



The Human Rights of Older Women

Thank you for the opportunity to inform the Independent Expert's report on the Human Rights of Older Women. Alzheimers New Zealand is very concerned about older women in Aotearoa who either have dementia or are caring for someone who has dementia. We are very pleased to be able to take this chance to help improve their human rights.

Alzheimers New Zealand and submission focus

Alzheimers NZ represents people living with dementia. We work at a national level raising awareness, providing information and resources, advocating for high quality services, and promoting research about prevention, treatment, cure and care.

We work with local Alzheimers organisations which provide support, education, information, and related services directly to members of their communities who are affected by dementia.

We have restricted our response to question 4 and the *specific challenges and concerns faced by older women, including on the basis of their accumulated life experience as compared to older men, in enjoying their economic, social and cultural rights ...*. The focus of our response is women living with dementia in Aotearoa, their human rights, and the urgent need for an implemented dementia action plan to help them access their human rights.

Older women are more likely to be affected by dementia

New Zealand is not the only country involved. Older women affected by dementia face many issues impacting on their human rights all around the world. In 2015, Alzheimers Disease International published a research review on women and dementia. Among its findings were that:¹

- Across all regions of the world, dementia disproportionately affects women.

¹ Rosie Erol, R; Dawn Brooker, D; Peel, E (2015) [Women and Dementia A global research review](#), Alzheimers Disease International

- More women than men develop dementia.
- A large proportion of carers of people with dementia are women, in both informal and formal capacities.
- Women provide a significant amount of unpaid care to those with dementia across all settings.
- Women are often in need of support to continue within this caregiving role, considering the associated health and financial difficulties involved.
- Women are often unaware of the assistance that is available to them as finding it is often confusing.
- The low status, financial rewards and inadequate training and support for paid care work impacts on women, their families and people living with dementia.
- There is very little research in any context involving women with dementia as participants which focus on the gender issues of living with dementia.
- There is a need for further research into the impact of dementia on women as caregivers over time.

Global trends feature in Aotearoa New Zealand

Many of the concerns raised in the international report are reflected in Aotearoa's experience. Alzheimers NZ research indicates that the estimated number of women who have dementia in Aotearoa is around 30% higher than the number of men. Women account for 67% of those aged 85+ who have dementia.²

Women are also more likely than men to be caring for someone with dementia. National data specifically relating to dementia, women and caring is unavailable, however the 2013 Census showed around 63% of all unpaid carers are women.

² [Dementia Economic Impact Report](#), 2017, p. 26

The recent UN visiting Independent Expert described people with dementia in Aotearoa as among the “most ostracized and the vulnerable of the vulnerable”.³

Lack of information renders issues invisible

As in other parts of the world, the lack of data around women, dementia, and human rights is a significant issue. It makes it very difficult to understand just what is occurring and what is needed. Despite being a signatory to the *Global Action Plan on the Public Health Response to Dementia 2017 – 2025*, New Zealand does not yet have an implemented dementia plan.⁴ Both of New Zealand’s major political parties have committed to such a plan, but positive action around implementation is yet to occur.

Right now, Aotearoa has no systematic, routine tracking and population-level monitoring of core dementia indicators which can guide evidence-based actions to improve dementia services. This lack of knowledge means it is very difficult for older women who live with dementia to (a) advocate for their rights, and (b) improve their ability to enjoy the rights they are entitled to. It means their voices are largely unheard. An implemented dementia action plan would solve many of these problems.

Older women with dementia in Aotearoa: what we know now

Alzheimers NZ has undertaken research on the lived experience of women with dementia. This qualitative investigation performed by Litmus indicates women need:⁵

- To be better treated by health services (health):

Woman with dementia: [The specialist] asked how I was. And I said, ‘I was fine’, and she said, ‘I wasn’t as good as I thought’. So of course, my instant reaction was, ‘how dare you talk to me like that’. And then she says, ‘you’re never going to be well’. (p.30)

³ Kornfeld Matte, R (2020) [End of Mission Statement by the United Nations Independent Expert on the enjoyment of all human rights by older persons, Ms. Rosa Kornfeld Matte, on her visit to New Zealand](#)

⁴ WHO (2017) [Global Action Plan on the Public Health Response to Dementia 2017-2025](#).

⁵ Smith, E., Lamb-Yorski, R., Thompson, A., & Grootveld, C. (2019). [This is our story: A qualitative research report on living with dementia](#). Wellington, New Zealand: Litmus

- To be able to retain as much self-determination as possible (social)

Woman with dementia: *It's all a question of admitting people with dementia have still got reasoning powers [sic] (p.37)*

Woman with dementia: *...I said, 'no I don't want to live with any family, I want to still be independent on myself, and if I go into a rest home, I can still be independent on myself.' [sic] ... (p.41)*

Woman with dementia: *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. ...If you're dealing with older people, let them make the decisions instead of forcing things. (p.43).*

Woman with dementia: *People with quite advanced dementia can still reason, given the opportunity to do so. So that's what I've been saying all the time and wherever I go. For goodness sake, let's work things through. (p.44).*

- To be able to remain engaged with life (social)

Woman with dementia: *I like being busy. I like my life to be occupied all the time. I don't like sitting around reading. I like to do things in life. (p.52).*

Woman with dementia: *I love coming ... I make little things and take it home and show them what I did today. And I make it at home and the young grandchild wants to know how to make it, so I show them. (p.58).*

Older women as care partners in Aotearoa: what we know now

As in other parts of the world, specific work on older women care partners is difficult to find, and work on older women care partners caring for someone who has dementia is largely non-existent. New Zealand's recent Welfare Expert Advisory Group work showed that older carers (of anyone) are particularly vulnerable to social isolation.⁶ Most older carers are looking after a partner or spouse. The demands on older carers' reduces their ability to take part in social activities, which can result in a lack of social connectedness. They

⁶ Welfare Expert Advisory Group (2019) [Current state: Carers of people with health conditions or disabilities](#)

may also be managing their own health conditions and require support themselves, alongside dealing with the demands of being a carer. New Zealand has developed [Mahi Aroha: the Carers' Strategy Action Plan](#) which does aim to address many of these concerns around caring generally.

Right now, the Alzheimers NZ research on the lived experience of dementia includes female carers reporting:⁷

- Difficulties accessing service provision (health):

Female care partner: *The doctor lets the caregivers down. We are relying on the doctor as we had no experience.*

Female care partner: *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.*

- Difficulties accessing respite care (health):

Female care partner: *I could get through to respite care, but they are very busy, as they have a big list.... .*

- Stigma and discrimination (health/ social):

Female care partner: *... they [the family] didn't come around, maybe because they didn't want to face the reality of accepting what has happened... Their thought was put her in a home, and I didn't get why they wanted to do that; she's still cognitive.*

Female care partner: *I get the feeling ... 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.*

- Lack of support:

Female care partner: *I'd love lessons about coping skills, and I feel like care partners get very little support in the current situation. I think it would be a big benefit to have a counsellor who was trained in this sort of stuff, but the general counsellor just told me*

⁷ Smith, E., Lamb-Yorski, R., Thompson, A., & Grootveld, C. (2019). [This is our story: A qualitative research report on living with dementia](#). Wellington, New Zealand: Litmus

to slow down and relax. I can't do that, I didn't feel like he understood me.

Conclusion

The *WHO Global Action Plan on the Public Health Response to Dementia 2017-2025* recognises the disproportionate impact of dementia on women. The *Alzheimers Disease International* report recognises that women will continue to provide care, whether this is due to societal expectations, or an individual wish to support members of their family and friends. It states that “whatever their motivation, there needs to be adequate and appropriate information and support in place to enable these women to provide care, and feel cared for themselves”.⁸ The international dementia plan requires signatories such as New Zealand to have their own dementia action plans in place. Such plans will include their own indicators, measures and standards which will help to meaningfully assess the ability of older women affected by dementia to access their human rights. We hope that progress in this area will mean we are able to describe a more positive situation around the human rights of older women the next time we report.

⁸ WHO (2017) [Global Action Plan on the Public Health Response to Dementia 2017-2025](#)