



Submission to the Finance and Expenditure Select Committee on the Budget Policy Statement 2018

... the magnitude of prevalence and costs of dementia make it one of the most significant public health burdens in New Zealand. As such, it needs to be one of the priorities for policy-makers.

[Alzheimers NZ and Deloitte \(2017\) Dementia Economic Impact Report Wellington: Alzheimers NZ](#)

Introduction

1. Thank you for the opportunity to comment on the Budget Policy Statement 2018. Alzheimers New Zealand congratulates the Government on its clear focus on sustainable development (p.1), desire to lift productivity (p.2), and inclusion of health as a priority (p.3). We share the Government's desire for the well-being of all our country's citizens and are particularly pleased to see Government's support for expenditure that will *focus on programmes that will reduce future costs that the Government faces ...* (p. 11).

Alzheimers New Zealand

2. Alzheimers New Zealand is a charitable organisation providing national representation for people affected by dementia. Our members support people in local communities who live with the diagnosis. Together we:
 - a) Actively support New Zealanders living with dementia on a day-to-day basis by providing in-community information, support and advice;
 - b) Provide high quality information and resources about dementia and its impact in order to assist policymakers' decisions about how best to deal with a major burden on our healthcare system; and
 - c) Help build a dementia-friendly New Zealand.
3. We wish to collaborate with Government and other bodies to both help reduce dementia prevalence, and to support people living with dementia to live well.

Our submission

4. This submission focuses on three key issues:
 - a) **Growing dementia prevalence has budget policy implications;**
 - b) **Dementia-related issues impinge on other Government budget policy goals; and**
 - c) **Reducing the budgetary impact of dementia**
5. The three issues are discussed in turn. The third contains our recommendations. A more detailed approach can be found in our 2017 [Briefing to the Incoming Minister of Health](#).

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Growing Numbers of People Living with Dementia have Budget Policy Implications

With no disease-modifying treatments for dementia currently available, health-care systems are in danger of becoming overwhelmed by the future costs of caring for people with dementia.

The Lancet Commission on Dementia Prevention (2017)

6. The Treasury reports that the ageing population will place upward pressure on some vital areas of government spending such as superannuation and health over the next few decades.¹ Dementia is not a normal part of ageing, but it is strongly correlated with age.
7. Right now, more than 62,000 people in New Zealand have dementia. Numbers are projected to increase to over 170,000 by 2050 in the absence of any clinical breakthrough in treatment and/or significant reduction in incidence.² These numbers do not include the many family and friends significantly affected. *The Lancet* describes dementia as *the greatest global challenge for health and social care in the 21st century*.³
8. Government and other costs associated with dementia are spiralling, and Alzheimers New Zealand's *Dementia Economic Impact Report* (Deloitte) estimates a 75% increase occurring between 2011 and 2016 (\$955 million in 2011 to \$1,676 million in 2016). New Zealand costs are projected to increase to \$4.6 billion in today's dollars by 2050 if nothing changes.
9. These estimates do not include costs associated with impacts on care partner health. People caring for those with dementia often ignore their own needs in favour of the person for whom they care. *The Lancet's* work shows 40% of family/whānau dementia care partners have clinically significant depression or anxiety which has implications for our already over-stretched mental health services.

Dementia-related Issues Impinge on Other Government Budget Policy Goals

It is unlikely that the usual specialist-led approach to dementia care can expand fast enough to keep up with the increases in need, and even more unlikely that healthcare coverage can be improved without rebalancing to give primary care a more prominent role ... Increasing the role of primary care services can unlock capacity within the system for diagnosis and continuing care and may be up to 40% cheaper than specialist care in High Income countries. Alzheimer's Disease International, 2016, *World Alzheimer Report*.

10. We understand Government seeks to provide strong services across health and faces pressure to deliver on numerous budget priorities. However, our health and other services are struggling to provide adequate support and services to people living with dementia now. The rapidly increasing numbers could completely overload the health system. Many people with dementia do not have a diagnosis (international evidence estimates around 50%). If

¹ [Treasury Briefing to the Incoming Minister of Finance, November 2107](#)

² [Alzheimers NZ DEIR \(2017\)](#)

³ [The Lancet Commission on Dementia Prevention \(2017\)](#)

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, up from 42% in 2015/16.⁴

11. There are also wider economic impacts. These include direct health system costs, aged and respite care costs, lower employment levels, lost taxation, days lost in sickness, community and housing modification costs, costs associated with around 40,000 care partners such as wages and taxes forgone, welfare payments, travel costs, and administration costs.
12. 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.
13. The economic cost estimate does not include health costs due to caring-related illness or disability. Neither does it include costs incurred, or income forgone due to stigma and discrimination. Even without these costs, the work done for Alzheimers New Zealand by Deloitte describes dementia as “one of the most significant public health burdens in New Zealand.”⁵ The World Health Organisation is so concerned about dementia that it has developed a global action plan, and New Zealand is a signatory.

Reducing the Budgetary Impact of Dementia

14. Changes which keep people as well as possible and at home for longer will achieve cost benefit ratios of \$6.60 for every \$1 invested and reduce the projected \$5 billion per year according to our economic impact report estimates. The main saving comes from delayed entrance to residential care. If entry into residential care for people with dementia can be delayed on average by only three months, there is a net benefit of \$66 million. If it can be delayed by 12 months, \$262 million per annum can be saved.
15. Successfully responding to the dementia challenge is possible. Investing now will reduce the long-term fiscal burden and greatly improve the quality of life for the large numbers of Kiwis who are and will be impacted by dementia over the next 30 years.

Alzheimers New Zealand Recommendations for Budget 2018

A. Top Priority

16. Urgent: Fully implement the *New Zealand Framework for Dementia Care (2013)*

- a) We are disappointed with the lack of progress in implementing the *Framework* to date. The dementia problem has become more urgent as a result.

⁴ [Associate Minister of Health \(2016\) *Healthy Ageing Strategy*](#)

⁵ [Alzheimers NZ DEIR \(2017\)](#)

- b) The *Framework* recognises that scaling up the existing specialist model of dementia care is unaffordable. It outlines an alternative approach, and is designed to ensure safety and affordability of services. It also aims to maximise the independence and wellbeing and of the person with dementia and their family / whānau / care partner.
- c) Implementing the *Framework* is an urgent priority and overarches all our other recommendations. Implementation is consistent with Government’s sustainable development goals. It is also consistent with the *Healthy Ageing Strategy’s* identification of those with dementia as a “priority population” and commitment to implementing the *Framework* to give people who are living with dementia the best possible independence and wellbeing”.⁶

B. Four Recommendations which, if accepted, will make a significant improvement

17. 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

- a) Risk reduction is vital given the lack of a cure for dementia. The *Lancet Commission on Dementia, Prevention, Intervention and Care* shows effective prevention measures have the potential to delay or prevent around 35% of dementia cases. Childhood education below age 12; active treatment of mid-life hypertension; increased physical activity; social engagement; reduced smoking; management of hearing loss, as well as management of late-life depression, diabetes and obesity; can all help to reduce levels of dementia. Essentially, *what is good for the heart is good for the brain*.
- b) Many of these activities are already New Zealand health promotion priorities. However much more could be done to target effective health promotion towards middle aged and older adults to help reduce the risk or delay the onset of dementia as recommended by the WHO.⁷ **We do not have an estimate of cost for this work at this stage.**

18. Create the navigation services outlined in the *New Zealand Framework for Dementia Care* at an estimated cost of \$9.6 million per year

- a) This is 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 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

⁶ *Healthy Ageing Strategy* p.34

⁷ [World Health Organization. \(2017\)](#)

exists. Overseas evaluations of these functions show positive outcomes for people with dementia and their care partners.⁸

19. Provide 12 months of post-diagnostic support for people diagnosed with dementia, and their family/whānau care partner at an estimated cost of \$4.8 million per year

- a) This approach is in place elsewhere. For example, in Scotland where the *5 Pillars Model of Post Diagnostic Support* provides people with dementia, their families and care partners with the tools, connections, resources and plans to allow them to live as well as possible with dementia and to prepare for the future. The model has been evaluated with positive results.⁹
- b) Such a measure can both delay the transition to residential care and reduce subsequent care requirements. It can also improve the quality of life for people with dementia and their family/whānau/care partners, and therefore reduce associated costs.

People are in shock when they receive a diagnosis. They don't know to ask, 'what's next'. It's not just about setting people up for the future, but also about preventing their decline.

Alzheimers NZ Consumer Advisory Group member

20. Produce high quality hard copy information to support people diagnosed with dementia, and their family/whānau, at an estimated cost of \$130,000 per year

- a) 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.
- b) 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.

C. Further recommendations to help people with dementia to live well and independently

21. Create and promote a dementia-friendly New Zealand in line with the WHO *Global Action Plan on the Public Health Response to Dementia* by:

- (i) Establishing a national public awareness programme on dementia to support and promote a dementia-friendly New Zealand; and**

⁸ Alzheimer's Society UK (2016) *Dementia Advisors: a cost-effective approach to the delivery of integrated care*; Clarke, C et.al. (2013) *Healthbridge. An evaluation of peer support networks and dementia advisors in the implementation of the national dementia strategy*, Department of Health UK

⁹ Kelly F et al (2016) "Facilitating independence: the benefits of a post-diagnostic support project for people with dementia." *Dementia* 2016 15(2) 162-180.

(ii) Actively supporting national dementia-friendly initiatives such as the *Dementia-Friendly Recognition Programme and Dementia Friends*

- a) 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 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.

Support is the key to me leading as normal a life as possible. People knowing and treating me as the person I still am. Giving me room to live.

Alzheimers New Zealand Consumer Group member

22. Ensure care partners can take planned breaks and support their own health by having access to a range of respite care options as is envisaged in the *New Zealand Framework for Dementia Care* and Action 22a of the *Healthy Ageing Strategy*

- a) Respite care is an important way in which care partners can continue to care. It needs to be adequate and consistent across New Zealand, as well as meet specific regional needs, and to enable care partners to plan for respite in advance.
- b) 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. Adequate levels of flexible, responsive and consistent respite care are urgently needed.

23. Follow 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”¹⁰

- a) New Zealand has no formal national data collection on dementia. This negatively impacts on our understanding of dementia in New Zealand, the supply and demand for services, and the costs associated with service provision.
- b) It is unusual to have so little data about such an urgent problem, and its lack presents a major barrier to making change. Alzheimers NZ fills some of the gap with commissioned reports from Deloitte regarding the economic impact of dementia. However, these figures are based on best estimates from overseas research and are approximations of

¹⁰ [World Health Organization. \(2017\)](#)

the New Zealand situation. As Brain Research New Zealand and others have stated, home-grown research on prevalence and other issues is needed.¹¹

- c) The *New Zealand Framework for Dementia Care* commits to numerous over-arching factors including monitoring and evaluation and culturally appropriate services. It is difficult to see how these can be achieved in the absence of local data.

¹¹ 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 201; *The dementia challenge: Is there hope and where is it?*