



29 November 2019

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Submission to the New Zealand Dementia Care Cooperative on the Draft New Zealand Dementia Plan 2020 to 2023

Introduction

- 0.1. The National Council of Women of New Zealand (NCWNZ) is an umbrella group representing over 200 organisations affiliated at either national level or to one of our 15 branches. In addition, about 450 people are individual members. Collectively our reach is over 450,000 with many of our membership organisations representing all genders. NCWNZ's vision is a gender equal New Zealand and research shows we will be better off socially, environmentally and economically if we are gender equal. Through research, discussion and action, NCWNZ in partnership with others, seeks to realise its vision of gender equality because it is a basic human right.
- 0.2. Our submission was prepared by the NCWNZ Health Standing Committee in consultation with individual NCWNZ members with relevant experience and expertise. and by drawing on relevant NCWNZ policies and resolutions.

1. Executive Summary

- 1.1. NCWNZ welcomes the opportunity to take part in the consultation on the Draft New Zealand [NZ] Dementia Plan 2020 to 2023 ("The Plan"). Our submission addresses the four key questions set out in the covering letter from the NZ Dementia Cooperative.
- 1.2. NCWNZ considers the principles, objectives and actions are all excellent, with some suggested additions that, if fully implemented and sufficiently resourced, mean the Plan would significantly improve the quality of life for people with dementia and their family/whanau and carers.
- 1.3. Our suggested additions and amendments focus on emphasising acceptance and respect, reducing stigma, sufficient support for family and carers, building local community support networks and acknowledging the wide range of professions/ sectors involved in implementing the Plan.

2. Introduction

- 2.1. The Draft NZ Dementia Plan 2020 to 2023 is particularly important for women as about 30% more women than men are living with dementia, and women are usually, the main carers for people with dementia.
- 2.2. NCWNZ has long advocated for better services and support for elderly people, disabled people and those with chronic conditions including dementia, and for their family/whanau and carers. Our submission in 2005 to *Standards New Zealand on DZ8134.6 Guidance for Community Services for People with Dementia and Audit Workbook*¹, emphasised many of the objectives and actions set out in the Draft Dementia Plan, including: holistic, integrated approach, access to appropriate, professional assessment, early identification and diagnosis; education and empowerment of the person and family/whanau and carers, active partnerships between family carers, people with dementia, professionals and service providers in the planning and provision of services; good governance and dynamic leadership.
- 2.3. Therefore, we strongly support these principles, objectives and actions with some suggestions for strengthening and addressing apparent gaps. We particularly welcome the holistic, integrated approach of the Plan, alignment with other Government Strategies and recognition of the importance of a healthy lifestyle and social connection as preventative measures, as with other chronic non-communicative conditions.
- 2.4. As noted, our submission is structured around the four key questions set out in the covering letter from the NZ Dementia Cooperative:
 1. Do the principles provide the right foundation for the Plan?
 2. Are the objectives the right ones?
 3. Will the proposed actions make a difference for people living with dementia?
 4. What have we missed?

3. 1. Do the principles provide the right foundation for the Plan?

- 3.1. We believe these are all excellent principles, but have the following suggestions and comments for improvements:
- 3.2. **Person-directed**- we recommend inclusion of a clear statement that people with dementia should be accepted and treated with respect. Difficult behaviour can be caused or exacerbated by attempts to control or hide that behaviour and to take away all agency from the person.
- 3.3. **Integrated**- other sectors such as Police and other first responders like para medics and the Fire Service, also have an important part to play. Schools are critical to education on healthy lifestyles and acceptance of people who are different, including those with dementia.

¹ <https://www.ncwnz.org.nz/wp-content/uploads/2013/06/S05.46-DZ8134.6-Guidance-for-Community-Services-for-People-with-Dementia-and-Audit-Workbook.pdf>

- 3.4. **Evidence based and best practice-** the statement “balancing medical care with person- centred care” is somewhat confusing in relation to the “person-directed” principle - that all medical care should be “person centred”. Is the intention here to say that medical interventions/medication should be balanced with lifestyle management?
- 3.5. **Specific populations-** we particularly support the recognition of specific needs of groups who already are disadvantaged in the access to health care and are at risk of misdiagnosis because of existing conditions.

Enablers

- 3.6. **Workforce-** a well-trained and skilled health and dementia sector work force is essential but other sectors such as Police and other first responders like para medics and the Fire Service, also need training in identifying and appropriately responding to people with dementia.
- 3.7. **Sufficient, sustainable financial resources-** this is absolutely critical, including realistic financial support to primary carers and sufficient, affordable respite care.

4. 2. Are the Objectives the right ones?

- 4.1. **Reduce the incidence of dementia-** we strongly endorse the recognition of the importance of a healthy lifestyle and social connection as preventative measures, as with other chronic, non-communicable conditions.
- 4.2. **Support people living with dementia and family/whanau and carers to live well-**this is possibly the most important yet challenging objective and where there can be tension or a mismatch with other policies. The Government aims to keep people living independently and out of residential care, but this can lead to social isolation, a driver and effect of dementia for those living alone. Local support groups can play a vital role here.
- 4.3. Caring for a person with long-term conditions like dementia, can have a huge, detrimental impact for others on health, wellbeing and financial security, and is a major reason that women give up work or work part time and have far less financial security in old age. Benefits, respite care and other support for carers needs to be considerably increased. Local support and “navigation” and respite care are important, but the proposed actions should also specifically include increased financial support.
- 4.4. **Build accepting and understanding communities--** Dementia attracts stigma whereas other chronic illnesses like stroke, do not do so to the same degree. Much of this arises from lack of knowledge, fear and embarrassment. we support the dual approach which combines, long-term community development approaches like local groups of Dementia Friends with specific campaigns to reduce stigma. It is encouraging to see initiatives like Westpac Bank’s dementia friendly actions, that highlight the important role business can play in reducing stigma and providing support.

4.5. **Strengthen capability across the sector-** these are all important actions but could be made clearer:

- Will the cross-sector group include other Government departments like Education?
- Will dementia standards be mandatory or “guidelines”?
- Will training be mandatory?
- Will education on dementia be given more prominence in basic medical school and other health training?

5. 3. Will the proposed actions make a difference for people living with dementia?

5.1. NCWNZ supports the key objectives and actions as essential first steps in improving prevention, diagnosis and support to people with dementia and their families; in particular reduction of stigma, development of local, community-based support networks and greater support to carers.

6. 4. What have we missed?

6.1. Below is a summary of the key suggested additions included in this submission:

Principles

- 6.2. **Person-directed-** this should include a clear statement that people with dementia should be accepted and treated with respect.
- 6.3. **Integrated-** other sectors such as Police and other first responders like para medics and the Fire Service, also have an important part to play. Schools are critical to education on healthy lifestyles and acceptance of people who are different, including those with dementia.
- 6.4. **Evidence based and best practice-** the statement “balancing medical care with person- centred care” is somewhat confusing in relation to the “person-directed” principle: all medical care should be “person centred”. Is the intention here to say that medical interventions/medication should be balanced with lifestyle management?

Enablers

- 6.5. **Workforce-** a well-trained and skilled health and dementia sector work force is essential and must be included and given sufficient emphasis in basic medical school and other health workforce training. However, other sectors such as Police and other first responders like para medics and the Fire Service, also need training in identifying and appropriately responding to people with dementia. Schools also have an important role to play in building awareness and acceptance of difference and healthy lifestyles to help prevent dementia.
- 6.6. **Sufficient, sustainable financial resources-** absolutely critical, including realistic financial support to primary carers and sufficient, affordable respite care. Benefits, respite care and other support for

carers need to be considerably increased. Local support and “navigation” and respite care are important, but the proposed actions should also specifically include increased financial support.

7. Conclusion

- 7.1. NCWNZ has welcomed the opportunity to contribute to the Draft NZ Dementia Plan 2020 to 2023 and looks forward to the further development of the finalised Action Plan which will contribute to the Healthy Ageing Strategy’s Implementation Plan.



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