



Alzheimers *News*

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A day we will never forget

pages 4, 5



Alzheimers News

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From the Editor

Welcome to the May edition of Alzheimers News. This is my first edition of this fantastic magazine, after taking the reins from our departing editor, Cass Alexander. There is much covered in this edition, including a touching

story from a couple facing the daily challenge of dementia.

In light of the recent Christchurch earthquake this edition focusses on the theme of 'community spirit'. We have a special feature on the Christchurch earthquake (pages 4 and 5) which includes some sobering statistics from this tragedy.

I hope our friends and colleagues in Christchurch have a swift recovery.

The Alzheimers New Zealand Annual Appeal and Awareness Campaign will this year be in the months of May and September, with many other events scheduled for the months between. For more information see page 7 or visit www.alzheimers.org.nz

News

New tools to improve safety for senior road users

Traffic safety is vital for all ages, but seniors often experience physical changes that can affect safe mobility. The NZ Transport Agency has launched a Staying Safe online toolkit - a set of new older driver education resources to help improve road safety for people over 70 years of age.

Included in the online resources is a section that looks at ways seniors can keep themselves safe when using public transport including alternative transport schemes.

The free tools are available at: www.nzta.govt.nz/traffic/senior-road-users



Over 3000 website visits in one month!

We are pleased to announce that in the last month we have had over 3000 visits to our website. The website provides up to the minute news and research, helpful publications, resources and information, a dedicated section on help and support for people with dementia, their family/whanau and carers. As well as all the information you need to know about our 23 local member organisations.

You can also make a secure online donation to Alzheimers New Zealand or any of our local member organisations.

To visit the Alzheimers New Zealand website please go to:
<http://www.alzheimers.org.nz>



Hats, Heels and High Tea

Beautiful frocks, fine china and sunshine made for a fantastic afternoon for the 75 who turned up to Alzheimers Tauranga's inaugural fancy dress fundraiser Hats, Heels and High Teas on 10 March.

The event was a great success raising over \$6,000 for local services, and 10% of ticket sales was donated to Alzheimers Canterbury.

Held at Mills Reef Winery, guests enjoyed champagne, a moving performance by soprano Sharon Elizabeth and an auction which saw a variety of donated goods go under the hammer in a flurry of nail-biting bidding.

Local MP and Minister of Health Tony Ryall attended the event and addressed some of the issues facing the dementia community as well as showing his support for our team in Christchurch. Alzheimers Tauranga manager, Jane Moore, expressed her deep appreciation to her sponsors saying "The success of Hats, Heels and High Teas is testament to the support of the Tauranga community."



Winner of the Hats, Heels and High Tea 'Best Dressed', Susan Harrison-Tustain of Tauranga

Two decades of dedication



Gisborne's Sherwood Club is sad to farewell a committed and caring member of staff.

After nearly 20 years of service, Sherwood Club's Barbara Larsen is moving on from her role as community coordinator to spend time with her family.

Barbara was employed in 1992 after the need was established for a day care centre for those people with dementia away from home.

Barbara was responsible for creating greater awareness and understanding of dementia amongst hospital staff, GPs and the Needs Assessment Service Coordination. She also developed and coordinated a training seminar at the hospital and local high school. Thanks to her efforts, many in-service training courses were made available to volunteers and paid staff. Barbara spoke about dementia on maraes, to Women's Institute Groups, schools, rest home staff and met and liaised with many other groups. She initiated the Anzac Day Remembrance walk, set up a carers support group and organised some pampering days for carers.

Barbara's passion for supporting those with dementia, saw her travelling down to Wairoa and as far up the East Coast as Te Araroa. Barbara says working at the Sherwood Club "never felt like work".

"It's always pleasing to go that extra mile as our families are all on a difficult journey. It has been a great privilege to take care of our Sherwood members and to have been made so welcome in our families' homes. Trust is a very important part of our work," she says.

Barbara has been a great advocate for people with dementia in Gisborne and is well regarded by her former clients and colleagues.

"This extraordinary woman gave tirelessly of her time, knowledge and energy and did so with her all-pervading love, cheerfulness and compassion. So many hearts were touched by her. She supported people however and wherever possible listening to what they wanted rather than imposing her ideas on them and was in favour of family-orientated care." Says Alzheimers Gisborne office secretary, Suzanne Orchard.

Former and present clients, colleagues and close friends were invited to share an afternoon tea and presentation at the Sherwood Club in March to celebrate Barbara's 19 years of service.

A day we will never forget

Two months on from the devastating 6.2 magnitude earthquake that hit Christchurch with such ferocity and speed on 22 February 2011, Alzheimers Canterbury manager, Darral Campbell shares how the Christchurch dementia community is coping, and how they are best able to be responsive to their needs.

Our initial response was to ensure immediate safety, working in collaboration with the various emergency services. It was great to see organisations such as the Ministry of Social Development (MSD) contacting every person over 65 in the Canterbury region.

The aged-care service providers in the region are collaborating to try and ensure good information flow. A helpline was quickly established and regular network meetings are now up and running as we move from rescue to recovery mode, both within the NGO sector and the Canterbury District Health Board (CDHB). In these meetings we work towards understanding emergency legislation, new structures, identification of issues and joint future planning. MSD is taking a lead role in this process in the community. We have a responsibility to ensure that we raise and represent the reality and concerns of our clients, carers and families.

In the early stages of the rescue we witnessed many cases of bravery, selfless acts of kindness and people working together because 'we are all in the same boat'.

Now, in the aftermath, we are beginning to see the fatigue, the daunting reality of the size of the task ahead of rebuilding. We know that practical support is a key component of psycho-social response. We are now increasingly dealing with the stress reactions of clients, carers and families.

Realities are: having to help someone with dementia manage; a port-a-loo in the street or a chemical toilet; showering at someone else's home; no planned respite available in

Christchurch; buses that follow different routes; having to shop, bank, socialise in places that are unfamiliar; being late for appointments because of detours and traffic delays; familiar landmarks, which gave a sense of place and of direction, no longer existing; having to move out of homes for weeks/months, sometimes permanently; support for people not being available because of their own losses in the earthquake.

Within our dementia community we have witnessed amazing resilience and creativity from families, carers and people with dementia as they grapple with the new realities of life in

Christchurch. We also see the impact of the overloaded services such as residential care, respite and day care. Even more than usual we need to support our clients in the community to manage with the limited support available. We need to attract funding to be responsive now, and to continue to be responsive in the months and years ahead, as the impact is significant and far reaching.

The support of our national organisation and member organisations has been heartening and we thank you and hope that you will continue to find ways to walk beside us and offer support in the long months ahead.

"we are beginning to see... the daunting reality of the size of the task of rebuilding ahead"

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

Photo source www.chch.catholic.org.nz



THE IMPACT IN NUMBERS

Of Christchurch's February 22 Earthquake

- Over 600 respite beds lost
- 500 rest home residents relocated
- 7 rest homes totally evacuated
- 2 rest homes partially evacuated
- 27,500 chemical toilets distributed
- Over 2,000 portaloos distributed
- 1363 aftershocks (since February)
- 45% of inner city buildings yellow or red stickered
- 200,000 tonnes of liquefaction silt moved
- Port Hills vertical movement of 40cm
- 15,000 schoolchildren affected by damaged schools
- 300 buildings earmarked for demolition
- Between 1500-2000 people treated for minor injuries
- 220 major trauma cases treated by Christchurch Hospital immediately following the event
- 182 people confirmed dead (on 17/03/11)



Tips for coping

Do what helps you and your family (don't make people talk if they don't want to). Think about:

- One step at a time
- Getting back to regular routines
- Regular sleep
- Exercise to reduce anxiety
- Healthy eating
- Realistic goals
- Saying 'No'
- Sense of safety
- Self and community empowerment
- Connectedness
- Calmness and hope
- Seek help when stress reactions don't improve

Remember: we are resilient.

Thanks to our volunteers

Alzheimers Canterbury has been overwhelmed by the support and hard work of its volunteers following the earthquake.

Living arrangements, basic amenities and accessibility have been compromised, compounding anxiety levels already experienced by the dementia community. Within two weeks of the earthquake an Immediate Response Volunteer Team (IRVT) was established to help address the needs of people with dementia and their families. Ten Volunteers, including four new volunteers, put their hands up without hesitation.

Working tirelessly around the clock these ten volunteers assessed the needs of many people with dementia, monitoring progress with water, electricity and sewerage services, providing feedback to the Alzheimers Canterbury volunteer co-ordinator and social workers. This information assisted in developing an ongoing strategy to better support these people and prioritise our services. The result was a turnaround of one week from the initial referral to the volunteers visit.

Six weeks on from the earthquake Alzheimers Canterbury volunteers continue to work hard adapting to the changing needs of clients and carers and working around the damaged infrastructure.

We thank them all for their tireless commitment.
Kia kaha Christchurch!



Put your hands up and **VOLUNTEER!**

Local Alzheimers organisations all over New Zealand are looking for volunteers for a wide range of tasks - from administration, to driving, to fundraising.

Call your local Alzheimers organisation today and put your hand up to help us make life better for all people affected by dementia.

Call 0800 004 001

or visit www.alzheimers.org.nz

Devoted general manager retires

Alzheimers Northland's Alma Douglas, has retired from her position as general manager but will continue with the organisation as a volunteer. Alma spent 20 years in a corporate environment but says she got the most satisfaction and fulfillment from her time with Alzheimers Northland.



Alma started with Alzheimers Northland on a temporary basis in August 2007. In October the same year she was appointed office manager reporting to an acting manager. 18 months later the general manager resigned and after three months acting in the role Alma was appointed to the position.

"The joy of seeing our clients enjoying their time at Day Service really warms my heart" says Alma. "I have been blessed and privileged to work with the Alzheimers Northland team over these last three and a half years."



**"Volunteering – every minute counts" is the theme for the
2011 Volunteer Awareness Week,
19th – 25 June.**

The Week coordinated by Volunteering New Zealand highlights that volunteers provide an invaluable contribution to our society and every minute they give counts. Those who manage/organise volunteer programmes need to consider how they involve volunteers so everyone – even the busiest – can volunteer. For everyone who is considering volunteering, it means every moment of their life they volunteer is valuable because everyone contributes no matter what amount of time they give. Volunteering opportunities are available through www.volunteernow.org.nz or 0800 865268.

Annual Appeal and Awareness Campaign

The Alzheimers New Zealand Annual Appeal and Awareness campaign kicks off in May 2011 and runs through until the end of September. As always, this is an opportunity to engage with our communities, sharing information about dementia and support offered locally as well as building awareness about the disease and raising much needed funds to support the good work of local Alzheimers organisations and their national body.

There are many events planned throughout the country: from public seminars to open days, and many fun activities as well. We will be working closely with our partners, such as Bupa, to host entertaining and informative fundraising events, and will have appeal days in May and September where we will be collecting with our partners, Progressive Enterprises, outside their Countdown supermarkets. And while you are in Countdown, don't forget to



grab a specially marked pack of lamingtons! These Kiwi favourites are made with love by the team at Elite Pavlovas who generously donate .20c from the sale of each pack. If you can't make it to one of our events or to your local Countdown, please consider donating through our website www.alzheimers.org.nz or by calling **0900 412 34** to donate \$20. For more information about events in your area please visit www.alzheimers.org.nz or call your local Alzheimers organisation on 0800 004 001.

Bupa Global Challenge - Shall We Dance

In June thousands of Bupa people across the world will take part in its biggest ever Global Challenge. It's all about getting communities moving, helping people lead longer, healthier and happier lives. Bupa Care Home and Retirement Village around New Zealand will be inviting communities to engage in dance related events. So dust off your dancing shoes and get ready to take to the dance floor with your local Bupa Care Home or Retirement Village.

For more information go to www.bupa.co.nz

Brain Awareness Week

76 countries around the globe united in a week-long celebration of the brain from 14 – 20 March 2011. This global campaign was to increase public awareness about the progress of brain research and benefits of keeping our brains healthy.

In New Zealand, The Neurological Foundation has been an official Brain Awareness Week partner for five years. Working closely with the The Neurological Foundation, Alzheimers New Zealand has been fortunate to be a part of this global campaign. This year we exhibited at the four Brain Days (Whangarei, Auckland, Wellington and Dunedin). Our exhibitions provided Brain Day participants with a variety of information and resources about dementia as well as a chance to meet with representatives from our local Alzheimers organisations.

Alzheimers Wellington's chairperson, Verna

Schofield, who participated in Wellington's Brain Day on 16 March, says: "It was really good to see the interest about dementia from a whole range of people, professionals to family members and friends." Verna joined Dr. Crawford Duncan (Psychiatry of Old Age, Capital and Coast District Health Board) who delivered a talk about dementia.



Alzheimers Northland Community Advisor Anne Wilson and Social Worker Robyn Barr spoke at Whangarei's Brain day about what services they provide to the dementia community throughout Northland.

In addition to these Brain Days, our local organisations had involvement in various regional public lectures throughout Brain Week. For example, Alzheimers Wanganui helped facilitate a local public lecture where neurologist and medical advisor to the Neurological Foundation, Dr Jon Simcock spoke about the latest progress in the understanding of brain disorders.

A word about communities

In light of the Christchurch earthquake and the theme for this Alzheimers News our national director and board chairman talk about the word community and what it means to them.

Alzheimers New Zealand national director, Johan Vos

Events such as the Christchurch earthquake really hit home the importance of community. In the world of aged care we often refer to our own individual sectors as communities and I like to think the dementia community is one where we exhibit qualities of support and solidarity.

The dementia community starts at the grassroots level, this foundation being the caregivers who so selflessly adapt to the new world of caring for a person with dementia and the daily challenges which this brings, as well as the many volunteers who work alongside them. They, in turn, are cared for by their family and friends, in many different capacities, from sharing a coffee to offering some form of respite. Supporting these people, and those who have dementia, are the many groups both formal and informal, who work within the wider community offering a range of services, assistance and Alzheimers New Zealand and our 23 local organisations are a big part of this.

Supporting these community based groups are the lead bodies and professional organisations, such as the national body for Alzheimers New Zealand, who work alongside the next tier up leading the way in advocating for better supports for those from the grassroots level up. This next tier are the multitude of associations, working groups, committees, and governance boards, who use their knowledge and experience to influence decisions made at the top tier of this community to benefit all. This top tier are our Ministers, local government, and international governance boards. Alzheimers New Zealand belongs to Alzheimers Disease International who sits at this level in the global sphere; however, we work with our Ministers and authoritative agencies to guide them when making decisions that affect our community.

This is of course cyclic, and those at the grassroots level are the ones who have the biggest say in deciding who sits at this top tier.

This year is an election year and our community has the opportunity to band together, in support and solidarity, to ensure that this top tier fully understands the needs of our community and responds accordingly.

I am proud to be a part of a community that cares and fully appreciates its members and their contribution from the grassroots up.

Alzheimers New Zealand board chairman, Martin Brooks

One of the more rewarding aspects of my position as the chairman of Alzheimers New Zealand is the opportunity to see the work done in the community by our local Alzheimers organisations. Of course much of this work could not be carried out without the support of the wider community. Whether it be support from local businesses, local people volunteering in various ways, or financial support from individuals, local trusts and the like, the support that we receive from the community is vital for carrying out our work.

The recent events in Christchurch have brought to the fore the importance of local communities and how critical it is to have this good support.

We as an organisation depend on this help in so many ways, there are the volunteers that give up their time to make visits to those affected by dementia, as well as the people who attend the various fundraising events that our local Alzheimers organisation hold. Without the people who stand on windy corners to collect for the street collection, we would not be able to utilise this source of funding. Anybody who has collected in a Christchurch southerly will know what I mean! One of the areas of volunteering that is often underestimated is the people that serve on the various committees and boards.



These people offer their skills and time to the organisation, and we would be in a sorry state if this did not happen.

Of course, one of the major aspects of our organisation is the support that we offer to our community. Any of us who have been in the position of caring for a person with dementia will attest to this, I am sure. Just having someone to ask about a particular issue or a friendly ear to listen can make all the difference to a carer or family member.

If we look at the many definitions of "community" we see that one is "sharing, participation and fellowship" This sums up what the community is to us and what we are to the community.

New facility for Napier

In December 2010, Alzheimers Napier purchased a new property to support the needs of their clients and growing referrals. However, in order to move into their new facility support is needed to help raise \$175,000 toward custom building this space to hold their Mahana Day Club for people with dementia and support groups for all affected by the disease.

Limited services are currently held at this facility however; dementia-friendly changes to the structure of the building must be carried out before all services can be implemented.

Alzheimers Napier received a \$25,000 grant from Eastern and Central Trust and a \$15,000 grant from Vavasour Charitable Trust for the purchase of the facility. Rotary Club of Ahuriri (Napier) Inc collected gold coin donations from the HMNZ Canterbury's open day as part of Napier's Art Deco Weekend. Plans for further fundraising initiatives throughout the year are underway including a garage sale in conjunction with Lions Club on 14 -15 May.



Caring for the carer

By Bupa Care Services CEO, Dwayne Crombie



In this issue I would like to highlight the work of Carers New Zealand, the support and advocacy group which seeks to help and provide assistance to the more than 230,000 informal carers

who provide care in the community.

Bupa Care Services is one of a small number of foundation partners for Carers NZ and each of these sponsor organisations actively supports their very worthwhile work. These partnerships were established with important principles such as active collaboration, support, advice and helping the consumer voice. Carers NZ has a good website and a widely circulated national magazine which shares knowledge and information and advice for difficult issues.

Many older people are cared for in the community by family or friends acting as carers. The role is often an "unsung" one and our community as a whole should be indebted to those who make such a huge contribution to care.

On May 23rd, Carers NZ will launch a major new national initiative to celebrate the role of the informal carer. The "Caring Moments" programme will kick off with an event at the Aotea Centre in Auckland. On display will be a collection of gallery quality photographs featuring carers and those they are caring for. The photographs have been taken by Terry Wynn, one of New Zealand's top photographers.

These photographs powerfully convey the message about the value of carers and the importance of their contribution to the wider community.

It is also timely to think about how we can support informal carers better as a country, i.e. who cares for the carers? We should find ways of giving carers skills and knowledge without making their burden any bigger or turning them into professional caregivers. We also know their own health suffers comparatively because of the greater stress they are under, so we need to support and look after them.



Our journey with Alzheimer's disease

Written by Auckland resident, Dolores Smith, who was diagnosed with Alzheimer's disease in 2004.



Dolores and her husband, Desmond Smith

I had always been a self-sufficient and capable woman but one day, out of the blue, my husband told me he had been noticing a change in me, particularly in the area of memory. He suggested I see my doctor. After initial hesitation I agreed to his proposal and made an appointment. I had no idea then what that simple act would lead to.

Well the doctor carried out some basic memory tests and said my response was just a little below average. She referred me to a clinic at Auckland hospital for senior citizens. From there it was decided that I should be referred to a special unit at Green Lane hospital where several more tests were carried out over a period of time and, eventually, a CT scan was performed. At the next appointment, the resident psycho-geriatrician sat Desmond (my husband) and myself down, looked directly at me and said: "You have Alzheimer's disease. Now what do you think about that?" It must be admitted that, as a clinical approach, this ranked somewhere near being hit with a sandbag!

We were frankly knocked into silence by the revelation and came out of the hospital that day and more than a little shattered. Where do we go from here? Was the first question we asked ourselves.

Desmond and I had agreed in the beginning that this whole matter did not require that our family of five girls be informed. We had decided to keep it close to the chest, largely

because of the undeniable social reflection such a diagnosis could often incur. Little distinction was made then by the general public between psychic disease and dementia. I have to admit though that, even then, Desmond's personal reaction to the matter was that one should almost go round with a sandwich board announcing the fact. Certainly, the situation deserved understanding and sympathy, rather than a superior disdain.

Nevertheless, the girls were kept in the dark for some months. But, eventually they began increasingly to question the changes, principally memory, in their mother's behaviour. So we agreed between us to tell them what was going on. At the end of our announcement Vivienne (our second daughter) set the tone beautifully by saying: "Well, you're still our Mum." That meant so much to me!

Despite all the reading and searching we did on the disease, there seemed no signs of anything

which would halt its advancement. The use of the drug Aricept appeared to be useful in at least slowing the progress, so we began daily dosage of this drug. Furthermore, medical research was convinced that regular exercise and the maintenance of good humour were definitely beneficial to patients with Alzheimer's disease.

The exercise bit was not too difficult at first because, for years, we had been in the habit of walking every morning before breakfast. Unfortunately, Desmond now began to notice that, although I had always been the more active of the two, I was beginning to show a great deal more tiredness with physical effort. Thus, our previous early morning walks started to lessen in frequency and it took considerable persuasion at times to get me out of bed for that purpose. We have compromised by arranging walks later in the day but all too often they get forgotten about.

As far as the humour side of therapy was concerned, laughter (at oneself and the other) is surely an indispensable part of a good marriage. So we had started using that ploy many years before. How crucial it now has become.

"You have Alzheimer's disease, now what do you think about that?"

Sometimes, laughing at ourselves is the only thing which keeps us from crying instead!

We attended an international conference on Alzheimer's disease in Wellington in 2007 and we came to realise more forcibly the problems that could occur for carers if precautions were not taken. So, when we returned to Auckland, Desmond told our daughters that a weekly outing with one or all of them would help the situation. He maintained that he didn't want to be away from me at all, but that time was regularly needed to gather his own thoughts and recoup the mental processes. He claimed that thinking constantly for two could be pretty difficult at times.

In the face of helpful advice from official sources, we began our own course of memory exercises using a mix of association, repetition and concentration. Such an approach resulted in my memory coming out of retirement occasionally. There was one particular habit which we started and which has lasted now for over four years. It began because our fiftieth wedding anniversary was coming up at the time and we sorely wanted us both to be fully aware for the occasion. So, from several months beforehand, we started to toast each

"Don't assume that I can't do anything until I show that I can't"

other over dinner with a remembrance of how long it was since our marriage. But this was not a simple remembrance. Oh no! It involved a solemn repetition of how many years, months, weeks, days and finally hours since that momentous event had occurred.

One of the results of all this, often painful, effort was not quite what we had imagined. To set the stage, Desmond had been preparing a poem for that day over a period of weeks and duly read his masterpiece to the assembled family and friends who received it all politely. Then, as he sat down from his marathon effort, I quietly said that I would like to say a few words too. So, I rose to give what I thought was a quick talk about our past and many of the wonderful people involved in it over a half century. This was all impromptu and done without any previous notes. It ended up not being a few words at all as I called to mind (and voice!) so much that had really mattered to us both. Everything seemed to come out so

readily that, after I sat down, one good friend suggested to Desmond that in future he should leave the talking to me!

Just in passing, we have continued that practice of remembering and toasting our wedding date each evening since the 50th. At

"Sometimes, laughing at ourselves is the only thing which keeps us from crying instead"

time of writing, it has now reached 54 years, 5 months, 1 week, four days and six hours. It has to be admitted that sometimes it is a pain in the neck for both of us. When my memory is particularly bad, the toast drags on and the dinner gets colder and I want Desmond to scrap the whole thing. But, to his credit, we persevere none the less.

After seven years of experience with the disease, it seems to us that self esteem, self confidence and dignity are essential requirements for people with Alzheimer's disease. Therefore, we constantly seek to embrace the attitude that Christine Bryden typified so well in her book, *Dancing with Dementia*, about living with this affliction: "Don't assume that I can't do anything until I show that I can't"

It is very pertinent that the members of one's own family be made aware of this way of

relating to the affected person. Otherwise, misplaced love and sympathy can get in the way of keeping the patient in their present state without too much deterioration. Studies would appear to support strongly the theory that the attitude of the patient contributes hugely to the rate of progress of Alzheimer's disease.

And that is the anchor on which we base a great deal of our response to the disease.

Naturally, based on this assumption, social activities of all kinds are critical and essential. Therefore, we try to maintain as much of our contact with people as is reasonable. Hibernation, seeking only one's own company, a practice so easy to slip into at later stages of life, is an absolute No No. Desmond tells me that, from the carer's point of view, amongst the hardest things to practice is the resolute pursuit of patience. But, without that virtue on the part of the carer, the journey for the patient is made so much harder.

News around the World

Solve it together

Alzheimers Disease International has produced a series of puzzles created by a carer as a way of communicating and engaging with her mother who has dementia. *Puzzle with Me* has been especially designed for caregivers, family/whanau and people with dementia to use together.



It provides an opportunity for verbal and non-verbal communication and is also helpful for redirection and calming. The puzzles are 12 pieces, large, easy to handle, and environmentally friendly.

For more information go to www.puzzlewithme.com

iPhone App that takes you on a journey through the brain

Alzheimers Society UK have developed a new iPhone application, called Brain Map, that allows users to explore the inner workings of the brain in a hope to raise awareness of dementia. Users can rotate and zoom into different regions of the brain and find out what they do. The application has a link to the Society's website, where users can find out more about dementia. The application is free and can be downloaded through the App store on your iPhone or by visiting www.alzheimers.org.uk/brainmapapp



15 million people provide 17 billion hours of unpaid care in America

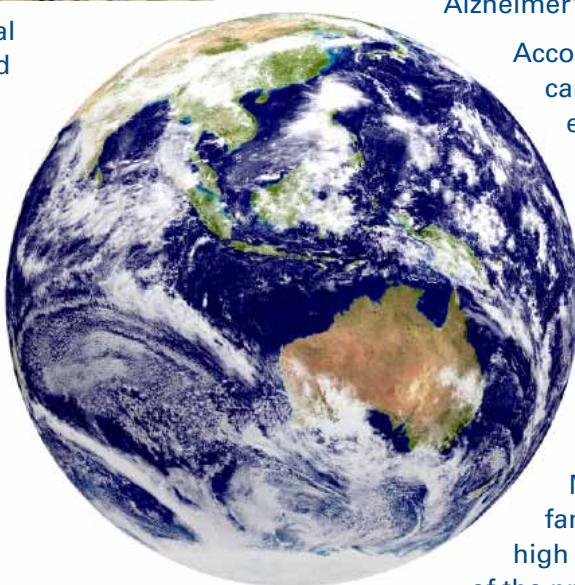
Almost 15 million Americans look after family members with Alzheimer's or another form of dementia, which totals 17 billion hours and more than \$200b in unpaid care, as reported in the American Alzheimers Association's annual report, Facts and Figures.



There are so many U.S. carers looking after their parents or other relatives that they could form the nation's fifth-largest state, reported the Alzheimer's Association.

According to the report, caregivers not only suffer emotionally but also physically. Because of the toll of caregiving on their own health, Alzheimer's and dementia caregivers in America accounted for \$7.9b in additional health care costs in 2010.

More than 60 percent of family caregivers reported high levels of stress because of the prolonged duration of caregiving and 33 percent reported symptoms of depression.



Alzheimer's Australia has a new website

Alzheimer's Australia launched their new website on December 10, 2010 with a new design and layout making it easier to navigate. All of the same information is present on the site including helpsheets, information on services, support, research and education materials.

Check it out: www.alzheimers.org.au

What's the right milk for me?



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

Do you ever wonder when you reach for your milk at the supermarket “is this the right milk for me?”

Milk is an important part of any diet. It provides essential nutrients: a good source of protein, a range of vitamins and the most reliable and easy to absorb source of calcium in the western diet. Indeed milk and foods made from milk make up one of the four food groups – at least three serves of which are necessary for older people to meet their calcium needs.

During the past 40 years we have seen a proliferation in the types of milk available. These have been developed to suit our health needs. Most offer us the option of less fat and more calcium but some are supplemented with other nutrients such as vitamins D and K. The dairy industry conveniently colour codes these.

Today, standard milk refers to homogenised milk. It is similar in composition to the milk which used to be delivered in bottles to our gate, except that it's been passed through a machine which physically breaks up the fat into smaller globules so they stay suspended in the milk and don't settle on top. Homogenised milk has approximately 3.5% fat and is colour coded dark blue.

Lite milk has a fat content half-way between homogenised and trim (1.5%). Many who find trim milks 'too watery' enjoy this alternative.

Trim milk, which was originally known as 'skim' milk is colour coded 'green'. It has between 0.1 and 0.5 % fat and approximately 30% more calcium than homogenised milk.

Calci-trim is a trim milk with even more calcium. It provides nearly twice as much calcium as homogenised milk (200mg calcium instead of 115mg per 100mls). It is colour coded yellow and is an excellent choice to boost the calcium intake of people who use little milk or who have high calcium needs.

Over our life cycle different milks suit our changing nutrient needs. Toddlers are encouraged to use homogenised milk, children

and teenagers a reduced fat milk such as lite milk, and adults a trim milk.

However, milks with a higher fat content are appropriate for older adults especially if a person becomes frail. Lite milk, homogenised or a calcium enriched homogenised milk such as Super Blue and Calci-strong (blue topped) or Mega Milk (orange top) are good choices. The calcium enriched options of homogenised milk are also fortified with vitamin D.

A small percentage of people, however, do not tolerate cow's milk. Up to 5% of babies may be allergic to proteins present. Because even small amounts of cow's milk protein can cause symptoms, parents must ensure their baby excludes from their diet all cow's milk and foods which contain cow's milk. Advice from a dietitian regarding suitable milk alternatives to ensure the baby receives adequate protein and calcium is recommended. Thankfully most babies outgrow this allergy by their second birthday.

Most adults who don't tolerate cow's milk experience unpleasant gut symptoms as a result of not being able to absorb lactose, the sugar naturally present in all mammalian milks. This condition is known as lactose intolerance or lactose mal-absorption. It is not an allergy reaction and symptoms only occur when a significant amount of lactose is consumed. Therefore dairy foods which contain only trace amounts of lactose such as cheese and foods which contain only small amounts of cow's milk such as a scone are tolerated. Soy milk or cow's milk which has had the lactose removed and replaced by an alternative source of carbohydrate are useful milk alternatives. These are packaged as long life milks so will be found in the supermarket and not under refrigeration.



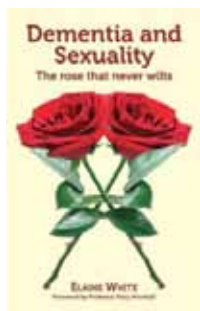
Review

Dementia and sexuality. The rose that never wilts.

By Elaine White

Reviewed by Vivienne Boyd

The author, who is based in New South Wales Australia, has worked as a clinical nurse consultant in geriatrics and aged care education for the past 20 years. She draws on her extensive experience in each of the book's three parts.



Part one: 'Setting the scene' includes sections on attitudes to old age, and how dementia can affect sexuality with changes in the brain.

Part two: 'Sustaining relationships' addresses the complexities faced at home by primary carers (chapter 4), then subsequent chapters focus on residential care settings emphasizing the importance of residential care staff establishing connections with families, with a model for engagement of residential care staff with family carers, and addressing ethical dilemmas in residential care.

Part three: 'Discovering solutions' includes a six-step problem-solving pathway in the context of person-centred care in residential setting.

Sexuality is a topic that can be all too easily placed in the 'too hard basket' for dementia information, education and ongoing support. This book addresses and dispels myths, and offers practical guidance for many situations people with dementia and those supporting them may face now or later. I recommend reading this entire book (it's not long) to staff supporting people with dementia who are in residential care, and the first four chapters in particular to family members of people with dementia living in the community.



Our regular reviewer Vivienne 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

Research

Dementia research in New Zealand

Director of the University of Otago's Brain Health Research Centre, Professor Cliff Abraham tells Alzheimers News about the Universities latest research.

Given the huge personal, social, economic and healthcare costs of Alzheimers disease, and its predicted exponential rise in the coming decades, there is an urgent need to develop new therapeutic strategies. In addition, we need to identify those who have Alzheimer's disease at its earliest stages so that any effective therapies that are developed can be delivered before there is significant deterioration of the brain tissue.

In late 2010, a five year programme of research on Alzheimer's disease commenced at the University of Otago to address these two important issues. First, new therapeutic strategies will be tested in animal models of Alzheimer's disease, focusing on harnessing the power of neuroprotective molecules that are already found in the brain. Second, the group is working to identify blood "biomarker" molecules that are indicative of Alzheimer's disease, in order to develop a blood test that will be sufficiently sensitive to detect the disease in its early stages. The research team is currently recruiting participants from the Dunedin area for this biomarker study, including both people with Alzheimer's disease and age-matched controls without dementia.

Funded by the Health Research Council, the team of researchers is led by Professor Cliff Abraham and extends across many departments in the University and Medical School under the auspices of Otago's Brain Health Research Centre. These researchers have had a long-standing research interest in mechanisms of memory and aging in the brain and plan to pool their collective expertise in anatomy, biochemistry, molecular biology, psychology and neurology to attack the difficult issues surrounding the treatment of Alzheimer's disease.

To volunteer to participate in the blood test study (Dunedin area only), you may contact Jill Leichter in Otago's Psychology Department (03-479-4066; jleichter@psy.otago.ac.nz).

Alzheimer's studies uncover new genetic links

A new set of genes linked to Alzheimer's has been discovered in a breakthrough that could pave the way to preventing people developing the disease, claim scientists.

Five new genetic variants have been discovered, doubling the number already known, and meaning that together they account for 60 per cent of all cases of the disease. The work, could lead to new treatments and preventions within the next 15 years, it was claimed.

Some of the genes are linked to inflammation and cholesterol in the brain which could mean that existing drugs could already exist to treat them.

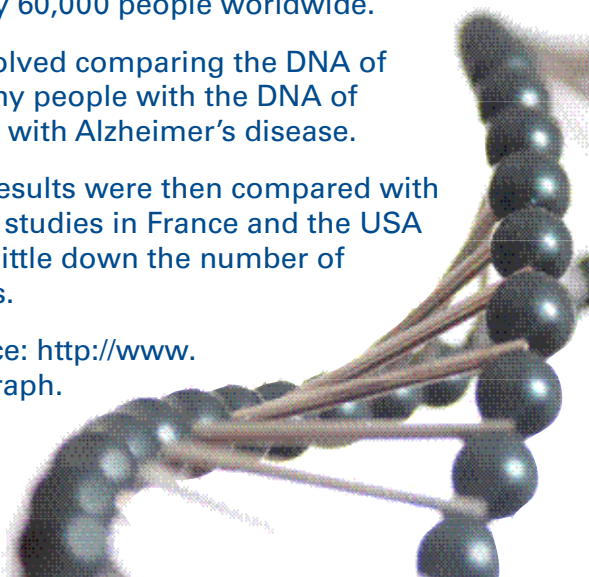
Others suggest whole new mechanisms not previously linked to the disease.

The results, published in the journal Nature Genetics, come from combining four separate genetic studies into Alzheimer's involving nearly 60,000 people worldwide.

It involved comparing the DNA of healthy people with the DNA of those with Alzheimer's disease.

The results were then compared with other studies in France and the USA to whittle down the number of genes.

Source: <http://www.telegraph.co.uk>



Ask the expert...

Dubbed a 'scientific breakthrough', but what does this discovery actually mean for people with Alzheimer's disease? We ask our scientific advisor Dr Phil Wood.

The discovery of further information about the genetic contribution to the risk of developing Alzheimer's disease is of interest especially if it adds insight into the causes and management of Alzheimer's disease. All of the 'new genes' seem to be involved in some way with cholesterol. What is lacking is how much this adds to making a diagnosis or even using this to help people identify their own risk. Each gene in itself is apparently a weak predictor and not in any way like those familial genes which can lead to a 1:2 ratio of Alzheimer's disease within a family. For example the added value of this genetic contribution is far outweighed by the well known ApoE4 gene, which, despite its contribution in itself, is not widely accepted as being essential for the diagnosis and is mainly used for risk prediction.

Even knowing such risk it may not help the individual as much as expected. It merely tells the person their overall probability without clarifying at what age they may circum, nor does not take into account all the other health and lifestyle risks they may or may not face.

People need to be wary of wishing to identify their risk of various diseases especially if there is little they can alter to reduce the risk. Furthermore such information can prejudice such matters as personal health insurance and other important life choices. We still advocate that we should all continue to get the best education we can, eat a healthy diet (what is good for the heart is good for the brain) and get regular exercise (especially if it exercises the mind at the same time). One cannot change genetics, but we can still make the best of what we have been given.



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MAKE YOUR NEXT CUPPA COUNT!

Local Alzheimers organisations all over New Zealand will be out in their communities in May and September sharing information about dementia and services available in their area, and raising funds to support their services.

One way YOU can help is to host your own *Cuppa for a Cause*.

Sit down with your friends, family, colleagues, community group or neighbours and talk about what dementia means to you. Do it over a cup of tea, and while it brews raise some money for this worthwhile cause. Maybe even challenge your friends to see whose *Cuppa for a Cause* can raise the most!

Information about *Cuppa for a Cause*, Cuppa Kits, and other opportunities to help us make life better for all people affected by dementia are available at your local Alzheimers organisation.

Get involved!



**CALL 0800 004 001 FOR
MORE INFORMATION**

Whatever your style, have a Cuppa for a Cause!



0900 4 1234 (\$20 donation line)



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Alzheimers New Zealand is a member of Alzheimer's Disease International, the umbrella group for 71 Alzheimer's disease organisations worldwide



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