



Submission: Discussion Document for Developing a New Strategy for an Ageing Population

Nā tō rourou, nā taku rourou ka ora ai te iwi

With your food basket and my food basket the people will thrive

A recently published book about the future of New Zealand reveals much by its contents. *The Big Question: What is New Zealand's Future* was published in July 2018 and contains chapters by Dame Anne Salmond, Judge Andrew Becroft, and many highly esteemed others. It addresses crucial issues such as children, prisons, jobs, climate change, and housing. The glaring omission is any chapter on our ageing population. The omission merely underlines how New Zealand society is not facing up to the demographic changes we are beginning to experience.

Alzheimers NZ (www.alzheimers.org.nz) is well acquainted with New Zealand's ageing population and is pleased to have the opportunity to engage in this discussion. We represent people who live with dementia (see Appendix 1) and put a great deal of energy into championing their wellbeing. We are dedicated to creating a dementia-friendly New Zealand where people with dementia and their care partners are empowered, supported and included, able to exercise their rights, and supported to live as well as possible (more about Alzheimers NZ can be found in Appendix 2). The experience of the community we represent underpins this submission.

As the *Discussion Document* acknowledges, there are many issues important for our ageing society. Our submission assumes that no single generation should live well at the expense of other generations, and it focuses on five topics:

1. Understanding the issues - data and measurement

2. Valuing older persons
3. Inclusion in the community (for example, housing, work, transport)
4. Physical and mental wellbeing
5. Sufficient quality services for older persons

Understanding the issues – data and measurement

People aged 65 and over are not a homogenous group. However, New Zealand data (labour force data for example) tends to lump everyone in the single 65+ age group, and then treat the group as if everyone's needs and characteristics are the same. This issue applies to the data we actually manage to collect.

A great deal of information about those aged 65+ is not collected at all. In our own sector, although large numbers of people in this age group are affected by dementia, New Zealand has no prevalence data; and little data collection, no targets or monitoring of diagnosis, and no quality indicators. This is despite requirements placed on us by our international obligations (the World Health Organization for example).

If we are all to live well in our ageing society, we must be able to articulate the issues we face and examine their dimensions. If we do not collect the information, then any analysis of such things as the supply and demand for services, cultural and gender dimensions, and the costs associated with service provision are impossible.

Valuing older persons

There is ample evidence that older people are not being valued. This is despite them being our parents and grandparents, uncles and aunts, the keepers of our traditions, our family histories, and our stories. Older people are frequently ignored, forgotten or diminished. These are our elders, our kaumatua, our kuia, and are deserving of our respect.

What we say about how older people should be treated, and how they are actually treated frequently do not coincide. The difficulties people over 55 have in getting jobs, despite their acquired wisdom and experience is just one example (p.14).

Alzheimers NZ is well aware stigma and discrimination are rife. They show up sharply in the community we represent, and members of our advisory group report being told to 'pack up their lives' and that they are 'no longer any good' for their jobs/community roles. They also describe being 'treated like a third person', or 'left out of conversations'. People with dementia describe being talked about as though they are not present. Some lose their driver's licence based on assumptions, without any assessment of their capacity to drive. Confidence loss, job/role loss, and social status loss goes with stigma and discrimination. The nation loses out as people withdraw and dramatically reduce their contribution to wider society. Our study of *The Economic Impact of Dementia* documents some of the social and economic costs found in our sector.

A second example of the low value we put on our elders is the current discourse around the *End of Life Choice Bill*. Too often disabilities, and many of the ailments associated with age (e.g. dementia), are portrayed as a tragic occurrence which is to be pitied, avoided, or nullified. We are told the End of Life Choice debate is about dignity, and the solution to maintaining dignity is deemed to be assisted dying. However, if the the debate was truly about dignity, it would be focused on how people live now, and the services urgently needed to help people to live well. That crucial part of the conversation is largely absent. A [despairing Human Rights Commissioner](#) declared that:

What we collectively need to focus on is better supports to enable disabled people to participate fully, funding, access to services, and changing attitudes. Instead we are talking about how we can help people end their lives.

Even existing policy attempts to address stigma and discrimination leave out our ageing population. The *Like Minds Like Mine* campaign is laudable but is silent on older people's needs. This is despite the 2012–2017 *Mental Health and Addiction Service Development Plan's* references to dementia and commitment to including older people with high-prevalence conditions as one of four priority populations (p.5). Some sort of action directed at how we treat and include our elders is urgently needed.

Inclusion in the community

The 1972 Royal Commission on Social Security recognised that being able to participate in society is a significant key to being able to live well. Older people can live well if they are able to participate in their communities. This means having enough income to enable participation, housing which is conducive to health and wellbeing, and accessible transport and services.

Housing is known to be key to social wellbeing and people's ability to participate. Many current policy settings across government assume most older people own their own homes and are mortgage free. Researchers Kay Saville-Smith and Bev James are showing this is rapidly changing and the proportion of older people in rental accommodation is growing and those owning their own home is declining. Without the financial cushioning effect of capital in an owned home, hardship for older people is more likely. Unless changes are made, the toxic cocktail of growing hardship, low social tolerance for cognitive and other decline, and a lack of social inclusiveness will result in heightened social isolation amongst our ageing population. Social isolation is correlated with a host of negative indicators and outcomes and is likely to result in magnified costs for government.

Given the social, personal, community and government costs associated with social isolation, greater inclusion of older persons needs to be a specific goal. There are various age-friendly community movements around the world; New Zealand is making progress but has a long way to go. Policy needs to incorporate a national strategy and action plan to address accessibility, age-friendliness, social and economic implications around the declining proportion of older New Zealanders who have a mortgage free home and/ or access to a defined benefit scheme to supplement their superannuation, the limited chances of well-paid jobs, and the compounding impacts of declining health.

Examples of needs in this area abound in our sector. People develop dementia and, depending on age, can lose their income. Care partners can also lose income. The costs of care sometimes result in family homes being sold prematurely resulting in shifts to smaller or less desirable accommodation sometimes in a different area. These shifts can compound problems with loss of support networks. All of these factors augment social isolation, increase

stresses, and all aspects of life become more difficult. Carers UK suggest 57% of carers lose touch with family or friends as a result of their caring responsibilities leading to increased isolation and emotional distress. Inclusive, supportive communities will help. However, the interface between age friendliness, models of caring, employment, taxation, and the welfare system provide the real levers for inclusiveness and these require examination.

Physical / mental wellbeing

Physical and mental health are obvious challenges with ageing populations. They have important government expenditure implications as well as implications for people's ability to participate and be included. We know that if nothing is done differently, care of older people will account for 50% of District Health Board expenditure by 2025/26, up from 42% in 2015/16.

Good strategies and policies to improve health and wellbeing are desirable but of little use unless they are implemented. For example, the *New Zealand Framework for Dementia Care* was developed in 2013, but there has been very little progress in implementation over the last five years.

Likewise, it is easy to state that elder abuse is a problem (p.24), but there appears to be unwillingness to address some of the lack of support which increases its likelihood. For example, we know that care partners who are family members are very important for people who have dementia. However, the relationship changes, stress, loneliness, lost careers, and reduced income, puts a strain on both 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. Large numbers of family/whānau dementia care partners have clinically significant depression or anxiety. Respite care is frequently difficult to access and/or is of insufficient quality. This becomes a source of additional stress for both those who care and for the care recipient.

Heightened stress, of course, is correlated with increased likelihood of abuse of either or both of the parties.

People are better able to stay connected if they are in good health. However current health promotion is focused on younger age groups, despite the knowledge that risk reduction initiatives directed at middle age and older adults can be of considerable benefit. In our own sector, around 35% of

dementia risk is modifiable. The Lancet's *Commission on Dementia* lists a number of measures which can be taken to help reduce the risk. These sorts of changes are not difficult to implement and can reap major benefits.

Sufficient quality services for older persons

If services are to meet the needs of older people they need to be adequate, flexible and consistent across the country. They also need to meet the needs of those who care. In our sector, we have over 62,000 people with dementia and over 40,000 care partners. The numbers are growing rapidly, as are their needs.

Demands for respite care will grow further as will demands for better options for residential care. Payment for carers will be growing issue, as will be issues around workforce flexibility to enable people to better combine employment with caring roles.

Other demographic changes will also have an impact. Many current policy settings, particularly those in the health space, assume older people live with their spouse/ partner, or are close to adult children who will provide voluntary care when needed. However, more and more older people are now living apart from those close family connections taken for granted in earlier times. Growing numbers of older people live alone and services are increasingly unable to adequately meet their needs.

Meantime, people's expectations have also changed. The result is New Zealand currently has a rapidly growing population of seniors with higher expectations than in earlier times, and a limited variety of services. New Zealand does not have a workforce strategy that will adequately provide the range of services people require.

The workforce problem has been known for some time, however, there seems to be no workforce policy to make sure there are adequate numbers of people with the right training to deliver quality services for this rapidly growing population. Services for older people is still regarded as an unattractive field for a career and is lowly paid compared to other areas, despite the recent pay equity settlement. Specialist knowledge is lacking, and career pathways are often limited. A different approach is clearly needed.

Proof change is needed is readily available. A recent OECD report shows that the New Zealand rate of anti-psychotic prescribing for those aged 65 and over rose between 2011 and 2015. The rate in Australia fell during this period and was lower than ours in the first place. Use of anti-psychotics in this way suggests chemical restraint is being used rather than patient centred care. Such an approach is totally at odds with respect, human rights, and is a small indication of the enormity of the change required.

We need approaches which work. Health and social services rely on a mixed model of provision with public, private and NGO organisations all included. All three parts need to be viable and sustainable in the long term yet there appears to be no strategy for the sector to achieve this. Reliance on the market has not worked and has left significant areas unable to deliver adequate services.

Conclusion and recommendations

We will all do well if our elders can thrive. However, New Zealand is not currently well prepared for the significant demographic changes ahead. Major changes are needed to create the environment and contexts which are beneficial to all, and to ensure that no one generation lives well at the expense of other generations.

We need to acknowledge our lack of preparedness, develop a strategy based on the evidence we have, and make changes whereby older people are included in our communities, able to get the services they require, carers are able to care, and the rest of us can look forward to our latter years with some sense of security.

Alzheimers NZ recommends New Zealand's strategy for responding effectively to its ageing population:

1. Is based on principles which include:
 - Promoting and achieving the best possible lives for older people;
 - Support for inter-generational balance;
 - A strong evidence base; and,
 - A focus on lives people want to lead.

2. Focuses on a society which is inclusive, non-discriminatory towards older people and those with cognitive impairments; where age and experience are valued, and where people are supported to contribute.
3. Recognises and incorporates the 'big levers' which foster social inclusion, for example, housing, employment, taxation, the welfare system, age-friendliness, accessibility, health, and social services.
4. Promotes and supports sufficient people with the right training and skills, together with the infrastructure needed to deliver services for the ageing population.

He whiringa takitahi ka hunahuna

He whiringa ngatahi, ka raranga, ka mau

If you plait the strands, one strand at a time, the ends will fray and fragment. If you weave them together, they will hold.

Appendix 1: What is dementia?

Dementia is an umbrella term used to describe a group of conditions affecting how well our brains work. Anyone can develop dementia, and the chances of its occurrence increases with age. Alzheimers disease is the most common type affecting around two-thirds of people with dementia. Vascular dementia, frontal-lobe dementia, and Lewy body dementia are also relatively common. Some people develop alcohol related dementias.

Symptoms people experience depend on the parts of the brain affected and include cognition, neuropsychiatric symptoms, and ability to carry out everyday tasks. Changes in memory, thinking, behaviour, personality and emotions are commonly observed. There is often comorbid illness.

Dementia is progressive with changes gradually spreading through the brain leading to worsening symptoms and eventual death. The condition is different for everyone, and what people experience, and how quickly they are affected is unique to them. What people can do, remember and understand may change from day to day.

Appendix 2– About Alzheimers New Zealand

Vision - Towards a world without dementia, Kia mate wareware kore te ao

Mission - A dementia-friendly New Zealand, Aotearoa, he aro nui ki te hunga mate wareware

Alzheimers NZ (www.alzheimers.org.nz) was established in 1986 and is the lead organisation at a national level representing people living with dementia and seeking to end its negative impact. We advocate at a national level for those affected by dementia by raising awareness, providing information and resources, advocating for high quality services, and promoting and enabling research about prevention, treatment, cure and care. Our patron is Sir Richard Faull, Director the Centre for Brain Research at Auckland University.

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. The services include assistance for newly diagnosed people about understanding and living with a dementia diagnosis; support for family, friends and whanāu coping with caring; support groups and day programmes.

We work:

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

We are currently focussing our attention on:

Delivering New Zealand-wide dementia-friendly programmes that challenge individuals and organisations to become involved:

- *Dementia Friends* an educational programme for individuals to learn more about what it is like to live with dementia and turn that understanding into simple actions that can help people with dementia to live well.

- *The Dementia-Friendly Recognition Programme* engages businesses and organisations in working with people living with dementia to embody dementia friendliness in their operations and activities.
- Producing a comprehensive set of services and standards for best practice dementia care designed to lift the quality of care and support and be the 'go to' standard for dementia care and support in New Zealand.
- Providing a comprehensive suite of information resources for people living with dementia, and practical support and advice through our website.
- Holding our 2018 conference which will be a platform for harnessing the best insights and knowledge from a range of sectors that can all help us to meet the dementia challenge.

The voice of people with dementia will be strongly represented in all of these initiatives, ensuring their right to determine their future is well and truly heard. Supporting them with a range of practical services remains at the core of what we do, including through our network of local Alzheimer's organisations.