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Champion rides
for dementia** *pg4*

**First WHO ministerial
conference on dementia** *pg7*
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FROM THE CHAIR SUSAN HITCHINER

In March, I had the pleasure of attending arguably the most significant event in the history of dementia - the World Health Organisation (WHO) Ministerial Conference on Global Action Against Dementia, in Geneva, Switzerland.

The Conference was perhaps one of the most inspiring events I have attended. The programme had a clear focus on the impact of dementia on individuals, families and close friends, and included moving first-hand accounts of the experience from people with, and affected by dementia. The two days reinforced my view of the importance of Alzheimers NZ's commitment to involving people with a diagnosis of dementia in everything that we do.

I was particularly struck, and energised, by the level of understanding and goodwill amongst both the Ministerial and NGO delegations for achieving dementia friendly communities, which I had not expected, and the clear discussion on the characteristics of those communities, and what we need to change in order to achieve safe, stigma-free communities for people with dementia.

In New Zealand, we currently have a strong focus on raising awareness of dementia and reducing stigma, with a view that with awareness, comes understanding and acceptance. In March, we were very fortunate to have World Champion and Commonwealth Games medal winning cyclist Eddie Dawkins and his coach and Halberg Award winner Anthony Peden, assisting us with that on a motorcycle rally for dementia.

Having high profile New Zealanders like Eddie and Anthony – and our two Champions for Dementia, Colin Mathura-Jefree and Reuben Thorne – work alongside us like this, creates important opportunities for greater discussion about dementia and how it impacts us all.

Thank you Eddie and Anthony for your generosity.



Susan Hitchiner
Alzheimers NZ Chair



YOUNGER ONSET DEMENTIA

STILL ALICE

We were pleased to see dementia in the global spotlight again in January, with the release of the movie *Still Alice*. We were also excited when lead actress Julianne Moore took home the Academy Award for Best Actress for her portrayal of Alice Howland, a linguistics professor who is diagnosed with young-onset Alzheimer's disease in her early 50s.

Still Alice provides a very authentic portrayal of the unique challenges of people affected by young-onset dementia, and the impact of the diagnosis on family and friends. The film was produced with the support of the Alzheimers Association in the US, and experts and volunteers, including individuals living with dementia, worked behind-the-scenes guiding both script and character development.

Our *About Dementia* television advertisements played before screenings of *Still Alice* around the country, and a number of local Alzheimers organisations held fundraising events alongside screenings in their areas.

Read a review of *Still Alice* and find out more at www.alzheimers.org.nz

ALZHEIMERS NZ AGM

The Alzheimers NZ AGM will be held on Saturday 2 May, at the Kingsgate Hotel, 24 Hawkestone Street, Wellington, from 10.30am – 4.30pm.

Please RSVP to admin@alzheimers.org.nz or phone 04 387 8264 if you wish to attend.

Still Alice highlights a very important and often overlooked dimension of dementia - younger onset dementia (sometimes called early onset dementia). The term 'younger onset dementia' is usually used to describe any form of dementia diagnosed in people under the age of 65.

Dementia in younger people has been diagnosed in people in their 50s, 40s and even in their 30s. For this reason it can be difficult to diagnose and its incidence in the community is still not clear.

Are the needs of people with younger onset dementia different?

A person with younger onset dementia may have different considerations because the dementia appears at an earlier stage of their life when they are likely to be more physically and socially active.

When diagnosed they may be:

- in full time employment
- actively raising a family
- financially responsible for the family
- physically strong and healthy.

Attitudes

An added difficulty can be the attitudes of other people. It can be difficult to accept that a younger person can have dementia, particularly when no obvious physical changes can be seen. It may appear that no-one else in the family or the person's age group understands what is happening.

The following tips from people in the early stages of dementia may help to deal with these attitudes:

1. **Be open and direct.**
Engage others in discussions about dementia and the need for prevention, better treatment and an eventual cure.
2. **Communicate the facts.**
Sharing accurate information is key to dispelling misconceptions about the condition. Whether a pamphlet or link to online content, offer information to help people better understand dementia.
3. **Seek support and stay connected.**
It is important to stay engaged in meaningful relationships and activities. Whether family, friends or a support group, a network is critical.
4. **Don't be discouraged.**
Denial of the condition by others is not a reflection of the person with dementia. If people think that dementia is normal ageing, see it as an education opportunity.
5. **Be a part of the solution.**
As a person affected by dementia, yours is the most powerful voice to help raise awareness, end stigma and advocate for more dementia support and research.

Children

Children may react strongly to a having a parent with dementia so it is important to talk openly about the changes that are happening because of the condition. Let them know it's okay to laugh - sometimes humour lightens the mood and makes coping easier. It may also be useful to let the school know about your situation and give them information about dementia to help them understand.

Supporting someone with younger onset dementia

For the family member who is supporting someone with younger onset dementia there are a number of issues and challenges that may arise, including financial pressures, role changes, and loss and grief for unfulfilled dreams.

Support people who are partners may have additional responsibilities, including raising children and managing finances. Sometimes family members and support people might have to consider to reducing or giving up work altogether to support the person with dementia.

Ongoing support

If you have any concerns about someone you know you should discuss this with your doctor in the first instance and also contact your local Alzheimers organisation for further advice and support on 0800 004 001.



Photo: Eddie Dawkins and Anthony Peden with Ruth Thomas, Alzheimers Tauranga Board Member (on the bike), and Dave Paddon, Alzheimers NZ Board Member (in the back left).

CYCLING WORLD CHAMPION RIDES FOR DEMENTIA

World Champion and Commonwealth Games medal winning cyclist Eddie Dawkins swapped pedal power for horsepower in March, leading a two-day motorcycle rally from Auckland to Taupo via the Bay of Plenty region, to raise awareness of dementia, and help educate New Zealanders about the things they can do to reduce their risk of dementia.

Eddie, who was accompanied by his coach and Halberg Award Coach of the Year Anthony Peden, has had two grandparents affected by dementia, making him one of the 2 out of every 3 New Zealanders who know or have known someone with the condition.

The rally attracted some excellent media coverage in all of the towns and cities it passed through, as well as national media coverage on One News. The rally was also well supported by local motorcycle clubs who joined Eddie and Anthony for various legs of the ride.

A big thank you to all of those who took part and to the local Alzheimers organisations who welcomed Eddie and Anthony so warmly to their home towns. Thanks also goes to Auckland Harley-Davidson for sponsoring Eddie and Anthony's motorcycles, and of course to Eddie and Anthony for taking time out of their busy schedules to help us raise awareness of dementia!

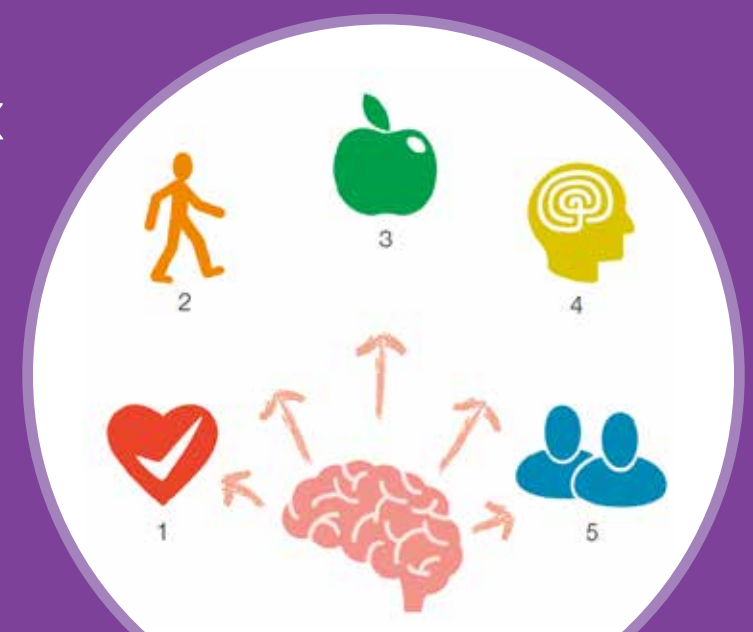
On the front cover:

Eddie with Tony and Marlene Baker, who are members of Ulysses NZ, Rotorua Branch. Marlene was diagnosed with dementia three years ago. Tony and Marlene still ride their 1995 GL1500 GoldWing motorcycle – Marlene as pillion! They ride regularly with Ulysses and love the company, friendship and generosity of the members.



REDUCE YOUR RISK OF DEMENTIA 5 SIMPLE THINGS:

1. Look after your heart
2. Be physically active
3. Follow a healthy diet
4. Challenge your brain
5. Enjoy social activity



ALZHEIMERS WANGANUI: GOODBYE JILL!



Alzheimers Wanganui has said goodbye to their hard-working Administrator Jill Jackson, who recently retired after ten years of service to the organisation.

"It's been really rewarding," says Jill, "When I started here our services were probably more about the people who support those with dementia. Now it's about both the person living with dementia and their support people."

Jill's dream is for a dementia-friendly community, where people with dementia are supported by their communities to continue doing the things they enjoy. She would love to see education programmes available for local businesses to teach them how to support people affected by dementia.

"So if someone went to the supermarket and became confused, they could feel free to go to someone working there and say, 'I have dementia, can you help me?'"

Thank you for all of your hard work and commitment Jill!



NEW CAR FOR SOUTH CANTERBURY

Alzheimers South Canterbury has a brand new set of wheels thanks to the Temuka Lions Club.

The Club started fundraising to purchase the vehicle at the instigation of late club member, Ira Graham who had a family member with dementia. Late in 2013 they contacted other Lions Clubs in the South Canterbury region and almost all made a contribution to the cause. An application to the Lloyd Morgan Lions Club Charitable Trust was also made enabling the club to purchase the vehicle.

The Club presented the 2014 Mitsubishi Lancer LS2000 to a very grateful Alzheimers South Canterbury at its meeting on 27th January 2015. The car will be used by the support team to visit clients throughout South Canterbury and will give the team better access to clients who live in the outer areas of South Canterbury.

DEMENTIA CHAMPION FOR NORTHLAND HEALTH CONSUMER COUNCIL

Dementia now has a strong advocate on the Northland Health Consumer Council (NHCC) with the appointment of Alzheimers Northland's Manager, Kevin Salmon, to the group.

The NHCC is made up of voluntary consumer representatives who report to the Northland District Health Board (DHB) Executive Leadership Team through the DHB Chief Executive Officer. Its purpose is to work with the DHB to develop effective partnerships and communication pathways between consumers and the DHB.

"It was my experience with my mother's ill health and our use of Northland health services that prompted me to put my name forward for the Council, but I obviously have strong views about the experiences of people affected by dementia with the health system," Kevin says.

"I'd personally like to see a specialist dementia ward at Northland Hospital with trained staff. I'd also like the DHB to recognise that dementia needs to be noted on the file of any patients with dementia coming into the hospital, and for those patients to be treated accordingly by staff with dementia training.

"Finally, I believe it's important that the Council adds genuine value to improving the DHB and the services it provides to the community."



INTERNATIONAL UPDATE

DEMENTIA ON THE GLOBAL STAGE AT WHO MINISTERIAL CONFERENCE

Dementia hit the global headlines again in March, at the first World Health Organisation (WHO) Ministerial Conference on Global Action Against Dementia, in Geneva.

The event was a significant milestone for dementia, as it was the first time dementia had been the subject of a truly global discussion, with government officials, researchers, Ministers and other government officials from around 60 nations, as well as experts from the research, clinical and NGO communities, coming together to discuss the global challenges posed by dementia.

Participants agreed on an important call to action - making dementia a global health priority.

"The discussions had at the first WHO Ministerial Conference were truly inspirational, and we were very pleased to see the conversations that began at the G8 Dementia Summit in 2013 being extended to the global stage," says Executive Director Catherine Hall.

"We were particularly excited to see a real focus on the impact of dementia on individuals and families, and the community response to that, as well as the need for research into treatments and a cure for dementia.

"There is an overwhelming amount of activity underway and planned, to



Hilary Doxford – person with dementia on the World Dementia Council, **Kate Swaffer** – Co-chair, Dementia Alliance International, and **Susan Hitchiner** – Chair, Alzheimers NZ

address the challenge of dementia - we look forward to seeing where this global discussion will now lead, and how New Zealand can participate in future conversations."

Videos content from the WHO Ministerial Conference in Geneva is available at <http://www.who.int/mediacentre/dementia-conference-live/2015/en/> or head to www.alzheimers.org.nz for a direct link.

G7 LEGACY EVENT – USA

On 11 February the G7 countries gathered in Bethesda, USA, for the third G7 Legacy event, which focused on the progress that has been made since the first G8 Dementia Summit, held in December 2013.

Highlights included an update from the World Health Organization on its research prioritisation project, which Alzheimers Disease International is involved in, and from the Organisation for Economic Development and

Cooperation (OECD) on big data and on dementia research budgets from the G7 countries. Each nation also updated on progress and current initiatives in their countries.

Find out more at www.alz.co.uk

IN MEMORY OF



**JEROME M.
STONE**

Early this year we were saddened to hear of the passing of Jerome (Jerry) H. Stone, founder and Honorary Vice-President of Alzheimer's Disease International (ADI), who passed away on 1 Jan 2015 at the age of 101.

As the President of the Alzheimer's Association in the USA, Jerry Stone brought together the associations who founded ADI in 1984 in Washington DC. Over the years Jerry visited many ADI Conferences. He gave his last formal presentation for ADI at the Alzheimer University on Public Policy and Campaigning in Chicago in 2010.

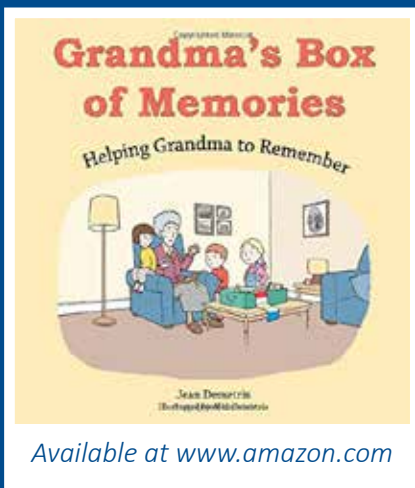
Jerry became involved with the Alzheimer's movement when his wife, Evelyn, was diagnosed with the disease in 1970. Jerry recognised the need for an organisation that would provide support for people with dementia and their caregivers and advance research toward treatment and ultimately, a cure.

Jacob Roy Kuriakose, Chairman of ADI said: "Jerry Stone inspired us all to make the Alzheimer's and dementia movement truly global, to be ambitious and think big and reach out to the global institutions. We will miss him a lot."

GRANDMA'S BOX OF MEMORIES

BY JEAN DEMETRIS

Book review



Review by Karen Foster,
Alzheimers NZ Board
Member

Alice has a Grandma with dementia who is sometimes confused and forgets things. Alice talks to her Dad about this and together they come up with a plan for how they can help Grandma remember some good times they have shared together. Alice's family joins in to add their own happy memories.

I read this book with my four year-old granddaughter and she enjoyed the story, participated in the storyline and we talked about what things she would choose to remind her of happy times. The next time my granddaughter visited, I found her "reading" the story to her teddy. The story helped the topic of forgetfulness to be easily talked about in a relaxed way and created an opportunity to ask questions. I liked the way the book covered the five senses: sight, taste, touch, smell and hearing when helping Grandma to remember.

I would recommend this book to adults looking for a book to read to/ with children who have a loved one affected by dementia. It provides a good opportunity for the adult and children to discuss the memory changes that affect their loved one and by sharing these memories they can distract them and help them feel settled.

ALZHEIMERS NZ CHARITABLE TRUST SMALL PROJECT ROUND FOR 2015

The Alzheimers New Zealand Charitable Trust is solely dedicated to dementia research. The Trust's primary objective is to support individuals and organisations undertaking medical and social research for the benefit of people (directly or indirectly) affected by dementia. In 2015 up to \$15,000 is available for research focused on the medical and social aspects of dementia. Any relevant topic will be considered.

The closing date for applications is Friday the 31st of July 2015. Applicants should follow the information provided in the document "Small Project Grants" available at www.alzheimersresearch.org.nz.

If you need any further information email Jean Gilmour, Convenor of the Research Advisory Committee, at J.A.Gilmour@massey.ac.nz.

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

Ph 04 387 8264

Email admin@alzheimers.org.nz

Web www.alzheimers.org.nz

Charity registration CC 21026

**For dementia support call
0800 004 001**

Alzheimers NZ is a member of Alzheimer's Disease International, the umbrella group for 84 Alzheimer's disease organisations worldwide.

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