



Alzheimers *News*

The magazine for the New Zealand dementia community | Issue 94 | August 2014

Working together for a global solution

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CATHERINE HALL
EXECUTIVE DIRECTOR

Kia ora and welcome to the latest edition of *Alzheimers News*.

Inside, we have a round-up of recent news - regional, national and international - as well as a preview of our upcoming World Alzheimer's Month activities, and details of our recently published Election Briefing 2014.

Some of the other highlights include:

- An overview of *Dementia: A Strategic Framework*, which we launched in April;
- The announcement of additional keynote speakers for our November conference, *Dementia: The Future is Now*; and
- Information on communicating with a person with dementia.

We always welcome your feedback and suggestions so please get in touch by emailing comms@alzheimers.org.nz or calling 04 387 8264.

In the meantime, thank you, once again, for your continued support.

Catherine Hall
Executive Director

MESSAGE FROM THE CHAIR SUSAN HITCHINER

Over the last nine months, we have seen an unprecedented global focus on dementia - attention that is both heartening and absolutely essential.

At Alzheimers NZ, we have been excited and inspired by the commitments made, and the action taken, by some of the principal players in the international arena.

Following the landmark G8 Dementia Summit in London at the end of 2012, the UK government appointed Dr Dennis Gillings as the World Dementia Envoy, and charged him with championing and unlocking investment into dementia research and development. Meanwhile, worldwide collaboration and information sharing at a community level has received a major boost with the formation of the Global Alzheimer's and Dementia Action Alliance. These initiatives are significant moves forward.

It is vitally important that in responding to the needs of people affected by dementia in Aotearoa New Zealand, we mirror the level of commitment being shown internationally. We also need to play our part in meeting the ever-increasing challenge dementia presents across the world as well as in our communities.

With the launch of *Dementia: A Strategic Framework* in April this year, we set the context for a New Zealand response. The framework, which is strong, aspirational and sector-wide, challenges all of us to galvanise our collective activity toward a shared vision and goals. You can find out more about the framework and its practical applications on pages 6-7.

As the challenge of dementia continues to grow, we need to ensure that people affected by dementia are placed firmly at the centre of everything we do. With a General Election within the next few weeks, we have also drawn on *Dementia: A Strategic Framework* to ask political parties the hard questions, and in our Election 2014 Briefing, to provide clear advice on our priorities for government action. You can read more about this on page 4.

Our next step is to host our biennial conference in Rotorua in November. The theme is *Dementia: The Future is Now*, and the conference will bring together the New Zealand dementia community. We are excited to have the opportunity to connect with a wide range of committed organisations and individuals, and we are looking forward to hearing from some of the foremost dementia experts from New Zealand and around the world.

I hope that many of you will be able to join us there, as we engage further with these issues and continue our work towards a world without dementia.

Susan Hitchiner
Alzheimers NZ Chair

NEW BOARD MEMBERS ELECTED

Two new Alzheimers NZ Board members were elected at our AGM in May.

Jan White who is based in Waikato, managed the Waikato NASC service (Disability Support Links) for 14 years and now has a national role with the Ministry of Health that focuses on equity and consistency for people with disabilities.

Jean Gilmour who is based in Wellington, was last on the Alzheimers NZ board in the 2000's. She is also Chair of the Research and Advisory Committee of the Alzheimers NZ Charitable Trust, and has recently been a member of the Alzheimers Wellington Executive.

WORLD ALZHEIMER'S MONTH 2014

September 2014 marks the third World Alzheimer's Month - an international campaign to raise awareness and challenge the stigma associated with dementia.

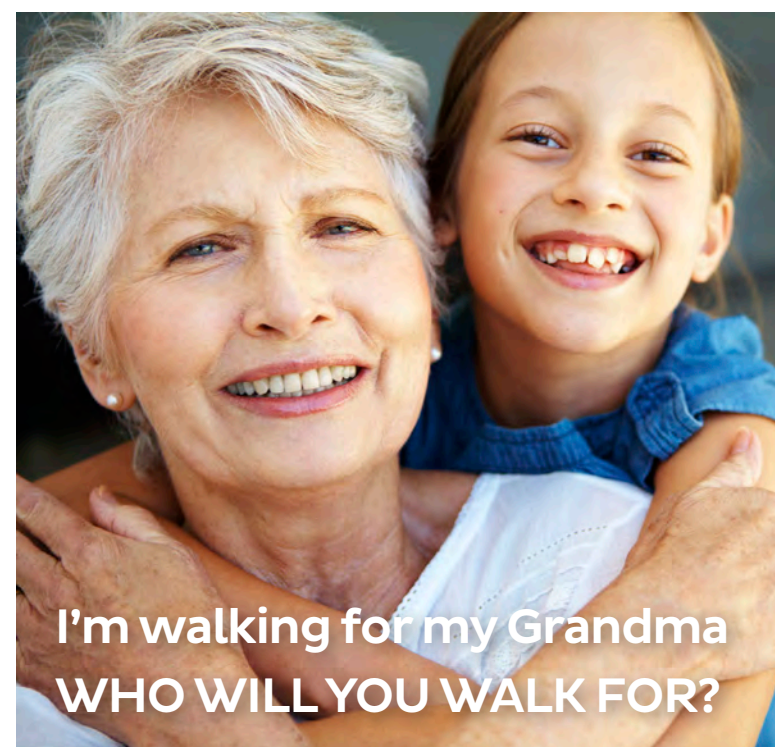
The theme for this year is *Dementia: Can we reduce the risk?*, focusing on the ways we may be able to help reduce our risk of developing dementia with brain healthy lifestyles.

Throughout September, Alzheimers NZ and its local member organisations will undertake a number of events and activities designed to raise awareness about dementia and to encourage members of the public to improve their brain health.

To celebrate World Alzheimer's Month, we are set to:

- unveil the second chapter of our National Dementia Awareness Campaign;
- launch the Memory Walk as a national event, taking place in 10 locations this year;
- release the 2014 World Alzheimer Report in New Zealand on September 17; and
- reveal the identity of the second Alzheimers NZ Champion for Dementia;
- promote the sale of the specially bred Dianthus Memories plant - a beautiful and fragrant gift, which will be available at garden centres nationwide.

Visit: www.alzheimers.org.nz/memorywalk to get involved in your local Memory Walk or contact Alzheimers NZ or your local Alzheimers organisation to find out what is happening near you.



The number of New Zealanders affected by dementia is growing rapidly. How this affects our communities is up to us.

Take a positive step for dementia this August/September and join a Memory Walk to raise awareness and support people affected by dementia.

Sign up for your local Memory Walk at www.alzheimers.org.nz/memorywalk



ELECTION BRIEFING

QUESTIONS FOR POLITICAL PARTIES

With Election 2014 fast approaching, Alzheimers NZ has written to each political party seeking information about their policy and plans to respond the challenge that dementia presents.

We have also provided parties with a full briefing paper, which both highlights the areas where action is needed and sets out the progress we want to see in each of these areas.

In summary, Alzheimers NZ wants to see urgent action:

1. To build a dementia friendly New Zealand;
2. To lift the quality of care and support that people affected by dementia receive;
3. To strengthen community and home-based support for people affected by dementia; and
4. For more investment in research.

Dementia is one of New Zealand’s most significant and growing healthcare challenges, and we need to work together to tackle it. Alzheimers NZ is calling for a collaborative response - for our people, our communities, and our economy.

You can read our full Election 2014 Briefing Paper online at www.alzheimers.org.nz, and make sure you check back before Election Day to find out how the political parties respond.

OUR QUESTIONS FOR POLITICAL PARTIES:

- What will you do to promote and support a New Zealand Dementia Strategy?
- What will you do to encourage and promote a dementia-friendly NZ?
- What will you do to strengthen community and home-based support for people affected by dementia?
- What will you do to lift the quality of care and support for people affected by dementia?
- How will you increase the investment in research into dementia?
 - How will you establish New Zealand’s leadership role in respect of dementia?

WORKING TOGETHER

FOR A GLOBAL SOLUTION

In our March issue of *Alzheimers News* we were pleased to inform you of the outcomes of the first ever G8 Dementia Summit, held in London in December 2013.

Since the Summit, we have seen an unprecedented international focus on dementia, and several exciting developments and announcements.

In February 2014, Dr Dennis Gillings was appointed as the World Dementia Envoy. Dr Gillings is the founder of Quintiles, the world’s largest provider of biopharmaceutical development services, and has provided consultancy to numerous companies and health organisations. As World Dementia Envoy his role is to champion dementia research and development and unlock investment in countries across the globe.

To support Dr Gillings in his role, the World Dementia Council has also been established. Council members include an influential range of experts in health and economics, leaders in research and medicine and directors and representatives of Alzheimers organisations across the globe. A backing of such calibre will provide significant support to our vision of working towards a world without dementia.

In addition to these outcomes, the UK Department of Health has also been working with ADI and the G7 nations to form the Global Alzheimer’s and Dementia Action Alliance (GADAA), the first global body to bring together government, the health and social care sector, charities and the volunteer sector and wider civil society to tackle the challenge of dementia.

These are exciting international developments and we will be keeping you well informed as they progress. A world without dementia can only be achieved with this collaborative, global effort.



NEW LIFE MEMBER



Alzheimers NZ Chair, Susan Hitchiner, presents David Ansell with his Life Membership Award, supported by Kathy Webb, President of Alzheimers Tauranga.

David Ansell was elected as a Life Member of Alzheimers NZ at the AGM in May. David was unable to attend the AGM due to ill health so we presented the award to him in Tauranga early April.

As President of Alzheimers Tauranga for 16 years, David has made a very significant contribution to the Alzheimers NZ federation and to Alzheimers Tauranga for more than two decades, formally and informally.

As a result of the dedication and responsible leadership and governance David displayed, Tauranga has been able to provide support, education, guidance, and advocacy to a larger number of people with dementia, and their families/whānau. Alongside that focus, David has actively contributed to the federation-wide and national effort as part of Alzheimers NZ.

On receipt of his Life Membership David said, “the ethos of Alzheimers Tauranga is that we have tried to maintain a steady focus on the support and information that is needed locally, and the conviction that we are fully part of a national organisation – that we have tried to support as best we can.”

“My hope is that other people will receive the same affirmation – and that this will bring a greater sense of belonging to one another as Members of Alzheimers NZ,” David said.

ADI ANNUAL COUNCIL MEETING:

NEW MEMBERS WELCOMED



Susan Hitchiner, Alzheimers NZ Chair, speaking with Mariella Guerra, new ADI Board Member from Peru.

Alzheimer’s Disease International held their 29th annual Council Meeting on 1 May 2014 alongside the conference; *Dementia: Working Together for a Global Solution* in San Jan, Puerto Rico.

Five new members were welcomed to the council; Morocco, Monaco, Nepal, Norway and Slovenia which took the member countries up to 84.

Three new board members were also elected:

- Mariella Guerra from Peru
- Gerry Sampson from the USA
- Markus Löfström from Finland

Andrew Ketteringham was elected as the new Treasurer and Glenn Rees, the current CEO of Alzheimers Australia, was elected as the new Chair. He will take over from Jacob Roy in April 2015.

ADI is also now a member of the Steering Group for the International Non-Communicable Diseases Alliance.

DEMENTIA: A STRATEGIC FRAMEWORK - AN OVERVIEW

When the Alzheimers NZ Board was elected in November 2012, they looked to the National Dementia Strategy 2010-2015 for direction and realised that the goals and action points set out in this strategy had either been achieved or superseded by events.

That was good news – but left the challenge of working out the next steps: what did we, collectively as a sector, need to do to continue our work for people with dementia, their support people, family and whānau?

By both replacing and building upon the National Dementia Strategy 2010-2015, *Dementia: A Strategic Framework* answers this question. It is strong, clear and aspirational, and it positions those affected by dementia firmly at the centre of everything we all do.

Dementia: A Strategic Framework has been developed with the whole sector in mind and it challenges all of us - organisations and individuals - to galvanise our collective activity toward a shared vision and goals.

The overarching vision – **towards a world without dementia** - is certainly stretching and, at the moment, we are a long way from that becoming a reality. That does not mean, however, that we should not be making every effort to move in that direction. Those affected by dementia now, and the growing number that will be affected in the future, deserve that commitment from us. In selecting the vision, we were also influenced by the people with dementia we spoke to – and their advice that what they were looking for was a cure.

We have also set out five goals, each with associated strategies designed to create the change needed to achieve that goal:

- We want to see a **dementia friendly New Zealand** in which people with dementia are involved in and participate in their local communities, and are safe; in which the health services are well placed to respond to the challenge that dementia presents; and in which the stigma that people affected by dementia experience is addressed.
- There is increasing evidence that **good brain health** is important. We need to know more about dementia and brain health, and we need to share the knowledge we gain. We also need to do more to increase public awareness so that dementia risk is reduced.
- We know that **early recognition and assessment** is crucial so that people with dementia can deal with legal and financial issues; be part of the planning for their care; and access the help and support they need. We also know that the system needs to do better in this area.
- We all want those affected by dementia – those affected directly and their family/whānau - to be **living well with dementia**, at whatever stage of the condition and in whatever setting.
- And to achieve all of this we need **high quality services** that are working collaboratively, have the necessary resources and capability, and are focused on the person.



APPLYING DEMENTIA: A STRATEGIC FRAMEWORK

Dementia is one of New Zealand's most significant and growing healthcare challenges. Our best estimate is that around 53,000 people in New Zealand currently have dementia - a number that we expect to triple to around 150,000 by 2050.

In meeting this ever-increasing challenge, the solutions are both large and complex. If we are to respond effectively and improve the lives of people affected by dementia now and in the future, it is clear that we need to work together, collectively.

For that reason, *Dementia: A Strategic Framework* has been deliberately designed to be applied by any organisation or individual working within the sector to their own situation or area of focus. Different providers and those working in different parts of the sector can use the sections of the framework relevant to them. Alzheimers NZ's work, for example, will be across the spectrum of goals, but if we look closely at the strategies, we will make a direct impact in some areas, and an indirect impact in others.

The strategic framework is a positive step forward for the whole dementia community in New Zealand. It provides focus and direction for us all, and the value of working collaboratively can not be overestimated: only when our respective contributions are taken together do we have the opportunity to achieve a world without dementia.



Champion for Dementia, Colin Mathura-Jeffree, and Alzheimer's NZ Board Member, Nigel Wynn, at the launch for *Dementia: A Strategic Framework*, in Wellington in April.

ALZHEIMERS TAURANGA BRAIN BUSTERS CHARITY QUIZ



Alzheimers Tauranga joined forces with the local Aquinas College football team last month to host the Brainbusters Charity Quiz 2014 - a popular and high energy fundraising event.

A total of 39 teams tested their brain power on the night, while well-known Kiwi comedian, Ben Hurley, acted as MC. In attendance throughout the evening, Ben warmed up the crowd with his trademark humour, helped out with marking, and raised nearly \$1000 with two auctions.

With more than \$7000 raised, Alzheimers Tauranga is looking forward to repeating the event next year, and would like to thank major sponsor, the Sanderson Group (Bethlehem Views and Bethlehem Shores) for its support.

DEDICATED DAUGHTERS RAISE FUNDS AND AWARENESS IN ROTORUA



Two Rotorua-based daughters, Joanne Tombleson and Christine Hobbs, have gone the extra mile to pay tribute to their loved ones, whilst raising much needed funds for Alzheimers Rotorua.

Joanne showed great endurance when she completed the Rotorua Marathon in May, in memory of her mother Ellen Phipps - a quiet, reserved and gracious woman and mother of six.

Joanne remembers her mum showing signs of memory loss when she was still a teenager, and after a dementia diagnosis, the family had a long association with Alzheimers Rotorua, receiving family support, education and information. Joanne's father, Syd, cared for his wife at home for many years, before extra help was needed and she moved into full-time care. Ellen sadly passed away in 2008, aged 71.

The Rotorua Marathon was Joanne's first, and she raised an astounding \$2288.60.

Just a few weeks later, over Queen's Birthday weekend, Christine and a supportive community of friends,

undertook Row for Ray - an annual event now in its third year.

Christine's father Ray Wooliams was a well-known businessman, former Rotorua Mayor, and deer farmer. After developing dementia in his early 70s, he was cared for in a home by his wife June, and Alzheimers Rotorua became involved, playing a supportive role. Ray, who was known for his sense of humour and quick wit, passed away in 2012, after 12 months in a residential dementia facility.

As well as raising funds and awareness for Alzheimers Rotorua, Row for Ray participants enjoyed a companionable long weekend of rowing on Rotorua's waterways, which included lots of stops and sightseeing, and shared food and drink.

Alzheimers Rotorua is extremely grateful to both Joanne and Christine for their efforts and for their financial contributions, which will be put to good use supporting people affected by dementia in the Rotorua area.



DEMENTIA:

THE FUTURE IS NOW

14 - 15 NOV 2014

BIENNIAL CONFERENCE
ROTORUA CONVENTION CENTRE



14-15 NOVEMBER 2014
ROTORUA
CONVENTION CENTRE

CONFERENCE 2014: UPDATE

The Alzheimers NZ Biennial Conference 2014, *Dementia: The Future is Now*, is being held in Rotorua from 14-15 November 2014.

The conference comes at a watershed moment for the dementia community, and at a time where there is an unprecedented global focus on dementia. To reflect this, *Dementia: The Future is Now* will showcase many exciting developments in research, prevention, support services, and treatment options both in New Zealand and internationally.

We are honoured to have some of the foremost dementia experts from New Zealand and around the world involved in the programme, and significant involvement from the New Zealand dementia community.

We look forward to seeing you there.

Our exciting list of keynote speakers is as follows:

- **Distinguished Professor Richard Faull**, Professor of Anatomy, Director of the Centre for Brain Research, University of Auckland; Director Neurological Foundation Human Brain Bank.
- **Professor Henry Brodaty**, Scientia Professor of Ageing and Mental Health, Director of the Dementia Collaborative Research Centre and Co-Director of the Centre for Health Brain Ageing, University of New South Wales.
- **Susan Hitchiner**, Alzheimers NZ Chair.
- **Professor Steve Illife**, Professor of Primary Care for Older People, Research Department of Primary Care & Population Health, University College London.
- **Glenn Rees**, CEO Alzheimers Australia and Chair Elect of Alzheimers Disease International.
- **Kate Swaffer**, has a dementia diagnosis and works as an advocate and activist for dementia care. She is the current Alzheimer's Australia Dementia Advisory Committee Chair.
- **David Troxel**, internationally known for his writing and teaching in the fields of Alzheimer's disease and long term care, he currently works as a writer, speaker and long-term care consultant.

To find out more and to secure your place, please visit www.alzheimers.org.nz/conference

COMMUNICATING WITH A PERSON AFFECTED BY DEMENTIA

We all need to be able to communicate well with those around us, but this can become frustrating and difficult when a diagnosis of dementia is involved - for both the person with dementia and their family and friends.

People with dementia have the same rights as anyone else – they deserve to understand and be understood. Each person with dementia is unique, and difficulties in communicating thoughts and feelings are very individual. It is up to all of us to adapt the way we communicate to suit the communication needs and style of the person with dementia.

Some changes you might notice in the person with dementia could include:

- Difficulty finding the right word to use- the person may compensate by using a related word;
- Being able to speak quite fluently, but without the conversation making sense;
- Struggling to understand what is being said or only understanding parts of the conversation;
- Not being able to read or write as well as before their diagnosis of dementia; and
- Losing their ability to follow the normal conventions of holding a conversation with someone, for example, they may interrupt or ignore the person speaking to them.

There are, however, many ways we can adapt the way we converse with a person who has been diagnosed with dementia. For example, we can:

- Maintain a caring attitude (it can be very frustrating for family and friends but it is important to remember that it is the diagnosis of dementia that has changed the way their loved one can communicate- it is not the person being 'difficult' or 'not trying');
- Remain calm and talk with a gentle tone;
- Keep sentences and instructions short and simple, and focus on one idea or instruction at a time;

- Give the person with dementia more time to understand and respond to questions - patience is essential;
- Remember that communication is much more than just talking- body language plays an important part and techniques such as pointing, demonstrating and showing you care by a gentle touch and smile are all important;
- Listen carefully to the person with dementia when they are talking- if they are having difficulty finding the right word or finishing a sentence, give them time or ask them to explain it in a different way;
- Make sure the environment is quiet and there is no background noise such as the TV or radio; and
- Stay in sight of the person with dementia when you are talking to them.

Along with employing these techniques, there are also things that family and friends should avoid doing. Try to make sure you do not:

- Argue or shout - this will only make the situation worse;
- Order the person with dementia around;
- Focus on what the person with dementia can't do instead of focusing on what they can do;
- Talk down to the person with dementia;
- Ask a lot of direct questions that rely on their memory; and
- Talk about them in front of other people as if they are not there.

It is also important to remember that as people age, the ability to hear and see may decrease. It is always a good idea to have regular vision and hearing checks, as difficulty with communication may not always be related to the dementia.

Adapted from Alzheimer's Australia and Alzheimer's Society fact sheets on communication.

ALZHEIMERS EASTERN BAY OF PLENTY

CAR RALLY



People living with dementia in the Eastern Bay of Plenty had a fun-filled day of adventure, when they recently participated in a specially organised car rally.

Following a health and safety briefing, volunteer drivers steered participants (a mix of people directly affected by dementia and their support people) along the tricky course. Leaving from the start point at two minute intervals, each car's team had to work together to solve a series of clues to find the correct route and answer questions along the way.

After the track was complete, the 32 attendees enjoyed fish and chips - served in true fashion out of newsprint - and stunning views over the harbour.

Alzheimers EBOP thanks all those involved in making this a great day out!

ALZHEIMERS NEW ZEALAND CHARITABLE TRUST: SMALL PROJECT GRANT AWARDS UPDATE

BY DR JEAN GILMOUR, CONVENER OF THE ALZHEIMERS NEW ZEALAND CHARITABLE TRUST RESEARCH ADVISORY COMMITTEE.

The Alzheimers New Zealand Charitable Trust, which promotes and supports dementia research, regularly makes Small Project Grant Awards of up to \$15,000, which support the development of clinical and academic research capacity.

In 2013, two grants were awarded: Dr Etuini Ma'u from Waikato District Health Board is leading a project entitled *The utility of the Maze Navigation Test* in predicting of on road driving performance; and Dr P.S.D.V. Prasadaraao, also from Waikato District Health Board, is working with researchers from the National Dementia Cooperative on a project to develop *An integrative review of the New Zealand literature of dementias and related conditions*.

The research projects funded in 2012 are still underway, but we can provide an update on their progress.

Alison McKinlay from Massey University reports that she is collecting data for her PhD study, *How do older adults cope with a diagnosis of mild cognitive impairment?* She is interviewing older adults who have received a recent diagnosis of mild cognitive impairment/neurocognitive disorder about their coping experiences.

Meanwhile, Dr Kay de Vries from Victoria University is lead researcher for a project called *Exploration of family/whānau/caregivers of people with dementia about their experiences of end of life care*. Thirty-two interviews have been conducted with caregivers of people with dementia. These have been transcribed and analysis is almost complete. This study will be published as part of a book.

Dr Emme Chacko from Auckland District Health Board has also reported on the completion of one of the first studies that received a grant in 2009: *Driving assessment and beyond - An observational study*. Dr Chacko notes that research on driving assessment is important, as while a proportion of older people with mild dementia are safe to drive, driving cessation is recommended at some point as the disease progresses.

Driving cessation can have a significant psychological and social impact on people with dementia and their carers. The study focused on the psychosocial and adjustment issues following driving cessation for seven people with dementia and their supporters with interviews within one month of the advice, and again six months later.

Most people with dementia were unhappy with the decision and supporters also found the driving cessation decision stressful. The preliminary findings highlight the need for a more comprehensive and streamlined process for driving cessation in those with dementia, and their carers.

For more information about the Alzheimers New Zealand Charitable Trust, visit www.alzheimersresearch.org.nz

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Alzheimers New Zealand

Level 1, 4-12 Cruickshank Street,
PO Box 14-768, Kilbirnie, Wellington 6241

Ph 04 387 8264 Fax 04 381 387 9682

Email admin@alzheimers.org.nz

Web www.alzheimers.org.nz

Charity registration CC 21026

0800 004 001
www.alzheimers.org.nz

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Yes, I would like to support people affected by dementia.

I would like to give:

☐ \$25 ☐ \$50 ☐ \$100 ☐ other \$ _____

I would like to support people with dementia and their families / whanau.

I would like my donation to go to:

☐ My local Alzheimers organisation

☐ Alzheimers New Zealand

☐ I've sent a cheque made payable to Al- zheimers New Zealand
or please debit my:

☐ Visa ☐ Mastercard Exp. /

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Please mail your donation to: Alzheimers NZ, PO Box 14-768, Kilbirnie, Wellington 6241

Your donation is greatly appreciated. Gifts of \$5 or more are eligible for tax deductions