



CEDAW Secretariat
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Submission on the Convention on the Elimination of All Forms of Discrimination Against Women

A: Introduction – our organisation and submission content

Alzheimers New Zealand is grateful to the CEDAW committee for the opportunity to submit on behalf of New Zealand women affected by dementia. We are also agreeable to our submission being posted in the CEDAW website for public information purposes.

Alzheimers New Zealand

Alzheimers NZ (www.alzheimers.org.nz) was established in 1986 and represents people in New Zealand who live 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 both a national level, as part of the wider dementia community and health and social services sectors, and as a member of the global dementia community.

Our strategy is to build a dementia-friendly New Zealand where 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.

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Dementia- an issue for women

Dementia is a major issue for women as it 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. Implications for women's health, social relationships and financial security present human rights issues, and challenge New Zealand's ability to achieve Sustainable Development Goal number five: '*Achieve gender equality and empower all women and girls*'.

More than 62,000 people currently have dementia in New Zealand. Of these, 57% are women. There are around 40,000 care partners; two thirds of people who care in New Zealand are women. Most of the formal care workforce is also female. All of these groups are negatively impacted by limitations on their access to human rights.

Our submission

There are many discrimination issues we could address; however, this submission is limited to three key aspects which can be clearly defined and where immediate change can occur:

1. Lack of data limits understanding of the scope of the problem;
2. Lack of legal safeguards around restraint for people with dementia breaches human rights; and
3. Poor implementation of healthcare provisions reduces human rights and fosters disadvantage.

B: Promotion of women's human rights and gender equality in law, policy and practice

Lack of data limits understanding of the scope of the dementia problem and its impact on women

The issue

The lack of a nationally consistent data collection on dementia, gender-specific or otherwise is unfortunate policy omission. It impacts our understanding of how the diagnosis impacts on the position of women in New Zealand, the supply and demand of appropriate services, and the economic impact on women and others.

Nature of the problem

It is unusual internationally to have so little data about such an urgent problem, and its lack presents a major barrier to understanding the disproportionate impact on women and making appropriate change. Alzheimers NZ fills some of the gap with commissioned reports from Deloitte on such matters such as the economic impact of dementia. However, these figures are based on best estimates from overseas research and are approximations of the New Zealand situation. Government already collects data about other significant conditions, such as diabetes, cancer and heart disease, so it is highly unusual that data about dementia is absent.

Possible solution

Alzheimers New Zealand recommends the New Zealand government follows the World Health Organization (WHO) recommendation in the *Global Action Plan on the public health response to dementia 2017 – 2025* 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).

Legal protections around restraint are needed for women with dementia

The issue

Unlike other groups, there are no legal protections around use of restraint on people with dementia. Restraint can be direct or indirect; environmental, physical or personal. Leaving people alone, unable to move, for long periods of time, is a form of restraint. The issue arises owing to a combination of safety concerns and society’s unwillingness to provide adequate dementia care and resources (see (Livingston et. al., p.41-2).

Nature of the problem

Perceived safety often takes priority when balanced against people’s rights to take risks. The *New Zealand 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 can then be an unintended consequence of people being left alone.

Dementia affects older women more than anyone else and legal safeguards for this group are absent. All sorts of groups which are not female dominated have greater legal protection. For example:

- Prisoners have the safeguards of the *Corrections Act 2004* and *Corrections Regulations 2005* which put major restrictions on both (93% male).
- The *Mental Health (Compulsory Assessment and Treatment) Act 1992* protects those receiving compulsory psychiatric treatment (60% male).
- 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 (majority male).
- The *Oranga Tamariki Act 1989*; or the *Children's and Young People's Well-being Act 1989* protects children in care (majority male).

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 (ibid.).

If addition, one third of people with dementia living in residential facilities are on antipsychotics – with significant questions about how much such drugs benefit them (see 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.

Possible solution

Alzheimers NZ believes any use of restraint must be minimised. We note the evidence that person-centred care reduces its use in care homes and hospitals and counters isolation. Change will require improved services and standards, and such changes must be implemented. More information about how this can happen is contained in section C of this submission.

Alzheimers NZ also recommends that government ensures those in residential care are protected by adequate **legislative** safeguards regarding restraint and isolation.

C. Specific human rights and equality challenges faced by certain groups of women in New Zealand

Healthcare for women affected by dementia is inadequate

The issue

When women with dementia and their care partners cannot access the 'highest attainable standard of physical and mental health' their human rights are breached. Human rights are also breached when women 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'. Sustainable Development Goal number three is relevant here: New Zealand is expected to; '[e]nsure healthy lives and promote wellbeing for all at all ages' [emphasis Alzheimers NZ].

Nature of the problem

The Alzheimers NZ Advisory Group does not believe that health 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 (including reducing stigma and discrimination);
- 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
- 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.

Possible solution

New Zealand developed the *New Zealand Framework for Dementia Care* in 2013. After five years there has been little progress in implementation, and the only result is the problem has become more urgent. Therefore, **our chief recommendation is for full implementation of the *Framework* as an urgent priority.**

Four initial steps will help progress this goal:

a. Risk reduction

Risk reduction 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. For example, greater attention to hearing loss could ameliorate isolation, counter depression and anxiety, and reduce cases of dementia by 9%. Other factors which can make a difference include social connection; ongoing learning; physical activity; childhood education below age 12; active

treatment of mid-life hypertension; reduced smoking; and, management of diabetes and obesity. Essentially, what is good for the heart is good for the brain.

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

b. Navigation services to help people access assistance

Navigation services help smooth the path for those with dementia and their care partners and are a priority action in the 2013 *Dementia Framework*. 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. Therefore, navigation services supplement rather than replace what already exists. Overseas evaluations of these functions show positive outcomes for people with dementia and their care partners.¹

Alzheimers NZ recommends that **navigation services are established across the country.** We propose navigation is first piloted in one or two District Health Board (DHB) areas, which could be started for a fraction of the cost of a national implementation. This allows assumptions about costs to be tested, and implementation questions to be addressed.

c. Twelve months post-diagnostic support to help people live well

The early post-diagnostic period is the time when a woman with dementia and her 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 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.

d. User-friendly information with high quality resources

Information which is easily accessible, consistent and regularly reviewed to represent 'best practice' is an essential component in supporting people with dementia and their care partners. Providing this information facilitates more timely

¹ See Alzheimer's Society UK (2016); Clarke, C et.al. (2013).

access to support for those affected by dementia and reduces some of the associated difficulties.

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.

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.**

Next steps:

After these initial steps have been put in place, two other key issues should be addressed; i.e.

e. Foster dementia-friendly communities

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 New Zealand's *Healthy Ageing Strategy* (e.g. Action Plan numbers 1a and 11b).

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*.

These programmes enable 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. They also engage businesses and organisations in working with people living with dementia to embody dementia friendliness in their operations and activities.

f. Ensure access to adequate appropriate respite care

Care partners without adequate support can burn out, get sick, or give up. *A Guide for Carers* emphasises the importance of having a break. 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.

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.

Alzheimers NZ recommends **Government ensure 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).**

Conclusion

Alzheimers New Zealand is left with the impression that, at minimum, people with dementia and those who care are a low priority for our Government. This is despite urgent and wide-ranging needs in the dementia sector, and easy ways of making significant improvements. We are hopeful that our recommendations will be seriously considered, and real progress can be made to improve the lives of those with dementia and those who care.

Thank you for considering our submission.

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