



Alzheimers *News*

The magazine for the New Zealand dementia community | Issue 104 | Summer 2016

New Champion for Dementia pg 2

**2016 Alzheimers NZ
Conference** pg 4

Our call to action pg 6



From the Chief Executive

Catherine Hall

As we are fast approaching the end of the year, my email inbox is still buzzing with feedback for our conference *Dementia Today: Diverse communities, Collective Action*. I am glad that so many conference participants have taken away great ideas and a sense of hope and inspiration, like I did too. I would like to thank everyone who came and took part, including the large number of people with dementia and their care partners. You all are what made these three days in Wellington such a huge success.

At the conference opening, Chair Ngaire Dixon spoke about a strategy for supporting the growing number of people with dementia we are proposing to Government. We suggest that government should support people with dementia earlier on, which would not just save the government money but also

improve quality of life for people with dementia. Read about our proposal on page 6.

This year, 2016, has been another busy year for Alzheimers NZ, and our 30th anniversary year. Have a look at our timeline on page 7.

I am now looking forward to the holiday period and 2017, and wish you a happy Christmas.



Catherine Hall
Alzheimers NZ Chief Executive

Popular author named as *Champion for Dementia*

Kate De Goldi is our fourth Champion for Dementia.

Kate is a well-known and award winning short story writer, an author of young adult fiction, a children's book author and a writer of journalism pieces.

She has won multiple awards for her writing including the American Express and Katherine Mansfield Memorial awards for short stories and the New Zealand Post Book of the Year Award in 2005 and 2009, the Young Adult section of the 2009 New Zealand Post Book Awards, the 2011 Margaret Mahy Award and the 2011 Young Readers'

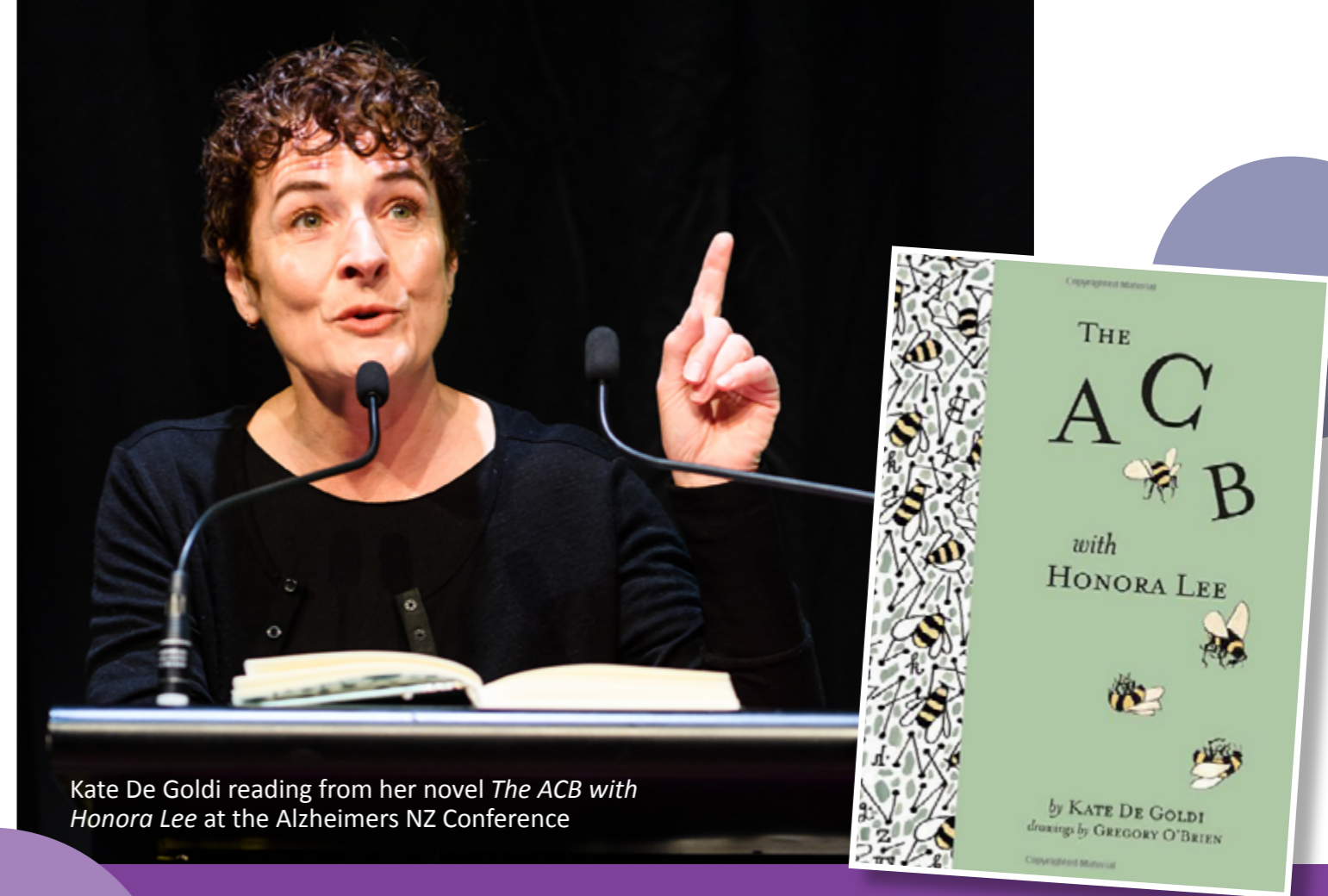
Award Corine Literature Prize. And earlier this year she won the Esther Glen Award for Junior Fiction at the 2016 NZ Book Awards for Children and Young Adults for her novel *From the Cutting Room of Barney Kettle*.

Her 2012 novel, *The ACB with Honora Lee*, explores the relationship between a young girl, Perry, and her cranky grandmother, who has dementia and lives in a rest home.

Kate's experience with dementia comes through her mother who

started showing signs of memory loss in her early seventies. Through her association with Alzheimers NZ, Kate is looking to honour the experience she had with her Mum and Dad and help raise public awareness of dementia.

Kate joins Kerry Prendergast, Colin Mathura-Jeffree and Reuben Thorne, who are already supporting Alzheimers NZ's awareness raising activities as Champions for Dementia.



Kate's story

Our family's experience of Alzheimers began when our mother started showing signs of memory loss in her early seventies. As her dementia worsened over the next few years a heavy burden of care fell on our Dad, and on my sisters who both lived in Christchurch. It was a very difficult and sad time – and made even more so when we started to suspect that Dad, too, had dementia.

Interestingly, we had, in a sense, been made ready for our parents' dementia by our experience with our maternal grandmother years before when she had lived with us. In dealing with Mum and Dad my sisters and I called on our vivid memories of Mum's patience with her mother, her instinctive ability to play along with Nanny's confabulations and repetitions, her great sensitivity and patience. We felt that Mum had, in a way, taught us how to be with *her* in her own strange, altered reality.

In the period before Mum went into care we sought and were given great help by Alzheimers Canterbury. It was enormously reassuring to know that here was a group of people who had seen it all before, who could acknowledge our difficulties and sadness but give practical advice as to every stage of the dementia trajectory. We were also greatly supported and uplifted by the loving care and attention Mum received when she was in care. Her new home became a new home for us, too – and her fellow residents, their families and

the extraordinary caregivers were a new community that touched our lives in marvelous ways. It was just like this, too, when we went down the same road all over again with Dad a year of so later.

Both our parents have died now. It is good to know that their struggle is over, though we miss them very much. But the legacy of their experience with Alzheimers is profound for myself and my sisters. We learned so much amidst all the sorrow. The big takeaway for me is this: though I may have felt that Mum and Dad were lost to me it does not mean they were not *there*. Though they may not have known who I was, or indeed who they were, they existed still, they were *themselves*. Though their lives were different and difficult by our measure it did not mean that they had no quality of life. It was incumbent on us to think more imaginatively about what their lives and selves had become and to see their humanity beneath the altered body and personality.

I feel very lucky to have the opportunity to work with Alzheimers New Zealand, to honour in a way the priceless experience I had with Mum and Dad. I look forward very much to helping raise public awareness of dementia and the work of this excellent organisation.

Kate De Goldi

Looking back at *Dementia Today: Diverse Communities, Collective Action*

The Alzheimers NZ 2016 Conference and ADI 19th Asia Pacific Regional Conference had a lot to offer for the 370 participants: vibrant keynotes, inspiring workshops and plenty of opportunities for the dementia sector to get together and network.

Major themes emerging from the conference were human rights and quality of life for people with dementia. It was only fitting that, in a world first, 20% of registrations were from people with dementia and their carers.



Minister of Health Jonathan Coleman



Keynote speaker Kate Swaffer, Dementia Alliance International, and Wendy Fleming, Alzheimers NZ Charitable Trust Chair, ADI Honorary Vice Chair and Alzheimers NZ Life member



The Alzheimers Taranaki team

“Congratulations for a great conference and great learning for the participants.” Theresa Lee, Executive Director, Alzheimer’s Disease Association Singapore



Keynote speakers Steve Iliffe, University College London, and Mary Mittelman, New York University School of Medicine



The Alzheimers Indonesia team with Alzheimer's NZ volunteer policy advisor Stephen Lungley



Panel discussion



In the exhibition space



ADI Chair Glenn Rees, Alzheimer's Wellington Chair Frances Blyth and Alzheimer's Disease Association Singapore President Ang Peng Chye

“I have been to many conferences both nationally and internationally and I can honestly say that this conference was one of the best.” Wendy Fleming, Alzheimers NZ Charitable Trust Chair, ADI Honorary Vice Chair and Alzheimers NZ Life Member



SoundsWell Singers, a Wellington choir for people with neurological disabilities



Keynote speaker Mick Carmody, Dementia Alliance International



Alzheimers NZ Chief Executive Catherine Hall, Chair Ngaire Dixon and keynote speaker Lee-Fay Low, University of Sydney



Keynote speaker Adelina Comas-Herrera, London School of Economics, co-author of the 2016 World Alzheimer Report

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“What an amazing conference! There was not only great info and great inclusion, but so much positivity and hope!” Al Power, University of Rochester New York

Our proposal to Government

Alzheimers NZ wants Government to adopt a two-tier strategy to improve post diagnostic support for people living with dementia.

Chair Ngaire Dixon unveiled the organisation's proposals at the Alzheimers NZ conference in Wellington.

"There is a dementia tidal wave looming as our population ages and we desperately need better care and support for people with dementia, and better care and support for their carers," Ms Dixon said.

"Obviously this needs additional government funding, but that should be seen as an investment."

She said Alzheimers NZ's proposals would have a three-fold impact.

It would increase the quality of life for people with dementia, and that of their carers, and increase the length of time that people with dementia can live in their homes before entering long term care.

Government would also benefit due to a reduction in the costs of providing long-term care for people with the condition and because there'd be few unnecessary hospital admissions that arise from the need for crisis intervention.

Alzheimers NZ Chair Ngaire Dixon speaking about the proposal to Government

ALZHEIMERS NZ PROPOSAL TO GOVERNMENT

Alzheimers NZ wants 12 months of guaranteed post diagnostic support for each person diagnosed with dementia. That's about 14,000 people each year.

Money would go towards a raft of initiatives, chief among them providing better in-home support and information services.

The organisation also wants the government to implement the Navigator role as a priority. This is a designated person in the care team for a person with dementia and is their first point of contact. The Navigator role is already part of government policy; government has not yet implemented it.

Alzheimers NZ's proposals will:

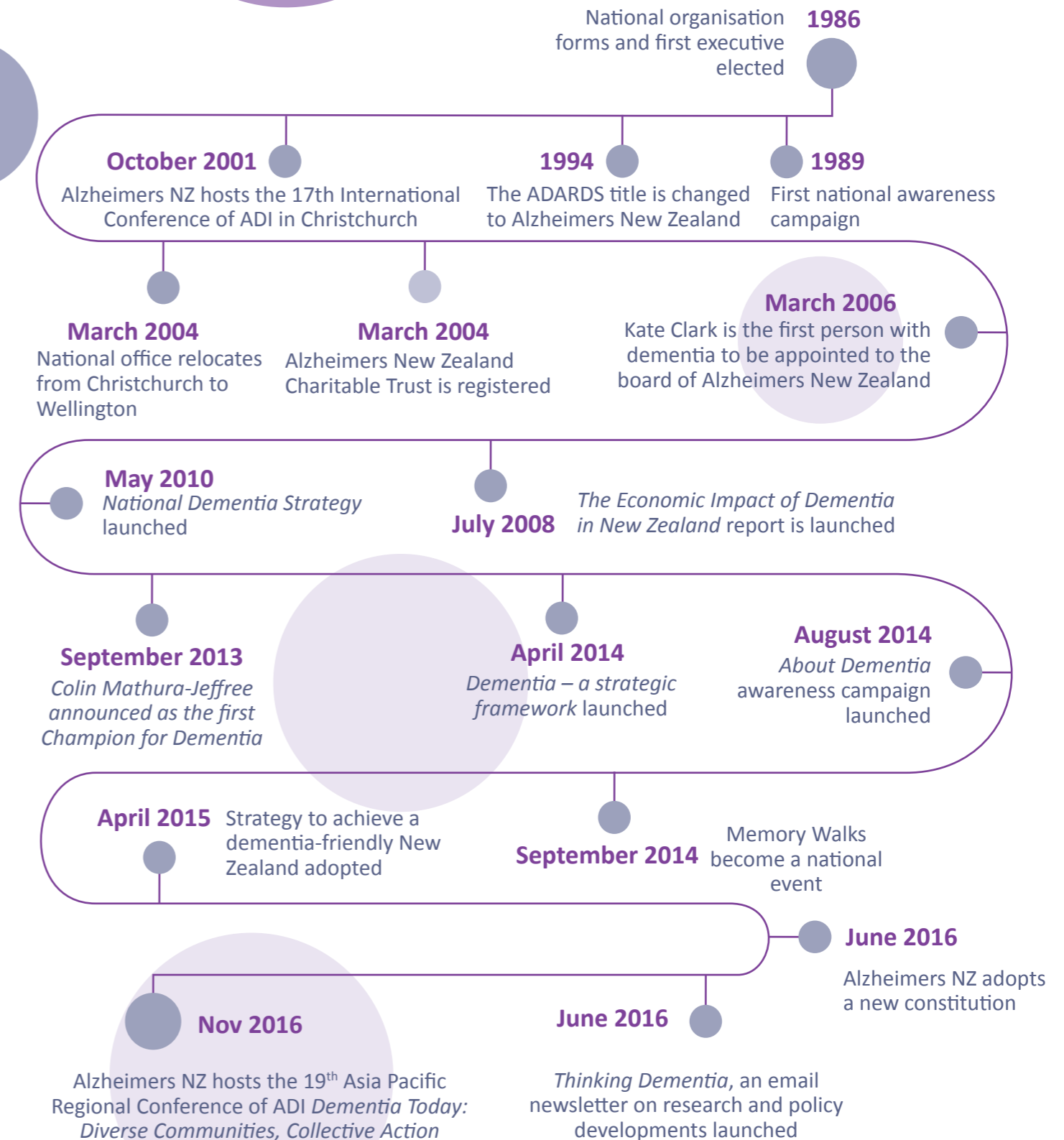
- increase quality of life for people with dementia, and their carers
- increase the length of time that people with dementia can continue to live at home.

Government would also enjoy:

- reduced costs in terms of providing long-term residential care for people with the condition
- reduced costs because there'd be fewer unnecessary hospital admissions that arise from the need for crisis intervention.



On 22 December 2016 it will have been 30 years since Alzheimers NZ, or Alzheimers Disease and Related Disorders Society (ADARDS) as it was called then, was incorporated.



International meetings in Wellington

Leading up to the Alzheimers NZ Conference, Alzheimer's Disease International held two events for national Alzheimers organisations in Wellington.



Alzheimers University is a series of workshops for national Alzheimers organisations, especially when they are new or emerging. The aim is to give participants the tools to identify their association's aims, provide information, raise money and awareness, effectively govern their association and influence public policy. This year the University focussed on advocacy activities and we were delighted to be joined by 15 colleagues from the Asia Pacific Region and Julie Butler from Alzheimers Otago.



Also ahead of the conference, ADI Members from all over the Asia Pacific Region met in Wellington for their Annual Business Meeting. At the meeting they took the opportunity to update each other on their work, including dementia-friendly initiatives and activities for World Alzheimers Month. A train-the-trainer programme for low and middle income countries was also discussed.

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Alzheimers NZ is a member of Alzheimer's Disease International, the umbrella group for 85 Alzheimer's disease organisations worldwide.

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