



Alzheimer's News

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The elderly guide the young



He whakaruruhau nga kaumatua mo nga rangatahi
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Alzheimers News

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I believe if this does come to fruition, it will encourage people to get an earlier diagnosis, which in turn will allow them to get their lives in order and hopefully give them strength to speak out and lower the stigma associated with this terminal illness."

Johan Vos, Alzheimers New Zealand's national director, writes about the importance of lobbying and its potential for change, on page 9.

Alzheimer's disease at World Economic Forum

Alzheimer's disease was on the agenda for the first time ever at the World Economic Forum (WEF), held in Davos, Switzerland in January. WEF panel moderator and CEO of the International Longevity Center, Dr. Robert N. Butler, told the panel that rapid increase in Alzheimer's disease is creating significant economic, social and personal problems and urged government, corporations and community representatives to act. President and general manager of Pfizer's primary care business unit, Olivier Brandicourt said Alzheimer's disease "presents a challenge on the scale of HIV/AIDS, an area in which we can take lessons from the global community approach."

He said the WEF panel provided the opportunity to find partners to work across sectors, industries and borders to give a voice to people who suffer from Alzheimer's disease and to curb its devastating effects. Executive director of Alzheimer's Disease International, Marc Wortmann, told the panel that research for better treatment must be supported and funding for dementia care must be increased.

"Unchecked, dementia and Alzheimer's will impose enormous burdens on individuals, families, health care infrastructures, industry and the worldwide economy," he said.

Alzheimers New Zealand is one of 71 members of Alzheimer's Disease International. Worldwide, 35.6 million people have dementia and these numbers are projected to double every 20 years.



News

PHARMAC looks at medication subsidy

In late January this year PHARMAC, the government's pharmaceutical management agency, proposed to subsidise a generic version of the dementia medication donepezil hydrochloride.

If the subsidy goes ahead, a three month prescription for a 10mg dose will cost \$14.06, as opposed the current cost of approximately \$120- \$200 per month. PHARMAC propose to fund Donepezil-Rex, produced by a generic pharmaceutical company based in India. It will make a decision around April this year following public consultation.

Although the decision to fund this medication is not guaranteed, the proposal signifies a major step for people with dementia, their whānau and community. Former Alzheimers New Zealand chairperson and current board member, Eileen Smith was moved when she read the proposal. "This will be a huge achievement for those of us who have spoken out for years for these types of drugs to be funded."

Libby's gift

As a tribute to her daughter Elizabeth (Libby), Auckland artist Agnes Wood, 89, donated a painting to the University of Auckland's Centre for Brain Research following its official opening in November last year.

Libby died in 2007 from early-onset Alzheimer's disease in her mid-50s. She donated her brain to the Neurological Foundation of New Zealand's Human Brain Bank, run by Professor Richard Faull, who also directs the Centre for Brain Research.

As a registered nurse, Agnes says Libby had an insight into what was happening to her.

"She knew what (the progression of the disease) meant, and faced up to that, which was tremendously brave. As a very loving family we all kept very close to her and we saw what a dreadful illness it is."

Libby was the nurse in charge of the instruments doctors use in the operating theatre. "Her first symptoms were getting the sets of instruments muddled. When that started it was terribly revealing. She was also very well-aware of other symptoms in her brain."

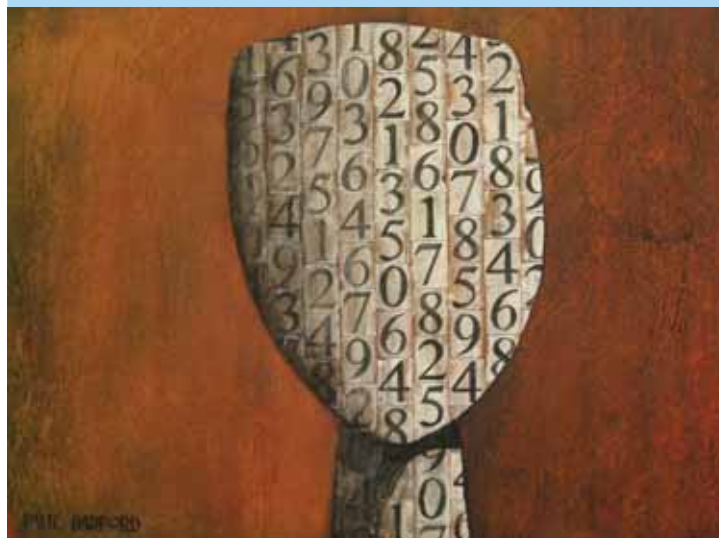
Libby sat down with her husband after her diagnosis and wrote a letter to the Neurological Foundation of New Zealand's Human Brain Bank, saying she wished to donate her brain to science.

Donated brain tissue like Libby's helps Richard and his team learn more about diseases such as Alzheimer's, Huntington's, Parkinson's, motor neurone disease, multiple sclerosis and muscular dystrophy.



Director of the Centre for Brain Research Professor Richard Faull, Agnes' son-in-law Derek Smith, Agnes Wood and her son her Chris Wood

"I made it my mission to support whatever is going to help combat dreadful brain diseases and help as much as I can with Professor Faull and his amazing brain organisation. An awful lot has to be done, and it's ongoing."



The donated painting, 'Archaic Greek Head' by Elam School of Fine Arts graduate Paul Radford, hangs on the wall of the Centre.

Professor Faull first saw the painting at the Remuera Gallery at the opening of an exhibition of Agnes' work, which coincided with her 88th birthday celebrations.

"We were talking in the gallery and Richard's eyes went to this painting and I said, 'what do you think of it?' and he said it was quite amazing, as it is a painting of a head filled with activity and he is so deeply involved with that sort of work," says Agnes.

Agnes is also a graduate of Elam and has been painting and teaching for 50 years. She trained under Colin McCahon and wrote a book about him in 1997 called *Colin McCahon: the man and the painter*.

Agnes says she and her family live with the impact of Alzheimer's disease every day.

"I made it my own mission to support whatever is going to help combat dreadful brain diseases and help as much as I can with Professor Faull and his amazing brain organisation. An awful lot has to be done, and it's ongoing."

Libby would have been very pleased of it all, I am quite sure. It's a wonderful painting. It's certainly had a very good reception."



Graham Camfield thought forgetting the names of people and locations was due to work-related stress at his school principal's job until a brain scan revealed he had semantic dementia at age 59. Three years on, Graham, who lives in Christchurch, is the second person with dementia on the Alzheimers New Zealand national board and brings to the role 40 years' knowledge of the education system.

Semantic dementia is a rare form of dementia, where shrinkage of the temporal lobes lead to progressive loss of the meaning of words, objects and faces.

"Knowing the type of dementia I have has helped me understand why my memory acted as it did. It explained why I confused courgettes and cucumbers and when I went out walking I would call a native wood pigeon a flying Kiwi!" says Graham.

He hopes his experience in the education sector will assist the organisation and his experience with dementia will be another facet to the board's strategy.

Graham has taught at a variety of levels, within eight schools. From 1972, when he was 24, he ran the Campbell Island Weather station (located 700 kilometres south of the South Island.)

On his return he became a relief teacher prior to restoring a permanent teaching position.

His initial involvement in Alzheimers New Zealand came when he attended a gathering in Christchurch about brain stimulation. From there he became a board member for Alzheimers Canterbury.

Graham says early diagnosis was paramount in helping manage the disease. He was given a list of suggestions from health professionals for keeping his brain active.

"Each day one needs to carry out activities, such as reading, doing crossword puzzles or games such as Sudoku, visiting interesting locations such as the museum, art galleries and going to events. For those such as myself who have utilised technology in the past, sustaining access to computer programmes can assist."

Currently, Graham participates in a variety of brain gym activities and is working with two research teams to determine needs and potential for programmes for people with a similar diagnosis.

"Dementia is like life: it never goes down a straight path for an individual or a family. I am currently following twists which were not planned for my future. It has been an interesting and challenging change."

Thanks to Alzheimers Canterbury for the use of excerpts from their article Just for You, which appeared in the September 2008 edition of their newsletter.

FreshChoice and SuperValue customers give generously

During November and December last year FreshChoice and SuperValue supermarkets raised money for Alzheimers New Zealand through coin collection boxes at their checkouts. Generous customers gave \$8,496 toward resources to help people affected by dementia.

The coin collection boxes are a great way to help worthwhile organisations in New Zealand, said FreshChoice and SuperValue Supermarkets marketing manager, Phil Power. "Alzheimers New Zealand was chosen by our owners and operators as a charity we wanted to support because of the worthwhile work the organisation does in our community."



Phil Power presents the cheque to Martin Brooks

Gene Genie

Sarah Lee's father Ray was diagnosed with early onset dementia in 2000 when he was 54. In mid 2009 Sarah was approached by TV3 current affairs programme 60 Minutes to participate in a story about genetic testing. Sarah tells Alzheimers News about her experience.

“Seeing my dad’s life change so dramatically due to Alzheimer’s disease and becoming a shell of the person he once was made me think, ‘is this something that could happen to me?’

After some discussion with my immediate family I agreed to take part in the programme. I believe my mind was already made up at the initial suggestion, but I wanted to make sure a support network was there. This was an opportunity for me to highlight this disease and its devastating effects; something Dad was always trying to do when he was able.

When the day of filming and testing came, we did some great footage with Dad before completing the test and interview. I was a bundle of nerves; not because of the test but because my story was about to go nationwide. My interview went well. The crew from 60 Minutes are an awesome bunch of people.

I had to fill a test tube with a certain amount of saliva, not including bubbles. When you are nervous it takes a while to do this. Once my forms were filled in, my saliva winged its way to America for testing.

Two weeks passed and my results were ready. I was introduced to a genetic counsellor from Navigenics via Skype to discuss the results and any questions or concerns I had. Nervous anticipation surrounded me that day.

My result showed my risk of prevalence for Alzheimer’s disease was extremely high. This didn’t come as much of a surprise to me, but it did indicate I was carrying two DNA markers for Alzheimer’s from both sides of the family, which I think came as a surprise to Mum. In saying all this, the counsellor was very quick to point out that whilst I may be predisposed to Alzheimer’s disease, it does not mean I am going to get it.

The key thing that I took away from this adventure is that DNA is not your destiny. In other words: we can do things in life which allow us to manage the “environmental” side of our lives, such as managing stress levels, exercising and eating healthily, all which decrease the change of developing Alzheimer’s disease.

I hope this programme has increased awareness, in particular of early on-set Alzheimer’s disease.



Sarah with her father Ray and her mother Eileen in a still from the 60 Minutes programme

So here I am now, nearly six months down the track. The reaction I received from doing the piece has been completely positive. Most people have said I was brave.

What has been incredible is the response from friends who have known Dad for a long time but haven’t seen him since his decline. They were shocked but there was also a greater understanding toward us as a family and the challenges we face on a regular basis. I have also undertaken some lifestyle changes personally, especially to reduce my stress levels.

Genetic facts

- Genetic testing for Alzheimer’s disease is not readily available in New Zealand. US company Navigenics tested Sarah for the presence of the APOE gene, which indicates a higher risk for the development of Alzheimer’s disease.
- The link between the presence of the APOE gene in a person’s genetic makeup and a future diagnosis of Alzheimer’s disease is inconclusive.
- Although children of parents who develop early on-set dementia have a higher risk of developing dementia, the Navigenics test Sarah took did not test for early-onset and only showed her at risk of Alzheimer’s disease after the age of 65.

Fun, free, brainy

Want to know more about how your brain works and meet the scientists and clinicians behind the latest neurological research? The University of Auckland's Centre for Brain Research holds its 'Brain Day' on Saturday 20 March. This event is part of International Brain Week, a global campaign to increase public awareness around the development and importance of brain research. Two seminars will take place every hour throughout the day.

There will also be hands-on experiments which anyone can participate in. Alzheimers New Zealand is a community partner to the Centre for Brain Research and staff will be present on the day if people want to know more about support available in the Auckland area.

"Alzheimers Counties Manukau is absolutely delighted the University of Auckland's Medical School has initiated the Centre for Brain Research and that internationally renown researcher Dr Richard Faull is the head of the Centre.

Alzheimers Counties Manukau is proud to be a community partner with such an illustrious Centre," says manager, Pat Durey, Alzheimers Auckland will have a stand on the day and clinical services manager Mary Lythe will present 20 minute sessions on issues for carers.

Sniffing out dementia

By Richard Taylor

"I know dementia when I see it," several neurologists have said to me.

One of them even told me he could diagnose Alzheimer's disease while sitting across the hall in his office and could only see a patient through a crack in the door. He made this claim because he said most folks who came to him for a diagnosis were so deep into their symptoms, it did not take a member of the college of neurologists to make a diagnosis.

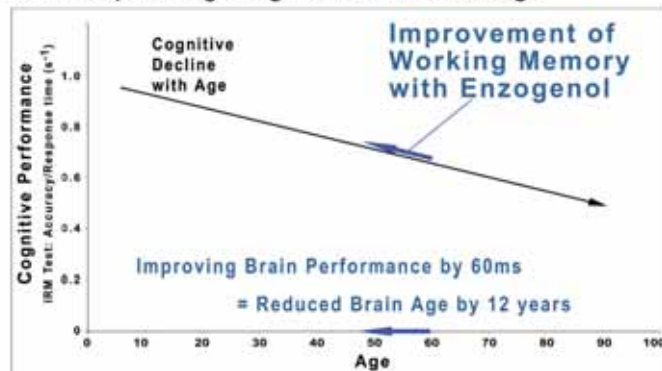
Dementia is a matter of degrees. It is not black and white. The issues for folks who have fading cognitive skills are not "what kind?" as opposed to "what can I do now?" Yes, there is some value in knowing what type of dementia you "probably" have, so you can be prepared for the symptoms, progression and severity of the that particular form.

Free Product Trial

Individuals, Carers, Nurses, Health Professionals - please contact us to participate in our free product trial.



Research evidence suggests that Enzogenol is a promising nutritional to support brain function and to help manage cognitive decline with age.



A clinical study in older men that were at risk of cognitive decline with age at the Brain Sciences Institute of Swinburne University in Melbourne showed improved brain performance equivalent to a reduction in brain age of 12 years after only 5 weeks on Enzo Professional. (4 caps/day = 960 mg Enzogenol).

Please contact:
Gary Furniss, ND, gary@cthealth.net.nz
ph 09 534 4758, mob 022 621 8870
Enzo Nutraceuticals Ltd, Auckland, NZ
www.enzoprofessional.com

But the most useful information from a doctor is the answers to personalised questions such as:

- What types of people should my family and I be surrounded by to enable me to continue to live a purpose-filled life?
- How will you manage and support my family and I?
- How do you support other patients with my diagnosis?
- How fast do you think the symptoms of my dementia will progress?
- How to you manage stress in caregivers of individuals with my diagnosis?

When you visit your doctor, make up your own list and bring it with you. Write down answers.

If the answers do not satisfy you, tell your doctor. If you are still dissatisfied, you can change doctors. Bear in mind, no doctor has all the answers you want, but stand up and speak out. You are the consumer.

www.richardtaylorphd.com

News around the world

Australia

A new online guide has been developed to help Australians with early onset dementia, their family and friends as well as those who think they may have symptoms of the disease. The guide, *Younger Onset Dementia: A Practical Guide* aims to provide information for people with dementia under the age of 65. This includes assistance on financial and legal issues, guidelines for diagnosis and advice about how early onset dementia can affect relationships, sexuality, driving and employment. The guide was produced by the Prince of Wales Medical Research Institute (POWMRI) and based on 20 years of research. "This is a collection of information especially directed to patients and families with young onset dementia. Before this publication people would have to rely on different bits of information from different agencies, which was overwhelming and confusing," says POWMRI Professor John Hodges who leads the Frontotemporal Dementia Research Group. To read the guide, please go to <http://tinyurl.com/y16ao7x>.



United Kingdom

Talk show host Michael Parkinson spent 2009 as a dignity ambassador for the UK government's 'Dignity in Care' campaign. The job entailed raising awareness to ensure older people in care are respected and treated with dignity as well as to promote the way older people are perceived. Parkinson visited a series of UK hospitals during the year, spoke with staff and shared examples of positive care programmes and leadership. Parkinson was aware of the UK's National Health Service, having spent the last two years looking after his mother, who died with dementia. You can read Parkinson's full report at <http://tiny.cc/YtTF4>.

USA

In *Alzheimers News'* December 2009 edition, the story *American Football risks* focussed on an inaugural study by the USA's National Football League (NFL) which suggested the rate of dementia for ex-America Football players was five times higher than that of nonplayers. Now, the NFL is encouraging all current and retired footballers to participate in brain research. The NFL is to give the Centre for the Study of Traumatic Encephalopathy at Boston University's School of Medicine US\$1 million toward this research. Previously, the NFL had denied a connection between concussions due to playing American Football and the incidences of dementia. Two new rules have also recently been applied to the game; firstly, an independent specialist outside of the NFL will determine if a player has concussion and whether or not they are cleared to play and secondly, any player with symptoms of concussion cannot resume playing in the same day.



The NFL will give Boston University US\$1 million toward reserach after a study earlier this year made the link between American Football related concussions and dementia.

Reviews

Connecting through music with people with dementia

by Robin Rio

Reviewed by Jeanine Campbell, diversional therapist, Christchurch

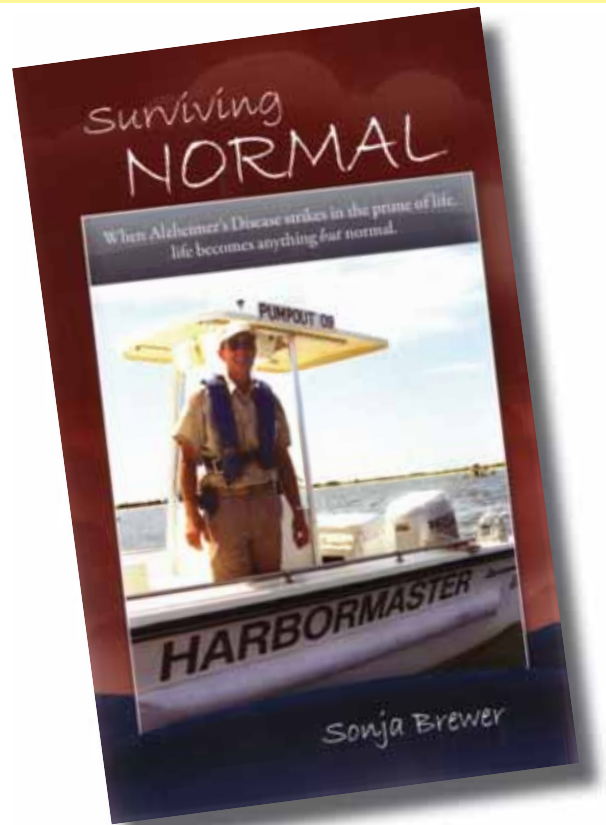
Author Robin Rio is Associate Professor of Music at Arizona State University. In this informative and easy to read book Robin emphasises the fact most people with dementia go back to music they remember when they were in their early adult years.

Throughout the book she writes about how to make a rhythm using percussion instruments, shakers and chimes and discusses ways to utilise movement using music.

Robin writes about how a person can become comfortable with their own voice and how to choose and sing appropriate songs. She suggests beginning with familiar songs such as *You are my sunshine* or *Happy birthday*.

Repeating songs which the person with dementia is interested in is emphasised, as is making up your own words to a specific tune if the person you are working with has attached themselves to one.

There are chapters with clear steps on how to structure your music sessions, including the value of an opening and closing song for each session to maintain structure. There is also a selection of common songs to start off with as well as suggestions for exercise sessions. This book would be valuable reading for anyone working with people with dementia.



Surviving normal

By Sonja Brewer

Reviewed by Vivienne Boyd, education coordinator, Alzheimers Canterbury

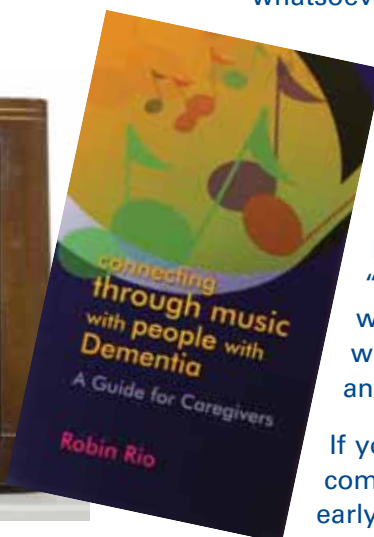
American woman Sonja Brewer's husband David was diagnosed with Alzheimer's disease at the age of 52. This book is Sonja's year-by-year journal of the seven years until David's death.

Sonja expresses her reflections, thoughts and feelings very candidly. During year one of David's disease she writes, "it is hard living with someone who has absolutely no thought or care about you whatsoever."

During year three she writes, "What I'm really feeling is that I am not up to this task of being a caregiver. I like order and logic. I certainly don't like Alzheimer's disease."

Reflecting in year five she acknowledges, "I certainly wasn't thinking about a book when I started this. But I am now. I know it will help others. I hope that it's not too sad and too depressing to help others."

If you are seeking a greater insight about the complexities and challenges which come with early onset dementia, this personal account provides that opportunity.



Most people with dementia go back to music they remember when they were in their early adult years.



Real, tangible change

Alzheimers New Zealand national director Johan Vos writes about how lobbying can bring about real change in the community and touches on government pharmaceutical management agency, PHARMAC's recent proposal to fund a dementia medication.

One of Alzheimers New Zealand key roles is to lobby and advocate local and national issues. Our advocacy not only relates to our work, but the work done throughout the entire spectrum of organisations and individuals who provide services to New Zealanders affected by dementia. This includes specialists, health care workers, residential care providers, community-based organisations and government.

On a local level, our advocacy focuses on issues affecting people with dementia and carers in their community, such as securing services and entitlements, or if these already exist, ensuring they are of the highest quality.

On a national level, Alzheimers New Zealand lobbies the government for policy change and advocates increased funding of the sector. As a leading and respected charitable organisation, our lobbying is based on what is best for all affected by dementia and we have the experience, knowledge and compassion required to represent and work for this group.

In 2008, Alzheimers New Zealand commissioned the Dementia Economic Impact Report to provide authoritative data to substantiate the costs and prevalence of dementia. This report has been fundamental in driving key messages, emphasising current statistics and ensuring the public are aware of the drastic increase in numbers of people with dementia projected in the coming decades.

One of our key advocacy platforms is to have dementia medication funded so it is accessible to all. After six months of lobbying PHARMAC for funding of cholinesterase inhibitor medications for people with dementia we finally received encouraging news on its intention to fund a generic version of the medication for people with dementia, Donepezil-Rex. A final decision is expected this month. If the proposal goes ahead, the cost of a 10mg dosage will decrease from \$120-200 per month to \$14.06 for a three-month supply.

This is a huge win for Alzheimers New Zealand and all those affected by this devastating disease, today and in the future. This is around 97% reduction in cost! It goes to show how effective lobbying produces tangible change for individuals and families.

Another lobbying platform is our National Dementia Strategy. Alzheimers New Zealand is currently consulting internally and externally for feedback. It will be presented formally at a Parliamentary function in Wellington on 6 May 2010 as part of our People, Policy, Partnerships Conference 2010.

The anticipated outcome is for government to recognise the sector-wide leadership and the recommendations of Alzheimers New Zealand in order to face the dramatic rise in dementia expected in the future and to put actions in place to best care for these people and their families and whānau.

In turn, we hope this strategy will help dementia become a national health priority and will improve delivery of health care services and intervention through early diagnosis.



National Dementia Strategy

For more information on our National Dementia Strategy, please contact Cass Alexander, communications advisor, on 04 381 23 63, 027 619 1911 or cass.alexander@alzheimers.org.nz.

The anticipated outcome of the National Dementia Strategy is for government to face the dramatic rise in dementia expected in the future and to put actions in place to best care for these people and their families and whānau

The elderly guide the young

*He whakaruruhau nga kaumatua mo nga rangatahi
- Maori proverb*

Young people can support the lives of their kaumatua and reduce the stigma of dementia, says Martin Brooks.

“Why doesn’t he speak?”

This question came from my five-year-old granddaughter, Ruby, when visiting my father at his rest home. This got me thinking about the effect dementia has not only on those of us directly involved, but also on the wider family.

Think of the loss grandchildren or great-grandchildren face when a grandparent is affected by dementia. There is the loss of life experience passed on by their elders. For example the question, “What was life like when you were young?” may not be able to be answered.

There is also the loss of family connections; “Who are those people in the photographs?” the grandchild may ask. Countless memories are lost for the coming generation.

Dementia is perceived as a disease which affects the elderly, but as we have said many times, it goes much deeper than that. How many children in New Zealand are in a similar situation to Ruby?

One of the things people involved with dementia care can do is encourage younger people to get involved in the lives of people with dementia.

A portrait of Martin’s dad Fred when he was in the army



This involvement could be a visit to someone like my father, or a more formal arrangement such as a school having an involvement with a rest home.

Just because someone with dementia may not be able to tell a story from A to Z, or forget who or what they are speaking about, doesn’t mean they don’t appreciate company.

Just the simple joy in my father’s face when a five-year-old sits with him makes a visit so worthwhile. These kinds of visits and support help reduce the stigma and embarrassment attached to dementia. It also educates the younger population about the disease and shows them people with dementia are not to be feared. Children especially are so adaptable and often take a person at face value. It is adults who tend to put blocks in the way by being overprotective. I speak of my own extended family experience here but I am sure my situation is not unique.

If you know of younger people who could take part in visiting people, start to involve them and begin their education process. I am convinced this will help to make life better for everyone affected by dementia.

A photo taken in Egypt during WW2 with Fred on the right



Martin is the Alzheimers New Zealand board chairperson. He cared for his great uncle Wally in his home in Christchurch. This began his involvement in dementia care and advocacy. Martin’s father, Fred has dementia and is in full-time care.

Fact File

Binswanger's disease

Binswanger's disease, also known as subcortical vascular dementia, is caused by the thickening and narrowing of arteries in subcortical areas of the brain. Blood supplied to these arteries decreases, resulting in the death of brain cells which causes a series of cognitive issues such as short-term memory loss, trouble with organisation, changes in mood and attention span, the inability to make decisions and inappropriate behaviour.

The most common feature of Binswanger's disease is 'psychomotor slowness', an increase in the time it takes for the brain to conduct an activity. The forgetfulness associated with Binswanger's disease is not as severe as that associated with Alzheimer's disease. However, changes to mood associated to this disease can cause feelings of apathy, depression and irritability. Those with symptoms of depression associated with Binswanger's disease may be prescribed antidepressants by their doctor. Changes in behaviour and cognitive ability in those with Binswanger's disease may be sudden, or may progress slowly.

This disease usually occurs in people in their forties onwards and can be diagnosed through a CT scan or magnetic resonance imaging, both which reveal damaged brain cells. Managing high blood pressure and diabetes and getting enough sleep are ways to slow the progress of the disease.

A 2002 study from Germany, published in the journal *Cerebrovascular Diseases*, revealed the medication memantine, which prevents excess entry of calcium ions into brain cells, can be effective in treating Binswanger's disease by improving cognitive function. Memantine (marketed under the brand name Ebixa in New Zealand), is not subsidised by PHARMAC.

Like other dementias, high blood pressure, diabetes and smoking are all risk factors for Binswanger's disease. Controlling these factors as soon as possible by exercising, eating a healthy diet and getting regular check-ups will help minimise your risk.

Swiss psychiatrist and neurologist Otto Binswanger discovered this disease in 1894.

Welcome to the Alzheimer's World

By Bob DeMarco

How do you react when someone suffering from Alzheimer's disease says something you know is incorrect or untrue? What are you feeling when this happens? Do you constantly correct them?

If you do, you are "cruising for a bruising". Say hello to your new found friends, anger, stress and angst. Do you really want to befriend anger, stress and angst? Sooner or later you must make a decision.

You need to start accepting that when a person with Alzheimer's disease says something they believe to be true, this is their reality.

Welcome to the Alzheimer's World. Don't be afraid or reluctant to step into this new and very different world. In Alzheimer's World, reality takes on a different shape. It is a reflection of what the person with Alzheimer's thinks and believes. It is this reality you must focus on, not the way YOU think things are or should be. I am asking you to develop a frame of reference; a new and different behaviour one hundred percent diametrically opposed to the way you usually think and act, and the way you have done so your entire life. Whew. This isn't easy. It could be one of the hardest things you have ever tried to accomplish.

Here is the bad news. Even though, as the main carer for my mother, I was well aware of what I needed to accomplish and I tried as hard as I could, it still took years to get and comfortable with Alzheimer's World. Once I made it there, I reaped rewards almost impossible to imagine or describe.

Find out more about how Bob stepped into the Alzheimer's world by reading the full article at www.tiny.cc/JLzzy. This is an excerpt from the Alzheimers Reading Room. www.alzheimersreadingroom.com.



Where does my money go?

In the wake of the global recession, many people are starting to ask questions about the value of their dollar. Am I getting value for money? Is that a fair price? And in the case of donations to charitable organisations: where does my money go?

So Alzheimers News approached Alzheimers New Zealand's marketing and fundraising manager Anthea Armstrong to help answer your questions.

Alzheimers New Zealand actively fundraises through various methods throughout the year. This could be a nationwide, week-long appeal or a sausage sizzle outside a local library and everything in between. All funds raised are vital for the organisation to continue our good work. Staff who manage local fundraising are often also those who deliver local services. In this case, all money raised is spent locally. This includes employment of staff, administrative support, overheads and printing. Funds raised nationally provide benefits across the entire organisation; funding our resources, advocacy work and information services such as our website.

Alzheimers New Zealand and our 23 local organisations enjoy 'charitable status' under the Charities Commission, which was established in 2007 as a crown entity. One of its mandates is to provide trust and confidence in the sector. A register of charitable organisations can be searched on www.charities.govt.nz.

As a respected charitable organisation, we place a high value on transparency. There have been various cases brought to light over the past few years where individuals have let down the very cause they have actively promoted. Alzheimers New Zealand works diligently to a code of ethics where no third party is paid to source funding on our behalf, and where funds are channeled directly as intended. We also observe the 'Donor Bill of Rights' which is advocated by the Fundraising Institute of New Zealand, and forms the basis of our donations policy.

Last year, our dedicated staff and volunteers supported approximately 5,000 people with dementia, including just over 2,000 newly-diagnosed people. As Alzheimers New Zealand prepares itself for the steep increase in people affected by dementia, its fundraising programme will become more sophisticated to enable more people to offer their support.

There are a lot of people who need our support today and a lot of money is needed to make this happen.

Philanthropy is based on voluntary action for the common good. It is a tradition of giving and sharing that is primary to the quality of life. To assure that philanthropy merits the respect and trust of the general public, and that donors and prospective donors can have full confidence in the not-for-profit organisations and causes they are asked to support, we declare that all donors have these rights:

A Donor Bill of Rights

1. To be informed of the organisation's mission, of the way the organization intends to use donated resources, and of its capacity to use donations effectively for their intended purposes.
2. To be informed of the identity of those serving on the organisation's governing board, and to expect the board to exercise prudent judgement in its stewardship responsibilities.
3. To have access to the organisation's most recent financial statements.
4. To be assured their gifts will be used for the purposes for which they were given.
5. To receive appropriate acknowledgement and recognition.
6. To be assured that information about their donations is handled with respect and with confidentiality to the extent provided by law.
7. To expect that all relationships with individuals representing organisations of interest to the donor will be professional in nature.
8. To be informed whether those seeking donations are volunteers, employees of the organisation or hired solicitors.
9. To have the opportunity for their names to be deleted from mailing lists that an organisation may intend to share.
10. To feel free to ask questions when making a donation and to receive prompt, truthful and forthright answers.

Courtesy of Fundraising Institute of New Zealand

CONFERENCE 2010

People, Policy, Partnerships

Wellington Convention Centre
6-8 May 2010



Alzheimers New Zealand Conference 2010

Convention Centre, Wellington, 6-8 May 2010

People
Policy
Partnerships



Welcome

Alzheimers New Zealand warmly invites you to our People, Policy, Partnerships Conference 2010. Attendance is a must for anyone involved with dementia, either professionally or personally. An impressive line-up of international and local speakers will provide practical solutions to issues for people with dementia, their cares, families, health and social workers.

Details and Registration

For more information on the conference, our speakers and the programme, please make sure you visit our conference website www.alzheimers.org.nz/conference2010

Supported by:



Conference and Events Ltd

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National Dementia Strategy

As part of the conference programme, Alzheimers New Zealand will present the National Dementia strategy to government at a Parliamentary reception.

Awards Dinner

Nominations are open for the inaugural "Academy Awards" of dementia care in New Zealand. Whether you are working on a treatment or rehabilitation initiative, a research project or 'just' making a difference in the lives of people with dementia, and their whanau in your day-to-day life, make sure you get yourself or your team nominated.

Programme outline

Thursday 6 May 2010

1.30pm - 4.30pm: Official opening/
conference programme

5.30pm - 7.00pm: National dementia strategy
launch at Parliament

Friday 7 May 2010

9.00am - 5.00pm: Conference programme

7.00pm - 11.30pm: Awards dinner, Duxton Hotel

Saturday 8 May 2010

9.00am - 4.30pm: Conference programme and
official close

Research

Smarter than your average rat

Hobbie-J, named after a Chinese cartoon character, is a smart rat. As an embryo he was injected with special genetic material to boost the memory-controlling NR2B gene. In future, a memory treatment made from NR2B may help people with dementia retain cognitive function. Lead researcher Joe Z Tsien at the Medical College of Georgia, USA, says Hobbie-J remembers objects for three times longer than normal rats and is better at negotiating mazes. However, the potential for this research to be beneficial to people with dementia has been criticised, as the brain cells of people with Alzheimer's disease die, rather than function ineffectively according to Dr John Hardy from University College London.



It's all in the hips

Women with an apple shaped body (wider in the middle than in the hips) double their chances of developing dementia if they live to be over 70 according to a study conducted at the Institute for Neuroscience and Physiology in Sweden.

Researchers measured the body shape of 1,500 women over an average of 32 years. Researchers say further research is needed as the relationship between dementia and weight is complex.

Smell the roses

Losing your sense of smell could be a symptom of Alzheimer's disease, according to research conducted on mice at the New York University School of Medicine and published in the **Journal of Neuroscience**. Physical symptoms of dementia in mice coincided with loss of smell. Researchers say noticing similar changes in humans may help to detect Alzheimer's disease earlier.



Dementia and cancer

People with cancer are less likely to develop dementia and vice versa, according to research published in the journal, *Neurology*. A Washington University School of Medicine team studied 3,020 people aged 65 and older for an average of five and eight years to see whether they developed dementia and cancer respectively.

People who had Alzheimer's disease when the research began had a 69 per cent reduction risk for cancer compared to those who did not. White Americans who had cancer at the beginning of the study had a 43 per cent reduction in risk for developing Alzheimer's disease.

However, the same did not apply to minority populations; those who started the study with cancer were more likely to develop Alzheimer's disease. Researchers think cancer and degenerative diseases such as Alzheimer's disease may share molecular similarities.



The eyes have it

Up to a year before the onset of any dementia symptoms, a new test may be able to detect neurological diseases such as Alzheimer's disease. Researchers at the University College of London say this test has the potential to help diagnose dementia earlier by detecting brain death. A special camera and fluorescent markers are attached to retinal cells as they are dying. The death of retinal cells is connected to the death of brain cells. Animals have been used in the study so far; researchers are hoping to use the test on humans in the next two years.



Hypertension

Woman aged over 65 with hypertension (high blood pressure) are at increased risk for developing brain lesions which lead to dementia later in life, according to the Women's Health Initiative Memory Study. Participants had their blood pressure and cognitive ability tested when they enrolled in the study. All 1,403 participants were free of dementia at the beginning of the study. Those with elevated blood pressure were found to be more susceptible to brain lesions; a risk factor for dementia.



Appetite hormone

People with high levels of the appetite hormone leptin have a lessened risk of developing Alzheimer's disease, according an eight year research study on 785 participants. Leptin is naturally produced by the body's fat cells and thought to regulate appetite. Those with the highest leptin levels were four times more likely to develop the disease. Researchers say it is too soon to use leptin as a preventative treatment for Alzheimer's disease, but it may help identify those at risk. The research was conducted at various US universities and published in the *Journal of the American Medical Association*.

Yes, I would like to help make life better for those affected by dementia!

Name:

Address:

I enclose my donation for:

Payment: Cheque Credit card

Card number: Exp /

Name on card: Signature:

I would like this donation to go to:

- Alzheimers New Zealand
- My local member organisation
- Alzheimers New Zealand Charitable Trust

Please send donations to Alzheimers New Zealand, PO Box 3643, Wellington 6140, or donate online by going to www.alzheimers.org.nz/donate



www.alzheimers.org.nz



0800 004 001 (local organisation freephone)



www.facebook.com/alzheimersnewzealand



0900 4 1234 (\$20 donation line)

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- How I can become a regular donor
- How my business can help Alzheimers New Zealand

Please send this information to: