



## Submission to the Finance and Expenditure Select Committee on the Budget Policy Statement 2019

*Kaua e takahia te mana o te tangata*

*Do not trample over people;*

Honouring our older people needs to be part of all aspects of society

Alzheimers NZ, Level 4 West Block, Education House, 178-182 Willis Street, Wellington  
PO Box 11 288, Manners Street, Wellington 6142

Phone 04 387 8264 Website [www.alzheimers.org.nz](http://www.alzheimers.org.nz) Charity registration CC21026 Alzheimers New Zealand Inc

*Improving the lives of people with dementia is both a moral necessity and an economic imperative (OECD)<sup>1</sup>*

## Introduction

Thank you for the opportunity to comment on the Budget Policy Statement 2019.<sup>2</sup> Alzheimers New Zealand (NZ)<sup>3</sup> strongly supports the Statement's wellbeing approach and the desire for people to live lives of purpose, balance, and meaning. We share the concern that too many people are left behind; loneliness and discrimination are far too common; family violence levels are unacceptable; and, that improving mental health is a priority. We also support the emphasis on productive, sustainable and inclusive growth, and Māori and Pacific wellbeing.

However, despite the worthy aspirations of the Budget Policy Statement, some of the most vulnerable people in Aotearoa are being forgotten once again. Numbers of people affected by dementia are growing rapidly in tandem with the ageing population. The impact of dementia on individuals, families/whānau, communities and our economy is significant, and the need for action is urgent. Budgetary consideration is vital.

Alzheimers NZ has a longstanding commitment to the wellbeing of those affected by dementia. Our strategy is to collaborate with Government and other bodies to both help reduce dementia prevalence and to support people living with dementia to live well. For this reason, we would like to meet with the Select Committee to discuss this submission.

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<sup>1</sup> OECD, 2018, [Care Needed: Improving the Lives of People with Dementia, Paris](#), p.3.

<sup>2</sup> Alzheimers NZ uses size 14 font in its documents in order to enhance dementia-friendliness and readability.

<sup>3</sup> 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. We raise awareness of dementia, provide information and resources, advocate for high quality services, and promote research on dementia and its impact. We also support local Alzheimer's organisations, our members, who provide services at a community level and engage directly with people with dementia and their supporters, family/whānau. We work:

- a. at a national level, as part of the wider dementia community and as part of the health and social services sectors; and
- b. as a member of the global dementia community.

Our strategy is to build a dementia-friendly New Zealand - one in which people with dementia and their care partners are empowered, supported and included in society, able to exercise their rights and live as well as possible.

## Submission outline

This document focuses on three key issues:

- a) Continuing to ignore the wellbeing of people living with dementia has significant budget policy implications;
- b) Dementia-related issues impinge on other Government well-being budget policy goals; and
- c) Recommendations for budget 2019 to reduce the economic impact of dementia.

## Continuing to ignore wellbeing of people living with dementia has budget policy implications

*What was a predicted wave whose leading edge lapped our feet in 2009 is now a wall of water bearing down on us<sup>4</sup>*

Dementia is common and is strongly correlated with age. Around 70,000 people in Aotearoa have dementia and the number is rapidly increasing. The population with dementia grew by 29% between 2011 and 2016. Numbers are forecast to increase to 170,000 by 2050 as New Zealand's population continues to age.<sup>5</sup> These numbers do not include the inter-generational impacts and the many family and friends significantly affected. *The Lancet* describes dementia as *the greatest global challenge for health and social care in the 21<sup>st</sup> century*.<sup>6</sup>

Government and other costs associated with dementia are spiralling.

Alzheimers NZ's *Dementia Economic Impact Report* (DIER) estimates a 75% increase occurring between 2011 and 2016 (\$955 million in 2011 to \$1,676 million in 2016). These costs are projected to reach almost \$5 billion by 2050.<sup>7</sup>

The economic cost estimate does not include costs due to caring-related illness or disability. People caring for those with dementia often ignore their own needs in favour of the person for whom they care. InteRAI data shows that 55% of family or friends caring for a person living with dementia report feeling overwhelmed by the person's support needs, and that 44% of primary carers

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<sup>4</sup> Dr Matthew Croucher, (2018), [Guest Editorial, South Island Alliance](#).

<sup>5</sup> Deloitte and Alzheimers NZ (2017) [Dementia Economic Impact Report](#) (DIER) Wellington: Alzheimers NZ. P.8.

<sup>6</sup> Livingston, G. *et al.* (2017) "[Dementia prevention, intervention, and care.](#)" *The Lancet*. DOI: 10.1016/S0140-6736(17)31363-6.

<sup>7</sup> Deloitte and Alzheimers NZ, *ibid* p.11.

report feeling distressed or angry because of the demands of caring for their loved one.<sup>8</sup> Other costs incurred, or income forgone result from stigma and discrimination. All these further cost implications relate to the key government concerns around both mental health and family violence.

Given the number and size of dementia-related economic and wellbeing cost implications, it is hardly surprising Deloitte describes dementia as “one of the most significant public health burdens in New Zealand”.<sup>9</sup> The World Health Organisation is so concerned about dementia that it has developed a global action plan, to which New Zealand is a signatory.<sup>10</sup>

Little action has been taken to date. There has been no additional investment directed at home-based / community specialist services for people with dementia for more than 10 years. Only residential care subsidies have increased. This is despite recognition that supporting someone with dementia costs significantly more than supporting someone with cancer or heart disease.<sup>11</sup> It is also despite widespread international recognition that the costs of not addressing dementia are profound.<sup>12</sup>

Alzheimers NZ is pleased to see the *Budget Policy Statement* priorities include both ensuring no one is left out, and regard for present and future generations. We are therefore disappointed no attention is paid to the cost and sustainability implications of New Zealand’s ageing population, and that one of the most vulnerable groups in our community is being forgotten.

## Dementia-related issues impinge on other Government budget policy goals

Alzheimers NZ understands and supports the policy statement focus on mental health, child wellbeing, opportunities for productive businesses, and Māori and Pacific incomes and skills. However, right now, our health and other services

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<sup>8</sup> InterRAI (2017) *Annual Report 2016/17* p.13. interRAI is a suite of over 20 clinical assessment instruments. In New Zealand, interRAI is the primary assessment instrument in aged residential care and home and community services for older people living in the community. interRAI stands for ‘international Resident Assessment Instrument’.

<sup>9</sup> Deloitte and Alzheimers NZ, *Op.Cit.* p. 14.

<sup>10</sup> World Health Organization (2017) [Global Action Plan on the public health response to dementia 2017 - 2025](#) Geneva.

<sup>11</sup> Rand Corporation (2103) [Dementia costs top those for heart disease or cancer, study finds](#), *Science Daily*

<sup>12</sup> See for example OECD (2015) [Addressing Dementia; The OECD Response](#), Paris, p. 22.

are also struggling to provide adequate support and services to people living with dementia. If nothing changes, the rapidly increasing numbers could completely overload the health system.

Many people with dementia do not have a diagnosis (international evidence estimates around 50%).<sup>13</sup> If nothing is done differently, care of older people (including large numbers of people with dementia) will account for 50% of District Health Board (DHB) expenditure by 2025/26, an almost 20% increase since 2015/16.<sup>14</sup>

The broader economic costs, currently estimated at \$1.7 billion (2016) include direct health system costs, aged and respite care costs, lower employment levels, lost taxation, days lost in sickness, community and housing modification costs. They also include costs associated with around 40,000 care partners such as wages and taxes forgone, welfare payments, travel costs, and administration costs.

However, dementia is not confined to older persons. Productivity losses for individuals with dementia are estimated at around \$240 million per year. These include reduced employment, absenteeism, and premature mortality.

The challenging economic policy fact, recognised overseas, but recognised less in Aotearoa, is that dementia will grow to become such an urgent and immediate issue it will distract future governments from progressing other priorities unless something is done now. If government is at all concerned about long term efficacy and inter-generational equity, it must act immediately. Inaction on dementia means saddling future governments and generations with a highly avoidable multi-billion-dollar problem.

## Reducing the budgetary impact of dementia: Recommendations for Budget 2019

The wellbeing budget is an opportunity for Government to act to protect New Zealand's long term financial and sustainability challenges by tackling issues relating to the ageing population. There is the opportunity to address the

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<sup>13</sup> Alzheimer's Disease International (2016) *World Alzheimer Report [Improving healthcare for people living with dementia coverage, Quality and costs now and in the future](#)*, Alzheimer's Disease International (ADI), London p.6.

<sup>14</sup> Associate Minister of Health (2016) [Healthy Ageing Strategy](#) Ministry of Health. p.13.

needs of those affected by dementia, better meet international obligations, improve the mental health of a significant number, reduce family violence, pay attention to Māori and Pacific needs, and assist inter-generational equity, as well as reduce future demands on the government purse.

A blueprint for a changed approach to dementia already exists in the *New Zealand Framework for Dementia Care*.<sup>15</sup> Implementing the Framework is an urgent priority and overarches all our other recommendations.

Implementation is consistent with Government's wellbeing and sustainable development goals. It is also consistent with the Healthy Ageing Strategy's identification of those with dementia as a "priority population" and its commitment to implementing the *Framework* to give people who are living with dementia the best possible independence and wellbeing".<sup>16</sup>

The *Framework* outlines an approach which is designed to ensure safety and affordability of services. It also aims to maximise the independence and wellbeing of the person with dementia and their family/whānau/care partner.

Our chief recommendation is that the Coalition Government commits to implementing the *Framework* with a clear pathway to full implementation, consistently, across the country. There are six simple steps government can take along that pathway now which have the potential to make a significant difference.<sup>17</sup>

#### *Six simple steps which can make an immediate difference:*

##### *1. Invest in prevention and risk reduction*

Evidence suggests a lifecycle approach to risk reduction could lower the number of people with dementia by 35%.<sup>18</sup> Education for our tamariki sets them up well for later life and can reduce dementia risk by 8%. Dealing with depression, reducing smoking, and increasing physical activity can reduce dementia risk by up to another 12%. Addressing hearing loss can reduce

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<sup>15</sup> Ministry of Health. 2013. [New Zealand Framework for Dementia Care](#). Wellington.

<sup>16</sup> Associate Minister of Health, Op.Cit. p.34.

<sup>17</sup> The steps have been costed where possible using a simple set of assumptions as a starter for discussion with officials. Steps that are 'pan-condition' have not been costed as Alzheimers NZ does not have information on which to do so. Costs for improvements to respite will be available early in 2019 when a report we have co-commissioned with IHC will be available.

<sup>18</sup> See Livingston, G., *et.al.* (2017) Op. Cit. p. 6.

dementia risk by another 9%. These things are not difficult but collectively could reduce dementia risk by almost 30%.<sup>19</sup> We do not have an estimate for associated costs in this area.

## *2. Invest in detection, diagnosis and support*

Increasing the role of primary care services will help people live better, help keep them at home for longer, and help the health system to be more sustainable across the generations. Alzheimers NZ/Deloitte estimate that if average age entry into residential aged care for people with dementia can be delayed by only three months, there is a net benefit of \$65.5 million per annum (2016 data).<sup>20</sup>

Post-diagnostic support is successful in Scotland, and we can do it here. Their 5 Pillars Model of Post-Diagnostic Support provides people with dementia, their families and care partners with tools, connections, resources and plans to allow them to live as well as possible with dementia and make plans. This model has been evaluated with positive results.<sup>21</sup> We estimate provision of 12 months of this type of post-diagnostic support will require an extra \$4.95 million per annum.

## *3. Invest in people's ability to live well by:*

- a. Creating the navigation services outlined in the New Zealand Framework for Dementia Care at an estimated cost of \$9.6 million per year*
- b. Producing high quality hard copy information to support people diagnosed with dementia, and their family/whānau, at an estimated cost of \$135,000 per year*

Navigation services are a priority action in the 2013 *New Zealand Framework for Dementia Care*. Navigation services provide the first point of contact for the person with the diagnosis, and their family/whānau, and enable them to find their way through the health and social support system. They provide advice, encourage self-management, explain the pathway, coordinate

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<sup>19</sup> See Livingston, G., *et.al.* (2017) Op. Cit. p. 6

<sup>20</sup> Deloitte and Alzheimers NZ, Op.Cit. p.65.

<sup>21</sup> [Alzheimer's Society UK \(2016\); Clarke, C et.al. \(2013\).](#)

referrals, and provide a point of continuity. Some aspects of these roles are already provided; others will require a dedicated role, and others could be provided via technology. Navigator roles supplement rather than replace what already exists. Overseas evaluations of these functions show positive outcomes for people with dementia and their care partners.<sup>22</sup>

Consultation with people with dementia and their family/whānau care partners as part of the development of the *New Zealand Framework for Dementia Care* highlighted a need for information which is easily accessible, consistent and regularly reviewed to represent ‘best practice’. Such information reduces some of the difficulties associated with dementia, reduces demand on health services, and facilitates more timely access to support.

Alzheimers NZ has worked with the Ministry of Health and DHBs to develop a nationally consistent suite of information resources for people with dementia and their care partners. That information is now available electronically. However, clinicians and others advise *hard copy* information is also needed.

4. *Raise awareness, tackle stigma and discrimination, and build inclusive and accepting communities within New Zealand by:*

a. *Establishing a national public awareness programme on dementia to support and promote a dementia friendly New Zealand; and*

b. *Actively supporting national dementia friendly initiatives such as the Dementia Friendly Recognition Programme and Dementia Friends*

Dementia friendly communities assist older people generally, and people with dementia specifically, to live better lives where they can play a full and meaningful role in their families and in their communities and get the help and support they need. This is acknowledged in the *Healthy Ageing Strategy* (e.g. Action Plan numbers 1a and 11b) and is already happening in Rotorua, which is working towards becoming a dementia friendly city. Evidence suggests that dementia friendly communities can and should work closely with the wider concept of age-friendly communities.

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<sup>22</sup> [Alzheimer’s Society UK \(2016\); Clarke, C et.al. \(2013\).](#)

5. *Ensure care partners can take planned breaks and support their own health by having access to a range of respite care options.*

Respite care is an important way in which care partners can continue to care. Too many care partners end up isolated, burnt out or develop anxiety/depression. We have a growing collection of anecdotal evidence about the inadequacy of respite care in New Zealand. These concerns require further examination and need to be addressed as a priority because inadequate respite care risks further increasing the national health burden.

Age/dementia friendly contexts, reduced discrimination, better primary care support will all help, but are not enough. Quality respite care which is consistent across New Zealand, meets specific regional needs, and enables care partners to plan for respite in advance is essential. Alongside IHC, we have commissioned a piece of work to develop better options around respite care. This work is due in early 2019.

6. *Follow the 2017 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.”*

What gets measured gets done. There are currently no national indicators against which dementia progress can be measured and monitored. New Zealand needs better data collection, meaningful indicators, and increased research especially when we are a signatory to WHO requirements to collect such data.

Alzheimers NZ, Brain Research New Zealand, and the New Zealand Medical Association continue to plead for quality, comparable information to better understand the nature of dementia and its implications for Aotearoa.<sup>23</sup> Ministry of Health national data collections are available for diabetes, cancer, arthritis, obesity, and stroke, but not dementia. Some data is available from interRAI assessments, and research projects are contributing valuable information. However, national data which can effectively inform policies and plans is needed.

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<sup>23</sup> Brain Research New Zealand (2017) “Homegrown research urged to gauge extent of dementia prevalence” quoted in *Stuff*, August 2, 2017. See also *New Zealand Doctor*, 5 April 2017; *The dementia challenge: Is there hope and where is it?*

## Conclusion

Alzheimers NZ supports the Budget Policy Statement's focus on the wellbeing of our people. We share the concern for vulnerable groups and the desire to make a real difference to the quality of people's lives.

Some of the most vulnerable and forgotten people in Aotearoa are those affected by dementia. Their numbers are growing rapidly with our ageing population. The impact of dementia on individuals, families/whānau, communities and our economy is significant, and the need for action is urgent.

Too many people are needlessly struggling – both people with dementia and their care partners. They lose their health, jobs, incomes, relationships, friends, homes, mana, and independence amongst other facets of human dignity.

The consequences of continued inaction on these problems are well-researched. Yet successive New Zealand governments have ignored dementia as a health priority.

Alzheimers NZ sees Budget 2019 as a major opportunity to start to make a positive change. It is time for Government to finally act; to take simple measures to improve the lives of those affected by dementia, as well as pay attention to New Zealand's ageing population. Action now will bring numerous benefits. One benefit will be more choices around budgetary policy in the future.

*The true measure of any society can be found in how it treats its most vulnerable members (Gandhi)*