



DEMENTIA...strikes at the very essence of what it means to be **HUMAN** page 7



Alzheimers News

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Correction

Within the "Appetite Hormone" article on page 15 of the March 2010 edition of *Alzheimers News*, it was incorrectly written that, "those with the highest leptin levels were four times more likely to develop the disease," when it should have read, "those with the highest leptin levels were four times **less** likely to develop the disease." Alzheimers New Zealand apologises for any confusion.

News

Drug subsidy



Government drug buying agency Pharmac's decision to subsidise dementia medication means a 98% price reduction for the 15,000 New Zealanders able to take it. The cost for an individual for the cholinesterase inhibitor medication, donepezil, will decrease from up to \$150 per month to between \$7 and \$14, depending on dosage, for a three month supply. The reduction in price should come into effect later this year.

The announcement was made on 6 May 2010 at the opening of Alzheimers New Zealand's People, Policy, Partnership Conference, where there was a palpable sense of celebration and achievement from delegates. The subsidy is a long time coming for people who benefit from the drug, which allows clearer cognitive function, as well as for those who have lobbied for it over the last decade.

The medications can allow clearer cognitive function. Pharmac's medical director Peter Moodie said his organisation was looking for value for money before he could fund the medication. Before the generic market opened last year, following the expiry of Aricept's patent, funding for cholinesterase inhibitors would have cost up to \$32 million, for what Pharmac saw as relatively small clinical benefits. "We are delighted to have this generic. We have been agonising about the funding of these cholinesterase inhibitors for some years," he said.

Former Alzheimers New Zealand board chairperson Eileen Smith, who appeared on TVNZ programme *Breakfast* as well as a *TV3 News* lunchtime bulletin on the day of the announcement, was delighted by the decision. "It has been 10 long years trying to make people understand that, while we recognise that this medication isn't a cure, it does enable the person diagnosed and their carer to have a prolonged quality of life, get their lives in order and come to terms with the diagnosis."

Eileen's husband Ray, 64, lives in a residential care facility. Taking a cholinesterase inhibitor medication gave her family, "a small glimmer of hope for the future."



Alzheimers New Zealand spokesperson Eileen Smith talks to *Breakfast's* Pippa Wetzell about Pharmac's decision to fund donepezil.

National Dementia Strategy

The National Dementia Strategy, launched at Parliament on 6 May 2010, calls upon Alzheimers New Zealand, the private and public health sectors, the Government and other community organisations to work together to cope with the rise in dementia over the coming decades and to help people with the disease and their families today. Over 200 guests were present for the launch, including Alzheimers New Zealand staff and board members, politicians, key note speakers from the People, Policy, Partnership Conference 2010 and other conference delegates throughout the health and social services sector.

Health Minister Hon Tony Ryall spoke at the launch, acknowledging dementia as a key issue for the future of New Zealand. He told the audience the Government was committed to working to ensure those with the disease received quality services.

“We are committed to working to ensure people suffering from dementia receive quality services and live as good a life as possible, whether at home or in residential care,” says Ryall.

Alzheimers New Zealand board member Nigel Wynn spoke about life with early onset dementia and how the Strategy will impact him and his family.

“There are a growing number of people under the age of 65 currently being diagnosed with dementia in New Zealand. This number only reflects those diagnosed. It is also expected to double every decade. This is why the National Dementia Strategy is so important,” he said.

Professor Peter Baume, a former Australian Health Minister instrumental in helping to make dementia a health care priority in his own country, appealed to Minister Ryall to make dementia a health care priority in New Zealand. He said the decision to do so in Australia was not driven by the Ministry of Health but by politicians. “Dementia causes the same amount of community disruption as other chronic diseases. There’s a lack of public appreciation for that fact. Making it a health priority encourages people to think and talk about dementia when they hadn’t done previously.”

He pointed out that only 50% of Australians are taking steps to prevent dementia and only one in three receive a formal diagnosis at any time during their journey with the illness.

For the full Strategy, please go to www.alzheimers.org.nz/national-dementia-strategy



Minister of Health Hon Tony Ryall at the launch of the National Dementia Strategy in Parliament

The National Dementia Strategy's eight strategic goals

- 1) Recognise dementia as a national health priority
- 2) Increase public awareness of dementia
- 3) Provide access to affordable and appropriate medication
- 4) Improve early diagnosis and management of dementia
- 5) Provide appropriate services to all people with dementia
- 6) Provide support to family, whānau and carers of people with dementia
- 7) Develop the workforce to deliver quality dementia care
- 8) Increase dementia research and the evaluation of dementia practices



People Policy Partnerships

Alzheimers New Zealand Conference 2010

Convention Centre, Wellington, 6-8 May 2010

The Alzheimers New Zealand People, Policy, Partnership Conference 2010 got off to a great start due to Pharmac's decision. It was officially opened by a pōwhiri from "seniors" kapa haka group, Te Roopu O Te Whanganui-A-Tara, while television's "The Attitude Doctor", Tom Mulholland, MC-ed with compassion and humour.

Labour Health Spokesperson MP Hon Ruth Dyson spoke about the carer's strategy as well as the National Dementia Strategy: "No one should underestimate the importance, the value and the power of a strategy if it is properly prepared, done in partnership with the Government and if it has an action plan."

The opening was followed by former psychologist Dr Richard Taylor's "Alzheimer's From the Inside Out" talk. Richard spoke about the moral obligation of society to spend money and time on those with dementia now, as opposed developing a cure for those without the disease.



Richard Taylor with Julie Dywer from kapa haka group Te Roopu O Te Whanganui-A-Tara

He pleaded with the audience and wider community to treat people with dementia as whole.

"Here I was, a psychologist who thinks he knows everything, and a PHD who knows he knows everything and I didn't know anything about Alzheimer's disease or dementia. We have a long way to go to understanding the humanity of people with dementia, and that is why I am here. We are not fading away, or half full."

Friday saw Alzheimer's Disease International's Professor Martin Prince, the man behind the *World Alzheimer Report* and the 10/66 project, talk about his evidence based around improving health and social welfare for people in low and middle income countries. Concurrent sessions looked at everything from driving and wandering to exercise and whākama (shame around dementia in Māori).

One of the stand out sessions throughout the entire conference was a panel made up of people with dementia, who took to the stage to talk about issues they face in their daily lives. Christchurch woman Heather Cameron, diagnosed with Alzheimer's disease in 2008 at age 55, and who lives by herself, says she copes by learning from her mistakes and making visual clues.

"What a maze of feelings you go through. Everyone goes through the process of facing the situation in their own sweet way, but for most of us it comes as a hell of a shock. I've finally come to realise that I no longer feel like a victim.

Life has dealt me a good hand of cards and I am truly grateful and I am moving forward. My philosophy is to do two things every day that I don't want to do in order to stretch myself and expand my ideas about who I am and what I am still capable of doing."

Keynote speaker Professor Jenny Abbey talked about research around confusion which can occur when caring for someone with dementia while they are dying; this confusion can often lead to family grief and staff dissonance, she said.

“The journey from diagnosis to death needs to be planned, and people need to be prepared. Comfort is the main word we need to be using. It’s a very simple concept but not so easy to implement. Families and people with dementia are dealing with grief. At some stage through the journey the notion that dementia is a terminal illness needs to be discussed and advanced care plans made. We have to provide the kind of death the person wants, not the kind of death we think is right for them.”

The inaugural Alzheimers New Zealand Awards Dinner at the Duxton hotel on Friday night really was the “academy awards” of dementia care. Award winners graciously accepted their awards, speaking of community support, passion and why the work they do is so important.

Actress Kristyl Noho performed selections from *Te Mahara – the Memory*, directed by Nina Nawalowalo, which gave an insight into one families’ journey with dementia, followed by Australian-Maltese singer songwriter Jay-P, who performed a couple of tracks inspired by his father’s illness.

“We have a long way to go to understanding the humanity of people with dementia. We are not fading away, or half full.”

The last day began with a stellar talk by Professor Richard Faull, of the Centre for Brain Research, who engaged the audience in the brain’s inner workings. This was followed by keynote speaker Professor David Ames’ session on detecting presymptomatic Alzheimer’s disease. Concurrent sessions included everything from the science side of things (epigenetics), to communicating through animals, to reducing stress and drug use within residential care settings. Keynote speakers Jenny Abbey spoke about staff burnout while Peter Baume talked about the controversial topic of advance directives. The keynote speakers all participated in a panel discussion, allowing the audience to ask questions.

The conference was closed by a mihi and thank you to all our guests. Feedback from delegates said it was a fantastic three days with a good balance of scientific and social research, story sharing, networking and training.

And the award goes to...



The team at Alzheimers Marlborough receive the Alzheimers New Zealand Charitable Trust Team of the Year Award

- Careerforce Carer of the Year: Sue Noble-Adams
- Summerset Volunteer of the Year: Colin Murray
- Alzheimers New Zealand Charitable Trust Team of the Year: Alzheimers Marlborough
- Bupa Supreme Award for Outstanding Contribution in the field of Dementia: Wendy Fleming

Thanks to our principal sponsor



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We take our hats off to them

Three years ago, when 25 'old time' hats turned up at an Alzheimers South Canterbury garage sale, president Diane Nutsford had an idea. After gathering another 70 hats to add to the collection, Diane and her team set about recruiting people from all walks of life to wear a hat each for three weeks, with the intention of raising \$200 per hat, through donations and fundraising.



Photo courtesy of Alexia Johnston/High Country Herald

The fundraiser's grand finale was held at Caroline Bay, Timaru with the theme, "On the Bay in Days Gone By". Entertainment included a barbershop chorus, country band, Highland dancing and bagpipes.

Edwardian ladies and gentlemen came dressed in their regalia and a vintage car group joined in festivities. About 40 hat wearers turned up for the event and the three most successful were awarded with prizes sponsored by local businesses.

"We made a profit of \$18,000, which was absolutely fantastic. It is amazing how many people have hats put away in the top of the wardrobe that they will never use. They were pleased to find a use for them," says Alzheimers South Canterbury community liaison officer Karen McKenzie.

The funds raised will go toward a volunteer programme, with some volunteers already recruited amongst the hat wearers.

Advertorial

NEW **CLINICAL TRIAL** FOR **ALZHEIMER'S** INVESTIGATIONAL DRUG IN NEW ZEALAND

New Zealand is taking part in the Concert Study, a global clinical research study with the goal of determining whether the investigational drug dimebon (latrepirdine) improves cognition (thinking and awareness), memory, daily functioning, behaviour, and the ability to care for oneself in patients with Alzheimer's disease who are already taking Aricept® (also known as donepezil HCl tablets).

Trial sites are at the CGM Research Trust at The Princess Margaret Hospital in Christchurch, and The Memory Clinic, Auckland.

Dr Philip Wood, one of New Zealand's leading experts in Alzheimer's disease [AD] and Director of The Memory Clinic, says there is no known cure for AD, however dimebon is one of several hopes for treating the symptoms of the disease and it is important to participate in clinical research.

While the cause of the disease is not known, top risk factors include age and family history and lifestyle issues such as diabetes and high blood pressure.

PLEASE CALL TOLL FREE
0800 222 337
TO FIND OUT MORE.



Dr Philip Wood,
Director, The Memory
Clinic, North Shore
City, Auckland.

"To be eligible, patients need to be diagnosed with the disease [brain scan] and have an assessed score that falls into a prescribed range for thinking and memory. They also need to be currently taking Aricept® (donepezil HCl tablets)."

"The study runs for 12 months and during that time carers will need to accompany patients on regular assessment visits," said Dr Wood.

Aricept® is a registered trademark of Eisai Co., Ltd.

Study has been approved by the Multi-Region Ethics Committee. Ref. No: MEC/09/04/039

Early Memory Management Alzheimers Tauranga

By Jane Moore, Manager Alzheimers Tauranga

Following the visit of Dr Richard Taylor to Tauranga in early May, we have implemented a Memory Management Course specifically for people with early stage dementia.

As Richard spoke so passionately about enabling people to engage in life to the best of their ability, it seemed a great time to launch this project, run in conjunction with the Mental Health Services for Older People Bay of Plenty (MHSOP).

Ten clients with memory loss were encouraged to attend Richard Taylor's seminar. We then invited them to attend an appointment with MHSOP to undertake a mini mental test. We collected those who needed transport and had scones and tea waiting to ensure people felt at ease on arrival. The test results identified seven clients suitable to attend. Diversional therapist, Marcia Rickman started the course in late May. Content covers 'How we remember', 'Finding our way', 'Mood and memory', 'Telephone talk', and 'Confidence in the kitchen.'

As the folk were leaving the first session we heard them say how great it was to know others had similar problems and how nice it was to meet new people.

At the end of the ten weeks we are planning to have a practical session where the group will catch a local bus then shop for and cook a shared lunch. A support group will be established to continue friendships and provide ongoing support and encouragement. On evaluation and review of this pilot we plan to deliver three courses a year.

'It is the quality of our interactions that determines positive outcomes.' (Jane Verity)



Alzheimers Tauranga manager Jane Moore and Richard Taylor

Bringing Dementia into the Public Eye



Dwayne Crombie, CEO Bupa Care Services

Like most attendees at the recent Alzheimers New Zealand conference on dementia, I enjoyed the balance of both the research focus and the practical presentations. However for me the highlight was the panel session involving people with dementia and those providing support to people with dementia. It was very moving to have such human insight into a condition which makes most of us all very uncomfortable. While each person made a very unique contribution, Richard Taylor in particular was truly memorable during this panel. He comes across so well, being very charismatic, engaging and inspiring. If only we could bottle this kind of interaction for the whole community, I am sure it would take us a great deal forward in terms of understanding and support.

Somewhat less inspiring is the struggle to get a national dementia strategy accepted as part and parcel of the government's health strategies and policies in New Zealand, let alone any commitment to implementation. Countries such as Australia, England and more recently Scotland have at least produced something official at government level either as a strategy or a framework. Neither major party in NZ has so far grasped the nettle in any constructive way, nor have we seen the bureaucracy manage anything coordinated either.

I realise it is easy to be a "knocker", but to see the inept and uncoordinated response in planning nationally for a condition which is becoming as important to society as heart disease and cancer hardly inspires confidence. Dementia doesn't have the heart string pull of child health, or the status of cardiology and the surgical disciplines, nor the gravitas of cancer but it strikes at the very essence of what it means to be human.

It is pretty clear that politicians will only respond when they perceive the community thinks an issue is important. Therefore we all have to continue to play our part in making this issue less "unspoken" and something our community wants to front up to and deal with appropriately.



Ageing drivers

With an ageing population, what is the best way to make sure older drivers are safe on the roads?

Alzheimers New Zealand office manager Heather Hind writes about the latest thinking around this controversial topic after attending an AA Driver Education Foundation Senior Drivers' Seminar in early March in Wellington.

Keeping people driving safely for as long as possible is in everyone's best interests, especially with an aging population who need to maintain independence and easy access to support services and social interactions.

Statistics from 2007 report 37 people over the age of 75 died on the road, making up 9% of the total on-road deaths. Older people tend to die in accidents because their bodies are much frailer. It is predicted there will be 61 fatalities (14%) in this age group by 2020. Out of that same age group, 580 people suffered "injury accidents" (non-fatal) in 2007, representing 4% of the total injury accidents.

Currently, drivers who hold New Zealand licences have to re-sit them at ages 75, 80, 82 and every two years after that. Medical certificates are required by a doctor, who will sometimes give their patient the option to sit an on-road safe driving test. To remove a licence from a person medically unfit to drive, the doctor must notify the NZTransport Authority (NZTA) who won't renew the licence.

During an on-road test, an occupational therapist (OT) and a qualified driving instructor will accompany the driver to assess how they get from A to B, where other road users are in relation to the driver, cognitive function and vision.

Older drivers may also have physical difficulties in handling their vehicle.

Useful tools to help overcome these include a wire hoop at the end of a rod to help pull legs onto pedals and handles attached to door frames to assist getting in and out of the vehicle. People may find over the shoulder seatbelts difficult to reach, so attaching a ribbon mid way down may be an easier way to get belted up.

For older drivers diagnosed with dementia, cognitive ability needs to be tested, both in familiar and unfamiliar driving areas. The person must understand the road rules, be able to negotiate heavy traffic, make reasonable decisions in good time, recognise road signs, judge braking times, make appropriate lane choices and be able to navigate. People with dementia may only be able to follow instructions when delivered one at a time, so they will need to be tested for their ability to navigate and pre-plan by giving broad or multi-layered instructions, rather than specifics, such as, "turn left now".

Keeping people driving safely for as long as possible is in everyone's best interests, especially with an aging population needing to maintain independence and easy access to support services and social interactions.

For people with dementia, renewing a licence every two years may not be satisfactory, as cognitive ability can sometimes deteriorate in a short period. For people concerned about their driving ability but who have been signed off to drive by their doctor, the on-road test is an option. You can find out more by contacting the NZTA on 0800 822 422.

The NZTA has also developed a pilot programme which will run throughout 2010 and 2011 to provide resources to assist older drivers. This programme will cover mobility scooters, walking safety and the needs of older drivers.

Disclaimer

The views and guidelines expressed in this article do not necessarily determine whether individuals are safe to drive. If you are concerned about your own driving, or the driving of someone else, please contact your doctor and/or the NZTA. Your local Alzheimers organisation can also provide you with more information: freephone 0800 004 001.

For the NZTA's information sheet on driving and dementia, please go to www.alzheimers.org.nz/resources.



Different Day Care

Day care is a bit different in Singapore, with maids and shopping malls, discovered Alzheimers New Zealand board chairperson Martin Brooks.

My wife Maria and I visited day care centres with Dr Li-Ling Ng, vice chairperson of the Alzheimer's Disease Association Singapore and Theresa Lee, executive director. After going to Li-Ling's favourite restaurant for a real local meal, we visited a secure unit centre for people with advanced dementia, situated in a housing estate complex.

We were impressed by the range of activities available, especially a napkin-making project conducted with great skill, in one case by a woman close to 100 years old. Art and exercise classes were designed to make the best of peoples' skills. We observed a group of young girls taking part and were informed these girls were maids from the families of the people with dementia.

Our next visit was situated in a large shopping mall, which we found intriguing. The owners of the mall set aside a section for community organisations, charging inexpensive rent. The facility was brand new and very well set up. A very enthusiastic (male) activities officer had the whole room, including Maria, taking part in various exercises. Once again, there was a good range of activities for people and an area set up just like a lounge at home.

We were impressed with both centres, especially the one in the shopping mall, which allowed families to drop a person with dementia off while they went shopping and gave the day care participants a chance to visit shops.

Most people in Singapore are looked after at home by family and residential care is not common, so these centres are very important for the care and support of both the person with dementia and their family.



Maria Brooks with Theresa Lee and a supervisor at the centre

Working Together

By Alzheimers New Zealand national director Johan Vos

Alzheimers New Zealand is a proud member of Alzheimers Disease International (ADI), the umbrella organisation of 77 national Alzheimer associations. ADI was established to strengthen the work of these umbrella groups and to raise global awareness. It collaborates with the World Health Organisation (WHO) through most of its six regions. Step by step, all national organisations, with the help of ADI, are working together to have dementia on the WHO agenda. The strength generated from having dementia on the WHO's agenda will have a flow on effect on the strategic direction of governments around the world, as it will inform their own strategies in coping with the disease.

ADI's 2009 World Alzheimer Report shows a staggering 200 percent increase in cases of dementia over the next two decades, culminating in 115 million people worldwide with dementia in 2050. That degree of growth is matched by our own numbers. Calculations from the *Alzheimers New Zealand Dementia Economic Impact Report 2008* (DEIR) report over 40,000 New Zealanders had dementia in that year. By 2050, this number is projected to rise to over 146,000.

Further reports issued by ADI in 2011 and 2012 will further push the WHO and various governments worldwide into setting strategic goals and action plans in order to cope with the rise of dementia and the strain on respective health systems. Given the projected and dramatic increase of dementia in New Zealand, Alzheimers New Zealand has collaborated with the sector to develop a National Dementia Strategy of its own. The first objective of the Strategy calls upon the Government to make dementia a national health priority.

Few diseases currently receive priority; cancer, cardiology and diabetes are on the list at present. Dementia equally deserves to be included in this group, considering how devastating the disease impacts communities and how much it costs this country (\$713 million in 2008, according to the DEIR).

National Alzheimer's organisations in the UK, Scotland and Australia have successfully lobbied their respective governments to make dementia a national health priority, with funding committed to ensure action points are implemented.

Although our Government's May budget increased health spending, this money is mostly tagged. Unless the Government takes dementia seriously, the cost will only get bigger in years to come. And the escalating cost will be paid by all New Zealanders in years to come.

On the road with Richard

In lieu of Richard Taylor's regular column, *Alzheimers News* brings you some photographs from the road trip he and his wife Linda took around the North Island, accompanied by Alzheimers New Zealand board member Nigel Wynn and his wife Tania.



From top to bottom: Linda and Richard enjoy a spectacular New Zealand view; Richard with some new friends at Alzheimers Hasting's Chatham Club; Richard with Tania and Nigel Wynn in Napier

Let It Be Me

Six people will find themselves on a journey with dementia as they rehearse for the New Zealand premiere of *Let It Be Me*, written by Carey Jane Hardy and directed by Anne Corney of Napier Repertory Player's. Cast: Sylvia (Josie Bell), Amy (Megan Pickering), Kate (Andrea Brigden), Trixie (Lorraine Jensen), Gregory (Steve McPherson), Colin (Jude Minor). The play runs from 1 to 10 July 2010. For further information, please contact Anne on (06) 843-9197 or BARRK@xtra.co.nz.

Good Cop, Bad Cop

By Bob DeMarco

If you are a bad cop, you are probably upset all the time by the behaviour of the person in your life with Alzheimer's. If you are a good cop, you have probably learned he or she isn't guilty of a crime.....

I'm thinking back to the beginning, when my mother would just keep eating and eating. She was always hungry. Once I took her out on Easter Sunday to brunch. It was one of those buffet style affairs. They had everything under the sun to eat. I watched in both amazement and horror as my mother, "chowed down".

I couldn't believe my tiny mother was eating more than me. We get home and I am thinking to myself, 'I am so stuffed I don't think I will be able to eat again that day.' It was around 2:30 in the afternoon. I'm sitting in the living room and here comes Mom with a bowl of cereal. I can't remember exactly what I said, but I do know this: bad cop.

Mom didn't remember she ate, and didn't believe me when I told her. She did believe she was hungry. It took a while to understand I could tell Mom she just ate until I turned purple and it wouldn't make any difference. This was long before good cop came on the scene. Bad cop wants to explain. Good cop finally comes to the conclusion that what bad cop is doing won't work.

It is six years later. Mom is still saying, "I'm hungry." It is not unusual for this to happen 15 minutes after she just ate a big meal. Bad cop would say in a rather harsh tone of voice, "you can't be hungry, you just ate." Good cop says in a nice calm low voice, "we ate a little while ago but we are going to eat again soon."

Doesn't work every time, but it usually does. Here is today's message. We are not cops. We are Alzheimer's caregivers.



Bob is the primary caregiver for his mother, Dorothy, and writes the Alzheimers Reading Room blog from Del Ray Beach, Florida. www.alzheimersreadingroom.com

News around the world

Early onset benefits

USA: The Social Security Administration has added early onset Alzheimer's disease to their list of 'compassionate allowances,' meaning people will have faster access to disability benefits without having to go through a lengthy application and appeal process. The Alzheimer's Association of America, who have been lobbying for the disease to be included on the list since 2003, applaud the decision.

"Now, individuals who are dealing with the enormous challenges of Alzheimer's won't also have to endure the financial and emotional toll of a long disability decision process," said President and CEO of the Alzheimer's Association, Harry Johns.

This is me

UK: A new leaflet to assist hospital staff about the needs of patients with dementia has been developed by a group of carers in England's North East and launched by the Alzheimer's Society. 'This is Me' provides information such as family background, what the person likes to be called, what they like to eat or drink and what may make them agitated or relaxed. The incentive has also been supported by the Royal College of Nursing. It was created in response to the UK Government's 'Counting the Cost' report, which found a large variation in quality of care for people with dementia in hospitals. This report also revealed 89% of nurses found it challenging to work with people with dementia.

Matron Aileen Beatty, leader of the trial, says the leaflet has helped her immensely. "When we know a little bit more about the person we are in a much better position to care for them and improve their stay in hospital." Alzheimers New Zealand has a 'Personal Care' booklet, written by family members, which covers personal history, interests and medical information. It can be purchased from Alzheimers New Zealand's national office or any Alzheimers member organisation for \$10.70 inc GST.

Sign language tools

UK: Research funded by the Alzheimer's Society through the University of Manchester is exploring the needs of deaf people with dementia who use British Sign Language (BSL).

The research hopes to improve care and support services for deaf people with dementia and their carers as well as improve the rate of early diagnosis through specially-created assessment tools in BSL.

"Our assumptions about what might be valued in care and support are based on hearing people's preferences, not rooted in an understanding of deaf people's cultural experiences. Information about dementia and related services does not exist in deaf people's preferred or only language," said lead researcher.

About 50,000 to 60,000 people in the UK use BSL to communicate.

First care centre in Delhi

India: The first day care centre for people with Alzheimer's disease will open in New Delhi. Currently, New Delhi, with a population of over 3 million people, has neither specialist residential care centres for people with dementia, nor day care centres, according to Indian Finance Minister A.K. Walia, who said the government would provide the land to build the centre. Six million people in Indian have dementia.

"Delhi, which has a number of good hospitals, should also take steps to provide a solution to the problem of Alzheimer's disease as well. With greater life expectancy, the cases of dementia will also increase, in these circumstances Delhi needs an Alzheimer's day-care centre," said Walia.



Review

The Selfish Pig's Guide to Caring

By Hugh Marriott

Reviewed by Vivienne Boyd

Pigs and piglets? What is their connection with the book's subtitle: *How to cope with the emotional and practical aspects of caring for someone?*

In the words of the author: 'I didn't write this book because I'm a trained journalist. I wrote it because I'm an untrained carer' (p11).

Later in the book he says, 'What I'm trying to do... is to face up fair and square to all the big matters that affect carers, without getting bogged down in the marshland of political or religious correctness...' (p145). And he does that, writing about significant topics including stress, sex and abuse, from his perspective of a husband who has cared for his wife (who has Huntington's disease) for many years.

Who are the pigs? Those of us who have come reluctantly to caring. And piglets? 'Person I Give Love and Endless Therapy to'.

In his view, for both parties, the disability is something they share. 'I know that the piglet is the one who has it, clinically speaking; but it's affected you nearly as much. Perhaps just as much, although in a different way. It isn't your piglet who has wrought the cataclysmic change in your life. It's the disability' (p331).

This book has many suggestions and tips to help carers care more for themselves. It also gives a great insight to paid carers and other readers about the day to day difficulties family carers face, both at home and in their contact with 'officialdom,' including individuals and organisations funded by or answerable to government.



Our regular reviewer Vivienne Boyd has a background in adult education. She is currently the 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.

Why Are We Here?

That is the question Alzheimers Marlborough asks itself after 21 years, moving from the first minutes of what was then an ADARDS (Alzheimer's Disease and Related Disorders Society) meeting in 1987, to the opening of the purpose-built day care centre in Wither Road, Blenheim in January 2009.

Local writer Cynthia Brooks has detailed the journey in a book called "Why are we here?" gathering the stories of supporters, staff, volunteers and clients over the last two decades. The book contains a wealth of fantastic photographs and anecdotes and shows the level of community support, passion, commitment and fun Alzheimers Marlborough has enjoyed.

"Cynthia researched intensively, reading all the minutes of our meetings since day one, resulting in a very comprehensive history. These moving stories are told with a great deal of sensitivity, and may be of help in the future to families starting down the track of Alzheimer's disease. This is a wonderful informative read. We recommend this book to all people, whether or not they are involved with dementia," says office manager of Alzheimers Marlborough, Linley Wetton.

Cynthia Brooks was nominated for the Kiwibank New Zealander of the Year award for her work in telling Alzheimers Marlborough's story and received a certificate of achievement for her efforts. Copies of this book can be purchased by contacting alzheimersmarlb@xtra.co.nz.



Carers and volunteers from 1989



Kids from Mayfair School with their Cuppa for a Cause cup in 1997

Web 2.0

Are family members and friends constantly “Twittering” or telling you they’ve “be-friended” someone through Facebook?

You may be one of the 1.5 million people in New Zealand who already have a Facebook account, but for those who are new to the idea, Facebook is an online, social networking site which lets you connect with others by posting messages, conversing, responding to news items and posting photographs and videos.

For the dementia community, it’s an addition to the traditional method of information, interaction and support found in support groups, meetings, newsletters, internet research and through the media.



Alzheimer's Society UK's Dementia Awareness Week's 'Remember the Person' campaign on YouTube

Before Facebook, New Zealanders affected by dementia were already members of the virtual world through the Dementia Advocacy Support Network, which hosts chat rooms, newsfeeds and blogs. The Alzheimer's Society UK also hosts 'Talking Point', an online forum connecting people and providing information and support. Alzheimers New Zealand's Facebook page aims to do the same thing. In time, we hope to see people blogging and using Facebook's discussion facility to start talking about key issues.

It's also a great way to see what is going on in the multi-media world of dementia. How many of you have seen the latest Alzheimer's Society UK's campaign, featuring John, a man who dresses like a woman or West Indies national and former pole vaulter Philip? We now have this information at our fingertips on YouTube, which is conveniently linked to Facebook.

Media coverage around Alzheimer's disease and dementia in New Zealand is also linked to the Facebook page, so there's no longer the need to pick up the paper to know what's going on.

If you are not already a fan, please go to www.facebook.com/alzheimersnewszealand to make friends and contribute to the community.

How to...

Becoming a fan of Alzheimers New Zealand on Facebook requires setting up a profile page (go to www.facebook.com and follow the 'sign up' instructions) and then go to www.facebook.com/alzheimersnewszealand (or search "Alzheimers New Zealand") and click on the "Like" button, which will make you a fan.

From there, you can post whatever is on your mind or upload photographs which all other fans will be able to see. When you become a fan of a page, updates from that page will appear in your news feed.



Links

- www.dasninternational.org
- <http://forum.alzheimers.org.uk/>
- www.youtube.com/user/AlzheimersSociety

If you would like any help around getting onto Facebook, or anything else about online media and social networking, please contact cass.alexander@alzheimers.org.nz

Research Grants for 2010

The Alzheimers New Zealand Charitable Trust is solely dedicated to dementia research. Its primary objective is to support individuals and organisations who provide medical and social research for the benefit of people, directly or indirectly, affected by dementia.

The Trust's first funding round for research grants was held in 2009 and the outcomes of these are below:

Medical Research Category

Matthew Croucher, Susan Gee, Margaret Francis, Rachael Beever and Gillian Bastion received a grant of \$6303 in the medical research category for the project, 'A settling effect at a difficult time of day? Short term effects of Tai Chi in an inpatient psychogeriatric ward.'

Prof John Miller and Viswanath Das received a grant of \$8500 for, 'The effect of peloruside and other microtubule stabilising agents on microtubule regulating proteins: Role in neurodegenerative diseases.'

Social Research Category

Dr Gary Cheung, Dr Richard Worrall, Dr Olivia Lee, Wendy Wright, Ester Wallace and Dr Carole Adamson received a grant of \$9750 for the study, 'Driving assessment and beyond - An observational study.'

New research grants and calls for small project grant applications 2010

In 2010 up to \$15,000 is available for research focussing on the medical and social aspects of dementia. Any relevant topic will be considered. Closing date for applications is Friday 27 August 2010. Applicants should follow the information provided in the document "Small Project Grants" available at www.alzheimersresearch.org.nz.



Research

Sense of purpose

In an *Archives of General Psychiatry* study, more than 900 people over the age of 80 had their personalities assessed to find a link between sense of purpose and developing Alzheimer's disease. Participants who felt good about past and future achievements and who had direction and purpose in life were less likely to develop the disease.

It is not yet known how a sense of purpose contributes to a reduction of risk of Alzheimer's disease, but lead researcher Dr Patricia Boyle says, "purpose in life is an indicator of human thriving that has long been hypothesised to buffer against adverse health outcomes." She says further research is needed in order to find interventions and treatments in order to enhance health and wellbeing in older people.



Fronto-temporal gene

A new gene linked to fronto-temporal dementia, more common in those under 65 years and which causes personality changes, has been discovered by a team of international scientists. Mutations in the chromosome 7 gene affected half of the people studied and its presence appears to speed up the progression of the disease. More understanding of the gene was required but scientists said their research could lead to future treatment.

Dementia carers more at risk

A 12-year study of 1,221 elderly couples from Utah, USA found carers whose partners developed dementia were six times more likely to develop the disease themselves. "The distress of watching one's spouse suffer from dementia and the physical and mental burden of providing dementia care are potential factors," said researchers, who also took into account factors such as socioeconomic status.

They said the chronic stress involved in caring may harm the hippocampus, the section of the brain responsible for memory. The research, which needs to be investigated further to develop interventions, was published in the May edition of the *Journal of the American Geriatrics Society*.



Computer test

A new computerised "fitness" test for the brain, developed at the University of Tennessee, is reported to be 95 per cent effective in detecting Alzheimer's disease and other forms of cognitive problems. Other diagnostic tests currently in use are reported to have only 69 to 71 percent accuracy. Developers say 60 per cent of cases of the disease are not picked up in a primary care setting, leading to missed opportunities for early diagnosis. You can trial the test at www.alzselftest.com.

Men's hormone linked to poor memory

The level of a particular sex hormone in older men can lead to poor memory, including Alzheimer's disease, according to an Australian study, which found men with higher levels of luteinising hormone (LH), led to poorer performance in memory tests compared to those with normal levels. The research was undertaken as part of the Health in Men Study, which has followed 12,000 men over the age of 65 since 1996. Although more research was needed into LH and older men, researchers said there was potential in developing drug treatments in future.

Better design

Researchers at Kingston University hope to set a blueprint for future layout of dementia care facilities. Aspects of good design included single-storied homes in villages to establish community; accessible gardens, visitor and child friendliness and the inclusion of everyday and stimulating activities for residents. "People who have been moved to a more stimulating home have shown significant improvement in their physical or mental condition that was not directly attributable to greater luxury or more staff," said lead researcher Professor Hilary Dalke.



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...sometimes my Nan
does strange
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Tamati, 6



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