

Improving Dementia Services in New Zealand

Draft New Zealand Dementia Plan 2020 to 2023

“we do not have a comprehensive and affordable plan... ..we cannot wait to take action. The job now is to weave these multiple strands of hope coming from multiple new initiatives into a comprehensive plan ... backed by strong... commitment expressed through resources and practical policies.” (Margaret Chan, WHO Director General, address to first Ministerial Conference on Dementia, 2015)

Dementia is a major challenge to New Zealand’s health system - it’s time for action

With no treatment or cure on the horizon Dementia is going to be one of the 21st century’s greatest global challenges for health and social care. It represents a major challenge for New Zealand creating major human, social, economic, health, workforce and economic costs. The current services are not capable of meeting the need:

- **Availability of and access to services is inequitable** - access to appropriate dementia services is inequitable across specific groups such as Māori, Pasifika, ethnic minorities particularly refugees, people living alone, and people living with young-onset dementia, deafness, intellectual disability, or neurological or psychiatric illness; and across urban-rural and District Health Board (DHB) boundaries.
- **Current gaps make service improvement urgent** - There are gaps across the dementia journey:
 - Pre-diagnosis: stigma, poor health literacy, no dementia prevention plan
 - Timely diagnosis: inadequate workforce capability to deliver diagnoses, inadequate support and care planning
 - Living well: limited and inflexible respite care, need for funded NGO-led living well programmes
 - Minimising symptoms: services limited to medical solutions and disability support.
 - Dying with dementia: need for greater synergy between palliative and dementia sectors.
- **Dementia is an important hidden player in the wider health system** - Dementia has multiple impacts in terms of acute hospital presentations, lengths of stay, failed discharges, need for aged residential care and for higher levels of that care, and health system harms especially falls and medication harms.
- **Population growth makes service development urgent** - The number of New Zealanders living with dementia is growing rapidly. There were estimated to be around 62,000 New Zealanders living with dementia in 2016. This is expected to rise to 102,000 by 2030. By 2050 the number of people living with dementia is expected to have almost tripled to 170,000. Most have family/whānau also affected by the diagnosis.
- **Future community expectations will increase, perhaps suddenly** – when a disease modifying treatment for dementia becomes available there will be huge demand for it. Any such treatment will be expensive and the system is not geared to respond.

Global Action Plan

New Zealand is not alone facing this challenge and in 2017 delegates at the World Health Assembly, including New Zealand, endorsed the *Global action plan on the public health response to dementia 2017 -2025* which provides a set of actions to realise the vision of a world in which dementia is prevented and people with dementia and their carers receive the care and support they need to live a life with meaning and dignity.

Areas for action in the Global Plan include increasing prioritisation and awareness of dementia; reducing the risk of dementia; diagnosis, treatment and care; support for dementia carers; strengthening information systems for dementia; and research and innovation.

Background

In 2013 the Ministry of Health (MOH) led the development of the *New Zealand Framework for Dementia Care* in partnership with the sector. The Framework provided a guide for DHBs to use as they worked with primary, secondary and community health and social support services to develop clear, consistent, well-resourced and easily accessible dementia care pathways. Limited implementation of the Framework has occurred since.

In 2015 the NZ Dementia Cooperative, Carers NZ and Alzheimers NZ co-hosted a Dementia Summit with 224 participants drawn from the wider dementia sector. Over two days, the participants discussed the steps needed to do more and better for people living with dementia. The overarching action identified at the summit was development of a national Dementia Plan.

In May 2019 a small group of dementia NGOs, clinicians, academics and providers (see Appendix 1) came together to develop a draft Dementia Plan for New Zealand. This draft document is now being circulated to the sector for wider input and feedback.

The First Dementia Plan

This is the first Dementia plan developed for New Zealand. The Plan is for three years only and focusses on the most urgent actions to make much needed progress for people living with dementia and for the health system. The Plan will also deliver on New Zealand's obligations under the Global Action Plan.

Kaupapa Maori

A separate process is underway to engage with tangata whenua as full Treaty of Waitangi partners to design a dementia action plan for Māori. Whether or not this action plan stands alongside or inside the national action plan, key Māori kaupapa that can improve dementia services for all is explicit within the NZ Dementia Plan.

Links to other Strategies/plans

The actions from this Dementia Plan are intended to fit within the second Healthy Ageing Strategy Action Plan. This Plan also has links to, and supports, other strategies and plans, including:

[Better Later Life – He Oranga Kaumātua 2019-2034](#) which sets out the actions needed for New Zealand to embrace the opportunities that an ageing population and longevity brings.

The Carers' Strategy 2008 and the Carers' Strategy Action Plan which provides resources and support to support care partners. The 2019 to 2023 Action Plan is currently out for consultation.

The New Zealand Disability Strategy 2016 which has a vision for New Zealand as "a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen".

Government Inquiry into Mental Health and Addiction 2018 which provided advice to Government about changes needed to the system.

The Health and Disability System Review which will identify opportunities to improve the performance, structure, and sustainability of the system with a goal of achieving equity of outcomes, and contributing to wellness for all.

Draft Action Plan for period 2020 to 2023

Vision, Goal and Principles

Vision - A New Zealand in which people living with dementia, their whānau / families and care partners live well and receive the support they need to fulfil their potential with dignity, respect, autonomy and equality and dementia is prevented as much as possible

The goal of this National Dementia Plan is to improve the lives of people living with dementia while decreasing the impact of dementia on them and their whānau / families as well as on New Zealand communities, the health system and the economy and to promote dementia risk reduction lifestyles.

Principles

The Plan is underpinned by eight cross-cutting principles that drive the way the plan will be implemented:

- **Person-directed** – people living with dementia, their whānau / families and care partners are placed at the forefront of decisions about their care and support, and empowered to contribute to decision-making
- **Reflecting Te Ao Māori throughout and guided by the principles of Te Tiriti o Waitangi** – Māori kaupapa is critical for in the development of the national plan and in the design, development and delivery of solutions and programmes
- **Comprehensive** – services cover the whole life-course of dementia from identifying that something might be wrong to end of life
- **Integrated** - all parts of the dementia sector work together and with other parts of the health sector in the implementation of the plan
- **Consistent** – nationally consistent quality-assured services are available to people no matter where they live

- **Equity** – people living with dementia have access to appropriate services that deliver the same high-quality health and wellness outcomes whoever they are, whatever their circumstances, wherever they live in New Zealand, and whoever delivers the services
- **Evidence-based and best-practice** – services are grounded in evidence and best practice, balancing medical care with person-centred care, to deliver solutions that are effective, sustainable and affordable
- **Specific populations** – services recognise and respond appropriately to the unique needs of the special groups within New Zealand’s population, especially: Pacific people, Asian people, the deaf community and people who have become hearing impaired, refugees, people living alone, LGBTIQA people, people with intellectual disability, people with young-onset dementia, people living with chronic and severe neurological and/or psychiatric conditions and those with addictions.

Enablers

Successful implementation of this plan relies on:

- a knowledgeable, skilled and supported workforce across the sector and health system as a whole – significant investment across the whole workforce is needed to achieve this as is a strategy to recruit and retain staff for the sector;
- systematic, routine population-level monitoring of a core set of dementia indicators to guide evidence-based actions to improve services and to measure progress towards implementing the actions in this plan; and
- sufficient sustainable financial resources that meet the identified service needs and are allocated equitably across the continuum of care alongside the required human and other resources.

“We live our best possible lives when: ... We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable” (Dementia Declaration: Our Lives Matter developed by people living with dementia on Alzheimers New Zealand’s Advisory Group 2019)

Action areas

The Plan for 2020 to 2023 is to focus on four objectives:

Objectives	Actions
<p>Reduce the incidence of dementia</p> <p><i>The diseases that cause dementia share many risk factors with other non-communicable diseases including heart disease, stroke, diabetes and cancer. Research suggests that proactive evidence-based interventions focused on modifiable risk factors could reduce the risk of developing dementia and/or slow progression by between 10% and 20%</i></p>	<p>Work with colleagues involved with other key non-communicable diseases and population health to design a health promotion programme that includes dementia prevention / brain health protection – for implementation, potentially in conjunction with other healthy ageing goals, in the next plan (beyond 2023)</p> <p><i>Suggested lead organisation/s: Health Promotion Agency/Sector NGOs</i></p>
<p>Support people living with dementia and their family / whānau care partners to live well</p> <p><i>People living with dementia and their support people can enjoy more full, active and meaningful lives when they have access to a timely, accurate diagnosis as well as to the right support and assistance. Doing so will improve quality of life, reduce the impact on the health system and reduce the costs caused by higher levels of care and emergency care. These services must be equitable in terms of access, tailored to individuals needs, and their quality must be assured</i></p>	<p>Test options to meaningfully support the provision of timely and accurate diagnosis and comprehensive management planning in primary care building on mental health initiatives as appropriate. Preparation of recommendations and business cases for local DHB and national solutions - for implementation in the next plan (beyond 2023)</p> <p><i>Suggested lead organisations: Lead DHB and PHO(s)</i></p> <p>Align/harmonise core features of DHB Cognitive Impairment Pathways to ensure national consistency. This will include investigating health technology options for cognitive testing to arrive at a recommendation for national adoption.</p> <p><i>Suggested lead organisations: DHBs/Primary Care sector leaders</i></p> <p>All DHBs to commission and/or deliver equitable, tailored and quality assured support services:</p>

Objectives	Actions
	<ul style="list-style-type: none"> • at least 12 months post-diagnosis support through the local dementia-specific NGO to equip people to live well • dementia navigation services for all people affected by dementia in their districts • flexible, available and accessible respite services so care partners can take required breaks <p><i>Suggested lead organisation: DHBs</i></p> <p>Work with palliative care and related partners to agree the actions required to build capability and capacity in health sector to better assist people dying with dementia - for implementation in the next plan (beyond 2023)</p> <p><i>Suggested lead organisations: MoH/Palliative care and dementia sector leaders</i></p>
<p>Build accepting and understanding communities</p> <p><i>Stigma and a lack of awareness, poor understanding and barriers to being included are among the most devastating things that people living with dementia and their support people experience – making it harder to get the help and support they need and increasing their isolation</i></p>	<p>Promote Alzheimers NZ’s Dementia Friendly Recognition Programme and the World Health Organisation’s Age Friendly Cities Programme</p> <p><i>Suggested lead organisations: All sector leaders</i></p> <p>Design a multi-level multi-channel de-stigmatisation campaign to raise awareness and increase understanding of dementia - for implementation in the next plan (beyond 2023)</p> <p><i>Suggested lead Organisations: NGOs</i></p>
<p>Strengthen capability across the sector</p> <p><i>The dementia sector is complex and fragmented, services are provided inconsistently across the country and making the changes needed to implement this plan is a major programme of work requiring credible leadership and a strong focus on capability</i></p>	<p>Establish a national cross sector stewardship and leadership group with clear lines of accountability at DHB, regional, and national levels</p> <p><i>Suggested lead organisation: MoH/DHBs</i></p> <p>Establish dementia and age friendly standards for delivering high-quality health services for people living with dementia including home, community, and residential/hospital care.</p>

Objectives	Actions
	<p><i>Suggested lead organisations: MoH (regulation)</i></p>
	<p>Design agreed national indicators, measures for the dementia sector and roll out this process as part of the outcome measures work within Health and Better Later Life – for implementation in the next plan (beyond 2023)</p> <p><i>Suggested lead organisation: Sector Leaders</i></p>
	<p>Make training support for best-practice medical care and disability and social support services more available across the sector in all DHB areas</p> <p><i>Suggested lead organisation: DHBs and provider agencies</i></p>
	<p>Increase investment in research on dementia, in particular on the epidemiology of dementia in New Zealand and on culturally appropriate ways of describing and approaching dementia with New Zealand's non-pakeha cultures</p> <p><i>Suggested lead organisations: Brain Research NZ/Ageing Well National Science Challenge, universities</i></p>

Appendix 1 - Who developed this draft Dementia Plan?

Alzheimers NZ and the NZ Dementia Cooperative facilitated a workshop in May 2019 to develop the draft Dementia Plan and invited:

- Alister Roberston – Alzheimers NZ Advisory Group member and person with dementia
- Matthew Croucher and Shereen Moloney, NZ Dementia Cooperative
- Paul Sullivan and Anne Schumacher, Dementia New Zealand
- Margaret Dudley, Sarah Cullum, University of Auckland
- Jane Large, Andrea Bunn, Elaine Plesner, and LesleyMaskery , District Health Boards
- Maria Scott-Multani, Arvida Group
- Catherine Hall and Jean Gilmour, Alzheimers NZ

This group then worked together to develop the draft Dementia Plan seeking input from their respective communities of interest and working alongside the Ministry of Health.