



Submission

**Government Inquiry into
Mental Health and Addiction**

June 2018

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Introduction and summary of recommendations

People with dementia are one of the most neglected groups in our society. Some have no voice, and the voices of others go unheard. Our submission reflects the voice of those affected by dementia. Alzheimers NZ met with Hon. David Clark, Minister of Health, in February and he recommended we make a submission to this Inquiry.

Our recommendations are consistent with the action areas of the World Health Organization (WHO) *Global Action Plan for the Public Health Response to Dementia 2017-2025* of which New Zealand is one of the 194 signatories. Our hope is for better targeted services to improve the quality of life of people living with dementia; a reduction in the impact of dementia on mental and wider health services; and, a reduced negative impact on and the economy as a whole.

In summary, our recommendations are to:

1. Fully implement the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013) to create an integrated approach to risk reduction, improve mental health and enable those with dementia and their care partners to live better lives.
2. Implementation of the *Framework* to focus first on:
 - a. Promoting dementia risk reduction by:
 - Encouraging prompt treatment of hearing loss;
 - Including older adults in mental health promotion campaigns; and
 - Extending existing preventative approaches to obesity, diabetes, and cardio-vascular disease to middle aged and older adults, and including information that will reduce the risk or delay the onset of dementia.
 - b. Establishing the navigation services outlined in the *NZ Framework for Dementia Care*.
 - c. Providing 12 months of post-diagnostic support for people diagnosed with dementia, and their family/whānau care partners to help them to live well.

- d. Producing high quality hard copy accessible information to support people diagnosed with dementia, and their family/whānau.
3. Following (2), shift the focus to:
 - a. Supporting people to live well and independently for as long as possible by:
 - Promoting and creating a dementia-friendly New Zealand, including developing a national public awareness programme; and
 - Ensuring care partners can take planned breaks and support their own health by having access to a range of respite care options.
 - b. 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” (2017, p.31).
4. Use the UN Convention on the Rights of Persons with Disabilities to support people with dementia to access their human rights, particularly regarding:
 - Stigma and discrimination;
 - Legal capacity;
 - Restraint, isolation, and inappropriate use of medications; and
 - Health services which support people with dementia and their care partners to live well.

Background

‘Dementia is the greatest global challenge for health and social care in the 21st century,’ Livingston, G et.al., (2017), *The Lancet Commission on Dementia*

Dementia is a significant and growing challenge

Dementia is one of New Zealand’s most significant and growing healthcare challenges. More than 62,000 people are currently estimated to have the condition. 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 (Deloitte and Alzheimers NZ, 2017, p.8). These numbers are just those with the diagnosis. Every one of these people has family and friends who are significantly affected. Four out of five New Zealanders know or have known someone with dementia, according to recent Alzheimers NZ research (2017, p.3). Alzheimer’s disease and other dementias have been reported as the leading cause of death in England and Wales, and the second leading cause in Australia.¹

Costs of dementia in New Zealand are currently over \$1.7 billion per annum and are projected to increase to almost \$5 billion in today’s dollars by 2050 if nothing changes. Costs are already estimated to have increased by over 75% since 2011 from \$955 million to \$1,676 million in 2016 (Deloitte and Alzheimers NZ, 2017, p.10). Increasing dementia costs will significantly increase financial pressure on mental health services and other parts of the health system. Reducing the projected cost increase is therefore an urgent priority.

While the impact of dementia is growing significantly with our ageing population, there is a lack of investment in supporting people living with dementia in our communities. The health system is already overwhelmed and struggles to provide adequate support and services to people living with dementia now. The rapidly increasing numbers projected over the next few decades could completely overload its capacity.

¹ References vary, see Office of National Statistics (2016) *Deaths registered in England and Wales (Series DR): 2015*, UK, and Australian Bureau of Statistics (2017) *Causes of Death*, Australia, 2015, Australian Bureau of Statistics.

Currently, it is estimated that only 50% of people with dementia have a diagnosis (Alzheimer's Disease International, 2016, p.6). Many of those with a diagnosis report inadequate, inflexible, and inconsistent services across the country. Care partners have significant unmet needs which place further demands on the health sector. The unmet needs, inequities, and unfair treatment underpin a series of human rights issues which are addressed later in this submission.

The link between dementia and wider mental health

'You look perfectly all right; you are bringing it on yourself by talking about it.' (Person with dementia quoting comment from a colleague)

There are many overlapping and parallel issues which sit at the nexus of dementia and wider mental health. Some of these are discussed below.

Care partner mental health

Dementia can cause changes in relationships, stress, loneliness, lost careers, and reduced income, putting 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. Around 40% of family/whānau dementia care partners have clinically significant depression or anxiety (Livingston et al., 2017, p.38). 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 (2015, p.2).

Psychiatric symptoms of dementia

Dementia may be foreshadowed by major depression, schizophrenia or apathy and irritability; sometimes psychiatric disorders complicate the course of dementia. Around 18% of people with dementia experience psychosis (Livingston, et. al., 2017, p. 27).

Depression and dementia

Depression is both a risk for and a common feature of dementia. It is unclear, if depressive symptoms are a cause of dementia at a time of vulnerability or an early symptom of dementia (ibid., p.9). Both result in withdrawal from social activity, forgetfulness, problems organising and planning, and mild cognitive impairment.

Spiralling impacts of mental unwellness

Care partner depression and anxiety symptoms also affect the person with dementia and wider society. They predict care breakdown, elder abuse, and earlier admission to residential care for the person with dementia (ibid. p.38).

Getting help can be difficult

Getting help can be a challenge. The *New Zealand Framework for Dementia Care* sets out 'good practice points' for dealing with depression and anxiety, the behavioural and psychological symptoms associated with dementia, pain, alcohol and drug addiction, abuse and neglect, carer stress and depression, and reducing stigma (pp. 31-37). However, the *Framework*, developed in 2013, has yet to be fully implemented.

Dementia as a mental health condition

There is confusion about where dementia sits vis-à-vis mental health. This is not confined to New Zealand. Such confusion and inconsistency about where dementia fits may result in it falling through gaps in administrative systems resulting in disjointed approaches and a negative impact on both those with dementia and their care partners.

The confusion starts with naming. Dementia types are variously described as neurodegenerative diseases, disorders or conditions. They are also referred to as mental disorders or cognitive disabilities.

Influential bodies which include dementia amongst 'mental health conditions' include the *Diagnostic and Statistical Manual* which has renamed it 'Major cognitive disorder' (UpToDate, 2018), the World Health Organization (2013)² the UK's influential Foresight Mental Capital and Wellbeing Project (2008), the Royal College of Psychiatrists, the Australian Government's Co-operative Research Centre for Mental Health, and the New Zealand Mental Health Foundation.

Yet, despite the connections drawn by international and national bodies, the new *Mental Health and Addiction Workforce Action Plan 2017–2021* (Ministry

²The Mental Health Action Plan 2013-2020 applies the term "mental disorders" to denote a "range of mental and behavioural disorders that fall within the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) including depression, bipolar affective disorder, schizophrenia, anxiety disorders, dementia [our emphasis], substance use disorders, intellectual disabilities, and developmental and behavioural disorders ...including autism"

of Health, 2018) makes no connection with the *New Zealand Framework for Dementia Care* even though it highlights links with numerous other policies and plans.

Assisting people affected by dementia – our recommendations

‘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

We are left with the impression that, at minimum, people with dementia and those who care are a low priority for Government action. This is despite urgent and wide-ranging needs in the dementia sector, and easy ways of making significant improvements. These are addressed in the section which follows.

New Zealand cannot afford to do nothing

There is currently no cure for dementia.³ The \$1.7 billion annual economic costs 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. Productivity losses alone for individuals with dementia are estimated at around \$240 million per year (Deloitte and Alzheimers NZ, 2017, p. 45).

The increased health costs due to caring-related illness or disability are not included in the economic cost estimate. Costs incurred or income forgone due to stigma and discrimination are also not included. Even without these costs,

³ However, substantial international resources are being dedicated to research to find a cure or a disease modifying therapy.

Deloitte describes dementia as “one of the most significant public health burdens in New Zealand” (ibid., p.14).

We have already referred to pressures on the health system. Specifically, 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 (Associate Minister of Health, 2016, p.13). Many of these older people will be affected by dementia.

Analysis Alzheimers NZ has undertaken with Deloitte estimates that making changes which keep people as well as possible and at home for longer could achieve cost benefit ratios of \$6.60 for every \$1 invested and reduce the projected \$5 billion per year future cost. 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, then \$262 million per annum can be saved (op.cit. p.65).

First steps to a better future for people living with dementia

Our organisation has identified initial steps to help make this happen and reduce some of the inequities. We support the *Healthy Ageing Strategy's* linked goal to “reverse or slow declines in health and function, and promot[e] and support behaviours and other factors that enhance people’s capacity” (Associate Minister of Health, 2016, p.33). We also support the *Healthy Ageing Strategy's* identification of those with dementia as a “priority population”, and its commitment to implementing the “New Zealand Framework for Dementia Care “... to give people who are living with dementia the best possible independence and wellbeing” (p.34).

Implement the NZ Framework Dementia for Dementia Care

Our chief recommendation is for full implementation of the *Framework* as an urgent priority. We are disappointed that after five years there has been little progress to date, and the only result is the problem has become more urgent.

Four immediate changes which will make a major difference and assist that implementation of the *Framework* are:

- *Prevention and risk minimisation* – delaying or preventing the incidence of dementia by up to 35%;
- *Dementia navigation services* – efficient and more timely access to services;
- *Post-diagnostic support* – helping people to live well and to prepare for the future;
- *High quality information resources* – dispelling myths and enabling ‘best practice’.

Prevent dementia and minimise risk

‘Prevention or delay of dementia onset is a public health priority with potential to reduce not only the disability of individuals but also the associated societal and economic burden.’

(Livingston, G. et al, 2017, p.14)

While New Zealand is working hard to reduce risks for mental illness, this is not apparent in the dementia sector. The WHO *Global Action Plan* mandates national efforts for prevention of ‘noncommunicable diseases in general and dementia in particular’ (p.20). Prevention is now a key element of many national strategies, for example, in Wales, Scotland, England, Australia, Finland, Italy, Indonesia, Greece, and the Republic of Korea.

Evidence compiled by Livingston et.al. for the *Lancet Commission on Dementia, Prevention, Intervention and Care* shows effective prevention measures do make a difference and have the potential to delay or prevent around 35% of dementia cases (p.6). For example, little attention is being paid to hearing loss which could ameliorate isolation, counter depression and anxiety, and reduce cases of dementia by 9%. (ibid. p.7). People with dementia are left out of mental health promotion campaigns despite such things as social connection, ongoing learning, and physical activity being known to be important elements of risk reduction.

We also know that childhood education below age 12; active treatment of mid-life hypertension; reduced smoking; and, management of diabetes and obesity can all help to reduce levels of dementia. Essentially, what is good for the heart is good for the brain.

The Lancet's recommendations are not new.⁴ Many of these activities feature in the *New Zealand Health Strategy* and *Healthy Ageing Strategy*. However, little is being done to target effective health promotion towards middle aged and older adults as recommended by the WHO.

Alzheimers NZ recommends quality dementia risk reduction and health promotion activities be directed at middle aged and older adults.

Provide navigation services to help people access assistance

'The aim is ... to help the person with dementia and their family and whānau navigate through the health and social support system. ... [Navigation services] will help by providing advice, encouraging self-management, explaining the pathway, coordinating referrals and providing a point of continuity. [When a specific navigator is involved] the role will be undertaken by a member of the person's primary health care team.' *New Zealand Framework for Dementia Care*, (p.21)

Navigating through the health and social support systems can be very confusing and frustrating. Navigation services help smooth the path for those with dementia and their care partners. They are a priority action in the 2013 *Dementia Framework*, South Island Alliance's vision and template for a shared model of care (2017), and are supported by the Productivity Commission (2015, p.17). Navigation services provide the first point of contact for the person with a diagnosis and their family/whānau as they begin 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 navigation services are already provided; others will require a dedicated role or could be provided via technology. Therefore, 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 (Alzheimer's Society UK, 2016; Clarke, C et.al., 2013).

Alzheimers NZ recommends that navigation services are established across the country. We propose navigation is first piloted in one or two DHBs, which could be started for a fraction of the cost of a national implementation. This

⁴ Apart from the finding about preventing hearing loss.

allows assumptions about costs to be tested, and implementation questions to be addressed.

Provide 12 months post-diagnostic support to help people live well

‘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 Advisory Group member

The early post-diagnostic period is the time when the person with dementia and their family/whānau start thinking about future plans and look around for solutions. Alzheimers NZ recommends providing a minimum of 12 months post-diagnostic support services for those diagnosed with dementia and their care partners. This is already in place in the UK. In Scotland, the 5 Pillars Model of Post Diagnostic Support provides people with dementia and 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.⁵

One of the advantages of this approach is it can both delay the transition to residential care and reduce subsequent care requirements. The post-diagnostic support can also improve the quality of life for people with dementia and their family/whānau/care partners, reducing both stressors and associated costs.

Provide user-friendly information with high quality resources

Alzheimers NZ recommends Government funds high quality information brochures to support people with dementia and their care partners to better understand the options after diagnosis.

Information which is easily accessible, consistent and regularly reviewed to represent ‘best practice’ is an essential component of support for people with dementia and their care partners. Providing this information facilitates more timely access to support for those affected by dementia and reduces some of the associated difficulties.

⁵ Kelly F et al (2016). See also Lithgow S (2014.)

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 advise hard copy information is also needed.

Taking the next steps in implementing the Framework

Foster dementia-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.”
Person with dementia

Most people with dementia live at home for most of the time after the diagnosis. Most want to continue to live their lives, and maintain their interests, activities, hobbies, and community connections. However, many do withdraw into the relative safety and comfort of their own homes and become isolated following a diagnosis. Increased isolation is associated with further cognitive decline (Livingston, G. et al, 2017, p.9).

Dementia-friendly communities assist older people generally, and people with dementia specifically, to live 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 New Zealand with Rotorua already well advanced towards becoming a dementia-friendly community (Dementia-friendly Steering Group, 2017). Evidence suggests that dementia-friendly communities can and should work closely with the wider concept of Age-friendly communities (Turner N et al., 2016).

Alzheimers NZ recommends Government take the following measures in line with the WHO *Global Action Plan on the Public Health Response to Dementia* (p.15):

- Establish a national public awareness programme on dementia to support and promote a dementia-friendly New Zealand; and
- Actively support national dementia-friendly initiatives such as the *Dementia-friendly Recognition Programme* and *Dementia Friends* (See Appendix 1).

Ensure access to adequate appropriate respite care

Care partners can only care if they have adequate support. Without this, they can burn out, get sick, or give up. *A Guide for Carers* emphasises the importance of having a break (Ministry of Social Development, 2016, p.21). 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.

For respite care to work it also needs to:

- Be easy to access and navigate, well-co-ordinated, proactive and responsive to the needs of family and whānau;
- Be available in a range of forms, therefore able to meet the needs of people at different ages and stages; and
- Involve appropriately skilled staff, with help available to care for and support people with dementia.

Advisory Group member, Alzheimers NZ

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.

Alzheimers NZ recommends Government ensures that care partners have access to a range of respite services and the ability to plan for a break in advance, as is envisaged in the *New Zealand Framework for Dementia Care* (p.25) and Action 22a of the *Healthy Ageing Strategy* (p.63).

‘... I feel pressure from health professionals to “put [husband] into care” for my own good. I feel that I am expected ... to send [husband] to [X, Y or Z] between 50-90 km away. In these places he is further isolated, has no visitors, he is alone, afraid as he feels his brain deteriorate and he feels bereft. The last place he was at ... he would have been left alone for most of the time with nothing to do...’ Alzheimers NZ Consumer Advisory Group member and care-partner

Improve our national data collection

New Zealand has no formal national data collection on dementia. This impacts our understanding of the condition in New Zealand, the supply and demand for services and the costs associated with service provision. For instance, while dementia is recorded as a major or as the leading cause of death in many countries, its importance as a cause of mortality is not recognised or often recorded in New Zealand.

It is unusual internationally 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 such as ones from Deloitte regarding the economic impact of dementia. However, these figures are based on best estimates from overseas research and are approximations of the New Zealand situation.

As *Brain Research New Zealand* and others have stated, homegrown research on prevalence and other issues is needed.⁶ Alzheimers NZ notes Government already collects data about other significant conditions, such as diabetes.

The *New Zealand Framework for Dementia Care* includes numerous overarching 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.

Alzheimers NZ recommends Government 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” (p. 31).

People living with dementia and human rights

‘... [P]eople living with dementia have the right to participate in society, and ... those responsible for protecting the human rights of people living with dementia should be held accountable for any human rights

⁶ 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?”, and Cullum, S et.al., (2018) “Do community-dwelling Māori and pacific peoples present with dementia at a younger age and at a later stage compared with Europeans? In *Int. J. Geriatr. Psychiatry*, 1-7.

violations. ... [T]here should be increased education about dementia to change attitudes of society and reduce stigma ... people living with dementia should be empowered to participate in decision making processes and to maintain their legal capacity.’ WHO (2015) P.4.

People living with dementia are as entitled to their human rights as anyone else. Too often the human rights of this group are either forgotten about or ignored. Alzheimers NZ would be delighted if this Inquiry could apply a United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) lens to its work to assist those affected by dementia to access their human rights. There are numerous examples of where access to human rights could be improved:

Stigma and discrimination (UNCRPD Preamble and Article 3)

Pejorative beliefs about dementia impact before diagnosis and result in people’s reluctance to get a diagnosis. Every member of our Advisory Group reports problems with stigma and discrimination.

Stigma and discrimination then follow the diagnosis. They reduce people’s ability to live full and meaningful lives and to contribute to society. 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 while people talk to my care partner’. Confidence loss, job/role loss, and social status loss follow. The nation loses out as people withdraw and dramatically reduce their contribution to wider society. Despite the close correlation with age, around 10% of those with dementia in New Zealand are under 65.

Anti-stigma and discrimination campaigns have not been applied to those with dementia. The *Like Minds Like Mine* campaign, while laudable, appears to be silent on this area, 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).

‘You can’t have dementia; you are too young’ (Person with dementia/
Advisory Group member quoting comment from colleague)

‘How can you drive when you have dementia?’ (Person with dementia/
Advisory Group member quoting comment from colleague)

Legal capacity (UNCRPD Article 12); Inclusion in the community (UNCRPD Article 19)

People who struggle to exercise their legal capacity are often assumed to have lives of little value. They are overlooked when it comes to quality care, and supportive palliative care is frequently absent. It is salutary that on the one hand, we are currently concerned enough about youth suicide to compassionately address unbearable pain and suffering and reduce suicide rates by reviewing mental health services while on the other hand, as we are considering the End of Life Choice Bill to ‘compassionately address unbearable pain and suffering via assisted dying.’ There appears to be a significant contradiction with one group of people’s lives potentially being valued more highly than the other. Equal rights have been forgotten.

People in vulnerable situations have the same basic human rights to live well as the rest of the community.

‘Confronted by her illness, her spirit rebelled and became fierce, as it had to. The fierceness was her essence, not an aberration. Mum wasn’t two people, one before and another after she got dementia. The disease robbed her of almost everything, but it freed her intuition.’

Desmond, P, 2018 *Song for Rosaleen*, p. 251

Seclusion and Restraint (UNCRPD Article 14)

Isolation (seclusion?) and restraint are significant issues in the dementia sector. Perceived safety is often the winner when balanced against people’s rights to take risks. *The Crimes Act 1961* effectively encourages restraint with its requirement that ‘anyone who has actual care or charge of a person who is a vulnerable adult and who is unable to provide himself or herself with necessaries is under legal duty to ... protect that person from injury.’ Restraint is then justified as a means of keeping people safe. Isolation (seclusion?) is more likely to be an unintended consequence of people being left alone. Both

can sometimes be a result of society's unwillingness to provide adequate dementia care and resources.⁷

People with dementia do not have the legal safeguards of other groups when it comes to seclusion and restraint. For example:

- Prisoners have the safeguards of the *Corrections Act 2004* and *Corrections Regulations 2005* which put major restrictions on both (Shalev, 2017, pp78-80).
- The *Mental Health (Compulsory Assessment and Treatment) Act 1992* protects those receiving compulsory psychiatric treatment (ibid., 81-82).
- The *Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003* protects persons who have an intellectual disability and who are charged with, or convicted of, an offence (ibid., 82-84).
- The *Oranga Tamariki Act 1989*; or the *Children's and Young People's Well-being Act 1989* protects children in care (ibid., 84-85).

People with dementia have never been the subject of a Human Rights Commission investigation. Direct or indirect use of restraint is known to undermine dignity and autonomy, cause distress, violate human rights, impair mobility and skin integrity and can be ineffective in preventing falls (Livingston, et.al. 2017, p. 41).

Leaving people alone in a room by themselves all day with no meaningful human contact results in numerous symptoms diminishing quality of life (for example anxiety, panic, depression, rage, poor impulse control, cognitive disturbances, perceptual distortions including hallucinations, paranoia and psychosis, migraines, heart palpitations, back and other joint pains, gastro-intestinal and genito-urinary problems, excessive sweating, insomnia, eyesight deterioration, lethargy, dizziness, weakness and profound fatigue, feeling cold, poor appetite, weight loss, diarrhoea, tremulousness and aggravation of pre-existing medical problems (Enggist et.al. 2014, Grassian, 2006, Haney, 2003, Shalev, 2008, 2014; quoted in Shalev, 2017).

If all this is not enough, one third of people with dementia living in residential facilities are on antipsychotics – with significant questions about how much

⁷ Livingston, Gill et al., op.cit.,. Care workers delivering care with inadequate training and resources might use restraints to try and prevent harm p. 41.

such drugs benefit them, according to the OECD (2015, p.14). There is good evidence that person-centred care reduces use of restraint in care homes and hospitals, counters isolation and effective seclusion, and this should be implemented (Livingston et. al., p. 41).

Health (UNCRC Article 25)

When people with dementia cannot access the “highest attainable standard of physical and mental health” their human rights are breached (UN, 1966, Article 12). Human rights are also breached when people cannot access ‘... health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among ... older persons’ (UN General Assembly, 2007, Article 25). Sustainable Development Goal number three is also relevant here: New Zealand is expected to; *‘[e]nsure healthy lives and promote wellbeing for all at all ages’* [our emphasis].

Dementia exacerbates existing gender health inequities. Women are more likely to get dementia, more likely to care for someone with dementia, and more likely to be engaged in low paid work caring for someone with dementia.⁸ Implications for women’s health, social relationships and financial security also present human rights issues, and challenges New Zealand’s ability to achieve Sustainable Development Goal number five: ‘Achieve gender equality and empower all women and girls.’

The Alzheimers NZ 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

⁸ See Savitch, N et.al. (2015).

- 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.

Government and the Community Working Together

Not for profit organisations play a vital role in New Zealand as identified by the Productivity Commission. We bring in money, solutions, community knowledge; access to communities of people who live with dementia; access to service providers, service users, volunteers, research and information. We also have specialist skills and are therefore not interchangeable with more generic organisations. The best solutions are found when government and not for profits work well together. Funding remains a significant issue for non-profit organisations and has important implications for our capability, capacity and ability to innovate.

We need to work together to break the silence around dementia and deal with the urgent issues. Government does this best when it works with effective non-government organisations. The non-government organisations do best when they have sufficient support to do their work.

Support is lacking at present. Addressing this situation means: targeted funding; services which match the needs of clients; responsiveness to Māori and Pasifika aspirations; continuous improvement and learning; meeting public expectations about equity and fairness; and, being able to provide decision-makers with information for making choices.

Our organisation is keen to work with Government and the rest of the not-for-profit and mental health sectors to effectively meet the looming challenges of dementia, and reduce its impact on individuals, families/whānau, communities, and our nation.

‘... 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’ (Deloitte and Alzheimers NZ, 2017, p. 14).

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Appendix 1– 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. 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:

- 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.

Appendix 2: 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.