SUPPORTERFAMILY UPDATE



Your tree of kindness

It's been an extraordinary year of kindness - YOUR kindness - towards people with dementia. Your support reminds us of a tree that spreads its branches to offer more shelter as it grows. Here's what's been growing on the tree over the last year, thanks to your kindness.

Dementia Declaration launched by Alzheimers NZ Advisory Group

More information resources to help people on their journey with dementia

Nearly 20 organisations in our Dementia Friendly Recognition Programme Significant funds to frontline dementia services

Milestone research into what it's like to live with dementia Standards introduced for best quality dementia care

> More than 6,000 people trained as Dementia Friends

New Zealand Dementia Action Plan developed

As it grows, the tree can spread its branches and support more programmes and people

Your donations feed the tree and make it strong

Your donations have been put to work in providing dementia services around the country, especially in areas where it's often hard for families and whānau to find the support they so desperately need.

And that's not all. People with dementia often feel the stigma, rejection and isolation of living with the illness. Friends 'evaporate' as one person with dementia told us and families struggle to cope.

So your donations have also helped us develop national dementia friendly programmes that are changing attitudes towards dementia.

Why give your dollars for dementia?

- It's one of the biggest health issues facing New Zealand.
- There is no cure yet for dementia and most of us know or have known, someone with the condition.
- There are about 70,000 people living with dementia in New Zealand and they, their families, whānau and loved ones are often struggling to cope.

It's time for Action

Catherine Hall, Chief Executive



As we hear more and more stories of people struggling with dementia, I get more impatient for New Zealand-wide action.

The team at Alzhiemers NZ, and our local organisations, deal with so many calls from distressed and frustrated people who find

it really hard to navigate the complexity of finding help for a person with dementia.

So last year, I became part of a leading group to develop a Dementia Action Plan to take to Government.

We now have a draft **NZ Dementia Action Plan** to present to Ministers and we hope to see the many recommendations acted on. These include being able to access best practice services wherever you are in the country and ensuring that people with dementia and their family and whānau are at the forefront of decisions about their care.

As one of our wonderful supporters, you are already part of our action plan to help people with dementia. We really couldn't do it without you!

You can find the NZ Dementia Action Plan at alzheimers.org.nz/Our-voice/Policy-document

In the research lab

Dr Andrea Kwakowsky, Senior Research Fellow at the University of Auckland, became the inaugural recipient of the Alzheimers NZ Fellowship. Andrea has been researching dementia since 2012, looking at the molecular, cellular and the cognitive basis of brain function during ageing. She is passionate about facilitating direct interaction between researchers and the community. Alzheimers Whanganui offers the gift of overnight respite a few times a year to relieve carers in an area where there are no respite beds.

You've given some kindness and companionship to older adults

For the second year in a row, Alzheimers NZ, with help from your donations, is supporting a service that brings comfort, companionship and social contact to older adults, including those with dementia. Provided by Presbyterian Support Upper South Island in rural Canterbury, the HomeShare service allows hosts to open their homes once a week to groups of adults aged 75–84 plus. Hosts are trained and supported and have a clinical support person on the team.

Feedback has been very positive, with comments including "It's good for my family", "I love the host's cooking, she is so friendly and polite", "I look forward to Tuesdays" and "I really like the friendship and caring people".



"What you get out of it is much more than you expect." – Marilyn McLellan, HomeShare Host

Services for people with dementia in Alzheimers Manawatu include an exercise programme, a singing group and Cognitive Stimulation Therapy.

The activities are based on science and stimulate the brain. 99

"I am still me"

That's the heartfelt call for recognition, dignity and support, from people living with dementia. And we are making sure it is being heard far and wide. Last year the Alzheimers NZ Advisory Group, (people with dementia and their care partners) told us what matters to them and it was recorded in their Dementia Declaration.

We are making the Declaration a cornerstone of our services and policies and we want other organisations, including Government, to do the same. As the Declaration says "We all want to be seen, valued, appreciated and loved for who we are".

You can find the full Declaration at alzheimers.org.nz/our-voice/dementia-declaration



Members of the Alzheimers NZ Advisory Group launch their Dementia Declaration

Real-life research provides a window on dementia

Research we conducted last year has opened a new window onto what it's really like to live with dementia in New Zealand today.

Real people give first-hand experiences about their day-to-day struggles with a health sector that provides often inadequate services and support.

The research shines a light on what people living with dementia need to live well, both from friends and family, and from the health sector. We are making sure their voices will be heard!



The way I'm treated can be hurtful...

My care partner will go outside and they'll [the neighbours] all talk for half an hour. I'll go outside and they say 'hello'.



If you think someone close to you may have dementia

- Firstly, it IS possible to have this conversation sensitively and mindfully.
- Choose a place that is familiar and comfortable, allowing plenty of time, so the conversation isn't rushed.
- Gently remind them that the symptoms you have noticed could be caused by any one of a number of treatable conditions.
- Suggest that the person see their GP for a general, routine health check, which we should be doing more often as we get older.
- If the person doesn't want to see a GP, you could consider mentioning your concerns to their GP yourself. Patient confidentiality means the GP is not able to give out information about a patient, but is able to receive information.
- It is up to the individual GP whether they
 decide to take any action on information
 received, so it's always better for the
 person to speak to the GP themselves.
- Talk with your local Alzheimers organisation for more help and support (see our website) or call us on 0800 004 001
- If the person does receive a diagnosis of dementia, acknowledging the diagnosis is an important first step.
- As a person with dementia told us, "Acceptance brings its own gift of peace."
- The sooner a diagnosis is made, the sooner the person will receive the help and support they need.

Ryman Healthcare joins Alzheimers NZ in fight against stigma

Alzheimers NZ and Ryman Healthcare have joined forces to increase knowledge and highlight and address the stigma associated with dementia. The two organisations are working together to build a more dementia friendly New Zealand.

Ryman Healthcare chief executive Gordon MacLeod said he was delighted to be working with Alzheimers New Zealand.

"Dementia takes a massive toll on those living with the condition, their care partners, and their families and we want to do all we can to help.

"Our team has a wealth of experience in dementia care and we want to use our resources to support Alzheimers NZ in its fight to improve knowledge and understanding of dementia."



Tell us in Ten – what you told us

Nearly two thousand of you completed our donor survey – thank you! About 70% of you know someone close to you with dementia, and that's why many of you support our cause.

Your feedback included:

"Best of all was that I phoned when desperate and you understood and gave direction how to deal with a matter, still thankful."

"Thank you for your great organisation and for all you do helping all of us 'touched' by Alzheimers during this difficult situation and giving the support where needed to ease the journey."

"Just reading peoples experiences and how they've overcome their own issues shows that there's hope for better quality of life."

"Keep going you are needed out there!"

"My Alzheimers is not yet too bad but I will keep in touch so I can get help when It worsens."

Some of you would prefer to receive communications from us electronically and we've made a note to action that.

Most of you also told us that you'd like donations to be put towards education resources, frontline services and where Alzheimers NZ saw the most need. Overall, you are most interested in hearing more about reducing the risk of dementia and the latest research. We 're also happy that the vast majority of you feel thanked and appreciated for your donations, because we can't thank you enough!

Alzheimers Northland educates local GPs, so doctors on the frontline fully understand the breadth of services on offer for their dementia patients. 99

With many thanks to you, our donors who continue to support our work and to the following organisations:















Nessbank Trust

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