



Alzheimers News

The magazine for the New Zealand dementia community | Issue 93 | March 2014



Find out more about the innovative Artzheimers programme on page 7



Kia ora, and welcome to Alzheimers News.

After a hiatus in publication (except for the special edition for World Alzheimers Month 2013), I'm pleased to advise that we will now be resuming publication of Alzheimers News on a quarterly basis.

Some of the highlights in this edition include:

- Information about the historic G8 Dementia Summit;
- An update about our November conference, *Dementia: the future is now*;
- Advice about our ongoing awareness campaign;

- Five simple steps to maximise your brain health;
- An introduction to our new clinical advisor Vanessa Pullan; and
- A featured initiative from Alzheimers Canterbury - the innovative Artzheimers programme.

If you have any feedback about this issue of Alzheimers News, or ideas for future content, we would love to hear from you. Please email comms@alzheimers.org.nz or call 04 387 8264 with your suggestions.

In the meantime, thank you for your continued support.

Catherine Hall
Alzheimers NZ Executive Director

Message from the Chair - Susan Hitchiner

For those of you who may not know me, I joined the Alzheimers NZ Board in November 2012 and took on the role of Chair in February 2013.

The last year has been one of major change for our organisation, and we have been ambitious and resolute in moving forward. The challenge dementia presents is significant and continues to grow and, as a Board, we are strongly committed to rising to that challenge. It is vital that we can continue to deliver for the people we are here to support: those with dementia, and their support people, family and whanau.

A major component of the change process for our organisation has been re-setting our strategic direction for a future that responds to and recognises changing external demands. Taking a collaborative approach, we have developed a strong, clear and aspirational Strategic Framework that the organisations working across the wider dementia community can all apply to their own areas of focus. I am looking forward to launching this Framework in the coming months and to working with others in the sector towards achieving its goals.

With a clear direction in place, we have now started to shift our focus. From rebuilding internal capacity in 2013, we have moved to developing our external services and providing more comprehensive support to our Members – the 21 local Alzheimers organisations that provide services directly for people affected by dementia in our communities.

We are excited to be able to build on the foundations we developed with our National Awareness Campaign in 2012/13 to deliver a stronger awareness programme into 2014 and beyond. Our work to increase community understanding of dementia and reduce the stigma that is still experienced by people affected by dementia is critically important.

We are also developing an advocacy and research strategy. This strategy will set out our approach for working with the Government and other decision-makers to advocate on behalf of people affected by dementia and promote increased levels of investment in research into dementia. Effective advocacy will also help to raise awareness of dementia and build understanding of its impact.

With a Clinical Advisor on board from late last year, we have successfully held our first set of professional development workshops across the country for our Members. We are also working with Members to strengthen the federation through initiatives focusing on organisational health, and services and standards.

We have achieved a number of changes and improvements over the last year, and we move into 2014 with enthusiasm, ready, as our aspirational new vision says: to work towards a world without dementia.

Susan Hitchiner
Alzheimers NZ Chair

Relationship with National Dementia Cooperative strengthened

We are pleased to advise that we have formalised a relationship agreement with the National Dementia Cooperative (NDC) under which Alzheimers NZ will support the operation of the NDC, in particular by managing financial systems to support the NDC's activities and contracting with staff and suppliers on its behalf.

The NDC was formed in 2011 as an informal group of individuals and organisations and now has over 700 members committed to improving the quality of life for people affected by dementia. The organisation operates by collaborating across its members, and sharing resources, information, knowledge and skills.

Members come from a wide range of occupations and backgrounds (including medical, nursing, allied health, carers, managers and academics); from small private providers, large corporations, not-for-profit, religious, and professional organisations, DHBs, and NGOs; and from all around New Zealand.

We believe this agreement will significantly strengthen the relationship between us, so we can support each other and work together to address the significant and growing challenge that dementia presents.

Historic G8 Dementia Summit held

The international dementia community reached a milestone in December 2013, when the first ever G8 Dementia Summit was held in London. The Summit saw expert researchers, pharmaceutical companies, representatives from the OECD, Alzheimers organisations and health and science Ministers of the G8 nations meeting to discuss global action on dementia.

Alzheimers NZ was pleased to see a very clear commitment to global collaboration, as well as some ambitious goals set around the treatment and cure of dementia. The group made a series of 11 commitments to address the growing challenge of dementia, including finding a cure or a disease-modifying therapy for dementia by 2025 (supported by increased funding for research); innovation to improve the quality of life for people affected by dementia; and calling upon society to continue to reduce the stigma, fear and exclusion experienced by people with dementia.

At a national level, Alzheimers NZ is calling for cross-sector and cross-agency collaboration on dementia involving Government, community-based / not-for-profit and private sector organisations and service providers to begin in order to support these international commitments.

To continue momentum, the G8 Dementia Summit participants have committed to a series of high-level forums throughout 2014 in partnership with the OECD, WHO, the European Commission, the EU Joint Programme on Neurodegenerative Disease (JPND), and the not-for-profit sector, to develop cross sector partnerships and innovation focused on:

- Social impact investment – UK-led
- New care and prevention models – Japan-led
- Academia-industry partnerships – Canada and France - co-led

In support of this work Alzheimers Disease international (of which Alzheimers NZ is a member) is establishing a global taskforce that focuses on facilitating research, further developing dementia friendly communities and awareness initiatives, and improving health and social care systems.

The next G8 Dementia Summit will be held in the United States in February 2015.

For further information on the commitments made at the G8 Dementia Summit visit: www.alzheimers.org.nz.



Champion support in Porirua

Late last year Alzheimers NZ's Champion for Dementia, TV personality Colin Mathura-Jeffree, joined Alzheimers Wellington's Porirua Supporter Group at Kemp Home and Hospital in Porirua for its regular monthly catch-up.

It was a lively group of about 15 carers including Austin McLean, who has been caring for his wife Margaret at home in Plimmerton for 17 years!

The group, which meets monthly and is run by Alzheimers Wellington Community Worker/Team Leader Liz O'Hare, provides a safe environment in which people who are supporting a person affected by a dementia can meet, share their experiences and learn from each other.

Colin was able to share his personal experience with his grandmother's dementia and listen to others' experiences with their loved ones.



Wellington Community Worker/Team Leader Liz O'Hare is pictured with Colin and support group member Austin McLean.

National awareness campaign to be extended

We are delighted to announce that we have successfully secured a contract with the Ministry of Health to continue our national dementia awareness campaign until 2016, following the conclusion of the first chapter in July 2013.

In November, Associate Health Minister Hon Jo Goodhew announced that \$1.25 million of the \$3.2 million identified in Budget 2013 for raising awareness of dementia and clinical education and training would be allocated to Alzheimers NZ. The remainder has been split between DHBs for clinical education and training for healthcare workers.

The \$1.25 million contract awarded to Alzheimers NZ will support our work to raise awareness of dementia and promote early detection and diagnosis so that people affected by dementia get the help and support they need. It will also see us liaising with regional dementia care pathways groups to inform them of the campaign tools and resources available to them.

We are also pleased to see the government investing in clinical education to support early detection and training for those working with people affected by dementia.

Glittering event raises funds to boost quality care

Alzheimers Eastern Bay of Plenty have benefited from a glittering charity event organised by Te Whare Wananga o Awanuiarangi to recognise 25 years of the organisation's valued support in the community.

Held in November 2013 and aptly titled Too Important to Forget, the black-tie event featured a charity auction, entertainment by Elizabeth Marvely and Anituatua Black, and guest speaker Dr Hinemoa Elder, visiting Associate Professor, Indigenous Research, and Post-Doctoral Fellow at Te Whare Wananga o Awanuiarangi.

Many local individuals, businesses and organisations gave generously to support the event, and funds were raised through the charity auction, raffles and cash donations on the night.

The funds raised will be used to deliver a broad-based education programme and to boost quality care in the Eastern Bay.

Alzheimers Eastern Bay of Plenty Chairperson Sally Shaw extended special thanks to Distinguished Professor Graham Smith and staff of the Wananga, as well as the team at Alzheimer's Eastern Bay of Plenty, who worked together to plan and organise the fundraiser.



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Internationally renowned experts to present at 2014 Conference

Some of the world's leading experts in dementia are set to visit New Zealand in November this year for our biennial 2014 conference.

From 14-15 November the Rotorua Convention Centre in Rotorua will play host to an exciting conference programme showcasing the many exciting developments happening at this watershed moment for the dementia community. The programme will cover advancements in research, prevention, support services and treatment options both in New Zealand and internationally.

Our three renowned keynote speakers are:

Professor Henry Brodaty

Scientia Professor of Ageing and Mental Health, Director of the Dementia Collaborative Research Centre and Co-Director of the Centre for Healthy Brain Ageing, University of New South Wales

One of the world's leading experts in dementia, Professor Brodaty will give the key note address, looking back on the 30 years that have passed since the New Zealand dementia community started to focus on helping people affected by dementia, as well as looking at what lies ahead.

Professor Steve Iliffe

Professor of Primary Care for Older People Primary Care & Population Health, Institute of Epidemiology & Health, Faculty of Population Health Sciences, University College London

With research interests in health promotion and mental health Professor Iliffe's address will focus on health promotion and early intervention in relation to dementia.

Professor Ngaire Kerse

Head of School of Population Health, University of Auckland

Professor Ngaire Kerse is a GP academic at the University of Auckland who runs a programme of research aimed at maximizing Health for Older People. Professor Kerse's presentation will take delegates through the demographics of dementia now, and into the future.

Call for Abstracts

We are now accepting abstracts for oral and poster presentations in the following categories: a dementia friendly New Zealand; good brain health; early recognition and assessment; living well with dementia; and high quality services.

This is a wonderful opportunity for us to profile the work of both local Alzheimer's organisations and the wider dementia community and we are looking forward to receiving a wide range of interesting and informative abstracts from across the sector.

You can find out how to submit an abstract and register for conference updates at:

www.alzheimers.org.nz/conference

Adventure for a cause

Late in 2013, the Wairarapa Four Wheel Drive Club held a Public Day to raise much needed funds for the local Alzheimers organisation.

Access was granted to private land to create a wonderful drive with a few challenges of rocks, bogs and creeks crossings, as well as views to take your breath away. A total of 87 vehicles covered the 135 kilometre distance from Martinborough to Gladstone (49 kilometres of which was off road, or on some very dusty tracks).

The event was a great success raising a total of \$4,742 for Alzheimers Wairarapa.



New facility opens in Napier

Alzheimers Napier celebrated the culmination of a three year journey with the formal opening of a new facility in November 2013.

The facility – named Wilding House – provides a base from which the specialist community team can operate, and also has a large section providing day respite. Within the centre there is also now the space to provide an ‘early intervention’ meeting place.

Alzheimers Napier President Kim Mayne was thrilled to finally see the completion of the project and paid special tribute to the part played by the organisation’s manager Rob Lutter.

Close to 100 people were present at the event with special guests including Health Minister Hon Tony Ryall, local MP Hon Chris Tremain, and Alzheimers NZ Chair Susan Hitchiner. The Deputy Mayor, Faye White, also attended along with many of the organisations involved in funding the project, and Alzheimers Napier volunteers, members, clients, management and staff.



Pictured left to right: Napier deputy mayor Faye White, Alzheimers Napier President Kim Mayne, Minister of Health Tony Ryall, Alzheimers Napier Manager Rob Lutter and Napier National MP Chris Tremain.

Stimulating the senses with art appreciation



Alzheimers Canterbury has introduced an innovative programme which uses art appreciation as a medium for stimulation for people with dementia.

While the concept is not new in other parts of the world, the programme, which has been named Artzheimers, is the first of its kind in New Zealand.

It is recognised that art appreciation provides a mechanism of stimulation and social interaction for people from all walks of life, and with a variety of disabilities, but in New Zealand there has been a tendency not to look at the role art appreciation could play for older adults and those with dementia.

The benefits of remaining active and staying socially integrated are well documented when it comes to dementia. Aside from the enjoyment, encouraging people to remain stimulated can contribute to maintaining independence, increasing understanding, and relieving anxiety and depression.

“Art is a fantastic tool for evoking memories,” Alzheimers Canterbury manager Darral Campbell says. “You don’t have to be good at art to enjoy this group. It’s been lovely to see people who don’t find it easy to verbalise enjoying art.”

As the Christchurch City gallery remains closed due to earthquake damage, sessions are held at one of the city libraries. Large ‘copies’ of the

works are displayed and handled by the group while the guide presents information about the history, culture, artist, content of the art work. The group is encouraged to contribute their thoughts, feelings and ideas, and postcards of the works are given to the participants to take home.

Feedback from the participants and guides has been overwhelmingly positive. June King, 78, attends the sessions every month and loves it. “I love artwork,” she says. “I’m no good at it myself, but I appreciate it.”

She keeps the cards from the sessions on display at home and often looks at them. “I really see something in artwork. I make up my own little stories for what I think it’s about. That’s what it does for me. I makes the old brain think and that’s what I need.”



New clinical advisor appointed

In late 2013, Vanessa Pullan joined the Alzheimers NZ team, taking on the new role of Clinical Advisor.

Vanessa has extensive experience in the healthcare sector, specialising in care of people affected by dementia. We have established Vanessa's role to underpin our work with good, current clinical knowledge and expertise.

Most recently Vanessa, who has a Masters in Nursing from Massey University, was employed by Hutt Valley DHB as Team Leader – Older Persons Mental Health Services. This role saw her facilitating implementation of Dementia Care Pathways in the Hutt Valley.

After many years of working with older adults in both hospital and community settings, Vanessa is excited to be working with Alzheimers NZ.

She is already hard at work, holding professional development days for member organisation staff around the country, focusing on updating our information resources, and playing a key role in developing our advocacy and research strategy.



Alzheimers NZ's Clinical Advisor, Vanessa Pullan

Dementia Care Pathways

The New Zealand Framework for Dementia Care was released in late 2013 following collaboration between the Ministry of Health and the wider health and social support sector, including Alzheimers NZ and its Member Organisations.

The Framework is designed to help District Health Boards (DHBs) develop their own local dementia care pathways, with the aim of reducing stigma; providing easy-to-understand and comprehensive information; and providing integrated, holistic dementia care and support.

As an advocate for integrated care, Alzheimers NZ welcomes the development of the Framework as a move forward in aligning services across the country, and ultimately helping people with dementia to have a better life.

This also links well to the challenge, set by Alzheimer's Disease International in the World Alzheimer Report 2013, to improve the quality of care – one aspect of which highlighted the importance of the integration and coordination of services

Local Alzheimers organisations are playing a vital role in the working groups formed by DHBs to develop and implement the local dementia pathways.

We are very pleased to see that the services provided by local Alzheimers organisations and other home and community support providers are being formally recognised within the new dementia pathways, and we look forward to the funding and contracting arrangements changing to support their implementation.

What's good for your heart is good for your brain

Many of us know the importance of taking care of our heart as we age, but did you know that the same philosophy applies to taking care of our brain? Like any body organ, our brain changes as we age and research shows that leading a “brain healthy” lifestyle may reduce the risk of developing dementia in later life.

While there are no guarantees that this will prevent you from developing dementia and other chronic diseases such as diabetes and heart disease, evidence has shown that the risk can be reduced by following five simple steps:

Step one – Looking after your heart

Research has shown that the risk of developing dementia increases as a result of conditions such as high cholesterol, high blood pressure, type 2 diabetes and obesity developing in mid life. These conditions can damage the blood vessels in your brain, leading to changes in how your brain functions and thinks. You can however make changes to your lifestyle which can both reduce your risk of developing these diseases, or help you manage existing conditions:

- Have your blood pressure checked on a regular basis and follow any treatment advice;
- If you are over 45 years of age, see your health professional for regular heart and stroke risk assessments;
- Have regular cholesterol, blood sugar and weight checks through your health professional;
- Seek help from your health professional on losing weight; and
- Stop smoking.

Step two – Increase your physical activity

There is evidence that suggests physical exercise is linked to better brain health and a reduced risk of developing dementia. We recommend the New Zealand Physical Activity guidelines, which state that you should:

- Be as active as you can throughout the day;
- Include at least 30 minutes of moderate intensity physical activity such as walking, dancing, cycling or swimming on most, if not all days of the week; and

- If possible, add some more vigorous exercise to your day for extra health benefits and fitness.

Step three – Challenge your brain with new activities

Researchers have discovered that challenging your brain with new activities helps build new brain cells and strengthen connections between your brain cells. New activities may also protect your brain from accumulating the damaging protein that causes Alzheimer's Disease.

There are a number of new and challenging activities you can take up as you age – anything new and unfamiliar will help mentally challenge your brain. Examples could include starting up a new hobby, learning a new language, taking up a musical instrument, and reading, enrolling in a course or researching a new topic.

Step four – Healthy eating

Like the rest of your body, your brain needs a wide range of healthy foods to work at its best. While there is currently no research to suggest specific foods reduce your risk of developing dementia, eating a healthy diet may help your brain to remain healthy and function at its best.

Similar to following a healthy heart diet, a healthy brain diet should include foods that have a high intake of “good fats” such as those found in olive oil, nuts and fish plus eating a variety of fruits, vegetables, grains and lean meat.

Step five – Make time for social activities

Being socially active provides your brain with mental stimulation and may contribute to reducing your risk of developing dementia. Activities could include:

- Catching up with friends and family;
- Organising nights out with your friends;
- Joining a community organisation;
- Getting involved in your local community;
- Becoming a volunteer.

Adapted from: Alzheimers Australia (2013), Five simple steps to maximise your brain health

Book review: Green Vanilla Tea

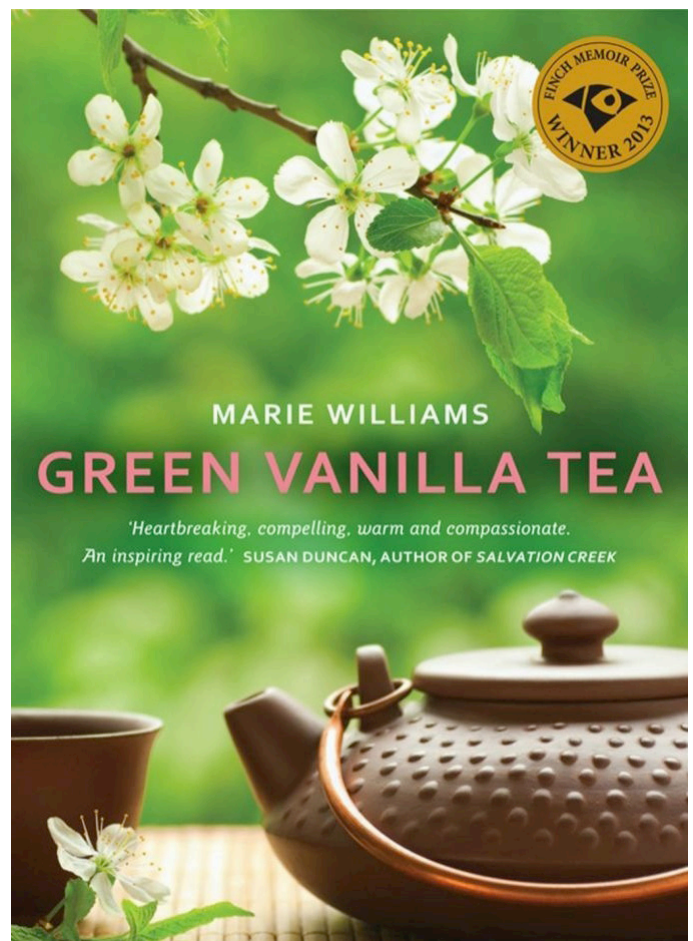
Green Vanilla Tea tells the true story of Dominic, diagnosed with frontotemporal dementia and motor neurone disease in his early 40's. Marie Williams, Dominic's wife, writes an inspiring and compassionate account of their experience.

Like many younger people diagnosed with dementia, Dominic had a career, and two teenage sons living at home. Dominic's career required him to travel and, at times, present at conferences.

In the beginning Dominic's life seemed to be unravelling. Work and travel related problems, miscommunication and fixations. Dominic's usual social graces were abandoning him. "When did this quirky behaviour move beyond endearing?" This unravelling progressed at a fast pace, a diagnosis was made after many tests and assessments, and Dominic's family admitted that they were losing Dominic, that he had entered a "strange and vague world".

Marie's enormous respect and love for Dominic was evident throughout the book. She realised early on that a non-confrontational approach to Dominic's behaviours would allow them to see the things that still mattered to him, and genuinely join him in his sense of accomplishment. As a result of this there were many special family times organised and shared, none more so than the creation of a quilt. The family could "wrap him in it so he could feel it when he had no more words"; a way to remember him "when none of our old Dominic was left". Marie knew that gathering stories would be important, "the first step in reclaiming Dominic".

A wonderful support network of family and friends worked alongside Marie and the boys. Marie took time away from her job when Dominic required someone to be with him both night and day. Marie's nights were broken with Dominic's relentless desire to walk and walk. Understandably this took its toll and, after a period of respite in a rest home, Marie was offered a permanent place for Dominic at the same rest home. Many people who care for their loved one with dementia will understand Marie when she asked "Is he sick enough to be in a rest home?" Marie realised that she had lost perspective, yet others could see how things had become. Dominic died soon after.



Green Vanilla Tea was written by Marie for her boys. It is her first book. The name came about because Dominic would enjoy making green vanilla tea for the friends who visited his home. Marie Williams lives in Australia. Medical management of Dominic's illness is similar to our own here in New Zealand, and there are similarities between the two countries (at that time in Marie and Dominic's case) including no established services for young people and no common language to convey or understand the multiple needs of a family in this situation.

Ita Buttrose, National President of Alzheimer's Australia writes a note to the reader at the end of the book. She talks about knowing the person with dementia – then there is hope of some quality of life for that person. Marie Williams shows us how that can be done in this beautiful love story.

Reviewed by Fiona Edwards, Community Liaison Officer, Alzheimer's Napier

International update: capacity building in dementia care

In December 2013, our Executive Director Catherine Hall attended the 16th Asia-Pacific Regional Conference of Alzheimers Disease International (ADI), of which we are a member.

Hosted annually by a member located in the Asia-Pacific region, the Asia-Pacific conferences focus on care and management of people with dementia in Asian and Pacific countries. The theme was Capacity Building in Dementia Care and the conference was hosted by the Hong Kong Alzheimer's Disease Association in collaboration with the Macau Alzheimer's Disease Association.

The programme featured internationally renowned dementia experts including Australia's Professor Henry Brodaty, ADI Chairman Dr Jacob Roy, Hong Kong's Professor Alfred Chan, and Italy's Professor Stefano Cappa.

Catherine noted that the conference was an invaluable opportunity for Alzheimers NZ to interact and learn from its counterparts in the

"What really struck me is that while we are all facing very different challenges in terms of our governments, funding and structures, the challenges faced by people with dementia are universal," she said.

"I'm looking forward to introducing some of the valuable things I learned from the other delegates."

The 2014 Asia-Pacific Regional Conference of ADI will be held in New Delhi, India from 7-9 November 2014.

We're also very excited to announce that New Zealand will host this conference in 2016. This presents a fantastic opportunity to showcase the work of Alzheimers organisations in New Zealand and the work of the New Zealand dementia sector as a whole. We're looking forward to welcoming our Asia-Pacific colleagues to New Zealand and to sharing and learning with them.



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Make sure your legacy lives on

The actions of individuals can make a real impact; by leaving a legacy you can help your local Alzheimers organisation or Alzheimers NZ to change the future for generations to come.

Planning ahead is all about making decisions today that accurately reflect your wishes for tomorrow. Communicating with loved ones on matters such as ongoing financial issues, your wishes relating to your Will, your long term care preferences, and arranging healthcare and enduring power of attorney is always best addressed when you have a clear focus on what you want your future to look like.

The gift of a bequest in your Will ensures that organisations like ours can also plan ahead.

We recommend that whether you're thinking of making a new Will, or updating an existing one, you consult a professional legal adviser. They'll make sure your Will is valid and that your intentions are clearly and legally stated.

If you have already included your local Alzheimer's organisation or Alzheimers NZ in your Will, or if you intend to do so, we would be grateful if you would let us know. This information will be treated in confidence and is not binding in any way, but we would like to have the opportunity to thank you personally for your generosity.

For more information about leaving a bequest, please visit www.alzheimers.org.nz or call 04 387 9682.

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