



Submission

Better Later Life

He Oranga Kaumātua 2019-2034

June 2019

I still want some control over my affairs and how things are done...The kids are more inclined to tell me what I should be doing. And sometimes I don't take their advice after thinking it through, and they have had to learn that's ok too (Person with dementia, 2019)

Introduction

Thank you for the opportunity to comment on Better Later Life; He Oranga Kaumātua 2019-2034. We are pleased to see the draft strategy as Aotearoa's ageing population is associated with significant change. It is vital the country has policy settings in place commensurate with the new demographic realities.

Alzheimers NZ

Alzheimers New Zealand (NZ) is keen to assist and is well placed to comment on changes which need to occur. Our organisation has been engaged with ageing population issues since our formation in 1986. Since that time, we have been representing growing numbers of people affected by dementia at a national level by raising awareness, providing information and resources, advocating for high quality services, and promoting research about prevention, treatment, cure and care.¹

Why this submission?

Alzheimers NZ has a strong interest in the issues considered in the *Better Older Life* draft strategy. Dementia issues provide a microcosm of ageing population issues. Therefore, Alzheimers NZ is well aware that:

- There are potential social, economic and cultural repercussions;
- Issues facing older people now are likely to both grow and broaden as a new generation with heightened expectations is increasingly described as 'older'; and
- There are implications for the entire population as current unmet needs collide with rapid increases in demand for services due to larger numbers of older people.

¹ Alzheimers NZ also supports local Alzheimers NZ organisations throughout New Zealand, each of which is a member of Alzheimers NZ. Our local Alzheimers organisations provide support, education, information and related services directly to members of their communities who are affected by dementia. These services may include:

- Information and education to assist with understanding and living with a dementia diagnosis
- Support for family, friends and whānau coping with the demands of caring
- Support groups and day programmes for people affected by dementia.

Due to the nature of dementia and its diverse implications, Alzheimers NZ has put considerable effort into learning about and communicating changes which can help improve the lives of both older people generally and people affected by dementia specifically. This submission provides a vehicle for our organisation to assist the Office for Seniors by contributing some of our acquired knowledge around creating a better, more sustainable future for us all.²

Submission outline

Our submission contains comments in three main areas:

1. How dementia presents a microcosm of ageing population issues;
2. The nature and direction of the draft strategy; and,
3. Learnings from Alzheimers NZ which can inform the strategy.

These issues are discussed in turn.

Dementia: a microcosm of ageing population issues

Dementia reaches into every aspect of society. It illustrates the scope of the ageing population issues, why the implications are major, and why action is urgent. A brief summary of the dementia issue and its wider implications is contained in the box on the next page.

² It is also designed to dementia-friendly, therefore we are using size 14 font.

Dementia is both common and strongly correlated with age. Around 70,000 people currently have the condition and the number is rapidly increasing. The population with dementia grew by 29% between 2011 and 2016 and numbers are forecast to increase to 170,000 by 2050.³ These numbers do not include the many family and friends significantly affected. Dementia is expensive. Health and social care costs for dementia almost match the combined costs of cancer, heart disease and stroke.⁴

Almost 25% of the population will be 65+ by 2036. If nothing is done differently, care of older people will account for 50% of District Health Board (DHB) expenditure by 2025/26, an almost 20% increase since 2015/16.⁵ Currently around one third of all hospital admissions are for people over the age of 65.⁶

Dementia puts a strain on social relationships. It changes relationships and causes stress, loneliness, lost careers and reduced income, putting pressure on a person's physical and mental health. People caring for those with dementia often ignore their own health needs in favour of the person for whom they care. Around 40% of family/whānau dementia care partners have clinically significant depression or anxiety.

The lack of services and support for people living with dementia causes so much needless harm. Human rights are often ignored; people are left out and encounter stigma and discrimination; there is increased likelihood of stress-related abuse; and, there are increased health costs due to caring-related illness or disability.

Dementia has a disproportionate impact on women. Women are more likely to be living with dementia and are more likely to be providing care and support – both in a family situation and in formal care situations.

There are also the assaults to the human spirit. Restraint through inappropriate use of medication, such as antipsychotics, is common. In addition, people are frequently denied social inclusion, legitimacy and love.

It does not need to be like this and those with dementia who are well supported, receive appropriate care, live in situations where they can be engaged, and are loved, can live well to the end of their lives.

³ Alzheimers NZ(2017) [Dementia Economic Impact Report](#) (DIER) Wellington: Alzheimers NZ. P.8.

⁴ Luengo-Fernandez, R., et.al, (2010). *Dementia 2010: The prevalence, economic cost and research funding of dementia compared with other major diseases*. Health Economics Research Centre, University of Oxford.

⁵ Associate Minister of Health (2016) *Healthy Ageing Strategy* Ministry of Health. p.13.

⁶ Ministry of Health *Publicly funded hospital discharges – 1 July 2014 to 30 June 2015* (2017) www.health.govt.nz/publication/publicly-funded-hospital-discharges-1-july-2014-30-june-2015

Nature and direction of the draft strategy

Alzheimers NZ congratulates the Office for Seniors on a clear, accessible, and comprehensive draft strategy. We support the vision and guiding principles and are delighted to see acknowledgement of people being valuable because of who they are rather than merely because of what they do.

We are pleased to see the clear recognition of older people's contributions to wider society, be it in paid undertakings, voluntary public roles, care for family and friends, being present to others, or community undertakings and contributions, which are so often taken for granted.

The strategy provides some useful background to the issue and its vision that "[o]lder New Zealanders lead valued, connected and fulfilling lives" makes sense. It then jumps to the universally appealing guiding principles about valuing people, safety, recognising diversity, whole-of-life and whānau-centredness, and collective responsibility for planning and acting for later life.

The strategy would benefit from some basis underlying the principles. For example, the Welfare Expert Advisory Group provided an anchor for its work by identifying some of the values that we New Zealanders tend to share.⁷ A similar approach could be taken here.

A second issue is that the practical implications of an ageing society reach beyond older people. While there is logic in focusing on people aged 65+ and those aged 50-64 (p.6), the nature of an ageing society has important implications for everyone whatever their age. There are significant intergenerational issues involved which impact on any strategy related to an ageing population, for example, we currently have many mid-life parents who are simultaneously caring for young children and elderly parents.

Learnings from Alzheimers NZ

Alzheimers NZ has an interest in all areas of the strategy, however we have a particular interest and expertise in four areas:

⁷ Examples include manaakitanga (hospitality, respect, care for others); ōhanga (ensuring people have an adequate income and standard of living); whanaungatanga (valuing whānau, families, children and relationships); kotahitanga (togetherness - people being able to participate meaningfully in communities); takatūtanga-creating something fit for the present and which will work for the future; and kaitiakitanga – being guardians of our resources), Welfare Expert Advisory Group (2019) *Whakamana Tāngata: Restoring dignity to social security in New Zealand*, p.63.

- Participation and social connection;
- Stigma and discrimination;
- Access to health and services; and,
- Accessible built environments.

Participation is key

Alzheimers NZ has a leading role in the Coalition to End Loneliness. We also have the evidence of our own work, particularly our recently conducted research on Living with Dementia.⁸ In a separate, but parallel undertaking, our Advisory Group composed of people with dementia and people who care for others with dementia recently developed and launched the *Dementia Declaration* stating what people affected by dementia require to live well (Appendix 1).

The remarkable factor about these undertakings is their consistent messages. The research shows over and over that people with dementia and their care partners want to be understood, respected and included.⁹

The Declaration writers open with a summary statement about how “We ALL want to be seen, valued, appreciated and loved for who we are”. It ends by declaring that no matter what a person’s state of health or disability, “I am still me”, worthy of love and “[my] presence matters” (Dementia Declaration, 2019).

Given the priority of being legitimate, being able to participate, to be engaged, and have as much control over their lives as possible, we suggest that participation and social connection becomes the first amongst the key areas for action in the draft strategy. All the areas in this section are relevant to Alzheimers NZ’s work and we are happy to assist with further developments.

Tackling stigma and discrimination is the second priority

Reducing stigma and discrimination is mentioned several times in the draft strategy (pp. 27; 37 and 43). In our experience, stigma and discrimination are such significant issues they warrant a section of their own. They are likely to

⁸ Alzheimers NZ (research by Smith, E., et.al) (2019), *This is our story: A qualitative research report on living with dementia*. Wellington, Litmus.

⁹ Alzheimers NZ (research by Smith, E., et.al) (2019), p.9.

require a specific, integrated approach which goes well beyond the awareness-raising envisaged in the draft.

There is so much stigma around growing old that it is even manifested in our approach to health. The increasingly popular view is that even tiny departures from perfect health constitute 'illness' and are potentially in need of 'treatment'. Already some are describing biological ageing itself as a 'disease'.¹⁰ The result is ever increasing expectations and exponentially growing demand for health services and a belief that being elderly, infirm, or in need of assistance is unacceptable.

Again, dementia provides a microcosm of the issues. For people affected by dementia, stigma and discrimination are tragically common for both those with dementia and those who care.

Every member of our Advisory Group cites problems with stigma and discrimination:

- People report being told to 'pack up their lives' and that they are 'no longer any good' for their jobs/community roles';
- People describe being 'treated like a third person', or 'left out of conversations while people talk to my care partner'; and,
- *Getting travel insurance is impossible* (advisory group member).

Even care partners are not exempt. This is highlighted in our recent research:

*I get the feeling at organised meals and outings the residents prefer not to sit by [name], and therefore this affects me too. I have stopped going to village social events as this was happening and does not make an enjoyable time for me.*¹¹

Discrimination stretches beyond dementia. Beliefs about elderly disabled people having lives of no value became evident in the discourse around the *End of Life Choice Bill*. Assisted dying is frequently portrayed as the way to maintain one's dignity in the face of what is deemed to be 'a meaningless life'.

¹⁰ Bulterijs, S., Hull, R. S., Björk, V. C., & Roy, A. G. (2015). It is time to classify biological aging as a disease. *Frontiers in genetics*, 6, 205. doi:10.3389/fgene.2015.00205

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4471741/>

¹¹ *Alzheimers NZ* (research by Smith, E., et.al) (2019). P.83..

Discrimination has been successfully tackled in the mental health sector. It has taken time, energy, resources and a concerted campaign, but it has had positive results. A similar approach may be needed with the ageing population.

The issue is significant as discrimination does real damage:

Younger person with dementia: *A lot of people treated me differently and that made it harder. And I thought, you know, I'm just a normal person really.*

Care Partner: *Like you were a numpty.*

Younger person with dementia: *Yeah, I felt like I was really dumb.*¹²

Improving access to health and social services

Alzheimers NZ is pleased to see recognition of the need for improved access to health and social services. We have been advocating for improvements in this area for a long time, and progress has been very slow or non-existent. For example, Alzheimers NZ has been seeking full implementation of the *NZ Framework for Dementia Care* since its publication in 2013 with little success.

Alzheimers NZ's evidence-based requests for improvement are set out in its [Recommendations for Budget 2019](#). There are strong similarities between our requests and the issues raised in the draft strategy. For example, Alzheimers NZ also wishes to see:

- Health promotion and risk reduction extended to middle-aged and older adults;
- People having equitable access to health care;
- Improved access to health care for vulnerable groups, e.g. support following a diagnosis of dementia; and,
- Assistance for people to find their way through health and social services, e.g. navigation services.

We know that improving access to health and social services is urgent as our recent research confirms some of the problems:

¹² Alzheimers NZ (research by Smith, E., et.al) (2019), p.39.

- “Many people do not know what services are available and whether they are eligible;
- People often do not know how to increase services as dementia progresses;
- Service availability varies across New Zealand;
- Some people living with dementia are able to overcome these access barriers, others are not; and
- Services are not meeting the diverse needs of people living with dementia”.¹³

*Nobody offers help, you’ve got to go and find it and ask for it. You have to go to your doctor and some doctors don’t want to give it either, which to me is quite strange (Person with dementia).*¹⁴

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. (Person with dementia)

Care partner needs

Care partners and their needs are omitted from the draft strategy, despite their central role in an ageing society. Their role is important, and they face many challenges. Care partners:

- Require support in performing their role;
- Are not paid;
- Frequently develop health problems as a result of their role;
- Are overwhelmingly women;
- When male, have numerous issues associated with being minorities in a largely female world;
- Need access to quality respite care in order to be able to continue to care;

¹³ Alzheimers NZ (research by Smith, E., et.al) (2019), p.56.

¹⁴ Alzheimers NZ (research by Smith, E., et.al) (2019), p.60.

- Often put their own priorities, careers, engagement in outside life aside in order to care;
- Are at increased risk of abuse;
- Are likely to be in reduced supply as the proportion of people living on their own increases; and,
- Reduce the burden on publicly provided services.

Care partner concerns raised in Alzheimers NZ research

Need for support:

I was too emotional. I was not great. I had a bit of an incident where I blacked out when I got the news. My body did a crash. I've had years of managing it and I was surviving on two to three hours of sleep for the past two years. So, my body just went, 'I can't do this anymore'. As much as you want to carry on, your body just says 'Nah'. I knew I wasn't at my strongest.¹⁵

Need to be able to get help:

It takes a crisis to get help. Like when he had a fall and went to the hospital. Then the GP said you need more help.¹⁶

Need for access to respite care:

Like other services, people living with dementia do not know what respite care is available, their eligibility for the service or how to access it. They do not know how to increase the hours of the service as the dementia progresses.¹⁷

Respite care needs to be of suitable quality:

One of the staff members [at respite care] noticed that [my wife] wasn't looking too enthusiastic. And she came up and spoke to [my wife] like she was an idiot child and said she was going to have morning tea and a lovely cup of coffee with cake. And I said, 'Oh, don't do this to [my wife]'. And [my wife] just said she didn't want to be here. I totally agreed.¹⁸

¹⁵ Alzheimers NZ (research by Smith, E., et.al) (2019), p.85.

¹⁶ Alzheimers NZ (research by Smith, E., et.al) (2019), p.60.

¹⁷ Alzheimers NZ (research by Smith, E., et.al) (2019), p.67.

¹⁸ Alzheimers NZ (research by Smith, E., et.al) (2019), p.68.

The experiences of people with dementia and people who are care partners illustrate an obvious and urgent need in the health and social service area. The second *Healthy Ageing Strategy* implementation plan has the potential to be an important vehicle for improvement. Alzheimers NZ hopes its development will remedy many of the current problems identified in this section.

Accessible built environments

Alzheimers NZ is pleased that the draft strategy identifies the significance of age-friendly built environments and the achievement of full accessibility for disabled people. There are basic human rights issues involved here. For example, the UN Convention on Rights of Persons with Disabilities includes the following:

Article 19 c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Cognitive and neurological disorders are common and occur throughout the population. Inclusive built environments need to ensure accessibility for these groups. As our community will attest, most people with dementia live at home for most of the time after diagnosis. Most want to continue to live their lives by maintaining their interests, activities, hobbies, and community connections.

Many changes are needed and some of the examples are simple:

- Unswept leaves make for slippery surfaces;
- Street lights which are not working make it hard to see;
- Public transport is still limited, and taxis are expensive;
- Automated processes in shops and at airports can be difficult to understand; and,
- Public toilets where everything is white are just confusing.¹⁹

The need for dementia-friendly communities has been acknowledged in the *Healthy Ageing Strategy* (e.g. Action Plan numbers 1a and 11b), however there has been little progress in this area. Likewise, local authorities may need more

¹⁹ see Alzheimers NZ (research by Smith, E., et.al) (2019)

than “encouragement to plan and act” to respond to an increasingly ageing population. Legislation and regulation may be required.

Alzheimers New Zealand has a considerable amount of knowledge about these issues with its [Dementia Friends](#) and [Dementia- Friendly Recognition](#) programmes and is keen to keep working with the Office for Seniors to improve accessibility which allows those with dementia and their care partners to participate in their community.

Once again, participation is key. We have reports of what can happen when people with dementia and their care partners attempt to participate:

There are groups that do walks locally but [name] can't get to them unless there is someone to take her so those things become difficult. Half priced taxis are still expensive. You know, it's a thirty-minute walk to take two buses to get to something that's only three miles away. It is ridiculous. (Care partner).

And:

What I notice is that crossing roads, and things like that, cars come around the corner and I'm too slow to get across. If the council could go through what could be done, it could make a difference. Even signage and things like that (Person with dementia).²⁰

Conclusion

Alzheimers NZ applauds the work undertaken by the Office for Seniors. We broadly support this clearly delineated strategy and are pleased to see such an accessible document which covers significant issues. Of course, a strategy will only be successful if it is accompanied by a relevant achievable action plan with sufficient monitoring and evaluation measures to enable assessment of its success.

Our organisation has a strong interest in and a great deal of knowledge about the ageing society as dementia represents a microcosm of the issues involved. In fact, there is such a strong relationship, that our Declaration developed by people affected by dementia contains many of the same issues covered in the draft strategy.

²⁰ See Alzheimers NZ (research by Smith, E., et.al) (2019), p.70.

Among other things the Declaration states that:

We live our best possible lives when:

We have the things we need to live well such ... an adequate standard of living, ... (Financial and economic security).

We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable. (Access to health and social services).

We have the things we need to live well such as housing, ... (Providing housing choices ... so people can age in the community).

A circle of support protects our wellbeing, allowing us to maintain strong mutual relationships with our families, whānau, friends, colleagues, and those who are important to us. ... We continue to be actively engaged in roles and activities which are meaningful and important to us. (Enhancing opportunities for social and community participation).

We live in knowledgeable communities that include, accept and understand us. We have the things we need to live well such as ... ways of getting where we need to go. (Providing accessible built environments so people can participate in their community).

In short, if we can 'get it right' for people affected by dementia, we can 'get it right' for everyone.

Recommendations

1. Draw upon Alzheimers NZ's expertise around issues affecting ageing societies.
2. Consider strengthening the strategy by
 - a. Providing an anchor consisting of shared New Zealand values to underpin the guiding principles adopted; and
 - b. Drawing attention to the fact that the ageing society has implications for everyone.

3. Consider putting the 'participation' section first amongst the key areas for action as more than anything, ageing New Zealanders want to be understood, respected, and included.
4. Strengthen the approach taken to stigma and discrimination given its all-pervasive association with ageing, frequent identification by older or disabled people as a major issue, and its clearly identifiable negative impact.
5. Consider the needs of care partners in the discussion about access to health and social services.
6. Maximise the opportunities to improve health and social services associated with the second Healthy Ageing Strategy Action Plan.
7. Ensure work on improving age-friendly built environments includes meeting the needs of those with dementia and other neurological / cognitive impairments.
8. Make use of Alzheimers NZ's expertise around age/dementia-friendly initiatives and knowledge.
9. Ensure the strategy is accompanied by a relevant achievable action plan with sufficient monitoring and evaluation measures to enable assessment of the success of the strategy

We have the same rights, privileges and obligations as everyone else.
(Dementia Declaration, 2019)



Dementia Declaration: Our Lives Matter

“We ALL want to be seen, valued, appreciated and loved for who we are.”

As New Zealanders living with dementia, we are citizens whose lives matter. We have the same rights, privileges and obligations as everyone else. Our Declaration sets out what we need to live well.

We live our best possible lives when:



We have control over our lives; we have support to make decisions that are important to us.



We live in knowledgeable communities that include, accept and understand us.



We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable.



We continue to be actively engaged in roles and activities which are meaningful and important to us.



We have the things we need to live well such as housing, privacy, an adequate standard of living, and ways of getting where we need to go.



A circle of support protects our wellbeing, allowing us to maintain strong mutual relationships with our families, whānau, friends, colleagues, and those who are important to us.



We are loved; our presence matters.

“I am still me.”

This Declaration was developed by people living with dementia on Alzheimers New Zealand’s Advisory Group.