

# Alzheimers NZ Annual Report 2022

Aotearoa, he aro nui ki te hunga mate wareware A dementia friendly New Zealand



## Who we are

We support people and whānau living with dementia mate wareware in Aotearoa New Zealand through our values of integrity, respect, inclusiveness, goodwill, dedication, integration and collaboration.

#### Vision

Towards a world without dementia mate wareware **Kia mate wareware kore te ao** 

### Mission

A dementia friendly Aotearoa New Zealand Aotearoa, he aro nui ki te hunga mate wareware

Strengthening the voice of people living with dementia mate wareware Supporting people affected by dementia mate wareware to live well Lifting the quality of care and support Building resources, readiness and capability

Influencing

Strengthening

Partnering

Sustaining

## Nau mai, haere mai **A message from our Chair and Chief Executive**

Kia ora koutou

It's been a year of change at Alzheimers NZ with the lasting impacts of Covid-19, some important steps taken as part of the Dementia Mate Wareware Action Plan, and the start of our Te Tiriti o Waitangi journey.

Despite the uncertainty, people and whānau living with Alzhiemers and dementia mate wareware remained at the centre of everything we do. We continued to share our Educational Dementia Immersive Experience (EDIE) across Aotearoa New Zealand, and developed a Cognitive Stimulation Therapy (CST) for Māori in partnership with Dr Makarena Dudley. Our local Alzheimers organistions also do some incredible work in their communities, which we have no doubt, is an immense support to the people they work with. Thank you for your ongoing commitment to your communities – we know it can be a tough job at times.

Covid-19 is still top of mind for the health sector and older people, and supporting people living with dementia mate wareware and local Alzheimers organisations remained a priority. While it's been great to see the world open up, it's important we keep those living with Alzheimers and dementia mate wareware safe.

Despite this, it's still been an incredibly busy year for Alzheimers NZ, and there's been a huge amount of effort put in by the team. Our Annual Report 2022 is only a snapshot of everything we've achieved over the year, and we're pleased with what we were able to deliver. As we settled into our new normal alongside the rest of the world, it was a privilege to attend the Alzheimer's Disease International 2022 Asia Pacific Regional Conference in Taiwan in November. The conference brought a great sense of reconnection with the wider sector and we left with a feeling of hope. This event followed the 35th Conference of Alzheimer's Disease International, which we attended online in June.

The conference reinforced the need for our Dementia Mate Wareware Action Plan, and we were pleased to see government's commitment to the Plan come to life this year. This included some funding in Budget 2022, appointment of the Dementia Mate Wareware Leadership and Advisory Group Te Whakaruruhau mō te Mate Wareware and the first meeting of the Dementia Mate Wareware Network. This is a great start, but there's still much to do and urgent funding needed to stabilise the sector. We continued to work with government, most notably with our Parliamentary Friends of Dementia, and closely with Minister Hon Dr Ayesha Verrall in her capacity of Associate Minister of Health.

Closer to home, we made a start on our journey to honour Te Tiriti o Waitangi as an organisation. Our Board and team committed to an education programme under the guidance of local experts. While there is still more to be done, we continue to honour these principles in our work.

We also had significant changes to our team in 2022. We said farewell to Dr Jean Gilmour, who has been part of our Alzheimers whānau for more than 35 years. Jean has made an immense contribution to our organisation as both a team and Board Member at local and national levels, and we honoured her recently as a Life Member.

Board Member Jan White, who we were lucky enough to keep on our Board for the first half of the year, also stepped down. Thank you both for your contribution to our cause – your support, guidance and expertise have been invaluable. Please join us to celebrate our achievements in this annual report, and we look forward to another exciting year ahead.

Ngā mihi



**Clare Hynd** Chair

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**Catherine Hall** Chief Executive

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# Highlights

Here are some of the moments which stood out for us this year.

## People

Congratulations to Board Member Alister Robertson, who received the Outstanding Achievement Award to Community or NGO Health Services at the Minister of Health Volunteer Awards in June. His substantial contributions to dementia mate wareware research, providing peer support, and as part of the expert national group working to develop the first Dementia Mate Wareware Action Plan for Aotearoa New Zealand were recognised.



## Services

We were delighted to launch our Educational Dementia Immersive Experience (EDIE) across Aotearoa New Zealand to help Kiwis to "see" what it is like to experience dementia mate wareware using state-of-the-art virtual reality. Whakaohooho Whakāro – Māori, a Cognitive Stimulation Therapy (CST) tool for Māori, was developed in partnership with Dr Makarena Dudley.

#### **Research and reports**

We partnered with Carers NZ and the Carers Alliance, Ministry of Social Development and IHC to release The State of Caring in Aotearoa report.

The report shows more than one million whānau carers in Aotearoa New Zealand are struggling, under pressure and do not feel valued. It is intended the survey will be repeated every two years to track how whānau carers are faring over time.

We also released the Alzheimer's Disease International's (ADI) World Alzheimer Report 2022, which highlights the lack of post-diagnostic care for people living with dementia mate wareware is a global problem.

ADI estimates as many as 85 per cent of the 55 million people with dementia mate wareware globally could be missing out on care. Research and reports are vital to ensure we can advocate for people and whānau living with dementia mate wareware in Aotearoa New Zealand.



### **Events**

The sector joined us for our webinar Addressing the dementia mate wareware challenge in the new "Health Ecosystem: A discussion with Te Whatu Ora" for World Alzheimers Month in September. We explored the growing challenge dementia mate wareware poses to our health system as our population ages.

We also attended the Alzheimer's Disease International 2022 Asia Pacific Regional Conference in December. The strong voice of people living with dementia mate wareware shone through during the event, and it was great to hear from new speakers who were able to share their insights about their condition.



## Making a difference

Influencing decision-makers to inspire and shape external change and lift the quality of support and care available

## **Taking action**

Some important steps in the Dementia Mate Wareware Action Plan were taken in 2022.

Te Whatu Ora and Te Aka Whai Ora appointed the Dementia Mate Wareware Leadership and Advisory



Group Te Whakaruruhau mō te Mate Wareware in September. Congratulations to Board Members Alister Robertson and Teresa Wall who are part of this group. The first meeting of the Dementia Mate Wareware Network was held in November, with hundreds of people from different parts of the sector joining us.

## **Advocacy**

In May, we supported changes to the Fair Pay Agreements Bill which impacts carers and their working conditions. In November, we supported the Accessibility for New Zealanders Bill and recommended that the definition of "disabled" should include people living with dementia mate wareware.

We also engaged closely with the Health, Quality and Safety Commission on the Code of expectations for health entities' engagement with consumers and whānau, and with the Aged Care Commissioner.

## **Virtual reality**

Educational Dementia Immersive Experience (EDIE) is the firstever virtual dementia mate wareware experience in Aotearoa New Zealand – hosted by highly trained experts from our Dementia Learning Centre.

"It was impressive. In health and clinical settings, there is always a need for people to be able to walk in another person's shoes, to better understand their experience or see things from another's perspective. EDIE really brought that home in quite a realistic way."

Te Whatu Ora – Health New Zealand Southern Portfolio Manager Health of Older People, Sharon Adler



### **Innovations in care**

We were proud to support two new programmes which were developed during the year.

A new, tailored Cognitive Stimulation Therapy (CST) Programme has been developed for Māori called Haumanu Whakaohooho Whakāro – Māori. This was in partnership with Dr Makarena Dudley, of the University of Auckland-Waipapa Taumata Rau. The official launch is set to be in 2023.

We were also delighted to support our Board Member Alister Robertson with the launch of his My Life's Journey app. This app uses reminiscence therapy to guide users to record and reflect on moments that weave together the story of their life.

Record your journey. Leave a legacy.





AOTEAROA, HE ARO NUI KI TE HUNGA MATE WAREWARE

#### **Dementia Friendly programmes**

We were excited more than 16,000 people have now joined us to become a Dementia Friend – an online module which helps people learn about dementia mate wareware and simple ways to help.

"It's given me a much better understanding of recognising dementia and how to care for people." Jane, Dementia Friend

Small, simple actions really do help!

We now have 24 organisations who have been awarded Dementia Friendly Recognition, including Mary Potter Hospice.

"Working as a whole organisation to meet the seven standards to achieve accreditation has challenged us at times, particularly for an organisation where dementia is not our main focus. However, we are delighted that we have achieved full accreditation in recognition of the work carried out by many for some years, and will continue to keep those living with dementia 'top of mind' at Mary Potter."

Mary Potter Hospice team

## One voice

Strengthening the collective of Alzheimers NZ and Members so we all are successful and working collaboratively to achieve our shared mission – a dementia mate wareware friendly Aotearoa New Zealand

#### Making a case

We worked collaboratively with Dementia NZ to present a funding case on the urgent need for \$9 million to support communitybased dementia mate wareware services. The case was presented to government in April, and we reiterated the importance of this message in our response to the Budget briefing.

We are now in the process of putting together a future-focused service delivery model to ensure the funding sustainability to meet demands in supporting people with dementia mate wareware.



## Data reporting

We took another big step forward in our national reporting, to allow consistent data collection and reporting for Aotearoa New Zealand. Most local Alzheimers organisations are now linked up to our national data warehouse.

This is important to help us demonstrate the difference we're making in local communities and where more support may be needed.

## Funding

We contributed a total of \$220,000 to frontline and national services from Northland to Southland with our National Donor Programme.

One of the highlights from our programme in 2022 was the launch of the Detective Luka and the Great Memory Mystery book, which helps children understand a dementia mate wareware diagnosis. Donors were given the opportunity to pay it forward by buying one for themselves, and a copy for whānau in need.

This programme is one way we'll continue to support our local Alzheimers organisations with the incredible mahi (work) they do in their communities.



The story brings to attention the challenges children face in understanding a dementia diagnosis of a loved one

For every purchase, additional copies are delivered to newly diagnosed whānau





## **Working together**

Partnering and collaborating within and beyond the dementia mate wareware sector to lift the quality of support and care, and build resources, readiness and capability

#### **Our experts**

We continued to work closely with our Mate Wareware Advisory Ropū and Alzheimers NZ Advisory Group.

Our relationship with the Ropū was strengthened through the year as they continued to guide and support us – we had a great hui (meeting) with them in June.

The Advisory Group met four times during the year – we're now working with Dr Bryan Betty, of the Royal New Zealand College of General Practitioners, to support the College with their work for people living with dementia mate wareware.



## A jolly good fellow

Congratulations to Dr Etuini Ma'u, who was named the 2022 Alzheimers New Zealand Fellow. Dr Ma'u is a senior lecturer in Psychiatry at the University of Auckland and consultant old age psychiatrist with Te Whatu Ora Waikato.



"This award will allow me to continue my research into dementia mate wareware prevention, focusing on modelling the cost-effectiveness of proposed dementia mate wareware prevention interventions."

Dr Etuini Ma'u

### Younger Onset Dementia Aotearoa Trust

We partner with the Younger Onset Dementia Aotearoa Trust (YODAT) to support their online support group which involves about 30 whānau across Aotearoa New Zealand. The group is planning to extend support to younger whānau members in 2023.

#### We can't do it alone

Partnership is at the heart of everything we do. We're members of New Zealand Carers' Alliance, Neurological Alliance, Health Coalition Aotearoa, Federation of Primary Health and New Zealand Coalition to End Loneliness (founding members).



## **Sponsors and supporters**

We couldn't do what we do without you. We'd like to thank our generous funders and supporters for supporting the important mahi (work) we do for people and whānau living with dementia mate wareware in Aotearoa New Zealand.

Our funders include:

Lead partner















Nessbank Charitable Trust H Munter and M Pharazyn Trusts

## Our team

Special thanks to our Patron, Champions for Dementia and Advisory Group for your ongoing support of Alzheimers NZ.

#### **Alzheimers NZ Patron**

Sir Richard Faull

## Board

Clare Hynd, Chair Ngila Bevan (Ngāpuhi), Vice-Chair Teresa Wall (Te Rarawa, Te Aupōuri), Vice Chair Alister Robertson David King Jan White (stepped down in August) Sarah France Sheryl Smail

## **Champions for Dementia**

Colin Mathura-Jeffree Dame Kerry Prendergast Kate De Goldi



Alzheimers NZ Patron Sir Richard Faull

### **Advisory Group**

Adrienne Henderson Alister Robertson Elizabeth Duke Fiona Parrant Helen Doyle Kay Grant Liz Hollier Maxine Pringle Rose Love Vicki Terrell

We want to thank Helen Doyle and Maxine Pringle for all they contributed during their time in the group.

## **Clinical and Scientific Advisory Group**

Alison Douglas Dr David Kerr Professor Grant Gillett Associate Professor Lynette Tippett Dr Matthew Croucher Professor Maurice Curtis Dr Phil Wood Associate Professor Yoram Barak

### Volunteers

And, of course, our wonderful volunteers.

Glenys Blair Gordy Kelland Janet Keilar John Ahradsen Michelle Bidwell Stephen Lungley

We would like to ackowledge the passing of Glenys, and thank her for her contribution to Alzheimers NZ. We also thank Stephen who left his role with us after eight years.

#### Staff

Thanks to our team, including those who finished up and started with us 2022.

**Chief Executive** Catherine Hall

#### **Accounts and administration** Christine Garrett, Sue Gwilliam, Ken Drayton

**Dementia Learning Centre** Dr Kathy Peri, James Paul, Ellen Bragger

**Fundraising** Rebecca Scelly, Helen Kelland, Colin Adam

**Services and standards** Lyneta Russell, Dr Jean Gilmour, Rob Thomson

**Policy and research** Philippa Fletcher, Stephen Lungley, Dias Suwido

**Communications** Harriet Payne, Daniel Paul, Amie Hickland

## Members

A big thank you to our Life Members and our local Alzheimers organisations for your support in 2022.

#### **Life Members**

Brenda Cromie David Ansell Diane Nutsford Dr Jean Gilmour Gaynor Duff Jimmy Fisher Judy Cooper Verna Schofield Wendy Fleming Wilma Bulman

#### **Member organisations**

Alzheimers Eastern Bay of Plenty Alzheimers Gisborne/Tairāwhiti Alzheimers Manawatu Alzheimers Marlborough Alzheimers Nelson/Tasman Alzheimers Northland Alzheimers Otago Alzheimers Taupō Alzheimers Tauranga/WBOP Alzheimers Taranaki Alzheimers Wairarapa Alzheimers Whanganui Alzheimers South Canterbury Alzheimers Southland

Contact details for our local Alzheimers organisations can be found on our website **www.alzheimers.org.nz/our-work/our-members** 



Alzheimers NZ Level 1, 15 Dixon St, Te Aro, Wellington 6011 04 387 8264 admin@alzheimers.org.nz

#### For dementia mate wareware support call 0800 004 001

www.alzheimers.org.nz

Charity registration number CC 21026



Alzheimers NZ is a proud member of the Alzheimer's Disease International, the umbrella group of 104 Alzheimers disease organisations