



Alzheimers *News*

The magazine for the New Zealand dementia community | Issue 87 | September



"Now is the time to think about the future"

page 26



Alzheimers News

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Writer/editor (except where otherwise stated):

Kimberley Ebbett

kimberley.ebbett@alzheimers.org.nz

04 381 2363 / 027 619 1911

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A virtual memory

A new iPhone® application (App) has been created that could be of benefit to people with dementia. *It's Done!* App remembers those smaller daily tasks, such as locking the door or turning off the stove, that can sometimes cause difficulties for people with memory problems. Apps are programmes for iPhones and iPads and some other electronic devices that are designed for lifestyle, productivity and entertainment.

With *It's Done!* users can simply mark tasks "done" as they do them. Later, to confidently recall if a task was completed, they can check the App which provides the date and time each task was completed. *It's Done!* can even notify others by sending an alert via text or email, providing an easy and practical checking system to support independent living.

For more information on this App visit <http://itsdoneapp.com/home.html> or the Apps store on iPhone® or iPad®



From the Editor



Welcome to our special September edition of *Alzheimers News*. In celebration of our 25th Anniversary, we have bumped up the magazine to a whopping 40 pages! There is so much to

read about in this exciting edition including the heart-warming story of a couple facing early onset Alzheimer's disease and the unique support they get from a special friend.

In light of the upcoming elections dementia expert and Alzheimers New Zealand friend Dr Matthew Croucher investigates voting with dementia on page 6.

Put the kettle on, sit back and relax as we take you on a journey through the last 25 years of Alzheimers New Zealand including the humble beginnings of each of our 22 local Alzheimers organisations in our 20 page special anniversary feature.

This is definitely one for the coffee table!

We are now on Twitter



Twitter is a social networking and microblogging website that enables us to send and receive messages called 'tweets' with members of the public who follow us.

Tweets are text-based posts of up to 140 characters displayed on our profile page. We also follow the tweets of other dementia related organisations around the world so we can be first in the know for all the latest news and research, which we can then re-tweet to you!

So, follow us on Twitter. Visit: www.twitter.com/AlzheimersNZ



... In other social media news, we now have over 400 followers on Facebook. Be one of the first to hear all the latest news and updates from Alzheimers New Zealand, check us out at <http://www.facebook.com/alzheimersnewzealand>

and don't forget to 'like' our page!

Top New Zealand designer supports Alzheimers New Zealand

New Zealand Designer Jill Main's unique home accessories range, created in support of Alzheimers New Zealand, have proven to be quite popular and over 400 of her specially designed tea towels have already been sold.

Alzheimer's is a cause close to Jill's heart as her mother was diagnosed with the disease in 2009. "Mum has always been a bit of a character whose bubbly and fun personality shows through in her simple songs and poetry.

"Evenings (or when her lover was playing golf) were the time to put the day's events in verse or work on some creative embroidery which showed her love of flora and fauna" says Jill of her mother.

Jill has incorporated some of her mother's poems and songs onto the tea towels. She has also included imagery of the Chatham Island Forget Me Not Flower reflecting her Mum's love

of New Zealand flora and fauna, and highlighting her support of Alzheimers New Zealand.

Profits for these tea towels are being kindly donated to Alzheimers New Zealand.

If you would like to purchase your own Jill Main Alzheimer's Tea Towel please forward your order and your contact details to sales. jillmain@xtra.co.nz. To see the colourful range visit www.jillmain.co.nz or for more details visit: www.alzheimers.org.nz/jill-main



An unforgettable dinner

Alzheimers Northland's recent fundraising gala dinner was certainly a night to remember, raising almost \$20,000 for the local Alzheimers organisation.

Those lucky enough to attend enjoyed top cuisine prepared by a variety of guest chefs from some of New Zealand's finest restaurants, including the Hilton Hotel in Taupo, Tonic in Whangarei, Huka Lodge in Taupo and Euro in Auckland.

The main event of the evening saw a range of donated goods going under the hammer in an exciting, lively auction raising a substantial \$8,200.

The entire event was put together by Robert Johnston, Alzheimers Northland's neighbour. Voted New Zealand's best maitre'd, Robert Johnston's expertise in fine dining really made this dinner a great success.

One of the special guests on the night was Alzheimers Northland's new manager, Kevin Salmon. Kevin has an extensive background with charitable organisations and has been a Rotarian for 22 years. Before his position with Alzheimers Northland he was a manager for Hearing Care, Whangarei.

"Filling departing manager Alma Douglas's shoes is going to be a big job, but I am confident that I can achieve everything asked of me and I am looking forward to working with the wonderful team at Alzheimers Northland" says Kevin.



Alzheimers Northland manager Kevin Salmon and his wife, Margaret



Alzheimers Northland staff Sue Peake and Cheryl Magee



Sidney, one of the fantastic wait staff

Dental Health for people with dementia

In 2009, Alzheimers New Zealand and the Eru Pōmare Maori Health Research Centre worked together on a research project to identify the oral health needs of Maori with dementia. Whānau of people with dementia were interviewed in Northland and the Eastern Bay of Plenty, and staff of Alzheimers New Zealand were surveyed.

The outcome of this research highlighted many issues carers faced when looking after the oral health of their loved one with dementia, as well as a lack of information about dementia and oral health.

In response to this, Alzheimers New Zealand developed an information sheet, available in Maori and English, for carers/whānau and people with dementia about oral health as well as an accompanying information sheet for health care professionals/staff.

Both information sheets are available for download on the Alzheimers New Zealand website: www.alzheimers.org.nz/resources



Alzheimers Marlborough's purpose-built centre impresses health minister

Health Minister Hon. Tony Ryall and Kaikoura local MP, Colin King enjoyed a tour of Alzheimers Marlborough's purpose-built centre on 18 June. Both MPs were so impressed by the facility and interested in the work of Alzheimer's Marlborough that the visit lasted over an hour. During this time, Alzheimers Marlborough staff and committee representatives had the opportunity to present the MPs with an insight into the importance of the work they do for people with dementia in their community.

Mr Ryall was very interested in the achievements of Alzheimers Marlborough since the centre was opened in early 2009, as well as the increase in demand for their services and the extension of day centre days (to four a week).

Mr Ryall was also very keen to get the perspective of a carer and had the opportunity to speak with committee member Lin Heywood, who cared for her husband with dementia. Mr Ryall asked Lin some very pertinent questions about her journey as a carer. He asked her where she had difficulties and where she gained support. She told Mr Ryall she could not have managed without the support of Alzheimers Marlborough and although her husband is now in care she still needed this support.

The visit was also a great platform for Alzheimers Marlborough to lobby with the MPs on behalf of our whole organisation.

"We mentioned the gap in our contract for support services and the actual cost to us to provide it. We mentioned the need for education



Kaye Clarke (Alzheimers Marlborough Support Worker), Hon. Tony Ryall, Helen Knapp (Alzheimers Marlborough, Fmr President) and Colin King (MP, Kaikoura) at Alzheimers Marlborough's facility in Blenheim

services in the home for people with dementia. We also talked about the importance of community respite being provided by trained carers in the person's home. We reinforced the fact that dementia care is a specialist area and all carers need training and that our services allow people with dementia to stay in the community with their family for longer saving government funding on rest home care" says Helen Knapp, preceding president of Alzheimers Marlborough. Alzheimers Marlborough was the first member organisation to establish a purpose built facility housing a day centre and administration all under one roof. To read more about Alzheimers Marlborough you can borrow their book *Why are we here?* from our library by emailing nationaloffice@alzheimers.org.nz

\$44m extra in Budget 2011 for dementia care

The 2011 Budget announcement in May delivered an extra \$44 million over four years to support people living with dementia.

"This significant funding increase includes \$40 million for residential dementia services. This is expected to lead to the provision of almost 200 extra dementia beds over the next two years," Health Minister Hon. Tony Ryall says.

In addition to this funding for residential dementia services is \$4 million for the provision of respite. How this money will be spent is still being considered but the Ministry of Health have indicated that they plan to better support people living with dementia and their carers in the community, so in-home support is likely to be one of the options offered.

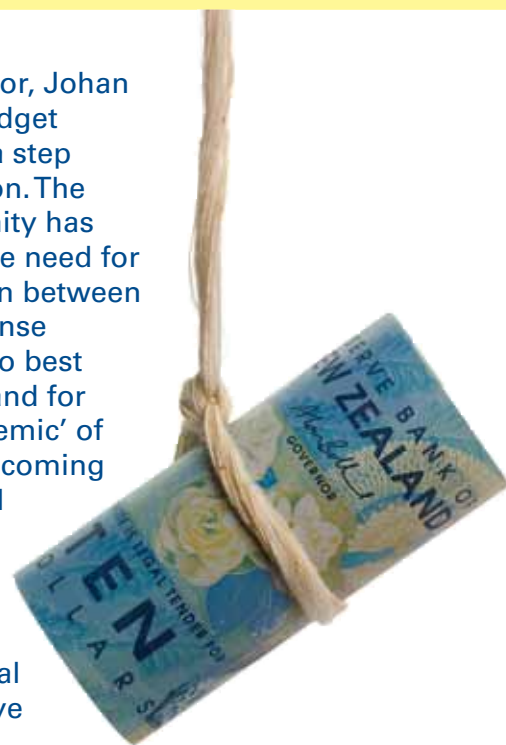
"Last year's aged residential care services review identified the most pressing need to expand dementia units, beds and services. We are committed to ensuring the public health service supports all people with dementia and their families during a very difficult period in their lives" said Ryall.

This announcement came as Alzheimers New Zealand enters into the second year of the National Dementia Strategy, launched in May 2010. The National Dementia Strategy clearly indicates the areas of priority that need to be addressed to better the quality of life for those who face the daily challenge of living with dementia. Its development led to eight action points, some of which have already been implemented, but all require investment in order to be realised.

Our national director, Johan Vos, says "This Budget announcement is a step in the right direction. The dementia community has long recognised the need for greater cooperation between all dementia response agencies in order to best prepare New Zealand for the expected 'epidemic' of dementia over the coming years. The National Dementia Strategy demonstrated the consistent needs of the sector and identified a practical approach to positive change.

"More beds obviously means an increase in capacity, meaning more dementia specialist staff will be needed across the sector. Alzheimers New Zealand is working with our sector partners to ensure that care standards are consistent across the country and meaningful, quality professional development for residential care staff will support this. Specific funding for the residential sector should go a long way to support benchmarking and best practice, so that people with dementia are receiving the right care at the right time.

"Quality care for people with dementia can be achieved through collaborative processes and a continuum of care. This means focusing on the person rather than the dementia and responding accordingly. This can only happen if a person with dementia can access support at an early stage, emphasising the need for robust personal care strategies in the community and a careful transition into residential care. More funding needs to be given to the community sector in order for this to be realised."



Ministry of Health helps to launch dementia awareness campaign

Minister of Health, Hon. Tony Ryall, has confirmed his support to launch a nationwide awareness campaign to educate the New Zealand public about dementia and to help de-stigmatise the disease.

As one of the key actions of the National Dementia Strategy, this awareness campaign is a huge triumph for Alzheimers New Zealand and the wider dementia community and will have a significant impact on how dementia is perceived in our community. The campaign will be multi-channelled, incorporating television commercials, a website, social media, information resources, public seminars, and high profile promotions.

Further support is now being sought to assist with delivering this ambitious project. The awareness campaign will be launched mid 2012.



Voting and dementia

Are people who have been diagnosed with dementia eligible to vote in Local Body and General Elections? Dr Matthew Croucher gives Alzheimers News the low down.

There is no published policy in New Zealand that specifically applies to people with dementia or other conditions that might affect capacity to vote.

However, there are two issues for general elections that need to be considered:

1. Enrolment

It is a requirement by law that all eligible adults are enrolled to vote. People are eligible if they are aged 18 or more, have permanent residency or citizenship, and have lived in NZ for a year or more prior to the election. This includes people with dementia (unless they are in a prison or prison hospital for a term of more than three years). Of course, most people with dementia will already be enrolled. However, if a person with dementia is not enrolled and cannot sign the enrolment forms due to being mentally incapable to do so, then any registered voter, their EPOA (Personal Care and Welfare) or their legal Welfare Guardian can fill in the enrolment form for them and sign on their behalf. There is a separate form that must accompany an assisted enrolment form, which you can get from the Electoral Office (0800 36 76 56).

2. Voting

People are not legally required to vote. If a person with dementia wishes to vote, they may do so according to the law, but they must not need assistance to the extent that there is any interference with their recording on the voting paper and what their intentions are. They must either cast their vote at a polling station on election day, or as a special vote at

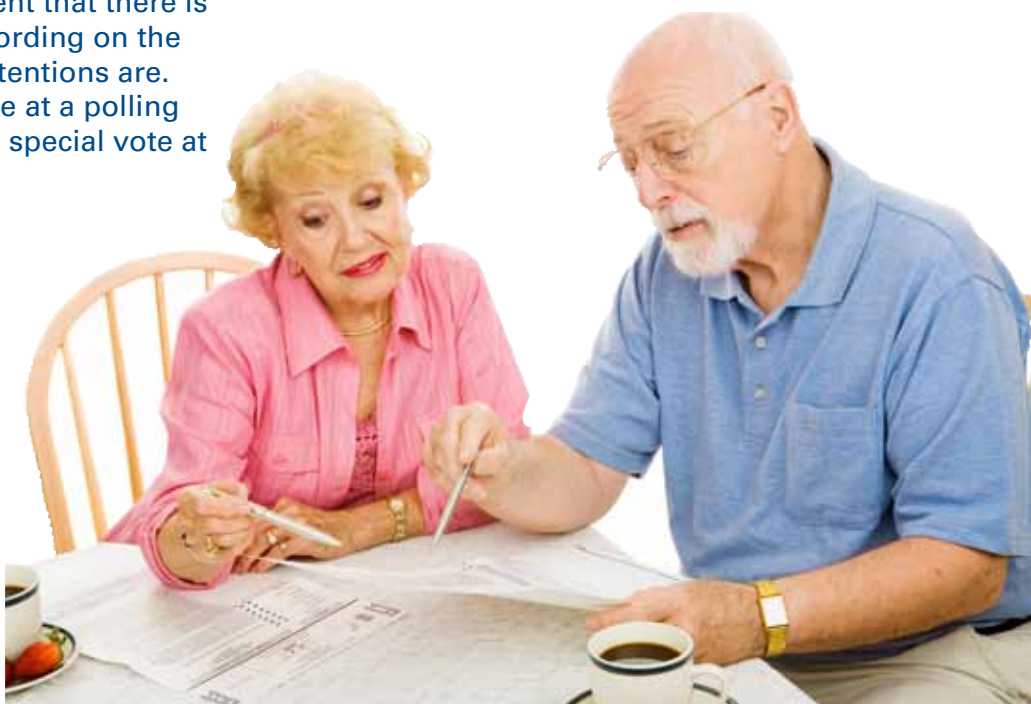
a designated polling station prior to election day, or if they are in care or in hospital, the institution should arrange with a Returning Officer to bring voting equipment to the institution. Individual citizens can also ask the Returning Officer to arrange for voting papers to be brought to them where they live if they cannot get to a polling station.

For other elections, such as the City Council and District Health Board elections, voting is by mail. It is presumed that citizens will cast their vote independently of anyone interfering with the process.

Applying common sense to these regulations, we know that some people with dementia lose the capacity to vote. On the one hand, we should work with people with dementia to enhance their capacity so that they can participate as citizens despite having cognitive impairment, but without in any way seeking to influence their voting behaviour. However, we must not push people to participate meaninglessly in a process that they do not initiate and cannot comprehend. This is a fine line to tread. To enhance someone's capacity to vote, we would need to explain the process and possibly explain what was on a voting form, but we must not interfere with the decision on whom to vote for.

Thank you to the Electoral Office for giving advice regarding this question.

For more information about voting in this year's election (Saturday 26 November) visit www.elections.org.nz



The new 'normal' - life on shakey ground



Nearly seven months after the deadly quake that changed the lives of Cantabrians forever, Alzheimers Canterbury manager, Darral Campbell describes how life has changed and what the impacts are of living on shakey ground.

The reality of living in Christchurch post-earthquake (and with the uncertainty of not when, but how big the next aftershock will be) is not something that is easy to describe to people living in other parts of New Zealand.

We are now living in a 'new normal', a kind of limbo state where we know in our heads that life is different but still in our hearts wish for, grieve for and hanker for our lost lifestyle/city.

As the demolition gains pace our landscapes are changing yet again; broken buildings and houses are being replaced by empty, sad, derelict looking sites. There is as yet no clarity about what will be rebuilt or when it will be rebuilt. Trucks carrying massive loads of dust and debris navigate through roads and streets still to be repaired. Footpaths are damaged, bus services are compromised and limited, usual events are not happening, continuity does not exist in the same way.

Every new aftershock or change of weather raises concerns about the challenges of staying warm, of keeping already badly damaged drainage systems working, of where to go to 'be safe/feel safe'.

Resilience is the new buzz word. How to maintain it is the challenge.

Our need to support our dementia community is greater than ever as people try to navigate their way through both the impact of dementia and the impact of the earthquake.

Someone recently struggling to understand what difference it could make to our workload said: "well, what does it change in the work you do?" My answer is nothing and everything.

The work normally done to support and educate about the impact of dementia is unchanged but it now must take second place to first dealing with how the earthquake is affecting daily life.

What's the impact for a carer, who in the middle of the night has to support their person with dementia back to bed after going to the toilet? Tenfold when that toilet is now a port-a-loo

several houses away down the street, a chemical toilet that needs to be emptied daily or is in a different unfamiliar home.

What's the impact for someone with dementia living alone, who has to list, photograph and gain a quote for every item damaged to send to EQC (Earthquake Commission)?

What's the impact for carer's trying to deal with EQC, heating assessors, loss adjusters, engineers, insurance representatives, city council staff, electricity companies, phone companies etc, not necessarily getting any clear

answers, and in all likelihood just having to 'wait and see'.

What's the impact for our older community knowing that many of the familiar landmarks have gone and that they are unlikely to live

long enough to see a new city built?

Dealing with the grief for these losses, learning new ways of coping and 'remaining resilient' are both significant factors related to the earthquakes as well as to dementia.

We can never look at dementia without looking at the living context of the people who experience it, and for those of us in Christchurch, that context is constantly changing. Learning to live with uncertainty is no longer just a theory, it is now reality.

It's a very long road ahead to rebuild, but here in Canterbury we are resilient, we will struggle and we will get there. Staying connected is the key.

Heke tipu oranga, he taonga tuku iho, ka pakanga ake, aue te aiotanga, te manowanui
"Persist in the battle and the journey for well being, it is a treasure handed down from the heavens, then comes confidence and peace".

To support Alzheimers Canterbury's recovery and people with dementia affected by the February 22 quake please donate online at:
www.alzheimers.org.nz/support-us

New property to meet community's growing needs

Alzheimers Hastings has purchased a new property to meet the increasing demand for community services.

This new site is conveniently adjacent to their current premises (Chatham Club) and will likely house all community services such as the community liaison officers, Younger Onset groups, carers groups, education groups and sessions etc. It is hoped that this new site, with its visible frontage, will also help to increase awareness and encourage drop-ins.

Moving these existing services will allow more room in the Chatham Club for day respite



programmes while also providing a facility to meet the needs of younger onset people with dementia.



Alzheimers Rotorua Community Officers Elaine Fox (left) and Lyn Soeters (right) with dedicated volunteer, Mike Sharp

disease when she was 55. Mike cared for her for many years with the support of Alzheimers Rotorua. When she passed away at the age of 61 Mike wanted to support Alzheimers Rotorua like they had supported him and began volunteering his time. He then joined the committee and then the board as vice chairman.

His own experience has made him a strong support to others going through similar journeys.

"He has always been there to lend an ear or provide advice to others who are caring for a loved one with early onset dementia. He also assists with our men's café memory group lunches, a very worthwhile social get together for men with early to moderate dementia" says Lyn.

Mike says being able to speak at events and tell his story to help others has been one of his highlights as a volunteer.

"I do it for joy of helping people"

But his biggest highlight is watching Alzheimers Rotorua grow into the well acknowledged organisation it is today.

When asked what he finds rewarding about volunteering at Alzheimers Rotorua, he humbly responds "I do it for joy of helping people. If I can just help one or two people a year I reckon I have done an alright job"

Alzheimers Rotorua will be the first to say that Mike's ever busy hands, empathetic ears and supportive words provide a much needed comfort to many. Thanks Mike!

Volunteer profile

Mike Sharp has been a dedicated volunteer of Alzheimers Rotorua for almost a decade. A true Jack of all trades, Mike lends his hands and head where ever possible.

With only two full time community officers at Alzheimers Rotorua, Lyn Soeters and Elaine Fox, the support they get from Mike is invaluable.

"Mike is always there to support, advocate, listen and help. He is the first one to volunteer to help with many of the laborious tasks like folding newsletters, attending support groups, washing dishes, and picking up and dropping people off who can't get to support groups" says Lyn.

Mike says he likes to muck in with the laborious tasks "so the girls don't have to worry about it" Mike's wife was diagnosed with Alzheimer's

Unsung Heroes

More than 420,000 New Zealanders provide care for ill, elderly, disabled and seriously injured family members and friends. Carers are the country's biggest health workforce, and their unpaid work has an annual value of more than \$7 billion. Caring can happen overnight, or gradually over time... for a short time, or for a lifetime. We can all expect to give or receive family care during our lives.

Carers NZ and the NZ Carers Alliance (of more than 40 national not-for-profits, including Alzheimers New Zealand) have launched the *We Care!* campaign which is aimed at all political parties, including the Prime Minister John Key. The campaign is calling for better recognition and awareness of NZ's family, whanau, and aiga carers, and for thoughtful decision making from our politicians so carers can get the help they have repeatedly asked for in government consultations.

John Key has in recent times called family carers 'unsung heroes'.

He sent a message of support to the launch of *We Care!* in May, where he stressed the importance that all New Zealanders, including his parliamentary colleagues, understand and appreciate the work that carers do every day.

John Key's parliamentary office has received in excess of 500 emails from carers thus far, and more than 50,000 *We Care!* postcards will be distributed to individuals before the November general election. *The We Care!* Facebook page has attracted more than 12,000 Friends since the launch.

we care a campaign for carers

I care!
Signed,
Joe Bloggs

Individuals and organisations can have a say and support the *We Care!* campaign, by:

- Signing and posting a *We Care!* postcard to the Prime Minister, John Key. This only takes one moment to do and no stamp is needed!
- Visiting www.facebook.com/wecarenz and 'liking' the campaign. More than 12,000 followers 'Like' the campaign already... stay up to date by joining us on Facebook!
- Visiting the campaign website www.wecare.org.nz and sending an email to John Key. This can be done anonymously, and you can write your own message or send our standard campaign message ('Please listen to family carers.').
- Uploading a photo message at the *We Care!* website. Pictures are worth a thousand words. Simply write a message on a large piece of paper, take a photo, and upload it at the site! Local Alzheimers organisations may wish to host their own *We Care!* meeting to make it easy for carers and other supporters to complete post cards, 'like' the Facebook page, send emails to John Key, and/or take and upload photo messages for the *We Care!* website.
- Hosting a *We Care!* rally in your area. This can be done in a public space (you may need to obtain Council permits to do this), or your organisation could combine this with a pre-arranged carer/supporter meeting or mingle event. Carers NZ can help promote your event to media, and can provide *We Care!* postcards and free carer infopacks.
- Arranging a meeting with your local MP and encouraging them to support family carers. Take a copy of this article with you to show them.

The *We Care!* campaign will run through the 2011 general election to mid 2012

For further information about the campaign, or to request postcards, carer infopacks, or other kinds of help to have a face and a voice in the *We Care!* campaign, phone Sara Rogers on 0800 777 797 or email sara@carers.net.nz

Frock up for a good cause

Whatever way you like to wear it, retro, vintage or modern, the perfect frock awaits you at Alzheimers Napier's new charity dress shop, which opened its doors to the public late August.

As cases in dementia are rapidly rising, Forget Me Not Frocks, the first Alzheimers charity store in New Zealand, is hoped to raise some much needed funds for Alzheimers Napier. The shop is staffed by volunteers, some of whom have early stage dementia.

Alzheimers Napier manager, Mairi MacInnes says "While some people with early stage dementia may no longer be able to continue working in their regular roles Volunteering (like working at the shop) gives them a real sense of purpose and meaning and the opportunity to give back to their community."

All dresses and accessories, which have been kindly donated by the public, are all designer labels or New Zealand made. The beautiful



collection spans from 1930's to today, so there truly is something to suit everybody's taste and budget!

"We have been so delighted by the support and interest so far. We have some beautiful, elegant outfits and accessories for sale at very affordable prices. Each item has a personal story, and all monies raised will help Alzheimers Napier" says Mairi.

The shop is located at Wilding House, 1 Wilding Avenue, Marewa – Opposite the Marewa shops – currently known as Deco Dental.



Quilts for Canterbury

It felt like a mid-winter Christmas in early June when three large boxes full of exquisitely made, cosy warm quilts arrived at the Alzheimers Canterbury office. This incredible gift was co-ordinated by the team at Alzheimers Marlborough for the Canterbury team to distribute to vulnerable members of the dementia community who have been affected by the earthquake. The quilts were made by members of the Marlborough quilting community during a 'Quiltathon'.

Nobody realised at the time just how important these quilts were to become, when Christchurch was hit with the double whammy 5.7 magnitude and 6.3 magnitude aftershocks the following week.

This time, when the electricity failed and cracks in houses opened up further, Christchurch was in the grips of hard frosty nights and a biting wind. Morale amongst people with dementia and their carers decreased even more as the liquefaction emerged yet again, and stress levels rose with the constant aftershocks and sleepless nights. With all this anxiety and uncertainty, it has been wonderful for the Alzheimers Canterbury social workers to present the quilts to members of the Canterbury dementia community.

One client was worried that her family had forgotten about her amongst all the earthquake drama. Her eyes lit up when she saw the quilt. "It's nice that something good is happening" she said.

Another was so 'over the moon' he couldn't wait to show his family his new quilt.

"This is so lovely" said another client "I'll think of you every time I use it".

The quilts have also been a real boost for carers who love the colours, the warmth, and the kindness behind them.

There are still many quilts to distribute as the Alzheimers Canterbury social workers visit people in their homes to see how they are coping.

At times this month it has felt as though Christchurch is back to square one, however the quilts have brightened the spirits of staff, people with dementia, and their carers and families – thanks to Alzheimers Marlborough.

Combating dementia with cognitive enrichment

A new study being undertaken at the Van der Veer Institute, in Christchurch, will explore whether a unique set of brain exercises could help slow mental decline.

Physical exercise and social contact have some benefits, but this latest study uses 'cognitive enrichment' procedures that researchers think will target key networks in the brain. Poor function in these brain areas is associated with early signs of dementia. Improving their function may help combat dementia.

First, 600 volunteers aged over 65 years are having an hour of cognitive tests that assess memory, attention and language. About 40 of those showing some cognitive impairment will be invited to have further tests and will then be divided into two groups. One of these groups will be assigned to 'cognitive enrichment' and the other to a 'waitlist control'. Some exercises improve attention and concentration, while others build on existing memories. Those included in the programme will follow the tasks for an hour or two, three or four times a week, for up to six months. A spouse, close family member or friend will also be involved – a cognitive support person, which adds another unique dimension to this approach. Participants will have a brain scan before and after the programme to look at the key brain networks. A third group of participants, recruited from those showing no impairments, will have scans to provide a comparison of the brain networks in question.

The project is led by neuropsychology researcher Professor John Dalrymple-Alford. The Van der Institute brings together researchers with a range of expertise to study dementia and many other neurological issues.



For further information contact: Leslie Livingston (study co-ordinator) via e-mail at: leslie.livingston@vanderveer.org.nz

International survey highlights great public desire to seek early diagnosis of Alzheimer's disease

Results of an international survey reveal that over 85% of respondents in the five countries surveyed say that if they were exhibiting confusion and memory loss, they would want to see a doctor to determine if the cause of the symptoms was Alzheimer's disease. Over 94% would want the same if a family member were exhibiting the symptoms. The findings were presented at the Alzheimer's Association International Conference 2011 (AAIC 2011) in July.

The survey of the U.S. and four European countries and was designed and analysed by Alzheimer Europe and the Harvard School of Public Health.

Some other interesting findings from the survey included:

- In four of the five countries, Alzheimer's disease was the second biggest health fear after cancer.
- Majorities in all five countries say that they know or have known someone with Alzheimer's disease, including about seven in ten in France (72%), Germany (73%), Spain (77%), in the U.S. (73%), and 54% in Poland.
- Few people recognised the severity of Alzheimer's disease with approximately 40% knowing that it is a fatal condition (33-61%).
- Nearly half believe there is a reliable medical test to determine if a person suffering from confusion and memory loss is in the early stages of Alzheimer's disease (38%-59%).
- The survey also found public interest in predictive testing.

Heike von Lützu-Hohlbein, Chairperson of Alzheimer Europe, said: "The results demonstrate the importance of being honest with patients when diagnosing Alzheimer's disease. As a former carer myself, I recognise how valuable it is for people to have first-of-all a name for all the uncertainties of their condition and then have the time to get their affairs in order. It will always be difficult to receive such a diagnosis but doctors need to empower patients and their loved ones to take the appropriate steps. The findings also show there is high awareness of Alzheimer's disease, which is a testament to the success of the many awareness campaigns coordinated by Alzheimer societies."

News around the World

Helping children spot the signs of dementia

Hong Kong Alzheimer's Disease Association, in collaboration with schools' Parent Teacher Associations and the Salvation Army, have developed a training programme for schoolchildren which will help them to recognise the signs of dementia. The project, which was conducted in Tai Po where almost 10% of the population are senior citizens, saw 2000 questionnaires sent to 20 primary and 23 secondary schools. Children were asked to complete the questionnaires, which focussed on their elder family members. An impressive 92% of the surveys were returned. As a result, 81 people received cognitive assessment and seven were referred. Family doctors in Tai Po were also offered training in how to diagnose dementia.

Building a better future for people with dementia in the UK

Alzheimer's Society UK and Alzheimer's Scotland have teamed up with Tesco, the world's third-largest retailer, to raise five million pounds. Funds received will go towards building a better future for people with dementia in the UK and helping to raise diagnosis levels from just 40% by 2014.

Mountain climber attempts 7 summits for Alzheimer's Research

Experienced mountain climber, Allen Arnette is climbing seven summits, the highest mountain peak on each continent, in a bid to raise \$1million for Alzheimer's disease research and awareness. Allan was a full time caregiver to his mother who had Alzheimer's disease. His experience caring for his mother changed his life forever and since her passing in 2009 he has made it his life's mission to help fund Alzheimer's research. He is well on his way to achieving his goal with three of his summits

conquered, including Mt Everest. He is currently on his fourth climb: Denali in North America. Allan is asking his supporters to donate a penny for every foot he climbs. His world journey for Alzheimer's disease involves climbing 130,000 feet while enduring temperatures that drop to 40 degrees below zero with 50 mph winds. To follow Alan Arnette's journey go to: <http://www.alanarnette.com>

Virtual Dementia Tour

An American rest home has developed a virtual 'dementia tour' to give caregivers a brief taste of what it is like to be elderly and living with Alzheimer's disease and dementia. Issues that the elderly may have when living with dementia, such as lack of feeling in the hands

and feet, poor vision, pain, arthritis and oversensitive hearing, are all simulated in several ways.

Participants on the 'tour' are given goggles that limit vision. They wear big headphones that play distracting bits of conversation and other noise. They also wear gloves and shoes with hard corn kernels in them, and their fingers are taped together. Participants are then given five simple tasks such as 'clear the dinner table' and 'put on a tie' and let into an apartment-style room with a strobe light. They have seven

minutes to do the five basic chores. Many participants cannot remember the five tasks, let alone complete them – even with a list of the tasks taped to the wall. Within the seven minutes participants start exhibiting some of the same behaviours as those with dementia, according to the rest home. Participating caregivers answer questions about people with dementia before and after taking the tour, and data collected shows that most people have a better understanding of how difficult living with dementia can be for the elderly after this experience. Caregivers then consider different approaches they will take to caring in the future, and one of the most common is to be more patient and offer simple instructions, one at a time.



Our past and our future

*By Alzheimers New Zealand national director,
Johan Vos*

2011 has so far been a year overflowing with milestones and events that will shape the history and memories of all who live in New Zealand. From the devastation of the Canterbury earthquake in February to the feverish excitement of the Rugby World Cup. There will be few who will reflect on this year at sometime in the future without nostalgia reminding them where they were at that time. This is an exercise our entire organisation is living as shoeboxes of photos and archives of yearbooks are dusted off as Alzheimers New Zealand collectively marks 25 years of making life better for all people affected by dementia.

This milestone anniversary is celebrated with contributions from local Alzheimers organisations throughout New Zealand in this very special anniversary edition of *Alzheimers News*. I am so proud to read the history, philosophy, and commitment that made

us who we are today.

In remembering our history it is important to think to our future and what commitments are needed for us to continue to deliver our promise to our community. We are very aware that one day soon cases of dementia in New Zealand will be at crisis levels, testing all resources if preparations are not made for this now. It is this foresight that Alzheimers New Zealand has given the candidates for the upcoming elections, through vital research like the Dementia Economic Impact Report (2008) and face to face engagement. The leaders and relevant members of key political parties should all now be well informed of the ever increasing threat of dementia to both our society and our economy. Partnering with the dementia community on important movements, like the National Dementia Strategy, is one way that they can diminish this threat. We hope that this active lobbying will have had some influence on their electoral promises and I urge you to read each party's manifesto before voting to ensure your vote counts.



Connecting

*By Bupa Care
Services CEO,
Dwayne Crombie*



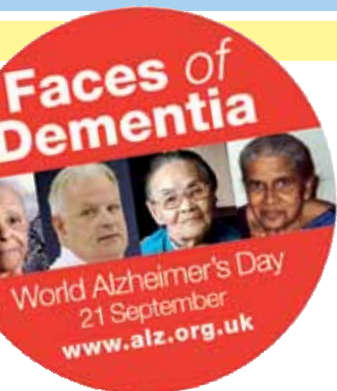
I recently went to see a delightful French film "My Afternoons With Marguerite".

The cast featured Gérard Depardieu, who is well known to non French audiences, and Gisele Casadesus as the nonogenerian (90+ years) woman who transforms his life in the movie.

Germain (Depardieu) lives in a caravan at the bottom of his mother's garden and otherwise lives a very simple village life hindered significantly by his inability to read and write. One day Marguerite, a refined and lovely old woman meets him in a park and introduces him to the world of books. This completely changes his life for the better and gives him all the self esteem and self confidence he has been lacking. At the end of the film, he repays the gift by "rescuing" the old lady from the clutches of a nursing home where she has been placed by her children who can no longer afford the flash retirement village she had been living in, presumably because she had been living just a little bit too long! Of course the French filmmaker circumvents difficult social issues by showing that the overcrowded nursing home from which she is rescued is a Belgian nursing home!

Obviously issues of ageing are being faced by each and every developed country but some things are simply a matter of national pride. Movies and indeed the media don't often portray older people in such a positive light, and the film delightfully gets across the point that most of us have something to offer each other, no matter our age or physical afflictions. Media and public opinion and increasingly social networking can have a profound effect on how ageing, disability and indeed dementia are viewed and perceived by the community and different groups within our community. One only has to see the phenomenal worldwide percentage growth in Facebook users who are aged over 50 years to understand the human desire to communicate with each other.

Growing old or having dementia, or having a family member with dementia is not something that we should be ashamed of. Ironically it results from our success in increasing our longevity as a species. While we strive to find a way of reducing the incidence of dementia, our immediate challenge as a society, is to find ways of showing that older people can make a contribution to the community and that we can enjoy life no matter what the disability. Each and every one of us can do something positive within our means. Equally as a community responding to this challenge, we are only limited by our imagination in using the media and social networking as tools for positive change.



World Alzheimer's Day 2011

Faces of Dementia is the theme for World Alzheimer's Day 2011, the annual global campaign to raise awareness for Alzheimer's disease and other dementias. Preparations are underway across our local Alzheimers organisations and at national office to build upon the success of last year's media coverage, events and activities. This year, as part of our campaign, Alzheimers New Zealand wants the public to recognise and pay tribute to the 'true faces of dementia'. We have set up a website to tell the stories of those affected by the disease through personal accounts, poems and pictures.

If you have a story to tell please email a copy to: facesofdementia@alzheimers.org.nz or send a copy to: PO Box 3643, Wellington 6140, New Zealand.

To visit our Faces of Dementia Website please go to: www.facesofdementia.alzheimers.org.nz

Alzheimers Disease International has set up a new website where people with dementia and Alzheimers organisations around the world can share event and activity ideas in preparation for World Alzheimer's Day. This website will be accessible through the ADI website and more details will be available soon through <http://www.alz.co.uk/>.



For more on World Alzheimer's Day visit: www.alzheimers.org.nz/world-alzheimers-day-2011 or to visit our Faces of Dementia Website please go to: www.facesofdementia.alzheimers.org.nz

My Perfect Partners

Written by Auckland resident Jenny Webb and her husband Chris. Jenny has early onset Alzheimer's disease.

"Our story began in 2005. I was working as a consultant and very occasionally I would have blanks, I wasn't sure where I was or what I was supposed to be doing. It was at this time I first went to my GP and it was put down to menopause. I didn't think much of it and when I moved to Auckland in 2007 I started a new role in a large Industrial business. Learning new things just seemed so much harder. About six months into this role, I realised I couldn't remember what was said in meetings that I had just attended or what actions I was supposed to be taking. From there it just got harder and I simply was not performing in my role. I had to stop working in February 2008.

Early on I would go walking and forget where I was going or how to get home. This sensation didn't last long, but was very scary. I would forget how to do things that I knew I should know, like cooking. At this time my balance was also affected - I would be walking with my husband Chris and would walk into him or I would fall down our stairs at home. This became such a problem that we moved to a single level home. I came close to burning the house down by cooking and forgot about it. There was smoke through the house but I didn't register that it was a fire, my dog barked and went crazy. I followed her out of the house and when I saw the flames I knew what I had done. It was very close call.

Making decisions on what I like or don't like, what I want to eat or what I want to do, became impossible. Nothing is easy any more. This disease is so very frustrating, I know how hard it is for me, but it must be a hundred times more difficult for my husband Chris. He is simply amazing. Both Chris and I have received wonderful support from Alzheimer's Auckland. In the beginning of our journey, it was very difficult for both of us and their support was amazing. I think as the disease progresses it doesn't bother me as much. I'm not sure why, maybe because I don't really think there is anything wrong now that we have so many strategies in place.

Then along came Gemma.

When we moved to Auckland our neighbours at the time had 2 dogs, Roma and Gemma. During the first year of our living next to them, Roma passed away leaving Gemma. When I gave up work I would take Gemma walking, she is lovely company and is very good natured. I noticed that when Gemma and I would go walking, and when I was disorientated she would either come back to me or start to lead me. It got to the point that I could say to her "take me home" and she would. She gave me confidence to get out of the house.

Gemma's family moved to Australia early on in 2008. Gemma was left on the property with the neighbour's brother, who was a chef. He worked late and slept till late. So I started having Gemma over during the day.

Gemma would start crying about 8am in the morning to come over, and would cringe when it was time to go home. She had cemented herself in our family.

At the end of 2008

Gemma's family asked us if we would like to keep her. We had realised that she was special but we had yet to appreciate how special.

In the early days I was very tired, I would sleep on the couch and leave the house open. Gemma wouldn't let anyone in the house if I was asleep - not even friends that were staying with us. Gemma started taking on extra duties - she would always walk closest to the traffic, if I started to wander toward the edge of the footpath she would push me back or hold her ground so I didn't go too close to the road. Gemma then started looking for cars - she has stepped out in front of me, stopping me from

crossing the road because a car was coming. I would have been badly hurt if it wasn't for her. I had come to rely on Gemma by now and wanted to see how I could get Gemma public access like a working dog.

We had Gemma assessed by a dog trainer, Flip Calkoen. He worked with Gemma to see how clever she was and if it were possible for her to be formally trained. Flip's assessment of Gemma was that she is the most intuitive dog he had ever worked within 30 years of training. Gemma can cross roads and get me anywhere I want to go. She knows at least 25 - 30 places that she can take me to on command.

Because I didn't have a physical disability, and because of Gemma's age she was unable to get public access. To cut a long story short, I approached my local MP and Rodney Hide, who is Minister of Local Government and is responsible for the Dog Control Act, to see if there was any way to get public access.

Finally I met John Key, over morning tea. He listened to my story and, as a result, he arranged public access for me. Around the same time we learnt about Perfect Partners Assistance Dogs Trust.

Gemma wears a balance harness when working. This allows her to guide me and if I do lose my balance, I can lean on her. I can tell if there are contours or steps from touching the harness.

I now have a support worker who comes in from 9 till 12 each day to help me organise myself and to be there when I eat. Gemma and I are on our own in the afternoons. She is an amazing dog who allows me to be independent and she gives Chris confidence to continue working, I would drive Chris mad if he was home with me all day. Gemma is our life line.

Gemma is now 8 ½ years old. She will work until she is 10. As my sight fails, I will need a fully trained guide dog. The training of this dog will cost \$30,000 over a two year period. Because of my dementia, I will not meet the criteria set by the association of the blind, and this puppy's training will be at our expense. I am hoping to get a special grant to assist us in this."

"She is an amazing dog who allows me to be independent"



Gemma, Jenny's special friend

For further information about Perfect Partners Assistance Dog Trust please visit their website www.ppadt.org.nz

Happy Birthday Alzheimers New Zealand



Gaye Philpott is a registered dietitian who works one-on-one with individuals and families in her practice Nutrition Matters in Palmerston North. www.nutritionmatters.co.nz

Congratulations to Alzheimer's New Zealand who celebrates its 25th birthday this year. I wonder whether there will be a birthday cake bearing 25 candles?

Celebrations the world over involve food. Whether its birthdays, Christmas or an anniversary, people come together to share and eat food. But is the reverse true. Can we celebrate food? I believe there are many reasons why in New Zealand we can.

One of the first principles I came to understand when I trained as a dietitian many years ago is that the more variety of foods one has access to the smaller the risk of missing out on some nutrients. Historically nutrient deficiencies occurred when populations had access to very limited food choices such as one dominant source of starch, small and unreliable amounts of protein-rich foods and just a few vegetables and seasonal fruits.

New Zealanders however have access to many different foods. I can choose to cook chicken, beef, lamb or fish.

If I don't want to eat animal based proteins I can choose legumes, tofu, seeds or nuts. I frequently substitute rice, pasta or noodles for potato and enjoy choosing from a significant range of different

coloured vegetables and fruit. I can choose a milk that best suits my health needs, yoghurt and numerous kinds of cheese, breads and cereals.

Living in a temperate climate we have distinct seasons so I can enjoy seasonal foods: asparagus in October; berries and stone fruits over summer and if I'm lucky every few years I might get a taste of whitebait! But when I can't access fresh produce I can easily access nutritious alternatives such as frozen vegetables and canned or dried fruits.

Today we cook these ingredients using a diverse range of cuisines. In any one week I may have prepared meals originating from Italy, India, Thailand, Mexico and Vietnam in addition to meals from my colonial roots. Even so I sometimes find myself wondering 'what can I cook tonight!'

Over the past thirty years scientific research has increased our understanding about how food affects our health so that nutrition guidelines today can help us reduce our risk of lifestyle diseases such as ischemic heart disease and Type 2 Diabetes. New Zealand has played a part in this growing body of knowledge and organisations such as the New Zealand Heart Foundation and health professionals such as dietitians disseminate these messages both at a population-based and individual level. Food industries too have responded: bread

manufacturers provide us with a variety of multi grain and wholegrain breads and the dairy industry provides us with reduced fat and calcium enriched milks.

Our knowledge about how food affects our physical performance has also allowed sports people to train harder



and for longer thus shaving milli-seconds off pool and track times and ensuring our sports teams are up there with the worlds best.

New Zealanders too can celebrate robust food labelling laws. Ingredient lists enable people with food allergies and intolerances to avoid the foods they react to. The Nutrition Information Panel (or NIP) allows us to check how much and what kind of fat is dominant in a particular food and if it contains too much sugar if we have diabetes.

Our food safety legislation directs how food should be stored, prepared and cooked so that when we eat out there is minimal risk of food poisoning.

And eating out, we do. Today New Zealanders are eating more and more meals out of the

home. There is a great variety of options to choose from. Whether that be a relatively cheap, quick Asian meal because we don't have time to cook ourselves or a special dining experience where chefs prepare and serve notable flavour combinations which leave us in awe. Of course I'd prefer it if it didn't include those takeaway chains which serve high fat foods and where many people eat too frequently.

But parallel to this trend is a resurgence of interest in cooking. Helped no doubt by a host of cooking programmes and competitions on TV, a multitude of recipe books and specialty kitchen stores which have rekindled our desire to cook healthy, tasty meals and bake treats to share with others. So let's bake a cake and celebrate!

Pathways on the diagnostic journey to dementia: from the UK to NZ

By Professor Jill Manthorpe

We recently completed a study for the UK National Institute for Health Research Service Delivery Organisation to explore the experiences, expectations and service needs of people with memory problems seeking a diagnosis. In this study (1) we interviewed 27 older people and 26 carers from different parts of England. On a recent visit to New Zealand, I had the pleasure of debating with practitioners if any of our findings were relevant to their practice.

We interviewed people when they had just been referred for memory problems and then after they had received a diagnosis of dementia. Their views about the process of memory assessment and diagnostic disclosure have been fed back to services and policy makers. Three key points emerged from looking at these experiences.

First, we concluded that people might like to know more about what will happen and when around assessments. Many people told us that they had been for many assessments but had not generally been told about the waiting periods in between. In England there is a push to early diagnosis and this might lead people to expect things to happen very quickly and that treatment will be on offer, but the reality can be different. We also found that people's experiences varied in terms of the information they received. There may be room for professionals to check time and again that information is clear; has actually been

supplied and time is available to discuss what it means for the individual. Finally, while many people received the news of their diagnosis as giving them some reassurance that at least a problem was now identified, for some this news was so distressing that extra support might be helpful. This did not seem to be widely available.

Is this relevant to New Zealand? We think so in three particular ways. First, it may be useful for assessment services and GPs to listen to people's experiences of assessment and to be alert to information confusion. Second, we are using the term 'person-centered' a lot in the UK and this could perhaps apply to the start of the dementia journey as well as to care and support later on. Our third observation is that such research is only possible when researchers and professionals work together. We think this makes for better research. And the same applies to researchers working with the voluntary sector. Our study benefited from the presence of members of local and national Alzheimer's Society groups at our regular meetings – they offered comments on our interview questions and debated our findings. We are grateful to these individuals for their support and commend this approach to fellow researchers.

Jill.manthorpe@kcl.ac.uk
Social Care Workforce Research Unit,
King's College London.

The full report of this study has been published and can be accessed at: <http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/2011/manthorpeetal2011transitionfinalreport.pdf> ; Manthorpe J., Samsi K., Campbell S., Abley C., Keady J., Bond J., Watts S., Robinson L., Gemski A., Warner J., Goodman C., Drennan V. and Iliffe S. (2010) The transition from cognitive impairment to dementia: older people's experiences. Final report. NIHR Service Delivery and Organisation programme.

Research

Surprise discovery allows scientists to block Alzheimer's

Scientists developing treatments for the brain disorder Creutzfeldt-Jakob Disease (CJD) have unexpectedly blocked the onset of Alzheimer's disease, the most common cause of dementia.

Researchers said they were "thrilled" at the unexpected discovery that two antibodies – extensively studied in relation to CJD – may also have an effect on Alzheimer's disease.

The finding, published in *Nature Communications*, represents a "significant step forward in the battle to develop drugs to treat Alzheimer's disease," they say. The lead came from an American study by researchers at Yale University in 2009, which showed prion proteins causing CJD also play a role in Alzheimer's disease.

The finding triggered a race by scientists to discover whether antibodies being developed as a treatment for CJD might also work against Alzheimer's. Now a study on mice at the Medical Research Council Prion Unit at University College London has indicated the antibodies block the damaging effects of a toxic substance called "amyloid beta", a protein which accumulates and becomes attached to the nerve cells in the brain.

Over time, through its interaction with prion proteins, amyloid stops the nerve cells from communicating, causing memory loss, the distinctive symptom of Alzheimer's.

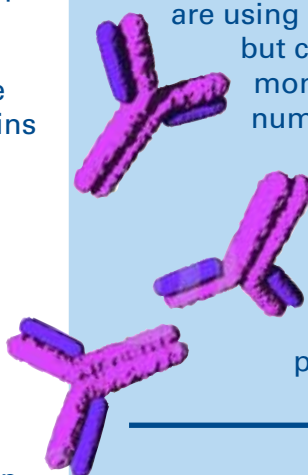
Clinical trials of drugs based on the antibodies are due to begin in humans next year as a treatment for CJD. If they are successful, the trials could be repeated for patients with Alzheimer's disease.

Ask the expert

An exciting discovery, but is this research really a breakthrough, or are we still a long way off? We ask our scientific advisor Dr Phil Wood.

These discoveries by the Medical Research Council Prion Unit at University College London are a very interesting and are a potentially important new line of research. However, to move from this study in mice to humans will involve not only providing suitable antibodies in humans (presumably humanised mouse monoclonal antibodies similar to the ones we

are using in research at the moment) but checking they are safe and then monitoring for the effects for a number of years afterwards. By way of example current trials of a similar nature are now into their third year and final results are still a long way off. It is a long and complex road to complete such research in patients with Alzheimer's disease.



What do you think?

Let us know what you think about this new research and other topical issues about Alzheimer's disease and other dementias on our Facebook page.

Check us out at <http://www.facebook.com/alzheimersnewzealand> and don't forget to 'like' our page!

Spinal fluid test predicts early Alzheimers

A test that measures proteins in the spinal fluid has been accurate in detecting which people with memory problems would go on to develop Alzheimer's disease. The findings could lead to a safe and accurate way to test for Alzheimer's disease at its earliest stages, before memory loss and other symptoms become evident and when treatment may be most effective.

In the study, which was published in the *Archives of Internal Medicine*, researchers looked at 102 older men and women who met clinical criteria

for Alzheimer's. They also studied 200 with mild cognitive impairment, Alzheimer's, and 144 who were mentally alert and free of serious memory problems.

The researchers looked at a trio of three proteins, or biomarkers that formed a "signature" pattern in the spinal fluid, the liquid that bathes the brain and spinal cord.

When they followed 57 of the patients with mild cognitive impairment for five years, they found that 100 percent of those who had the characteristic protein markers went on to develop full-blown Alzheimer's.

Full story www.alzheimers.org.nz/spinal-fluid-test/

Miracle switch that turns memories on and off

Turning memories on and off with the flick of a switch sounds like the stuff of science-fiction. But researchers at the University of Southern California, using a brain implant that duplicates the neural signals associated with memory have managed to do just that.

Scientists taught rats to learn a task, pressing one lever rather than another to receive a reward.

Using embedded electrical probes, they recorded changes in the rat's brain activity between the two major internal divisions of the hippocampus.

During the learning process, the hippocampus converts short-term memory into long-term memory.

Researchers blocked the normal neural interactions between the two areas using pharmacological agents - leaving the rats no longer displaying the long-term learned behaviour.

Using a prosthetics model the researchers then developed an artificial hippocampal system that could duplicate the pattern of interaction between the two internal divisions of the hippocampus.

Lead researcher Theodore Berger, of the University of Southern California, said: 'Flip the switch on, and the rats remember. Flip it off, and the rats forget.'

Long-term memory capability returned to the pharmacologically blocked rats when the team activated the electronic device programmed to duplicate the memory-encoding function.

The scientists next plan to duplicate their rat results in primates, with the aim of eventually creating prostheses that might help the human victims of Alzheimer's disease, stroke or injury recover function.



Review

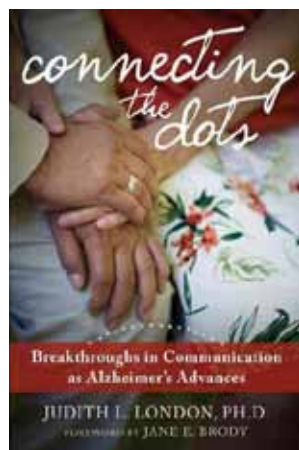
Connecting the dots: *breakthrough in communication as Alzheimer's advances*

The first six (of 33 tools) are the basis for any connection with a person who has Alzheimer's disease (or other dementias) postulates the author, a psychologist with 16 years' experience working with people with advancing Alzheimer's in residential care in USA.

The book is divided into two parts –the first part focusing on how to go about initiating connecting and communicating, with each of chapters 2 - 12 including one or two case studies. The case studies outline the author's experiences of 'connecting' with a person individually and in a therapeutic group setting. From each case study she goes on to outline 'lessons learnt' plus 'relevant tools and related comments'. Chapter headings each clearly identify the chapter theme e.g. chapter 4 'But you just said that! Beyond repetition, repetition, repetition'.

Each of the five chapters in the second part of the book sets out more detailed information on the topics raised in part one e.g. chapter 15 'How do I get my loved one to change? Managing ordinary to challenging behaviour' which includes 17 ways to promote cooperation (pp144 – 146) and 9 ways to improve sleep (pp149 – 150) and a chapter 'How about you? Care for the caregiver'. A glossary of terms, recommended resources, and list of references complete the book.

Family members supporting a person with dementia in the community may prefer to go straight to the summary of tools with related comments (pp171-181), as the setting of each of the case studies is in residential care, then browse through chapters of particular interest. The tools are relevant to both family members and health professionals wherever the person with dementia is living. The use of subheadings, text boxes and every day language all enhance the readability of this book.



By reviewer, Vivienne Boyd, education coordinator at Alzheimers Canterbury. Vivienne is also a registered diversional therapist who has worked with people with dementia in both community and residential settings



Our 25 years

2011-a year of celebration for Alzheimers New Zealand, our organisation turns 25!

As part of our 25th Anniversary it is especially fitting to acknowledge and pay homage to our organisation's roots in Canterbury. 2011

has been a challenging year for Alzheimers Canterbury, as it has endured and overcome significant trials following February's devastating earthquake. They have shown true resilience and strength. This same resilience and strength can be attributed to the first group of dedicated Cantabrians that started Alzheimers Disease and other Related Disorders (ADARDS) in 1983; here lay the beginnings of our organisation. In this feature we go back to these beginnings and reflect on some of the major milestones of our 25 years.

In the beginning

In the early 1980's there was little public awareness of Alzheimer's disease in New Zealand and virtually no support services available to people with dementia and their carers.

"Typical public perception at the time was that people with memory loss didn't know what was happening to them, so that people who were caring for them should just place them in care if they could no longer manage at home. There was little in the way of support at this time, really a very grim picture" says Gaynor Duff, member of the 1983 Steering Committee.

Stigma and lack of knowledge at that time was the motivation behind the steering committee coming together and looking at what else could be offered in the way of support for families and people with dementia.

There was a lot of stigma attached to the disease in the early to mid 1980's.

"Even general practitioners (GPs) didn't seem particularly aware of what could be done to support people with dementia. There was also a lot of stigma attached to going to psychiatric hospitals for care and people were accessing services too late" says Gaynor

A dedicated group of family members and health professionals came together with the mutual aim of better supporting families living with dementia. This steering committee was composed of health care workers, researchers, GP's and social workers.

"We wanted to include anyone who was interested in dementia and in the aims and objectives of the steering group and it was pleasing to see how quickly we grew" says Brenda Cromie, member of steering committee 1983.

The steering committee had four major aims:

1. Support for carers
2. Education
3. Raise public awareness
4. Research – looking at evidence based best practice

One of the committee members, Ian Sheering, was a researcher at Health Planning and Research Unit and provided the steering group with premises for their meetings in Colombo St, Christchurch. "It was a shared facility; there was one person who had to come in and use the office from time to time while we were meeting, but it didn't matter - we had a base to work from" says Gaynor.

ADARDS

Based on the work of the Alzheimers Society in New South Wales, Australia, the Alzheimers and Related Disorders Society Canterbury (ADARDS) had its beginnings in 1983.

People's awareness of dementia was heightened by a documentary called 'The Silent Epidemic' which aired on television. By the time ADARDS had their first public meeting in July 1984 the public had started to realise that dementia was a serious issue. "It was thought that maybe 35 or 40 people would attend. In fact, almost 150 turned up.

"There were lots of queries, mainly from carers and we knew we were on the right track then, in terms of forming the Alzheimers Disease and Related Disorders Society, ADARDS for short" says Gaynor.

What this Christchurch team had begun was soon replicated, with other ADARDS groups developed throughout New Zealand. In 1984 ADARDS, Canterbury was the first society to be incorporated, which led to the first national conference, and the formation and incorporation of a national society.

National organisation

The first national conference of ADARDS was held in Christchurch from 31 October to 2 November 1986.

"The national conference was a huge acknowledgement that Alzheimers awareness was generally on its way; getting three times the number of people we expected was a huge surprise. We were highly organised but had to change the venue to cater for the numbers" says Caroline Oliver, member of Executive Committee, 1984 – 1993.

"There was a great feeling about it, at last we were getting going and there was a feeling of real support and cooperation amongst all the regional groups" she says.

As part of this conference a general meeting was held at which the national organisation was formed and the first executive elected.

The national executive consisted of:

Arthur Sandston (president), Grace du Faur (vice president) and Jan Harrison (secretary).

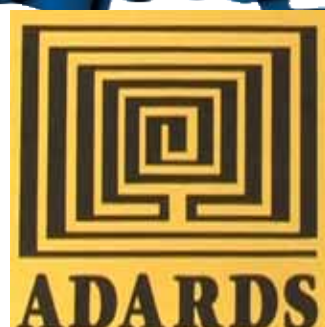
In the report that was published after the completion of the conference, the inaugural president of ADARDS, Arthur Sandston, noted that the main purpose of setting up the national

body was to "enable the local organisations to work together better and to educate the New Zealand public and the medical and related professions as to the nature of Alzheimers Disease and Related Disorders".

He went on to say that the primary objectives of the national organisation are to "present a united front in facilitating and encouraging the co-operation and further development of activities within and between member societies and the New Zealand Society itself with the aim of improving treatment, quality of life and well being of all people with dementia and those who have the care of people with dementia".

There were just 11 member organisations in the first year: Auckland, Waikato, Tauranga, Manawatu, Hawkes Bay, Rotorua, Wellington, Nelson, Canterbury, Invercargill and Southland.

On December 22, 1986 the national organisation officially became incorporated.



Launching the first national newsletter, NZ News, at Government House, November 1983



National Office

The committee started developing national resources, out of which grew a need for a national resource coordinator. Jan Harrison, the national executive secretary at the time, was appointed to this role.

Jan started out as a volunteer on the Canterbury committee as a carer representative. She then moved on to work at ADARDS Canterbury as a resource officer. Her background in education and her experience with ADARDS Canterbury made her an ideal candidate for the role.

"When I first started as the national resource coordinator I was given a cardboard box with two files in it and no office" says Jan.

Dementia was a cause close to Jan's heart as her father had had it. Her personal experience drove her commitment to the cause and kept her motivated. "My passion was in education and that grew to education about dementia following Dad's passing" says Jan.

Jan moved into the office with ADARDS Canterbury at the Disabled Persons Centre in Worcester Street, Christchurch and reported to the National Executive Committee.

1989 saw the first national awareness campaign organised and facilitated by Jan.

Jan became increasingly busy as the sole national office staff member and the decision was made to relocate the national office. Jan moved out of the ADARDS Canterbury office



National Office staff at Sun Alliance House, 1996.

L-R Jan Harrison, Ros McBeth, Judith Stoothoff, Lexie Bell

and into the Old Girls' High Building in Cranmer Square, Christchurch and her hours increased to 25 per week.

"It was a classroom basically, second-hand desks and an electric type-writer where you could only see one line of text at a time" says Jan.

The extra space allowed the national office to grow and two more paid part time staff were appointed, Judith Stoothoss, secretary, and Lexie Bell who looked after the finances. The three then moved to Sun Alliance House, Hereford St and then later to Triune House, Armagh St. National office remained in Christchurch until 2004 when it relocated to Wellington. Jan left the organisation before this move.

First national staff training day, Truby King Centre, Wellington, 1996





Alzheimers New Zealand – A new name

In 1994 the ADARDS title was changed to Alzheimers New Zealand in order to bring better recognition and affiliate the organisation to the international body Alzheimers Disease International (ADI).

The core business of Alzheimers New Zealand was advocacy, information, raising awareness, supporting member organisations, and fundraising.

The first Cuppa for a Cause fundraising event took place in 1995, with the idea derived from Ireland's successful national tea day.

The National Executive remained the governance body to Alzheimers New Zealand until this changed to a board structure in December 2004.

In 2001, the first International ADI conference was held in New Zealand. The conference, which had both New Zealand and international speakers, attracted 1,200 delegates from across the world. Again, twice as many registrations than expected were received.

From humble beginnings in Christchurch, our organisation has continued to evolve over the last 25 years. From the original 11 member organisations we have grown to 22 member organisations. From one sole national office staff member we now have four staff who work closely with our local Alzheimers organisations. We are the leading body for dementia in New Zealand. Our National Dementia Strategy, launched in parliament in 2010, has set clear action points to address the threat of dementia and priorities to improve the lives of those who have the condition and those who care for them. It is a call to action for the dementia community, the aged care sector and the government. This authoritative document has been instrumental in influencing government's recognition of dementia and its growing prevalence in our nation.

Our lobbying, advocacy and awareness campaigns have seen the government commit an additional \$44 million to dementia in this year's budget.

But all this would have not been possible if not for those first few dedicated, committed and passionate people who wanted to make life better for all people with dementia, an ideal cemented in our organisation's mission statement.

Thank you to all those who have been a part of this journey. Happy 25 years Alzheimers New Zealand.

Above and right:

Launching 'Cuppa for a Cause' at parliament, 1995

Above L-R: Lady Reeves, Mad Hatter (MP), and a giant teapot made and donated by Temuka Pottery.

Right: Lady Reeves (in red) and Sir Edmund Hillary (right), and another giant teapot from our sponsor, CHOYSA



Our timeline

1985 - Steering committee formed



1986 - First national conference organised by Alzheimers Canterbury and held in conjunction with Gerontology conference.

1986 - National organisation was formed and first executive elected.

July 2002 - "Remember Me" exhibition and nationwide tour launched at Te Papa, Wellington by Dame Silvia Cartwright.

April 2003 - Professor Martin Devlin commenced external review of Alzheimers New Zealand.

8 December 2003 - The proposed new structure to meet operational expectations, from Prof Devlin's review, was announced.

March 2006 - Kate Clark became the first person with dementia to be appointed to the board of Alzheimers New Zealand. Also in the same year all local Alzheimers organisations signed the Alzheimers New Zealand Agreement to work together collaboratively.

December 2004 - Hand-over of national executive to new Alzheimers New Zealand Board.

July 2008 - The Economic Impact of Dementia in New Zealand report was formally launched at Parliament.

May 2010 - National Dementia Strategy launched at Parliament.

July 2011 - Ministry of supports major nationwide awareness campaign to destigmatise dementia, \$ funding secured.

1987 – National organisation became officially incorporated – national co-ordinator appointed.

1989 – First National Awareness campaign.

October 2001 – Alzheimers New Zealand hosted the ADI 17th International conference.

1994 - The ADARDS title was changed to Alzheimers New Zealand.

March 2004 – National office relocated from Christchurch to Wellington.

March 2004 - Alzheimers New Zealand Charitable Trust was registered.

June 2004 – Alzheimers New Zealand Charitable Trust inaugural meeting.

October/November 2004 – Board nominations and elections.

October 2004 – A special General Meeting of Alzheimers New Zealand adopts changes to Alzheimers NZ Constitution.

Health
wide
to de-
250,000

September 2011 - Further funding for a major nationwide awareness campaign is secured from Pub Charity. Plans begin for the launch in 2012.....



Past, Present and Future

Alzheimers New Zealand board chairman, Martin Brooks, reflects on the last 25 years for Alzheimers New Zealand and his hopes for the organisations next 25 years.

This year we celebrate the 25th anniversary of Alzheimers New Zealand. As we commemorate this milestone I think it's not only important to look back and recognise what we have achieved as an organisation but also look toward the future and what still needs to be achieved. In short, we should continue to progress on presenting a united front to improve the lives of those affected by dementia, by raising government, professional and community awareness, promoting education and training and being aware of the needs of differing cultures within our community.

Looking back, I do believe that Alzheimers New Zealand has made huge strides in awareness; I also believe that we have improved accessibility to training for both those involved in professional care and those of us who care for loved ones at home.

But our job is not done. Our challenge is to keep this momentum going and continue to build on the foundations that have been set over the last 25 years. Now is the time to think about the future. As an organisation we need to be visible in our community. I think that it is fair to say that

there are not many people who have not been touched by dementia in some way, whether by a family member or a close friend.

Young people too are affected. In my own personal case, my nephews and nieces never really knew their grandfather who had dementia. By the time they could have listened to his stories he could no longer tell them. This generational gift of memories is missing for many of our youth today, and will do so even more in the future. There are also many young people involved to some degree in the care of a person with dementia.

One of the ways we can continue to build awareness is to involve high profile personalities, both locally and nationally. Looking at overseas countries we see that in the USA they have Alzheimers Champions and in the UK, Alzheimers Ambassadors. Public awareness campaigns will continue to help increase awareness and above all reduce the stigma of dementia.

With the increase in early onset dementia and younger people being affected, we need to push for more support and programmes that are targeted at this group. The needs of a person in their 50's are markedly different from those of a person in their 80's. Society needs to acknowledge this and ensure that the most effective support is available.

It has been proven worldwide that early diagnosis and intervention is by far the most effective way of support. Ignoring the disease will not make it go away. My mother often told the story of her grandfather who was wheeled out on Sunday afternoons to be with the family but for the rest of the week he was kept apart with 'senile decay'.

Thankfully, we have come a long way from those days and I believe the work of Alzheimers New Zealand can be accredited to this reduction in stigma and rise in awareness. Now we look to the next 25 years as we continue to grow and "make life better for all people affected by dementia".

Alzheimers New Zealand Board Chairperson, Martin Brooks signing a strategic partnership with Careerforce, 2011



We have 22 local Alzheimers organisations spread across New Zealand, some as old as national office, some older and some a bit younger, but each with their own unique history and story to tell. Read about your local Alzheimer's organisation history so far in this special 25th Anniversary Feature.

Alzheimers Hastings

The Hastings Society was first established in Hawkes Bay in 1994, by social workers at the District Health Board (DHB) who identified a gap in the community for people affected by dementia.

Initially it was set up as a daycare to provide social stimulation for people affected by dementia and respite for their carers, with some information and material distribution. It accommodated up to eight clients per day, four days per week, but decreased by 2003 to three days per week.

In 2004, the facility was named the Chatham Club; clients became members giving them a sense of belonging to a club. Community services commenced and a community liaison officer was appointed. The community liaison officer provided assessments, ongoing support, education, and advocacy.

During this time publicity and awareness of the service increased.

Services have continued to develop and increase and in 2008 the Society purchased and adapted its own facility.

Services now include:

- Chatham Club that accommodates 27 members five days a week and provides:
 - At Home with Dementia – A Community Service that provides:
 - Assessment – home visits
 - Ongoing support – for changing

phases of the disease

- Education – both formal and informal
- Advocacy/liaison with other agencies
- Group support:
 - Support Groups and Carers Groups
 - Both carers and people with dementia Memory Café
 - People with dementia groups; Companion Group (for younger people affected by dementia) and Cognitive Stimulation Therapy

Alzheimers Hastings now has eight staff members and 15 volunteers.

They have two contracts with the Hawkes Bay DHB and a memorandum of understanding with Napier Alzheimers, Mental Health of Older People and strong relationships with the NASC (Needs Assessment Service Coordination) agency.



The Alzheimers Hastings team outside thier facility

Alzheimers Canterbury

In the early 1980s there was little public awareness of Alzheimer's disease in New Zealand and virtually no support services were available to people with dementia and their carers. This prompted a small group of Christchurch social workers to form the first ever support group in New Zealand dedicated to helping people care for those with dementia. *(Please read 'Our 25 Years feature for more on Canterbury's beginnings).*

Support groups for carers remain an integral part of Alzheimers Canterbury and as the

organisation has grown and developed, it has incorporated the important roles of education, volunteering, advocacy and support to all people affected by dementia.

Today, Alzheimers Canterbury has 11 staff members, 524 members, 40 volunteers and 22 corporate members. They offer a range of social work, support and education groups and services to all people affected by dementia in Canterbury, as well as education on dementia to the Canterbury community. In the past year, they have seen over 400 new people affected by dementia.

Alzheimers Nelson

On Wednesday 31 July, 1985, Helen Webber, Fiona Miller, Rosemary Hollyer and Margo Bandy got together to discuss establishing a group to relieve the carers of people with dementia.

It was decided to hold a fortnightly luncheon meeting starting in August 1985.

The first Day Care was held on August 1986 at the Hospital Social rooms in Franklyn Street, Nelson.

In the beginning there were no paid workers just a team of nine volunteers. Today, they have four paid staff members, and a team of 40 volunteers who donate on average 700 hours per month.

They have 140 financial members and now support nearly 800 people affected by a dementia in the area.

Alzheimers Nelsons highlights over the past 25 years include:

- Becoming an Incorporated Society in June 1987.
- A well-established programme of education for carers, families and professionals



*20 years + Volunteers (25th Anniversary day also)
Trixie Roselli, Coral Small, Anne Langridge, Olive Jeffries
and Margaret Knight.*

provided by their education field worker.

- A Day Care programme in Nelson that runs five days a week. Alzheimers Nelson also have a partnership approach with Presbyterian Support for this programme and other support services.
- They now have an Alz Café that is hosted in Nelson and Motueka that meets one morning each month to provide a social gathering for staff, volunteers, families and their loved ones with a dementia.
- Four Support Groups run each month for carers of those with a dementia in the Nelson/Tasman region. They also run education sessions for carers as well as caregivers and Early Memory Programmes for people with dementia.

Dawn Allan (office administrator), Heather Lackner (Richmond field worker & educator), Helen Webber, Lyn Hurst (then Motueka Day Programme coordinator, Lyn has now left us), Sue Cochrane (Nelson field worker), Linda Glew (chair of Alzheimers Nelson) and lastly Rose McDrury (Motueka field worker).



Alzheimers Southland

Alzheimers Southland started much like other local Alzheimers organisations, with a group of concerned family members and carers of people with dementia in the area.

They became ADARDS Southland, an incorporated society, but after a name change in 1997 became Alzheimers Southland.

There was a short time in the mid 90's where the society went into recession but with the assistance of Alzheimers Otago and a few carers, it was up and running again and stronger than ever.

Some of the carers from the beginning are still involved in Alzheimers Southland, holding positions on the board of trustees.

Alzheimers Southland now have two full time staff, an office in the CBD, around 20 volunteers and 159 members. They provide support, information, education and advocacy to people with dementia, their family/whanau and carers. They are also one of the very few Alzheimers Societies which does not have any District Health Board Contracts and so rely entirely on community funding, membership and donations.

Alzheimers Eastern Bay of Plenty

In 1988, after attending the Alzheimers National Conference in Tauranga, the seeds were sown for an open day in Whakatane to gauge the need for a local support group in the area.

In August that same year an awareness open day was held at Mary Shapley Rest home Lounge where 75 people attended.

Following the open day the first official meeting was held in September. From there regular monthly meetings were set up and have continued until today. In 2001, the meetings were given the name of 'Memory Café'.

1990 saw the ADARDS Whakatane's first Annual General Meeting, where their first president was elected.

In 1992, they appointed their first field officer, who, at the time, was paid with petrol vouchers.

Three years later in 1995 ADARDS Whakatane received their first funding from the Regional

Health Authority and then in the same year their first Lottery Grant. This extra funding meant they could appoint another staff member in the role of a coordinator.

That same year the Opotiki group formed and held their first meeting.

June 2000 was an exciting time as finally the organisation was able to move into their own office.

Four years later they moved to a new office on Arawa Road where they are today.

ADARDS Whakatane became Alzheimers Society Inc-Eastern Bay of Plenty in 2005.

An application to the Ministry of Social Development in 2010 led to the establishment of a Men's Shed Programme in partnership with Peria House, Opotiki. The project successfully continues today.

Alzheimers Eastern Bay of Plenty today has four staff, 279 members and 20 volunteers.

Alzheimers Otago

Alzheimers Otago was started in 1982 as the Dunedin Dementia Support Group by a collection of carers and health professionals.

In 1985 they became an Incorporated Society and were named ADARDS Otago Inc.

The year 1994 saw the employment of their first staff member; a coordinator for 20 hours per week. Otago at that time acted as an umbrella group for North Otago and Southland, with a membership of 60.

In 1995 they changed their trading name to Alzheimers Society Otago Inc.

Otago hosted the Alzheimers National Conference 1996 and again in 2003. For the 2003 conference Baroness Jill Pitkeathley was persuaded to attend as key note speaker from the UK. Jill's encouragement helped the formation of the Carers Alliance with Alzheimers Otago's role acknowledged by that group.

A pilot project,

funded by the Southern Regional Health Authority, was initiated in 1997 and this formed the basis of Alzheimers Otago's community support officer services. These services are still provided today and the contract remains in place, although now with the District Health Board.

In 2006, they opened a satellite office in Oamaru to provide services to North Otago and in 2007 an office in Alexandra for Central Otago. In 2011, Queenstown will be added to the Otago catchment.



Elsa Fyfe, Wendy Flemming and Norma Selbie ready to "address the haggis" at the 2003 National Conference dinner at Larnach Castle



Signing the World Alzheimers Day charter, 1997



Alzheimers Marlborough

On 17 June 1987, the first Alzheimers Committee meeting was held at Wairau Hospital following a public meeting held the day before, where 120 people attended.

The request from the community was for day care services, day and night sitters and telephone support. Support group meetings were held by the Wairau Hospital social worker.

Two Wairau Hospital senior nurses along with the hospital social worker recognised the need for a community based organisation to offer support to families affected by dementia and for public awareness of the disease.

The two nurses attended the first meeting of the Christchurch ADARDS Society, as it was known then, and determined that Blenheim would also have such a group. They also recognised that there was a significant problem with the medical profession not being able to diagnose the disease until it was well advanced.

A committee was made up with the two nurses and a Methodist minister as secretary, along with four other women.

The first paid staff, Kaye Clarke, was appointed in December 1987 as day care supervisor. Her wages came from a one off grant from the Department of Social Welfare.

On 11 February, 1988 the AMARDA Club Day Care Service officially opened.



Some of the highlights from the past 25 years include:

- 1990 gaining loyal supporters in the local media, which created a lot more publicity and in turn gaining support from the community. Fundraising activities were organised by community groups, like Blenheim Lionesses'. The committee increased to 18 and by 1993, and financial membership increased to 98.
- Alzheimers Marlborough assisted in the support group meetings run by the hospital in 1991. This led on to Alzheimers Marlborough eventually running them.
- 1993 they started support group meetings in Picton.
- 1996 they purchased a local community bus after for transporting clients to and from the Club.



- In 2000 they gained recognition from the Health Funding Authority. This resulted in a successful grant application receiving the first regular funding of \$5000 per annum.
 - In 2001 a partnership with Presbyterian Support was formed.
 - On 22 February 2009 they moved into their own purpose built day centre and administration building.
- Today, Alzheimers Marlborough has 50 volunteers, 154 financial members and seven staff.

Alzheimers Northland

In 1985 a group of carers (who all had parents with Alzheimers), led by Dr Bill Parkes, a local geriatrician, were concerned about the lack of support and information about dementia in Northland. The group each put \$5 into a kitty to buy some stationery and formed the beginnings of what is now the Alzheimers Society Northland. These volunteers, originally called ADARDS Northland, met in each other's homes and contributed a lot of time, energy and finances to the cause.

In 1991 these founders approached the District Health Board for financial assistance to run a pilot project to ascertain the demand for services in Northland. A social worker, Paula Carpenter, and part-time office worker, Dawn Scharnweber were employed. The pilot project was to run for one year. Paula and Dawn were the first paid staff and worked from the Old Town Hall, 71 Bank Street, Whangarei.

After 12 months, Paula left and two part-time support workers were employed to work alongside Dawn. ADARDS became an incorporated society in 1992.

In 1997 an office was set up in Kerikeri which was the beginning of their presence in the Far North. Anne has been with the society for 15 years – their longest serving employee! Dawn left in 1997.

In 1998, due to refurbishment work at the Old Town Hall, the group had to move to an office in Hunt Street on a temporary basis. Instead of returning to work in the Old Town Hall, the current premises at 321 Western Hills Drive was found and purchased.

In 2001 a mobile day care service was established serving the Hikurangi, Waipu and Dargaville areas.

In 2003, with a lot of physical help from the founders and volunteers as well as financial help from the ASB Charitable Trust and Lotteries Seniors, an extension was added to the building. This allowed them to hold a day care centre in Whangarei. In particular, five men whose wives were all at the Alice Court Alzheimers Unit at the Kamo Home and Village worked voluntarily for months to transform an empty, unfinished, unlined, unpainted and uncarpeted shell of a hall into the valuable day care centre it is today. These men will always be known as the Alz Angels!

Alzheimers Northland registered with the Charities Commission in 2008 and in 2009 changed their legal name to Alzheimers Society Northland Incorporated.

Today, they have 12 staff, 140 financial members and support approximately 600 people with dementia, their caregivers and families/whanau throughout Northland.

Alzheimers Taranaki

On 14 April 1987 a meeting was held at Barrett Street Hospital to discuss the need to form a regional ADARDS group. With the assistance of Jan Hide from the national organisation, which had formed in Christchurch the year before, a committee of 14 people was established and Pat Wesley from Omahanui elected as president.

In November the same year a very successful public meeting was held at the Devon Hotel. Over 140 people heard guest speaker Dr David Lindemann, the executive director of ADARDS California, talk about his work.

By the middle of 1988 ADARDS Taranaki had established a monthly Carers Support Group and a small group of volunteers providing a Be-Frienders Service to people caring at home (one of these dedicated volunteers was still helping out at the Friday Club up until the beginning of this year – giving over 22 years of service to Alzheimers Taranaki). They had also compiled

and printed their first local newsletter and had Dementia Booklets available for sale.

In August 1988, they began providing Day Care at a private house next to Pukekura Park in Gilbert Street owned by Tom Hibbell. His wife suffered from dementia and he was happy for them to use a large room that opened onto a beautiful fenced garden. This group met for many years before it eventually moved to a room provided by the Elderly Services at Base Hospital.

Although over the years the the committee has shrunk a little and it's not so easy to find volunteers, Alzheimers Taranaki now have five part-time staff, an office in town, around 30 volunteers and 131 members.





Alzheimers Gisborne

In 1990, a small group of volunteers realised the need for a support organisation for those affected directly and indirectly by dementia-related diseases.

A Telethon for the Aged was held, and with some money from this as well as some from Lotteries, these volunteers formed the Alzheimer's Gisborne Committee of ADARDS. This committee would provide support to both people with dementia and their carers. Monthly meetings were set up and a local social worker and doctor became involved.

After a great deal of research and fundraising, the Sherwood Day Centre (or Sherwood Club) was founded in 1992. Most of the clients came from the community with some from a local rest home.

Initially, the Sherwood Club was open for two days a week and had two paid staff and a number of volunteers. Through the years, it has operated out of church halls, the Harry Barker

Clubrooms and the Dunblane Rest Home lounge. Finally, in 2003, it moved into its leased premises at the Morris Adair Building.

Alzheimers Gisborne have grown from a small group of staff, clients and volunteers to what they are today with their own well-equipped premises. With four paid staff and 24 volunteers, they provide quality care three days a week, affording much-needed respite for carers.

There are now two carer support groups that meet monthly. One is a social group and the other is an educational group which provides carers with a better understanding of dementia and answers to any questions that they may have. In this way, both the clients and the carers are supported.

A great deal of money has been raised through various projects over the years. Apart from the financial benefit to the organisation, this has resulted in an increase in public awareness about Alzheimer's. It is hoped that by having a greater understanding of the disease, the stigma attached to the word 'Alzheimer's' will gradually lessen.

Alzheimers Taupo

Alzheimers Taupo was formed after an interim committee of just three women organised a public meeting on February 22, 1989. They were overwhelmed by the response, as 110 people attended. The first executive committee was then elected with 11 members.

Five years later, after receiving funding from the Lotteries Board, the first field officer was appointed.

Today, Alzheimers Taupo employs two part time field officers and has a permanent office. They



also have an executive committee of 10 people, all enthusiastic in their vision to help make life better for all those affected by dementia.

In 2009, Alzheimers Taupo entered into the Mizuno Half Marathon event where they were awarded for being the most visible team. Alzheimers Taupo feel they succeeded in raising both their profile and awareness of Alzheimer's and dementia in their local community, which has gone a long way to help dispel the stigma that is associated with dementia.

Above - Alzheimers Taupo Committee Members dressed up at Christmas

Left - Mizuno Half Marathon Event

Alzheimers Napier

The first support services were established in Hawkes Bay in 1982, by a group of social workers who identified a gap in the community for people affected by dementia.

Late in 1986, a Napier Social worker came to a carer support meeting and suggested setting up a specialised day centre for people with dementia. This would have a dual role of providing day respite for carers while providing a stimulating program for people with dementia.

The group started one day a week at the Coleman Day Ward, Napier Hospital. However, due to numbers, people could only attend for about 6-8 weeks and then they had to give their place to someone else; most unsatisfactory. A steering group was set up to obtain funding and a venue to accommodate the need. Funding was obtained from the Springhill Trust for six months (\$16,000) and under the umbrella of Hawkes Bay ADARDS, the day centre was underway at St Andrews Hall, Atawhai, two days per week, with two paid staff and a small army of volunteers. When told of the philosophy of the centre, Ted Waaka, principal of Taradale Primary School immediately came up with the name 'Mahana' meaning place of warmth and caring.

The Mahana Club was the very first dementia specific day centre in New Zealand and original staff presented the concept and successes at the ADARDS conference in Tauranga.

In 1990, the Committee started the work for the society to become incorporated.

Further funding via grants, membership and

donations ensured continuance of the service, which had minimal paid staff but a large contingent of volunteers.

The group had several temporary homes, moving to 46 Nelson Crescent in 1994. By this time, the Mahana club was operating four days each week with 8-10 attendees per day.

Community services commenced to provide support, education and advice to people with dementia and their carers/families. With funding via a district health board pilot scheme, these community services really 'took off' and staff increased to two community liaison officers and further support groups were established.

An ageing committee and increased workload saw restructuring in 2006 and the employment of a service manager to oversee the day to day running and expansion of services. Also, due to demand, in 2007 the Mahana operations increased to five days per week.

Alzheimers Napier now have nine staff members. The Mahana club has a capacity of 15 members per day and operates five days per week.



*Mahana Club and
Alzheimers Napier's car*



*Hutt Mayor David Ogden
and Kate Clark plant a tree to
mark 25 years of Alzheimers
Wellington*

Alzheimers Wellington

A small group of 13 Wellington residents were concerned with the lack of services in the area for people with dementia. This prompted them to set up a local Alzheimers organisation, ADARDS Wellington in 1987. The following year they appointed their first field officer and, in 1992, their first coordinator.

2002 saw Alzheimers Wellington move to their office in Petone from which they still operate out of today. They have continued to grow steadily with service centres also now based in South Wellington and on the Kapiti Coast. With the growth in service demand the team expanded with the appointment of an education officer and a team leader community services in 2010.

Alzheimers Wellington currently has seven staff, 22 volunteers, 354 individual family members and 22 corporate members. Its strength remains the working partnership between its volunteers, members, paid staff and strong community links.

Alzheimers Wanganui

In 1986 an informal group of carers of people with dementia, brought together by a local health nurse, began meeting monthly at the local hospital. The first committee was formed in 1989 with Margaret Story as president. Meetings continued with hospital staff support until 1994. Margaret, now 95, was made a life member in 1997 and became a patron in 2000. She continues to take a keen interest in Alzheimers Wanganui.

In 1990 ADARDS Wanganui became an incorporated society; ran a six module carers education course based on an Australian model; began their newsletter and established a small library.

In 1995 their first paid community worker was employed for 10 hours per week funded through grants from a Telethon Appeal and NZ Lottery. She worked initially from home, then from a very small office in the Community House managed by a roster of volunteers. Funds raised through grants, donations, membership and on-

going fundraising enabled the organisation to gradually increase paid staff to meet community needs.

Various moves followed – first to a slightly larger, shared office; then to a small house, and in November 2003 to their present home – a highly visible, purpose-designed, centrally situated suite of rooms in the central business area.

Much of today's work centres around "The Group" – social interaction for people with dementia in Marton and in Wanganui who are collected every week to enjoy various community based activities while their carers have a few hours of regular respite.

Today, Alzheimers Wanganui has three staff members and 20 volunteers providing information, education – both formal and informal, on-going support for people affected by dementia, group support, and advocacy/ liaison with other agencies and awareness. Staff cover the rural Rangitikei and Waimarino areas of Marton, Bulls, Taihape, Raetihi and Ohakune.

Alzheimers Rotorua

Rotorua Alzheimer's Society was originally launched in the mid-90's with strong carer input, this faded over time and the Society went into recess until 1997.

In 1999, Rotorua Alzheimer's Society provided services to 37 people with dementia and 66 family members, a total of 103 clients.

Their client numbers and annual expenditure over the ensuing 11 years has increased six-fold. Today they provide services to 232 people with dementia and 464 family members, a total of 696 clients.

They have been fortunate to have had a reasonably slow turnover of board members and have always had one or two members who were carers. Alzheimers Rotorua has retained two outstanding staff members for the last decade, Lyn Soeters and Elaine Fox. They are the public face of Alzheimers Rotorua and are credited with creating the depth of respect, credibility and reputation the organisation is known for today for with local health service providers.

One of the most pleasing changes over the last 14 years for Alzheimers Rotorua has been the increase in awareness within the local community about dementia and its affect on people and their families. The time and energy staff and board members have invested over

this period in raising public awareness and reducing the stigma of dementia has had hugely beneficial outcomes. The continuity of care and service the staff provide to clients, carers and family for the duration of their journey with dementia is anecdotally highly valued and appreciated; they know they are not walking this pathway alone.

Alzheimers Rotorua's wish for the future is to sustain the same quality of support so they can continue to make life better for all people affected by dementia in the Rotorua region.



Alzheimers Rotorua's Lyn Soeters (right) and Elaine Fox (far right) with two of their volunteers collecting for their appeal

Alzheimers Auckland

The groundwork for the formation of an Auckland Alzheimer's Society was set in place at a public meeting in the Custom House, Auckland in September 1984. The occasion was a public address by a visiting American nurse, who had a long history in the care of dementia in the United States.

Following this formal address, over 50 people meet to discuss the need for a carers' organisation in Auckland. The decision was made to appoint a steering committee.

In October 1984 the Mental Health Foundation made a grant of \$750 to the steering committee towards initial set up costs of an Alzheimers Auckland Society. By the end of that year the first committee for the Auckland Alzheimer's Society was in place.

Committee meetings in those early days took place in several venues from private homes to local hospitals. The Society was then offered space for an office by the Wesley Hospital. A phone was installed and a roster of volunteers answered queries.

By mid 1987 the Auckland office of ADARDS (as it was then named) was based at the Wesley Day Centre at the hospital. The Auckland Methodist Mission had kindly cleared a cleaner's cupboard and storeroom for office use, which had its own entrance.

An office organiser was employed part-time, funded by the Department of Social Welfare under the Disabled Persons Services Programme, to attend carers' enquiries, collate data, and arrange the roster of volunteers.

By early 1989 two offices had been rented at the Disability Resource Centre in Royal Oak.

In 1990/91 the Auckland Society was split to allow a separate society for the Manukau City/ Franklin District.

In 2006 a fundraiser and clinical services manager were appointed. By 2008, Alzheimers Auckland had 19 staff members.

The Alzheimers Auckland and Counties Manukau re-connected to work together as one again in 2010. They officially became united as Alzheimers Auckland Charitable Trust in 2011.

Alzheimers Auckland today:

- 26 staff
- Operates from six sites across Auckland.
- Runs 34 carer support groups each month.
- Holds 23 carer education programmes a year.



Alzheimers Auckland patron, Lady June Hillary, cutting a cake to mark their 25th anniversary

- Holds weekly activity groups and one to one socialisation sessions for people with dementia.
- Holds carers cuppas, and Christmas events each year for more than 500 family carers.
- Has a budget of 1.4 million – half of which is raised from the community.
- On any given day is helping more than 1000 people with dementia and their families – around 6000 people in total.





Alzheimers Wairarapa

A steering committee was

formed in July 1998 at a meeting hosted by the Wairarapa Organisation for Older Persons. Following this meeting, Alzheimers Wairarapa was established as a sub-branch of Wellington. In 2003, Alzheimers Wellington applied and received funding for a part-time field officer for the Wairarapa area.

Alzheimers Wairarapa became an incorporated society with charitable status in 2004 and became the 23rd member organisation of Alzheimers New Zealand.

They then began to work towards a Day Activity base for clients. The District Health Board (DHB) was interested in the idea but described Alzheimers Wairarapa as "too small and inexperienced in this field." They then approached Presbyterian Support who was enthusiastic locally, but unfortunately their head office did not respond. Undeterred, they organised an Art Auction and raised enough funds for the venture.

Shortly afterwards, they formed a partnership with Glenwood Private Hospital, as they could use their contract with the DHB to run the Day Activity Group. This commenced in the Hospital premises in May 2006 with just three clients. They soon realised the Hospital was not the right environment for these people with early dementia so moved to the Masonic Village hall in July 2006. The client base then increase to six.

In 2007 a group was formed made up of staff and committee from Glenwood Hospital (G),

Alzheimers Wairarapa (A) and Presbyterian Support (PS), known as GAPS. From this group, public education and information were identified as important and a brochure was printed and delivered to all rest homes and doctors surgeries throughout the region.

Due to the efforts of a committee member, Alzheimers Wairarapa received a grant of \$10,000 from the Paul Newman Foundation in 2008. This provided five education programmes of four weekly sessions over two years. With a current grant from Masterton Trust Lands Trust, they are about to hold their sixth series of education sessions.

Today, Alzheimers Wairarapa run their day care service twice a week, for 14 to 18 clients each day.

They have 32 volunteers, 140 subscribers and 128 clients with 118 carers. They now have two staff, and a committee of seven that manage and govern the organisation.



The Alzheimers Wairarapa team at their fundraising auction, 2010



Alzheimers Ashburton

Originally named ADARDS the society held it's very first recorded public meeting on 8 June 1988. 100 attended from which an executive and committee were elected.

In 2008 Alzheimers

Ashburton celebrated its 20 year Anniversary. Over the years the society has provided ongoing education and support to families and carers of people with dementia as well as the community. It has achieved many milestones along the way, including the establishment of its office, an office co-ordinator and field officer (1991-2011), allowing them to better support their community and achieve their aim of 'making life better for all people affected by dementia'.

Today, Alzheimers Ashburton has 95 members and supports about 40 families.

Left - Ashburton Mayoress, Julie O'Malley helps the Alzheimers Ashburton team collect for their 2009 appeal

Alzheimers South Canterbury

Alzheimers South Canterbury started in 1981 when Alisa Bailey (manager of Talbot Hospital at the time) initiated the first support group meeting for people with dementia in the community.

In 1985 Alzheimers South Canterbury held their first public meeting. Five years later in 1990 they became an official group and formed a committee.

In 1993 after receiving their first grant, Alzheimers South Canterbury opened an office staffed on a roster basis by volunteers.

A constitution was signed and Alzheimers South Canterbury became incorporated in 1995. In the same year their first mystery bus trip was held and their first newsletter issued.

1999 saw the first paid staff member employed, which was a field officer; the following year they hit the streets for their first appeal.

Today, services include monthly carer support groups in Timaru, Waimate and Geraldine; monthly coffee groups in Timaru and Temuka; monthly walking group in Timaru; regular seminars for carers, members of the public and professionals; volunteer programme (Jolly Volly Service) offering in-home support to give carers a break while providing a social



Hats go flying at Alzheimers South Canterbury's unique fundraising event, 2010

opportunity for person with dementia; regular newsletters; regular social events; and talking with community groups.

Alzheimers South Canterbury now has two staff. A community liaison officer who provides support, education and information to 180 families. They also have a volunteer coordinator who recruits new volunteers and arranges training and support for them, promotes the services, and looks after the Jolly Volly Service.

Alzheimers Manawatu

The Manawatu [ADARDS] support group was established in 1985, mainly through the efforts of social workers from the Services for the Elderly Team at the Palmerston North Hospital in response to the needs of caregivers.

ADARDS Manawatu Support Group was formally established in 1987 and was incorporated under the constitution of the national body on 25 November 1992 as Alzheimer's Society Manawatu Inc.

In August 1991 the first Day Care Centre based in Ihaka Street, Palmerston North was developed. This was first managed by a woman named Yolande O'Keefe until Trish Mellings took this role over in January 1993. Gavin York started working at the centre in 1992 where he still remains as the divisional therapist.

"We have come a long way since 1 August 1991 when Yolande and I had our one and only client." wrote Trish in Alzheimers Manawatu's 1994 newsletter.

In 1994 the group entered the technological age

with the purchase of a computer for the centre.

During this year Alzheimers Manawatu's first National Awareness Day saw collections on the streets and displays around town. This event attracted extensive radio coverage and boosted the profile and awareness of the society.

1995 saw the first field officer appointed and in the following year the society moved premises to Tremaine Avenue to cater for the increase in clients. In 2002 the centre moved to a new home on Featherston Street, Palmerston North where they remain.

Today, Alzheimers Manawatu has approximately 63 clients who attend the centre each week.



Alzheimers Manawatu manager, Trish Mellings, opening the new centre in 2002

Alzheimers Tauranga

Alzheimers Tauranga first started with a group of informal carers who provided support to each other.

In 1989 Valma Hallam volunteered her time as a be-friender providing support to people affected by dementia. Over time, Valma gradually received payment for travel costs and eventually wages for her work. Valma is still a member of staff today, she now carries a full case load and delivers six support groups a month.

As time went by Valma was joined by other part-time staff (administration and field workers) this allowed an increase in service delivery and clients. Staff were scattered around with an administrator working from home and Valma working from a small room at the Wesley Methodist Church.



By 2008, with five part-time staff working from two small office rooms at the church, the time had come to find more space and again the church helped with offering Alzheimers Tauranga the location of the ex-minister's house two doors down the road. A collaborative effort was undertaken to make the premises fit for purpose.

Their current facility provides four offices, a nice domestic kitchen and a sunny meeting and training room. As well as that, they have a lovely back lawn that has been made suitable for people with dementia to garden and recreate when attending activity and companion days at the centre.

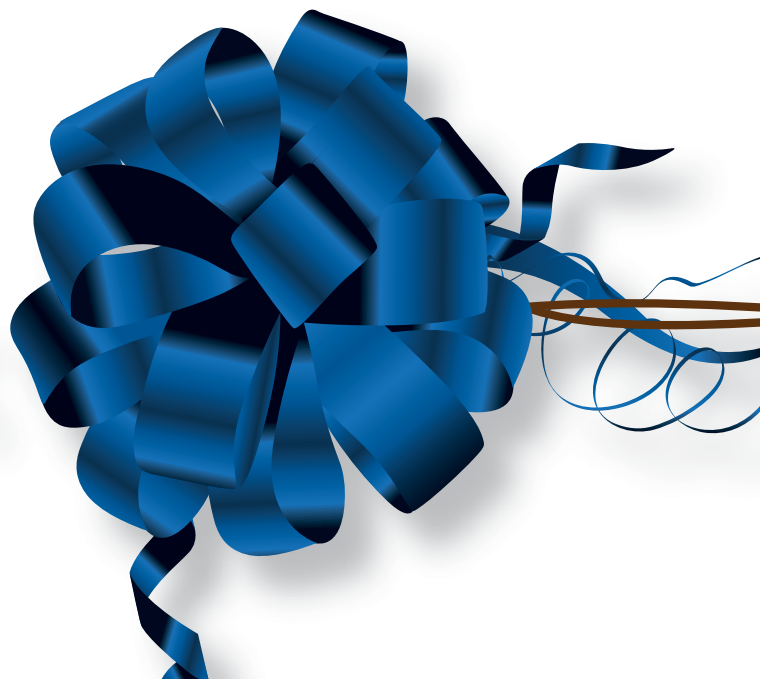
Today, Alzheimers Tauranga has six staff, 34 volunteers, and approximately 250 financial members. Alzheimers Tauranga support 260 families providing individual home visits, carer support groups, education sessions, courses and activity groups for people with dementia and a volunteer service.



In 1988, ADARDS Tauranga hosted the first National Conference in New Zealand "In Focus, 1988" with approximately 270 people attending. The Minister of Social Welfare, Dr Michael Cullen, addressed the Conference and Peter Dunne MP and under secretary to the Minister of Health presented to the conference.

With the generous support of the Wesley Methodist Church, in 1997 Alzheimers Tauranga put forward some funds and the church built on two rooms for the society to operate from.

In late 2002, a review was completed that was to take Alzheimers Tauranga to the next level and in 2004 a manager's position was created, allowing the committee to focus on governance. Staff levels started to grow and security of succession planning was in place.



Alzheimers Waikato

In October 1984 a group of people affected by dementia met to discuss the possibility of setting up an organisation. Early the following year a public meeting was held and ADARDS Waikato was established as an incorporated Society. The first newsletter went out in July of 1985, with the aim of keeping members informed.

The organisation relied solely on volunteers until 1988 when the first field officer, Barbara Moore, was employed. She worked from home. In December 1989 it was decided that the group would rent an office in the Disabled Resource Centre, now known as Life Unlimited, in Palmerston Street. The group voted to change their name from ADARDS, to Alzheimers Waikato, in line with other organisations, in December of 2001.

The organisation operated from Life Unlimited until September 2003 when they moved into the impressive Art Deco Building at 1 Mill Lane.

Here the organisation flourished and grew – more staff were recruited, cars were leased and the list of services expanded according to client needs for many years. The newly appointed manager and board chair moved the group to a new larger premises in Frankton in March of 2009.

Sadly, the Society was forced into liquidation and their doors closed in July 2009. With a grant from the Todd Foundation the previous educator, Jane Kay, was re-employed part time and worked from her home. During November Jane and previous support co-ordinator, Wayne Pruden, set about a 180km walk from Te Kuiti to Thames to raise the funds to start up again. They were supported by Florence Monson, also a previous support co-ordinator, who drove a support car loaned and sign written by Ingham



L-R - Florence Monson, Jane Kay and Wayne Pruden on the memory walk to raise funds to re-establish Alzheimers Waikato, 2009

Honda.

In January 2010, Alzheimers New Zealand Waikato began operating under the auspices of Alzheimers New Zealand. St Stephens Presbyterian Church kindly made a small office available at a nominal charge.

Thanks to the help and support of a wonderfully dedicated committee led by Robyn Riddle, and the generosity of many individuals and groups in the Waikato community, Alzheimers Waikato is once again an independent local Alzheimers organisation. The Alzheimers Waikato Charitable Trust was registered in January 2011. Four staff members, Jane Kay, Florence Monson, Wayne Pruden and Margaret Brewerton are employed and have been able to expand into three offices in the Church. Margaret Brewerton who began working in a broom cupboard at Life Unlimited in 2001 is back with the organisation as administrator and even has an office. From here it certainly is onwards and upwards for this local Alzheimers organisation!

Alzheimers New Zealand would like to send its appreciation and sincere thanks to the many staff, volunteers, members, supporters, donors, sponsors, granters, colleagues, partners and friends who have walked alongside us on our journey so far, and look forward to our journey ahead.

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Alzheimers New Zealand – Level 3, Adelphi Finance House, 15 Courtenay Place, PO Box 3643, Wellington 6140
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