



Alzheimer's 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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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.

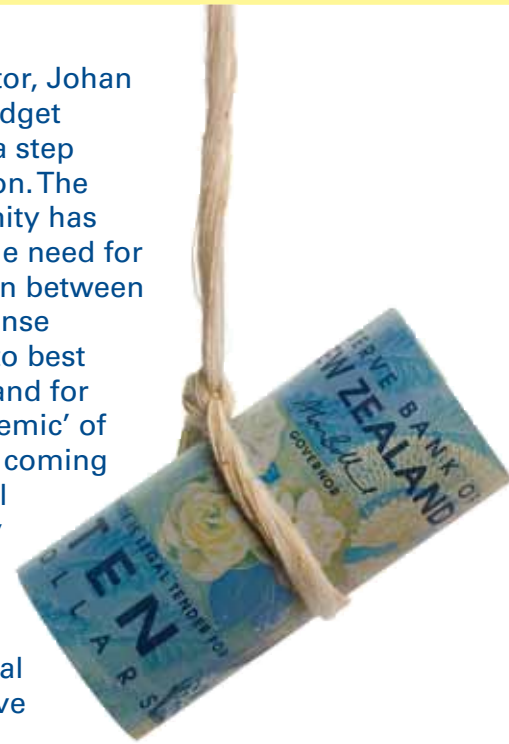
“Last year’s aged residential care services review identified the most pressing need to expand dementia units, beds and services. We are committed to ensuring the public health service supports all people with dementia and their families during a very difficult period in their lives” said Ryall.

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

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

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

J 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 has 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.

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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 affect 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.

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

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!

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*

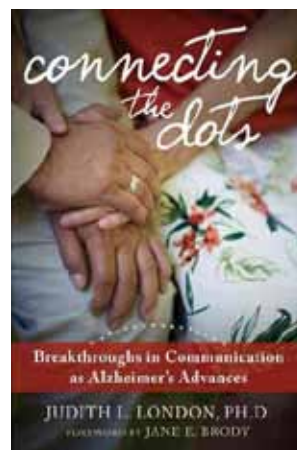
The first six (of 33 tools) are the basis for any connection with a person who has Alzheimer's disease (or other

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