



Improving Dementia
Services in New Zealand -
Dementia Action Plan 2020 to
2025
May 2020



New Zealand
Dementia
Cooperative



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Why we need a Dementia Action Plan

“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” The Dementia Declaration, developed by people living with dementia on Alzheimers New Zealand’s Advisory Group in 2019

The lives of people living with dementia in Aotearoa New Zealand matter - they have the same rights, privileges and obligations as everyone else. Aotearoa New Zealand needs to support people living with dementia to be respected and valued, to exercise their rights to contribute to and participate in their communities and families, and to get the help and support they need.

With no treatment or cure on the horizon, dementia is one of the 21st century’s greatest global challenges for health and social care. It represents a significant challenge for Aotearoa New Zealand, creating major human, social, economic, health, workforce and economic costs. People living with dementia are amongst the most vulnerable in Aotearoa New Zealand and services are not currently capable of meeting their needs.

This Dementia Action Plan has been developed by a small group of dementia NGOs, clinicians, academics and providers (see Appendix 1) to **drive** the changes needed to address this challenge and improve the health, independence and quality of life of people living with dementia in a sustainable way. The changes will build on the services and supports currently in place.

The Plan is for the **whole dementia sector** – people with dementia and their care partners, the primary care workforce, community groups, home support providers, residential care, health professionals, secondary care and specialist services, district health board management, educators, researchers, policy makers and Government.

The **most urgent steps** for the next five years are set out in the plan. These steps are based on best practice (*Lancet Commission on Prevention and Care of Dementia, 2017*) and Aotearoa New Zealand guidelines (*Aotearoa New Zealand Framework for Dementia care, 2013*). Work is still needed on detail such as volumes, costs, outcomes and measures/indicators.

There is also much more that is needed beyond the steps set out in this **first** Action Plan. Our hope is that this Action Plan will be followed by future Plans lead by the Ministry of Health, so that over time Aotearoa New Zealand has system-wide, integrated and nationally consistent system and suite of services that improve the quality of life of people living with dementia and reduce the impact of dementia on the health system and economy.

The Plan has been strongly supported by the sector. The immediate priority facing us all is to deal with the Covid-19 crisis. Once that is done, Government must respond to the urgent and growing need for a to support people living with dementia. We look forward to working with the Ministry of Health and District Health Board as they take the practical steps needed to give effect to the objectives set out in the plan.



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Kaupapa Māori

Significant equity issues exist for kuia and kaumatua living with dementia in particular relating to dementia risk factors and poor access to culturally appropriate health services. Addressing these requires a process to engage with tangata whenua as full Treaty of Waitangi partners to develop solutions grounded in Te Ao Māori and that that will work in Aotearoa New Zealand for Māori whānau.

Some initial discussions occurred during the process of developing this Plan and we hope a specific process with tangata whenua to design a dementia action plan for Māori will now occur. It may be the action plan for Māori stands alongside or inside this Dementia Action Plan.

In the meantime, this Plan acknowledges Te Ao Māori and the principles of Te Tiriti o Waitangi and is based on the principle that a kaupapa Māori approach underpins the design, development and delivery of solutions and programmes.

Links to other Strategies/Plans

Global Action Plan

Aotearoa New Zealand is not alone facing this challenge. In 2017 the World Health Assembly (including Aotearoa 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.

Implementation of this Dementia Action Plan would meet Aotearoa New Zealand's obligations under the Global Action Plan. The Global Plan includes areas for action in relation to 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.

Aotearoa New Zealand Strategies and Plans

The actions from this Dementia Plan are intended to support the Healthy Ageing Strategy's Priority actions 2019–2022.

This Plan also has links to, and supports, other strategies and plans, including:

- [Health Ageing Strategy 2016](#) which sets out the strategic direction for the next 10 years for the delivery of services so that older people live well, age well and have a respectful end of life in age-friendly communities. The current focus is on the priority actions for 2019 to 2022.
- [Better Later Life – He Oranga Kaumātua 2019-2034](#) which sets out the actions needed for Aotearoa New Zealand to embrace the opportunities that an ageing population and longevity brings.
- [The Carers' Strategy 2008 and the Carers' Strategy Action Plan 2019 to 2023](#) which provides resources and support to support care partners.
- [The Aotearoa New Zealand Disability Strategy 2016](#) which has a vision for Aotearoa 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 Aotearoa 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 Kaiāwhina Workforce Action Plan 2015-2020](#) which is a five-year action plan with a 20-year vision for the Aotearoa New Zealand health and disability Kaiāwhina (non-regulated) workforce.

We also expect it will provide direction as the recommendations from the Health and Disability System Review are considered and implemented. The draft Dementia Action Plan was shared with the Review.

Dementia is a major challenge to Aotearoa New Zealand - it's time for action

What's needed to improve the lives of people living with dementia and reduce the impact on the health system is well known and accepted, and has been for some time.

A best practice-based guide for District Health Boards - the *Aotearoa New Zealand Framework for Dementia Care* - was developed in 2013.

In 2015 a summit co-hosted by NZ Dementia Cooperative, Carers NZ and Alzheimers NZ identified a national Dementia Plan as the most important first action for Government to take.

Internationally, in 2017 the World Health Assembly (New Zealand is a Member) adopted the *Global Action Plan on the Public Health Response to Dementia 2017 -2025* and later that year a Lancet Commission published a comprehensive metanalysis of the research into what works for dementia (*Lancet Commission on the Prevention, Intervention and Care*).

However, New Zealanders living with dementia are still being let down by inadequate services of variable quality, and the current services are not capable of meeting the growing demand, therefore the system is under increasing pressure:

- **Current gaps make service improvement urgent** – Services exist but there are gaps across the whole dementia journey:
 - *Pre-diagnosis*: poor health literacy remains a significant issue and there is no plan or national activity focussed on dementia prevention.
 - *Timely diagnosis*: there is inadequate workforce capability to deliver timely and accurate diagnoses, as well as inadequate support and limited care planning for those who are newly diagnosed.
 - *Living well*: the system is complex and difficult to navigate, care planning is inadequate, community-based living well programmes are hard to access, limited in availability and underfunded, families are overwhelmed yet respite care is limited and inflexible.
 - *Dying with dementia*: palliative care services for people living with dementia are poorly developed.

- ***Access to and availability of services is inequitable:***
 - access to services is inequitable across urban-rural and District Health Board (DHB) boundaries.
 - access to services is also inequitable depending on which specialty people present to (e.g.: neurology versus older persons mental health).
 - there are limited 'by and for Māori services' for kaumātua based on Te Ao Māori, and other providers are too often unable to deliver services that meet their needs as described under Te Whare Tapa Whā.
 - limited services exist for specific groups such as Pasifika, ethnic minorities and refugees, people living alone, people living with young-onset dementia, people with significant hearing impairment, people with intellectual and developmental disabilities, and people living with long term neurological or psychiatric illness.

The quality of services is variable:

- services are not quality assured against dementia friendly criteria.
 - services are often task rather than person-centred and often limited to medical solutions and disability support.
 - opportunities for meaningful connection, activity and stimulation are limited or non-existent.
 - responsive behaviours associated with dementia without the use of psychotropic drugs.
- ***Human rights are ignored or overlooked*** - stigma and discrimination create barriers to accessing services and support, decision-making authority is often denied to people living with dementia or their decisions are not respected, and the statutory model is substituted not supported decision making.
 - ***Population growth makes service development urgent*** - The number of Aotearoa New Zealanders living with dementia is growing rapidly. There are estimated to be around 70,000 Aotearoa New Zealanders living with dementia in 2020. This is expected to rise to 102,000 by 2030 and 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.

- ***Dementia is an important hidden player in the wider health system*** - Dementia has multiple impacts in terms of lower thresholds for acute hospital presentations, increased lengths of stay, failed discharges, increased need for aged residential care and for higher levels of that care, and health system harms, especially falls and medication harms. Hospitals struggle to treat people with dementia who often emerge with worsened ability to function than when they were admitted.
- ***Dementia is a major cause of disability and dependency among older adults*** – Dementia has been estimated to account 11.9% of the years lived with disability due to a noncommunicable disease, and has a significant impact not only on individuals but also on family/whānau, communities and societies. Most people with dementia have other significant conditions affecting their health and wellbeing, adding to the disability and dependency they experience.
- ***Dementia leads to increased costs*** - The economic cost of dementia to Aotearoa New Zealand increased by 75% between 2011 and 2016, with the total cost of dementia to Aotearoa New Zealand in 2016 estimated to be \$1.7b increasing to \$4.6b by 2050. People with dementia and their families/whānau face significant financial impact from the cost of health and social care and from reduction or loss of income.
- ***Workforce issues are worsening*** – Significant numbers of additional staff will be needed as the numbers of people living with dementia increase. Recruitment and retention is already a problem given remuneration levels, poor access to education opportunities and an ageing workforce. There is no workforce strategy to make sure there are adequate numbers of people with the right training to deliver quality services for this rapidly growing population.
- ***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.

“I strongly agree with this action plan from the vision, goal, principals, objectives and enablers. There are systems that you have addressed that need to be put in place. There needs to be investment and financial resources need to achieve support in the workforce and therefore making the process supportive, available for people with dementia and families

Having experienced difficulties going through this journey I strongly believe government needs to invest in the time to support a growing number of individuals and families affected by dementia.”

Feedback on draft Dementia Action Plan

Dementia Action Plan 2020 to 2025

Vision

An Aotearoa New Zealand in which dementia is prevented as much as possible; and where people living with dementia, their whānau/families and care partners receive the support they need to live their best possible lives, with autonomy, meaning and dignity.

Goal

To improve the wellbeing of people living with dementia while decreasing the impact of dementia on them, as well as on Aotearoa New Zealand communities, the health system and the economy.

Principles

The Plan is underpinned by seven interlinked principles:

- **Wellbeing focussed and person-centred** – people living with dementia, their whānau/families and care partners are empowered to be at the forefront of decision-making about their care and support so they thrive; living with autonomy, meaning and dignity; participating in and contributing to their families and communities for as long as possible
- **Human rights** – people living with dementia are citizens whose lives matters and have the same human rights as everyone else, including those in the *Convention on the Rights Persons with a Disability*
- **Acknowledges Te Ao Māori and the principles of Te Tiriti o Waitangi** – a kaupapa Māori approach underpins the design, development and delivery of solutions and programmes that will work in Aotearoa New Zealand for Māori whānau
- **Comprehensive and integrated** – services cover the whole life-course of dementia from developing dementia to end of life, with all parts of the sector working together to support people living with dementia and to implement the plan
- **Equity** – people living with dementia have access to appropriate services that deliver high-quality health and wellness outcomes so they can reach

their full potential whoever they are, whatever their circumstances, and wherever they live in Aotearoa New Zealand

- **Evidence-based and consistent** – services are grounded in evidence and best practice, incorporating person-centred care with health care, to deliver solutions that are nationally consistent, effective, sustainable and affordable
- **Specific populations** – services, solutions and resources recognise and respond appropriately to the unique needs of the special groups within Aotearoa New Zealand’s population. These will include: Pacific people, Asian people, the Deaf community and people who have become hearing impaired, refugees, people living alone, LGBTIQ people, people with intellectual and developmental disabilities, people with young-onset dementia, people living with chronic and severe neurological and/or psychiatric conditions, those with addictions, homeless older people and people housed in corrections facilities.

“[Support groups] give networking, sharing stories and ideas. We talk about medication, diet, funny happenings. We talk about all sorts of things. I find them very therapeutic just to discuss things.” Quote from This is our Story, 2019)

Actions areas

The Plan for 2020 to 2025 is to focus on four objectives:

1. Reducing the incidence of dementia - 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 population risk of developing dementia by between 10% and 20% and/or slow progression.
2. Supporting people living with dementia and their family/whānau care partners/supporters to live their best possible lives - People with dementia and their family/whānau care partners/supporters 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 individual needs, and their quality must be assured.
3. Building accepting and understanding communities - Stigma and a lack of awareness, poor understanding and barriers to inclusion 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.
4. Strengthening leadership and capability across the sector - The dementia sector is complex and fragmented, services are provided inconsistently across the country. Making the changes needed to implement this plan is a major programme of work, requiring leadership from government and a strong focus on capability across the sector.

Actions for each objective are set out in the following table. Agencies have been suggested to lead the collaborative work required for each action including drawing together those that will need to be involved, including tangata whenua, people living with dementia, community groups, service providers, professional colleges and guilds.

Objectives	Actions
<p>Reduce the incidence of dementia</p>	<p>Work with colleagues involved with other key non-communicable diseases and population health to design and implement a health promotion programme that includes dementia prevention/brain health protection</p> <p><i>Suggested lead organisation/s: Health Promotion Agency and sector NGOs</i></p>
<p>Support people living with dementia and their family /whānau supporters/care partners to live their best possible lives</p>	<p>Investigate and implement options to improve the provision of timely and accurate diagnosis and comprehensive management planning in primary care building on mental health initiatives as appropriate</p> <p><i>Suggested lead organisations: Lead DHBs and PHOs</i></p> <p>Align core features of DHB Cognitive Impairment Pathways to reinforce a national approach, including 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, person-directed, culturally appropriate and quality assured support services for people with dementia and family/whānau supporters/care partners based on a holistic health model such as Te Whare Tapa Whā, including as the first priorities for improvement:</p> <ul style="list-style-type: none"> • at least 12 months post-diagnosis support to equip people to live their best possible lives, including but not limited to: <ul style="list-style-type: none"> ○ information on what to expect, the services available and their rights ○ tools and support to plan and prepare for the future

Objectives	Actions
	<ul style="list-style-type: none"> ○ support services to strengthen resilience and wellbeing ○ Cognitive Stimulation Therapy and other proven interventions to maximise function ○ a long-term plan including referrals to ongoing services and supports ● improve the design, quality and availability of the existing community and home-based services so they support people living with dementia to remain at home with autonomy, dignity and independence ● dementia navigation services to coordinate and support access to needed services including emergency support, so people have as smooth as possible journey through the course of their dementia and get the services they need and that are right for them ● support for family/whānau supporters/care partners including information, education, support and flexible, available and accessible respite services, including but not limited to: <ul style="list-style-type: none"> ○ In home ○ Small group ○ Rural ○ Part and full day activities ○ Residential ○ Planned and urgent/as required <p><i>Suggested lead organisation: DHBs</i></p>

Objectives	Actions
	<p>Work with palliative care and related partners in accordance with the Palliative Care and Health Ageing Strategy Action Plans to build capability and capacity in health sector to better assist people dying with dementia</p> <p><i>Suggested lead organisations: MoH/Palliative care and dementia sector leaders</i></p>
	<p>Work with mental health and related partners as part of the implementation of the recommendations from the <i>Government Inquiry into Mental Health and Addiction 2018</i>, so people with dementia and care partners do not miss out on the mental health services and support they need.</p> <p><i>Suggested lead organisations: MoH/mental health and dementia sector leaders</i></p>
	<p>Start work with specific populations (such as pacifika/those living alone) to identify unique needs and develop solutions for each</p> <p><i>Suggested lead organisations: Ministry of Health/ lead DHBs and Sector NGOs</i></p>
Build accepting and understanding communities	<p>Support planned work by MSD and the Law Commission to review statutory mechanisms for decision making and consent with a view to shifting toward a supported decision-making model</p> <p><i>Suggested lead organisations – Sector NGOs</i></p>
	<p>Improve understanding of dementia and ageing within Aotearoa New Zealand communities by promoting and supporting Alzheimers NZ’s Dementia Friendly Recognition Programme and the Office for Seniors’ WHO Age Friendly Cities Programme</p> <p><i>Suggested lead organisations: All sector leaders</i></p>

Objectives	Actions
	<p>Design and implement a multi-level multi-channel campaign to raise awareness, increase understanding of dementia and tackle stigma and discrimination</p> <p><i>Suggested lead Organisations: Health Promotion Agency and Sector NGOs</i></p>
<p>Strengthen leadership and capability across the sector</p>	<p>Establish a national cross sector stewardship and leadership group that includes people living with dementia, tangata whenua and sector representatives with clear lines of accountability at DHB, regional, and national levels to lead implementation of this Plan and monitor implementation</p> <p><i>Suggested lead organisation: Ministry of Health</i></p>
	<p>Working with tangata whenua to develop a dementia action plan for Māori</p> <p><i>Suggested lead organisations: National leadership group</i></p>
	<p>Design agreed national indicators, measures and standards for the dementia sector and roll out this process as part of the outcome measures work within the Health Ageing Strategy</p> <p><i>Suggested lead organisation: National leadership group</i></p>
	<p>Establish human rights-based dementia/age friendly standards for delivering high-quality services for people living with dementia for primary care, home and community services, residential care and hospital and other secondary care services. Standards that are:</p> <ul style="list-style-type: none"> • human rights based • person-directed • based on holistic frameworks such as Te Whare Tapa Whā

Objectives	Actions
	<ul style="list-style-type: none"> • work to reduce the use of antipsychotics in residential care <p><i>Suggested lead organisations: QHNZ, Ministry of Health, sector NGOs, provider leaders</i></p>
	<p>Develop and implement a workforce strategy that address both the long-term growth needs of the dementia and aged care sector, and the impact of the ageing workforce, so there are sufficient numbers of appropriately skilled and qualified people available when needed</p> <p><i>Suggested lead organisation: Ministry of Health (Workforce)</i></p>
	<p>Improve training support for best-practice medical care and disability and social support services and make this education more available across all parts of the dementia and aged care sector, home and community care, primary care, and within the core health service</p> <p><i>Suggested lead organisation: Ministry of Health and DHBs, Dementia NGOs, Provider agencies</i></p>
	<p>Increase investment in research on dementia, in particular on the epidemiology of dementia in Aotearoa New Zealand, on culturally appropriate ways of describing and approaching dementia for tangata whenua and within Aotearoa New Zealand, and on what works to support people living with dementia</p> <p><i>Suggested lead organisations: Brain Research NZ/Ageing Well National Science Challenge</i></p>

Enablers

Successful implementation of this plan relies on:

- **Government allocating sufficient financial resources** that meet the identified service needs and are allocated equitably across the whole continuum of care, including prevention, primary care, community and home support, residential care and end of life, together with better and more flexible funding options to support family/whānau care partners/supporters.
- **A knowledgeable, skilled, valued and supported workforce** across the sector and health system as a whole – significant investment across the whole workforce is needed to achieve this. A strategy is also needed to recruit and retain the growing workforce of appropriately skilled and qualified people the sector will need as number of people living with dementia grow.
- **Stronger links across the dementia sector** including primary care, secondary care and specialist care, community and home based care, residential care, palliative care, mental health and first responders – to improve quality, and support comprehensive and integrated services throughout the course of the dementia journey.
- **A partnership focussed commissioning model** that recognises the differing requirements of the very diverse dementia sector combined with flexible funding arrangements for individuals and families to support choice and person-centred care.
- **Systematic, routine tracking and population-level monitoring of a core set of dementia indicators** to guide evidence-based actions to improve services, drawing on both international research and Aotearoa New Zealand specific research, and to measure progress towards implementing the actions in this plan.
- **Related work in other sectors proceeding** including:
 - flexible funding options for care partners under the Carers Strategy Action Plan

- implementation of the recommendations from the Welfare Expert Advisory Group in relation to benefit levels
- review of the Protection of Personal and Property Rights Act relating to consent and decision making.

What is this Plan based on?

This Plan is based on the information, evidence and research outlined in:

- *Convention on the Rights of Persons with a Disability (2008)*, United Nations
- *Aotearoa New Zealand Framework for Dementia Care (2013)*, Ministry of Health
- *Aotearoa New Zealand Dementia Summit, Final Report (2016)*, NZ Dementia Cooperative, Carers NZ and Alzheimers NZ
- *Dementia Economic Impact Report (2017)*, Deloitte for Alzheimers NZ
- *Dementia prevention, intervention, and care (2017)*, Lancet Commission
- *Global Action Plan on the Public Health Response to Dementia (2017)*, World Health Organization
- *Awareness and perceptions of dementia (2018)*, Summerset and *Awareness and understanding of dementia in Aotearoa New Zealand (2017)*, Alzheimers NZ
- *Care Needed: Improving the Lives of People with Dementia (2018)*, OECD
- *Dementia Declaration: Our Lives Matters (2019)*, Alzheimers NZ Advisory Group
- *This is our Story: A qualitative research report on living with dementia (2019)*, Litmus Research for Alzheimers NZ
- *InterRAI* – aggregate published data from the interRai assessments
- *National Dementia Stocktake Report (2020)*, District Health Boards.

The Plan was also refined and improved based on the feedback received during the consultation on a draft of the Plan released for comment in late 2019 (see Appendix 1).

Appendix 1 - Who developed this Dementia Action Plan?

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

- Alister Robertson – 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
- Makarena Dudley and Sarah Cullum, University of Auckland
- Jane Large, Andrea Bunn, Elaine Plesner and Lesley Maskey, District Health Boards
- Maria Scott-Multani, Arvida Group
- Catherine Hall and Jean Gilmour, Alzheimers NZ

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

The Draft Dementia Action Plan was circulated for comments within the dementia sector in early November 2019, with comments closing at the end of January 2020.

The consultation incorporated a broad range of stakeholders through recruitment networks, including people living with dementia and their care partners, health, allied health and other professionals with an interest in dementia, District Health Boards, national professional organisations and networks, and local and national community networks and groups. There were 358 responses to the online consultation. An additional 14 individuals or organisations provided feedback outside this channel, and a further 25 individuals provided feedback specifically on their experience with Cognitive Stimulation Therapy.