
- e) Consultation of at least one other, independent physician; and
- f) Termination of the patient's life with due medical care and attention<sup>7</sup>

At the other end of the continuum, Luxemburg permits advance euthanasia directives, but the person must have a terminal condition, and be unconscious for euthanasia to be carried out.<sup>8</sup>

Alzheimers New Zealand has suggested in a previous submission that:

*One solution would be that the person with dementia, in association with a person with their current or future power of attorney, decides on what stage of their dementia they wished to die while they were still mentally competent. This stage might be when they no longer recognised family or friends or when clinical staff agreed they were in ongoing pain. It is important that the decision that the person with dementia made when they were they were mentally competent is paramount, even when they are no longer mentally competent.*

*A key issue is that time will pass between the original decision and the time that a person has reached the agreed stage. By this time, they may no longer be mentally competent. There is therefore a possibility that the person with the power of attorney and/or clinical staff could decide that this original decision is no longer valid. It is our belief that the views of the person with dementia are always paramount.*

*It is important that the topic is discussed periodically with the person with dementia to ensure that they have not changed their mind. Without clear evidence that the person with dementia has changed their mind, perhaps agreed by a third party such as a lawyer and/or a psychiatrist, the original decision will stand. At the time the initial decision is made, the person with dementia should be aware of the possibility that they may change their mind. This will remain a complex challenge.<sup>9</sup>*

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<sup>7</sup>[Advance directives requesting euthanasia in the Netherlands](#) (2017)

<sup>8</sup> [Should Medical Assistance in Dying Be Extended to Incompetent Patients with Dementia? Research Protocol of a Survey Among Four Groups of Stakeholders from Quebec, Canada](#) (2017)

<sup>9</sup> [Alzheimers NZ submission to Health Select Committee 2016](#)

“I would like to feel I could put a legal document in place for end of life care that once I could no longer eat, drink, or toilet myself I could have assistance to legally end life. Something that family member and GP, and lawyer all signed making it binding.”

*Alzheimers NZ Consumer Advisory Group member with dementia*<sup>10</sup>

“We feel that this whole issue is extremely complex and that people with dementia are in a unique situation. We feel that the issue of competence is what makes it extremely difficult. While people with dementia could make a rational decision at the time, their ability to change their minds could be compromised if their mental competency has deteriorated.”

*Alzheimers NZ Consumer Advisory Group member and care partner*

## **Quality End-of-Life Care for People with Dementia**

There is a common perception that many people with dementia find life unacceptable. While this is true for some, there is a wide body of anecdotal evidence and academic research on people with dementia, their family/whānau, dementia consumer groups, care partners and health professionals both in New Zealand and internationally that shows this is not true for most.

Research and clinical knowledge shows that end of life is often a particularly difficult period for people with dementia, their families/whānau and their care partners. While it is difficult to alleviate all the problems faced by those affected by dementia, or anyone approaching death, introducing or further developing numerous steps might enable the difficulties to be reduced.

These include:

- a) Promoting greater public awareness that dementia is a terminal condition and the importance of future planning while it is still possible;
- b) Promoting advance care planning within all parts of the healthcare system to ensure that it is offered to all those with life-limiting illnesses, including dementia.

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<sup>10</sup> Alzheimers New Zealand's consumer group is made up of people with dementia and people providing a support for someone with dementia

- c) Providing training to all staff working with people with dementia on person centred care and the importance of dignity at the end of life;
- d) Significantly increasing coordinated care for people with dementia and their family/whānau and care partners whenever a decision is made to withhold or withdraw care. Factors which assist this include good access to palliative care, more research on the final days of dying with dementia, and professional training for people working with people with dementia;
- e) Increasing research on detecting and treating pain in people with advanced dementia; and
- f) Increasing the availability, skill level and funding of services to support people including those with dementia to die in their own homes. Research suggests most people with dementia would prefer to die at home.

With the right palliative care a person can have an improved quality of life with their dignity maintained and symptoms managed to help them feel as comfortable as possible until their death.

### **Living Well with Dementia**

People affected by dementia and their care partners need to be able to access quality services and resources to live well. Alzheimers NZ firmly believes that if adequate services and resources were available most people with dementia would not feel that medically-assisted dying was a preferable option (legal or not). We are strongly supportive of Article 25 of the UN Convention on Rights of Persons with Disabilities which promotes the right of people with dementia to the type, quality and volume of services that enable them to live well.

The Alzheimers NZ Consumer Advisory Group does not believe that services currently available in New Zealand are adequate to meet demand. They advise us that people living with dementia within New Zealand communities need and want services which:

- Are hopeful, and that support them to live every day to the fullest;
- Support them to remain at home for as long as is right for them;

- Recognise and respond to the unique needs of the person with dementia and the person supporting them – both together as a family unit, and separately; and
- Are nationally consistent and integrated, with support offered to help people affected by dementia navigate through the myriad of individuals and organisations they interact with when accessing services.

Based on these reports and our knowledge of the day to day experience of people affected by dementia and their family/whānau, Alzheimers NZ does not believe that the services and resources available in New Zealand are of the required quantity, quality and type to enable people with dementia and their families/whānau to live well. There is limited data in New Zealand to answer the question *How well does New Zealand do in providing services and resources for people affected by dementia?* OECD compiled material demonstrates that the quality of services delivered to people affected by dementia in OECD countries is poor:<sup>11</sup>

- a) More than half of all people living with dementia do not have a diagnosis;
- b) One in three people living with dementia in our communities leave their home only once a week;
- c) Providing unpaid care results in families and friends 20% more likely to experience mental health problems as well as making it difficult for them to undertake paid work. This has implications for our economy and already over-stretched mental health services;
- d) A third of people with dementia living in residential facilities are on antipsychotics – with significant questions about how much such drugs benefit them;
- e) Hospital costs are three times higher for people with dementia than for other people, irrespective of the reason why they are in hospital; and

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<sup>11</sup> [OECD \(2015\), Addressing Dementia: The OECD Response, OECD Health Policy Studies, OECD Publishing, Paris](https://www.alzheimer.dk/media/194510/oecd-addressing-dementia.pdf)  
<https://www.alzheimer.dk/media/194510/oecd-addressing-dementia.pdf>

- f) A third of the people with dementia who come out of hospital return to their homes and communities with reduced functional ability. Half of these people never recover.

While New Zealand did not contribute to this work, there is no reason to believe the situation is materially different here.

New Zealand would do well to implement the *New Zealand Framework for Dementia Care* (2013). This 2011-2014 document outlines what must be done “to give people who are living with dementia the best possible independence and wellbeing” as stated in the *Healthy Ageing Strategy*.

Four related initiatives will immediately enhance the quality of life for people living with dementia and reduce pressure on the person and their family as their dementia progresses:

- a) Extend the existing preventative approaches to obesity, diabetes, and cardio-vascular disease to middle aged and older adults, by including information that will reduce the risk or delay the onset of dementia;
- b) Create the navigation services outlined in the *New Zealand Framework for Dementia Care*;
- c) Provide 12 months of post-diagnostic support for people diagnosed with dementia, and their family/whānau care partner; and
- d) Produce high quality *hard copy* information to support people diagnosed with dementia, and their family/whānau.

Other activities to support people to live well and independently with dementia for as long as is possible include:

- a) Promoting a dementia-friendly New Zealand, including a national public awareness programme;
- b) Ensuring care partners can take planned breaks and support their own health by having access to a range of respite care options; and
- c) Following the WHO recommendation to “collect and use the necessary data on epidemiology, care and resources relating to dementia [in New Zealand] in order to implement relevant policies and plans”.

“... Almost every morning my husband asks me what he could do to be a part of the community. He finds his life aimless, isolated and without a sense of purpose and, as a result, becomes depressed. It seems that once the diagnosis is declared most of the brain is assumed to have disappeared. ... He says he would like to die, but doesn't know how, [but] if I take him out he usually has a mood swing in the opposite direction.”

*Alzheimers NZ Consumer Advisory Group member and care partner*

## Conclusion

The desirability of providing more options for people affected by dementia is often raised as an argument for the provision of medically-assisted dying. While it is true that some people with dementia find life unacceptable there is considerable academic and other research and reports from individuals and their families/whānau showing this is not true for the majority.

We believe that people with dementia have a right to the same services as any other New Zealanders. Therefore, if Parliament decides to support End of Life Choice Bill people with dementia should have the same access to that choice as other citizens.

Appropriate safeguards should be introduced for all people seeking medically-assisted dying. Specific safeguards would be needed to protect people with dementia wishes to exercise their rights to medically assisted dying.

End of life is often a particularly difficult period for people with dementia, their families/whānau and their care partners. Better end of life care and support would reduce those difficulties.

We know that access to quality services is a key component of whether a person with dementia can have a decent quality of life. It is likely this is also true for many other life-limiting conditions.

We also know that New Zealand does not provide adequate levels of service and support for people with dementia and suggest that provision of those services may reduce any demand for medically assisted dying. A blueprint to provide better care and support does exist. It can be found in the *New Zealand Framework for Dementia Care* (2013).

“Having seen what he went through [father] has made me aware what is in store for me and my family. Hence, like my father, I would like the option to be medically assisted in dying. ...

Access to quality services and an excellent quality of life would reduce any preference for medically-assisted dying. If such services were available and I was able to continue to have a good quality life, I would gladly die without medical assistance.”

*Alzheimers New Zealand Consumer Group Member*