



Alzheimers News

The National Newsletter of Alzheimers New Zealand Incorporated

Issue 76 December 2008

2008 Election Results

With the result of the Election now known, Alzheimers New Zealand is looking forward to meeting the new Minister of Health, Hon Tony Ryall and other relevant Ministers in the National-led Government.

These meetings will be another opportunity to promote the 2008 Economic Impact of Dementia in New Zealand Report which provides the definitive data about people with dementia in this country. We will be urging the new Government, Ministries of Health and Social Development to consider the impact of dementia on people's lives and to plan for the future.

Prior to the Election, the Hon Tony Ryall wrote an article for Alzheimers News (unfortunately arriving too late for publication) outlining the state of the current health system, with a particular focus on what the National Party would deliver for the Health sector, particularly those living with dementia and their carers.

We thought it was timely to consider some of the points from the Minister's article, particularly around the state of the health service and National's solutions.

The Minister offered a number of solutions for those living with Dementia. These included placing more emphasis on achieving the priorities of the Carer's Strategy, through providing more information and awareness of dementia, protecting the health and wellbeing of carers and providing training and pathways to employment for carers.

Another point was National's plan for respite care with the expansion of the availability of dedicated respite beds for those with dementia within the aged-care and health sector.

Two other promises made by National in the lead up to the Election were:

- Increasing the funding for subsidised medicines by an extra \$180 million over three years and improve New Zealander's access to medicines.
- A boost in funding levels for the Aged Care Sector which includes \$18 million to retain aged-care nurses and \$5 million for respite care.

All these issues are very important to Alzheimers New Zealand, our member organisations and the sector as a whole. We will keep you updated on the new Government's progress.



Alzheimers New Zealand's Conference

People, Policy, Partnerships is the theme of Alzheimers New Zealand's conference to be held in Wellington on 6-8 May 2010.

The conference will provide a platform for discussions around a number of key areas and will bring together an impressive line up of speakers from New Zealand and around the world. Other speakers will include people living with dementia who will share their stories and experiences with conference delegates.

Conference organisers, Conferences and Events, will be working closely with Alzheimers New Zealand to ensure the event is successful and furthers our mission statement "making life better for all people affected by dementia".

Anyone wanting to attend this conference is encouraged to start planning for it now. More information will be published on the Alzheimers New Zealand website over the coming months and regular conference updates will feature in future editions of Alzheimers News.

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Chairperson's Report



At the October meeting I accepted the Board's nomination to serve as Chair until the next AGM. I will work hard to justify their vote of confidence in me.

There are exciting times ahead as we see the Economic Impact of Dementia Report being used as a key document at an external reference group for

the Ministry of Health. It is good to see it becoming a living document within the halls of power!

We also go into full planning mode for our next conference in May 2010. Our conference committee will be providing regular updates and calling for speakers.

Our TV ad campaign finally began in mid October, somewhat later than we had hoped. As expected, responses have been varied and I want to express my special thanks to the People with Dementia Reference Group who were so positive in supporting the Board's decision to go ahead with this campaign. It was obvious that this younger group, (many of whom have been involved with presentations at our conferences), wanted the issues of early onset Alzheimer's Disease out there in the public arena.

We also received feedback from other people affected by dementia and, if they would like to be part of our external reference group, they should contact their local member organisation and put their names forward.

One of the key areas the Board is looking at is how the present economic climate will impact on not-for-profits. The financial downturn will be felt by carers if there are employment issues and will create additional stress.

I know that we, and our member organisations, will do everything we can to help all those affected by dementia through these difficult times.

Colenso creates television advertisements for Alzheimers NZ

Earlier this year Alzheimers New Zealand accepted a generous offer from Auckland advertising firm Colenso BBDO to produce a range of television advertisements to raise awareness of Alzheimers amongst the general public.

The advertisements were screened on TV1 and TV3 throughout October and so far, have been met with mixed feedback from people living with Alzheimers, their carers and general members of the public.

Colenso BBDO were asked to create an advertising campaign that raised awareness of Alzheimer's Disease and alerted people to the early signs of this form of dementia.

The Board is saddened by the resignation of our National Director, Lucille Ogston. Lucille has been with us for nearly two years and her first task was to ensure our 2007 conference went smoothly. This year she organised the launch of the Dementia Economic Impact Report which went without a hitch. Lucille's work with the media gave us unprecedented coverage during awareness week.

Lucille has a great gift for building strong relationships and she will be missed by us all.

Lastly, on behalf of the Board, I wish you all a safe and Happy Christmas and New Year.

Dr Bryan Bang

Dr Bang resigned from the Alzheimers New Zealand Board in October. I would like to acknowledge the work that Bryan did in the 18 months he spent as a Board member.

Bryan's contribution to the Board stretched over a multitude of subjects and his input enabled us all to have a better understanding of legal and constitutional issues. Bryan was always able to keep the Board Meeting flowing smoothly by not only his skills as Chair, but also bringing a little light relief with his amusing little anecdotes. The Board and staff at National Office send our warmest wishes to Bryan and Elizabeth. I'm sure that we will all catch up with Bryan at the next AGM.

Eileen Smith
Chairperson

COLENZO BBDO

The partnership resulted in the advertisements telling emotional stories of people with Alzheimers, targeting middle New Zealanders who weren't aware of the disease.

The three television advertisements that were produced showed different every day scenarios; one showed a woman forgetting where her car was parked, the second portrayed a man in a shop who becomes disorientated and confused, he doesn't remember why he is there. The third execution in the series featured a man in a restaurant who didn't recognise his wife.

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National Director's Report



With the front page of nearly every newspaper and magazine full of financial doom and gloom at present it's great to be able to start this report with some positive financial news. The Summerset Group has agreed to become a sponsor of Alzheimers New Zealand for 2009. The main focus of the sponsorship agreement will be Summerset's commitment to raising money during the 2009

Alzheimers Awareness and Appeal Week through staff and residents promotions. Thanks Summerset – especially Tristan and Amanda. More details on page five.

It's hard to know how a voluntary organisation like ours might fare in the next eighteen months. We need to keep our brand visible, build on the relationships with our membership and supporters, funders and sponsors and continue to offer invaluable support to the many people living with dementia in this country. Alzheimers New Zealand will continue to watch for any opportunity to strengthen the financial base for its member organisations as well as for itself.

Following the recent change of government, Alzheimers New Zealand will be meeting with the relevant ministers and policy makers in the new National Government as soon as possible and will continue to press for a nationally-coordinated dementia strategy. We will also be taking every opportunity to talk with these people about the quantity and quality of work undertaken by Alzheimers New Zealand member organisations around the country.

We are delighted that Nicky Wagner, National List MP for Christchurch Central, has agreed to take over from the

retiring Member of Parliament, Marion Hobbs, as facilitator of the Parliamentary Friends of Alzheimers Group.

It's great to see two pages in this newsletter highlighting some of the celebrations our member organisations have had this year. We could have filled the entire sixteen pages with stories and pictures of the work going on around the country. Many of our groups are coming of age – not just in numerical terms – but in terms of the comprehensive support services offered to people living with dementia. Many of these member organisations are providing this on a financial shoestring.

This is my last report as National Director for Alzheimers News. After nearly twenty years involvement – initially with Alzheimers Canterbury and then National Office – it is time for me to have a change. One of the joys of working for this organization has been meeting the people who want to support us. Two groups of people come to mind instantly. The medical experts – where else in the world would you be able to personally contact a world renowned medical advisor by telephone and receive an instant response to a question about dementia? The other group is the people in the commercial sector. They too, enthusiastically offer our organization so much. We need to keep these relationships strong.

I will always follow the progress of the member organisations with interest; you do indeed "make life better for all people affected by dementia".

Lucille Ogston
National Director

Be careful this Christmas

Christmas is the time of year where opportunist thieves are at their sneakiest, and often take advantage of vulnerable people. We want to remind everyone not to give personal details or pin numbers out to anyone over the phone or in person who claims to be from

a bank or similar organisation. If someone asks for personal information, ask for their company details, say you will check with the company and call them back. If you suspect they aren't who they say they are, stop the conversation and call the police.

New website on its way

Work on Alzheimers New Zealand's new-look website is underway. The site will be launched soon and will be a one stop shop for anyone looking for information, advice and support relating to dementia.

The site will also have information on Alzheimers New Zealand's 23 Member Organisations as well as links to relevant national and international websites.

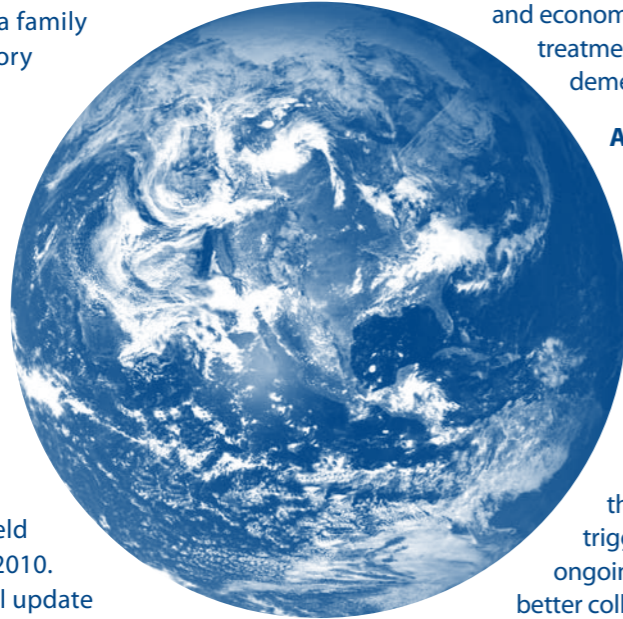


The World in Brief... Global interest in risk reduction

Alzheimers Foundation of America: A new initiative to assist with the early detection of Alzheimers was launched by the Alzheimers Foundation of America (AFA) last month. Free memory testing was offered by the Foundation to adults at 2,000 sites across America who had memory concerns and a family history of Alzheimers. The memory testing establishes a baseline score for future comparisons for screening. The testing is aimed at promoting early detection of memory problems so people can seek the appropriate intervention.

Greek Association of Alzheimer's Disease and Relative Disorders:

Greek Association of Alzheimer's Disease is hosting ADI's 25th International Conference to be held in Thessaloniki, Greece in March 2010. Experts from across the globe will update Conference delegates on achievements in the medical field, new and innovative research and best practice in dementia care.



Singapore Alzheimer's Disease Association: ADI's 24th Annual Conference "Dementia: Engaging societies around the world" will be held next year in Singapore. The conference, taking place over a 4 day period from the 25 – 28th of March will focus on a range of issues including the global and economic impact of dementia, emerging treatments for Alzheimers and ethics in dementia care.

Alzheimers Europe: Alzheimers Europe welcomes the decision by the Council of European Union to make Alzheimer's Disease a European health priority. The council adopted a common commitment by member states to combat diseases such as Alzheimers. The council committed to 6 points of action in relation to Alzheimers, including the need to better understand what triggers Alzheimer's Disease, provide ongoing support for community initiatives, better collaboration with researchers across Europe, the creation of European initiatives to address neurodegenerative diseases such as Alzheimers and the creation of research and development strategies.

Summerset Supports Alzheimers New Zealand



Summerset is a subsidiary of AMP Capital Retirement Properties Limited and is one of the top three retirement villages in New Zealand. This company has agreed to become one of Alzheimers New Zealand's principal sponsors for 2009 which is great news for us. The sponsorship has broad benefits for the organisation, with a clear focus on help with fundraising.

Summerset has twelve villages either fully completed or under development in the North Island. However Summerset's plans for growth include several villages under consideration in the South Island. In all, Summerset offers a welcoming home to over 1400 New Zealanders, in modern, purpose-built rest home or hospital facilities.

Summerset's CEO, Norah Barlow, is President of the Retirement Villages Association.

Summerset is notable for its philosophy of consideration and care. As Norah Barlow puts it, "we aim to create villages where warmth and welcome are tangibles, where we would be happy for our parents to live."

These sentiments are more than a mindset, as they have practical ramifications too. "Our villages are modern – the first was built in 1997 – with consideration for every aspect of an elderly person's life. Wherever the individual may be in the continuum of care, we want to see them enjoying a high quality of life and respect."

If anyone would like to talk to Summerset, and find out what each village has to offer, please call **0800 786 637**.



Sparking conversation – tips for talking to people with Dementia

Over the Christmas and holiday period, family and friends will be visiting and

those not used to living or caring for someone with dementia may find it hard to engage them in talking about everyday things and occurrences.

To engage someone who has dementia in a conversation, start off by carefully selecting an object for the person that has a pleasant association or sentimental value. This sparks the emotions or stimulates the senses. These objects could include such things as a special piece of memorabilia or a family photo.

Other tips for sparking conversation with someone who has dementia are:

Using the selected object, ask the person an appropriate question about the object; this can include such things as:

- **What does the object say to you?**
- **What are your thoughts when you see this?**
- **What are your thoughts when you feel this?**

Only ask one of these questions, and make sure it's the most

relevant for the situation, and then wait patiently. It's when you ask these types of questions, you set the person up for success because no matter what the answer is, it's going to be correct.

Questions to avoid in a conversation with someone with dementia include:

- **"What is this?'**
- **"Who is this person in the picture."**
- **"Do you remember...?" or worse "Don't you remember"**

Questions like these only set the person up for failure. They ask for facts stored in the memory and this is the very area that is the most challenged in people who have dementia. They are usually acutely aware that their memory is failing and therefore simply give up and will not even try to answer.

In contrast, by using questions such as "What are your thoughts...?" can make the visit a warm and rewarding experience for both parties.

Source: Jane Verity, Founder and CEO Dementia Care Australia

continued from page 3... *Colenso creates television advertisements for Alzheimers NZ*

Popularist/candid camera style humour was used to capture attention. Having Alzheimers, and the behaviour that is exhibited was likened to having a trick played. This analogy was used to demonstrate how it feels, the confusion and uncertainty in that moment. In its simplest form we showed people forgetting. The audience were engaged with what they believed to be a funny, candid camera type situation, but then they were hit with an impactful twist, that in fact there is nothing funny about being someone in that situation, confused and disorientated.

The stark and obvious contrast between the humour and the reveal, left the viewer with the emotional realisation of what Alzheimers is. The music subsides, we focused on the reaction of the person with dementia, then the line was revealed. 'When you live with Alzheimers your mind plays tricks on you every day.'

The television advertisements were played on the major

television networks who generously donated airtime to the cause. There are many wonderful people who made these advertisements possible with a special thanks going to Plaza Films, the Production Company who donated a huge amount of their time and resource to the project.

It has been an emotional journey of discovery and understanding for Colenso-BBDO. It's hugely emotive, engaging and powerful advertising. The agency is incredibly proud of the work, and of the client for understanding the need and value in a creative advertising solution that stood out and created real emotion. The work has been seen and regarded by people around the world who have seen it online, from New York to Australia and London. Alzheimer's New Zealand has made an impact, and has taken a step forward to being recognised and understood in the hearts and minds of New Zealanders.

Gemma Findlay, Account Director, Colenso-BBDO

Air Travel

As the holiday period draws nearer, many of you will be getting ready to leave your homes to go away on holiday. To make sure you're well prepared for your holiday travels, Dr Chris Perkins, a member of the Medical and Scientific Advisory Group of Alzheimers New Zealand, has produced some helpful tips for travelling by air.

New Zealanders like to travel a lot! About 25 per cent of our citizens over 65 were born overseas and often want to return home, perhaps for one last visit. Once they have a diagnosis of dementia, people in the early stages of the disease will be keen to live life to the full and this is likely to involve travel.

Leaving New Zealand usually involves flying and most trips are long, involving many time zones and stopovers. This is stressful for most people, but may be more so for the person with dementia and their companion.

There is very little published literature about flying with dementia. However, one study of medical emergencies on flight (Dowdall 2000) made no mention of dementia. Psychiatric problems, mainly anxiety and phobias were fifth on the list.

The information in this fact sheet comes from local focus groups (Whakatane, Tauranga, Hamilton), New Zealand expert opinion and the small amount of published data is available internationally. Geraldine Hancock, psychologist, Tauranga did much of the work. We are grateful to geriatricians, old-age psychiatrists, airline and travel doctors for their input.

Flying itself does not seem to be a major problem, but the rituals of getting on and off planes, arriving in strange places, eating and sleeping at odd times, multiple changes and fatigue can be challenging. Despite this, people with mild to moderate dementia seem to be able to travel successfully, especially if they are used to air travel and are going to familiar places.

Considerations before travel

First you need to consider whether you really want to travel. Have previous trips with the person with dementia gone well, or has it been difficult for them to leave familiar surroundings? How do they cope now when away from home? It may be a good idea to go away for a local trip and see how things go after three or four hours in the confined space of a car or a bus and staying in strange accommodation. It might be better for the carer/spouse or partner to go away alone or with someone else rather than not enjoying a trip with someone who soon forgets all about it. Most family members we spoke to felt they could judge accurately whether the person with dementia was capable of travel, but if uncertain found it helpful to talk with someone who knew the person well.

The person with dementia should be in the best possible physical and mental health before travelling. People should never travel with unstable or untreated behavioural or psychological symptoms; they will only get worse. Don't leave it too late. People with advanced dementia don't travel well.

Planning the journey

You cannot do too much planning. Make sure the arrangements are watertight at all stages, especially at the other end of the journey; pre-book pick-up arrangements at the destination airport. Ensure that the person with dementia knows what is happening and carries an itinerary with them. Fill in forms before getting to the airport. Have a back-up plan if the person gets lost.

Maximum air travel time should be 3-4 hours (avoiding long-haul flights if possible) with about 3 hours time difference to prevent jet lag.

It is best to travel during daylight. Our advice is to start fresh in the morning after a good night's sleep, perhaps at an airport hotel, rather than spending all day getting organized and collapsing exhausted on the plane. Plan to sleep at the destination and have the person with dementia take a sleeping tablet if the GP recommends this.

The Travelling Companion

It is vital to travel with someone, even if dementia is only mild. The most disastrous tales we heard were of people with dementia being put on a plane in one country, but getting confused somewhere on the way and becoming distressed or lost before they got to their destination. It might be better to have two traveling companions, one to stay with the person with dementia while the other gets the luggage or goes to the toilet. Sometimes people with dementia forget they are meant to be waiting for their companion to come back and go off in search of them.

The most useful quality in a traveling companion is the ability to stay calm under all circumstances! Staying with understanding friends at the other end can make it much more relaxing for everyone.

The Airline

Airline staff really only need to know about the condition if there are likely to be problems interfering with self-care or causing stress to others. Pre-book assistance if the person with dementia is travelling alone. However, people who had travelled unanimously agreed that the airline staff were very helpful. If you can afford it, travel Business Class where it is quieter and there is more room and attention given.

Ask for an aisle seat, close to the toilet if necessary. Get on first and get off last. Sometimes a wheelchair reduces tiredness and discourages wandering. You will need to book this before the flight. The airline staff, if informed, will help you to avoid queues.

Avoid "air-terminal stress"

Make sure you have easy connections - no rushing through the airport - between flights and as few connections as possible. Do not travel with a group as it is difficult to keep

up. Spend time in the quiet parts of the airport such as the Business Lounge or the chapel. Some people use earplugs or a walkman to reduce the noise. Turning off hearing aides at take off has been suggested (Louw & Chan 2002).

Information

The person with dementia should carry their own and their companion's details, home address and where they are staying on arrival. Carry a doctor's letter with clinical information about general health and medications as well as the dementia, including how to contact the doctor; email, phone, fax. If you have prescribed medication for emergencies (e.g. for agitation) make sure you have instructions on how to use it.

Medical

Learn to recognise delirium (acute confusion) and know how to prevent it. You may need to get some education from healthcare staff before you go. Common causes in this situation are dehydration, alcohol, lack of oxygen, lack of sleep or sensory overload. Check with your GP whether the person with dementia would benefit from supplementary oxygen.

On the plane

Follow the usual rules for healthy flying. Make sure you and the person with dementia drink plenty of fluids. Avoid alcohol; it dehydrates as well as increasing confusion in even small amounts, especially at high altitudes. Eat regularly. Hunger may cause the person with dementia to get agitated or restless. It is a good idea to take supplies of food and fluids in case there are delays to the flight or serving meals.

On a long flight, exercise around the cabin will reduce physical discomfort and DVT risk. While flying it is recommended to wear elastic stockings and/or take aspirin to prevent DVT. Leaving one watch set at home time will ensure medication is taken at the correct time. On the plane the toilets are too small for two people, so the person with dementia will need to be able to manage for himself.

He / she may get lost on the way back to the seat. Flight assistants cannot assist with meals, personal hygiene or the administration of medication.

On arrival

The airline may be able to assist you to get quickly through immigration and customs. A strange large airport can be disorientating for anyone but may be particularly difficult for the person with dementia. You need to make sure they keep up with you. We heard of one man who walked away while his wife was watching for the suitcases on the baggage carousel.

Travel Insurance and fitness to travel

Travel insurance does not cover dementia per se, but is usually sufficient for medical illnesses that may occur in addition. The airlines ask that people with conditions that might make flying problematic be reviewed by their GP. If the GP has concerns, they fill in a form that is sent to the airline doctors to review. The main psychiatric concerns are phobias and unstable psychiatric problems which could pose a hazard to other passengers.

Summary

Long-distance travel is possible for people with mild-moderate dementia. However, it requires careful planning to ensure that it is enjoyable for the person with dementia and their companions. *Bon voyage!*

References

- Louw, D. and Chan, D. (2002) *Air travel and older people Age and Ageing* 31: 17-22
Dowdall, N. (2000) "Is there a doctor on the aircraft?" *Top 10 in flight emergencies British Medical Journal* 321:1336-1337



Global Charter helps make Alzheimers a world-wide issue

ADI launched their Global Alzheimer's Disease Charter on World Alzheimer's Day this year. The objective of the Charter is to bring Alzheimer's Disease onto the world stage to ensure international and national action is taken to make it a health priority around the world.

Promotion of the Charter aims to increase respect for people with dementia as members of the community and argues for appropriate access to health and social care. The plan recognises that the role of family carers is important and families need to be supported.

By supporting the Charter and signing the petition you will be helping to raise awareness about Alzheimers and the care needs of the 30 million people world wide who have dementia. Since the launch there's been over 2000 signatures collected, however, more are needed to reach the target of 10,000 by March 2009. So far New Zealand is number 20 on the list of countries taking part. To help ADI reach their target of 10,000 signatures, encourage your friends, families, workmates and neighbours to sign the charter at www.globalcharter, and help make Alzheimer's Disease a global health priority.

Member Organisations celebrations during 2008

This year has been a busy year for Alzheimers New Zealand's 23 Member Organisations. Below are some of their achievements.

Alzheimers Auckland



Dr Chris Perkins hosting one of two public seminars in Auckland.

To celebrate World Alzheimer's Day this year, Alzheimers Auckland asked Dr Chris Perkins to host two public seminars to help with raising community awareness about Dementia. The seminars entitled 'An Overview of Dementia in New Zealand' addressed some of the challenges and issues associated with dementia, including the benefits of early diagnosis, care-giving and de-stigmatisation of the disease.

Alzheimers South Canterbury



Alzheimers South Canterbury staff and members spread the word at their country stall

World Alzheimer's Day was celebrated in South Canterbury with a stall at the local country fair. Members sold salads and other food made by committee members and volunteers. The stall was a good opportunity to promote their organisation and the healthy eating message.

Alzheimers Hastings



Alzheimers Hastings Mountain Climb

Alzheimers Hastings has had a busy 2008. A number of events were held during the year including a mountain climb, the annual golf tournament and a move into a new building. The mountain climb raised \$1700 for World Alzheimer's Day and the golf tournament raised an additional \$20000.

Alzheimers Taranaki



Members in the "Cuppa for a Cause" campaign in Taranaki.

Awareness and Appeal Week in Taranaki this year was a huge success due to the enthusiasm of the volunteer collectors, people supporting the national "Cuppa for a Cause" campaign and local residents and businesses. The Taranaki Daily News and Midweek newspaper provided support throughout the week.

Alzheimers Manawatu



Residents outside the newly opened extension

During the year, Alzheimers Manawatu, held the official opening of the Marion Kennedy Day Centre extension in Palmerston North. The extension would never have been achieved without the support and financial help of local Alzheimer's members, community groups and funding organisations.

Alzheimers Tauranga



Alzheimers Tauranga staff

Alzheimers Tauranga celebrated the opening of the organisations new centre in August. The new building has four separate offices and a large lounge for meetings. Many local dignitaries attended this special occasion.

Alzheimers Nelson



Members from Alzheimers Nelson

Restructuring has been the focus of Alzheimers Nelson during the year. The management structure of the organisation changed to a governance structure and has allowed planning to take place for the creation of a strategy and business plan. A special AGM was held to approve the changes and local members accepted the way forward for Alzheimers Nelson, 25 years after the organisation's inception.

Alzheimers Whakatane



Alzheimers Whakatane members cutting the birthday cake

Alzheimers Whakatane celebrated 20 years of operation with a fantastic birthday party. Peter McRae, as Master of Ceremonies introduced original and former committee members and staff. A very special afternoon enjoyed by all.

Meaningful Activity

Richard Taylor is an American living with dementia. He regularly produces a newsletter focusing on the day to day challenges people with dementia face and often speaks out about the advice medical professionals give to caregivers regarding activities for people with dementia.

Alzheimers New Zealand is grateful to Richard for allowing us to print extracts from his newsletter in this magazine.

"Meaningful Activity in the daily life of someone living with dementia is important. The professionals advise our caregivers to help the person they are caring for to find a new hobby, volunteer somewhere doing something, fold and refold all your socks and towels, play Bingo with others or other meaningful activity.

"What about jogging, or writing 500 times: 'I've lost interest in life, especially my own life. I'm scared; I'm lonely' I sarcastically reply."

Why don't "they" (whoever "they" maybe in your life) get "it"? When you leave your job, you can't drive, you must of necessity ask for help doing things you did by yourself in the recent past – when this cosmic convergence of restraints comes into your life following the words "You have dementia, probably of this or that type" you (we) lose our sense of purpose. Our reason for waking up in the morning, and staying awake all day sometimes quickly, sometimes slowly, but always inevitably erodes and eventually disappears. Our reason for feeling good about ourselves, the reason for working at staying alive, fulfilled, growing and fully being, goes away.



Richard Taylor

Please spend a little time engaged with people with dementia helping us figure out what are the elements of our purpose (new and/or old), and how we can participate in activities that fulfil our need to lead purposeful and joy filled lives. Thank you very much!

Source: Richard Taylor's May 2008 Newsletter

Research investigating oral health issues affecting Māori with dementia and their whānau



Dr. Jean Gilmour

E rau rangatira mā, tēnā koutou katoa.. Alzheimers New Zealand is working with the Eru Pōmare Māori Health Research Centre to identify oral health issues affecting Māori with dementia and their whānau. The Eru Pōmare Centre has a research grant from the Health Research Council and the Ministry of Health to establish oral health research priorities for Māori with

low incomes, with disability and older Māori. The oral health needs of Māori with dementia is included in this research as international research has established that the oral health of people with dementia is worse than those without dementia in both the community and in residential care.

The research will start in 2009 and once the project has ethical approval, a survey will be sent to all member groups

about oral health issues for people with dementia. Whānau will be interviewed about their experiences and issues in relation to oral health and dental care services.

This project provides the opportunity to raise awareness of oral health issues for Māori within the organisation and develop oral health educational resources for whānau caring for people with dementia. The issues for Māori with dementia are also likely to be relevant to other people with dementia and their families. Alzheimers New Zealand will be contacting member groups for expressions of interest in being involved with the project. There is funding to cover member groups costs with assisting with the whānau interviews. The Eru Pōmare Centre will lead the ethical approval process for the project and Dr Jean Gilmour from Massey University will lead the development of the survey tool and qualitative interview processes. Please contact Alzheimers New Zealand National Office or Jean Gilmour (J.A.Gilmour@massey.ac.nz) if you want more information about the project or are interested in being involved.

Recession impacts Not for Profit Sector

In this time of global recession everyone feels the financial impact. We asked two people involved in the finance and volunteer arena for their views.

For economists, a recession means the economy has shrunk by two quarters in a row. For every one else it means something a lot more personal and involves greatly reduced business profitability, possible closure of business, job losses or reduced wage growth over time, and part-time work.



Tony Alexander, BNZ Chief Economist

When confronted with reduced revenue and profitability, the reaction of most businesses is to cut back on their discretionary spending. For many, this will take the form of delaying planned capital expenditure, reducing inventories, rationalising product lines and running a fine tooth comb through expenses. This is where an impact on the non-profit sector can start to show up.

Businesses will look to cut back on their advertising and marketing efforts and there is a tendency to cut sponsorship as well. The key point to note, is that a lot of the spending cutbacks are temporary and when they happen they make the downturn in the economy worse. Once economic conditions start to improve, re-establishing these expenses tends to boost growth in the economy quite firmly.

This suggests that most non-profit organisations should anticipate some extra questioning from businesses about the value to them of their sponsorships over the coming year. The challenge for the receiving organisations is to retain the existing arrangements where possible and if not, then to focus on maintaining contact during the period of weak business revenue growth to assist with re-establishing the relationship once economic conditions improve - which in this case probably means 2010.

The same applies for individuals who will look to cut expenses as their job security declines. This mainly means fewer purchases of houses, cars, appliances and furniture. But it also means donations are likely to be cut. The challenge here for non-profit organisations is probably the same as the one facing retailers, and that is to maintain brand recognition during a period when responsiveness to marketing is probably going to be relatively low. This is vital because eventually consumers will once again open their wallets (probably 2010), and it will be those brands that have maintained awareness in the minds of consumers that are most likely to benefit. The trick is figuring out the most cost-effective way of maintaining this brand awareness during a period when revenue may be restricted.

Writing this the week after the US and NZ elections is an interesting experience. When we consider the wider environment, it is even more challenging. International financial insecurity and falling economic markets, as well as the realisation of impacts of climate change and peak oil are raising fundamental issues we have been avoiding for a long time. It feels like we are on the cusp, and possibly at the mercy of significant changes. So what does this mean for voluntary organisations?



Tina Reid, Executive Director, New Zealand Federation of Voluntary Welfare Organisations.

I hazard a guess that we will hang on – resilience and persistence are hallmarks of the sector that are long proven. But we need to consider what is involved in achieving this – and ensure we are using the resources we have as wisely as possible. We need to prepare ourselves to manage increased demands in these insecure financial times. It is essential also that we be visible and speak up – and ensure we are engaged with each other and other sectors. We have considerable experience and insight to bear in being part of the solutions rather than the problems.

Firstly there are obvious impacts for our clients – if the forecast increases in redundancy and unemployment do eventuate, we can expect to have more clients calling at our doors. So there will be more need for the full range of social and welfare services in our communities. There may also be more skills on offer voluntarily – to operate support services and run Committees.

Many organisations, and particularly funding Trusts, rely on investment income – and returns are at an all time low. There will be less income for many of us, and Trusts will have an even harder job making their funding decisions. So many organisations will have reduced income. Unfortunately, income from gambling sources may well not be affected in the same way – consider that this year's Melbourne Cup betting from New Zealand alone was reported as up on the previous year's figure. Now that could be considered just a break from the doom and gloom, but more conspicuously, a few weeks ago, the whole of New Zealand invested \$33 million in one week, chasing the largest Lotto prize since it began. This activity will inevitably add up to increased gambling revenue. Expectations of Government support and funding for our activities need to be renegotiated in an entirely new Government. The National Party have acknowledged

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Caring for the Carer this Christmas

The physical and emotional demands of caring for someone with dementia can be high and often increase throughout the Christmas and New Year periods with the added demands the season brings.

Therefore, it is important if you're caring for someone with dementia that you take some time during this busy season to look after yourself or these demands will wear you down and make caring for a person with dementia even more difficult.

Stress can be heightened during the Christmas season and while everyone handles it differently, it's important that stress is managed effectively.

Some options for dealing with stress include:

- A consistent schedule can make life easier when living with a person with dementia.
- It often helps to remember you're not alone. Ask friends and family members to help out during the Christmas period. Alternatively contact support agencies such as Alzheimers New Zealand's member organisations who can provide you with practical advice and support.
- Learn as much about dementia as possible and encourage friends and family to do so as well.
- Understand that a person with dementia is not being difficult on purpose, rather their emotions and behaviour are affected by dementia.
- Look after yourself by looking after your diet, get regular exercise and maintain social contacts and lifestyle.
- Be realistic about what you can expect of yourself, and recognize that taking care of yourself is better for everybody.

It's important during the Christmas and New Year period to continue with the activities that you enjoy throughout the rest of the year. Some people say they feel guilty when they leave the house, or enjoy an activity without the person with dementia. However, families and carers have a right to



follow their own interests outside their caring role. In fact, it's essential that they do to help manage personal stress. Someone who has regular breaks will be a better carer.

If you are having trouble coping with the additional stress Christmas brings, or with feelings of guilt about having time away from the person you are caring for, it is a good idea to talk these feelings over with a supportive friend or relative.

Taking care of yourself means asking for help now and again, as well as planning ahead for what help you may need in the future. Help often, but not always, comes from relatives, friends and neighbours. It's a good idea too, at times of high stress, particularly at this time of year, to seek outside help.

Some ideas to use when asking for help include:

- Make it an aim to share the care of the person with dementia.
- Don't hesitate to ask for help.
- Suggest specific ways that friends and family can help, such as bringing a meal or helping with the housework or shopping.
- Organise regular breaks for yourself. A friend or relative may be able to care for the person with dementia on a regular basis so that you can have a few free hours.
- Use the services of Alzheimers New Zealand member organisations and other support agencies in your local area.

Caring for someone with dementia can be difficult, and is made more so with the pressure of Christmas. Remember to look after yourself, ask for support from friends and family if necessary, and for further advice and support, contact Alzheimers New Zealand or one of our local member organisations.

Source: Adapted from Alzheimer's Australia.

Changes to Enduring Power of Attorney Act

There have been recent changes made to the Enduring Powers of Attorney (EPA) Act. The EPA is a legal arrangement where you (the donor) can appoint another person to act on your behalf, if for example you go overseas or lose the capacity to make and understand the consequences of decisions.

An EPA continues to operate or only comes into effect should you become mentally incapable.

There are two types of EPA, the first is a Personal Care and Welfare EPA, this is where one person is appointed as your attorney to make decisions about your personal care, including deciding what rest home is appropriate, or what general medical treatment you should have. They cannot make decisions relating to marriage or divorce, refuse consent to standard or life-saving medical treatment like a blood transfusion, or consent to medical experimentation.

The other type of EPA is a Property EPA, this is where an attorney is appointed to manage and make decisions about your property, which includes everything from your house and land to businesses, bank accounts, life insurance, shares and all other possessions such as furniture and jewellery. This could also include how to invest your assets, what to spend your money on and decisions about your house.

Important changes were made to the Act in September this year, these include:

- A clearer definition of mental incapacity in relation to personal care and welfare enduring powers of attorney.
- Strengthened witnessing requirements when setting up an enduring power of attorney.
- New duties on attorneys to consult with donors and act in donor's interests as well as restricted ability for attorneys to benefit themselves or people other than the donor.

Most of the changes apply to all EPA's made before or after 26 September 2008, however some will not apply to EPA's that are in effect on that date. An EPA costs a fraction of the price of what a court order will cost to obtain and is less stressful than a court order. However, anyone wanting to obtain an EPA should consult with their lawyer in the first instance.

More information on the Enduring Power of Attorney Act can be found on the Office of Senior Citizens Website - <http://www.osc.govt.nz/enduring-powers-of-attorney/index.html>

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Recession impacts Not for Profit Sector

the role of the sector as providing a huge range of services which could not be provided by Government – although this was not expressed in very clear policy statements. So it is essential that we engage with them to forge the changes that can be expected. We need to plan for change. This means having a hard look at where you are placed going into these times – in terms of your strategic and business planning, your relationships with funders, your staff and volunteer relationships and your ability to respond to change, to take up opportunities and be ready and able to act accordingly.

Become a FANZ

(Friend of Alzheimers New Zealand)

Alzheimers New Zealand relies heavily on the generosity of the community to carry out its mission statement "making life better for all people affected with dementia". Your donation will help to provide the resources and information needed by local member organisations of Alzheimers New Zealand.

If you would like to become a Friend of Alzheimers New Zealand please contact National Office on :

Phone: (04) 381 2362

Fax: (04) 381 2365

Email: nationaloffice@alzheimers.org.nz

Students experience Alzheimer's Disease first-hand

Not for profits, like Alzheimers New Zealand, appreciate any support the community can offer. For example support from YMedia, a youth run social enterprise group with a passion about growing through giving back, enabled Alzheimers New Zealand to have a presence at Massey University, as part of a competition YMedia held throughout July and August of this year.

The competition connected a group of enthusiastic tertiary students with community groups, including Alzheimers New Zealand, with an objective of creating a new, low-cost digital presence for the organisation that could be used for sponsorship while creating awareness of the disease.

The team's objectives were three-fold: to show prospective sponsors the benefits of joining forces with Alzheimers NZ; to raise awareness of Alzheimer's Disease amongst the local community and to encourage the general public and businesses to donate to Alzheimers New Zealand.

Firstly, the group created an online memory game to simulate the frustrations of living with Alzheimers in a game



experience. The memory game is well known amongst the general public; it involves a set of cards laid-out and the person playing tries to pick the pairs based on memory. The game counts down from 25 seconds, and if the game is completed within the time, prospective sponsors will donate 10c to Alzheimers New Zealand.

Secondly, the team created an installation exhibition that consisted of 1000 post-it notes with a wide range of thoughts written on them. These were posted all over a popular stairwell at Massey University used by most students. As people reached the top of the stairs the post-it notes were reduced, with some not having any thoughts on at all. The team placed a sign at the top of the stairs reading "The time that it has taken you to climb these stairs, they may have already forgotten".

At the end of the stairwell, on the doors opening to the café, two signs were placed that had the Alzheimers New Zealand logo, the website and a line that read "Help us make life better for those affected by Alzheimers".

The competition educated the group about Alzheimer's Disease and how it affects those living with this devastating condition.

The Ymedia team (Left to right) John Mazenier – General Manager SunMicro System, Anna Hermann, Jamie Surridge, Richard O'Brien, and Josh Stuart.

Health Education Trust

Health Education Trust is an organisation Alzheimers New Zealand works closely with and whose sole aim is to educate staff who provide care in residential care facilities and home-based support organisations all around New Zealand.

Health Education Trust programmes are produced in Christchurch and used by rest homes, retirement villages, specialised dementia care, nursing bureaus, home care organisations and DHB's. Staff complete the programme with the help of an On-site Assessor.

Health Ed Trust provide three very comprehensive programmes. The first is a practical course aimed at a person who has had no training at all in aged care and some of the 12 topics include understanding the ageing process, personal care, nutrition, medication and basic first aid.

The second programme is the ACE Dementia Series and begins with simple explanations of the different types of dementia, and moves into Person Centered Care, Caring for the Carer's, Managing the Effects of Dementia and Understanding Behaviour. One module requires the caregiver to complete a detailed case study of a person living with dementia.

The third ACE programme is a series of modules that are needed for the caregiver to achieve a Level 3 National Certificate In Support of the Older Person.

More information on Health Ed Trust can be found at:
www.healthedtrust.org.nz

Antipsychotics in Dementia: Best Practice Guide



Dr Chris Perkins has put together an overview of the Antipsychotics in Dementia Best Practice guide for Alzheimers New Zealand

The Guide is produced by BPAC New Zealand an organisation funded by Pharmac and District Health Boards. It is based on clinical recommendations from New Zealand old age psychiatrists (FRANZCP,

Faculty of Old Age) and supported by the (scanty) published evidence in this area.

The over-use of antipsychotic medication in residential care has been a cause for concern both in New Zealand and overseas. This resource, for all those caring for patients with dementia, is a response to this concern. The focus is on the treatment of behavioural and psychological symptoms of dementia (BPSD) and the safe use of antipsychotics in dementia. The "Rationale" section explains that most BPSD are transient and do not need medication: that antipsychotics are often ineffective, have adverse effects, need to be targeted and monitored and should only be used as a last resort if the patient or others are at risk of harm.

BPSD are present to some degree, in more than 80% of people with dementia. The Guide describes what the symptoms are (wandering, calling out, aggression etc.) and their consequences, such as caregiver stress. There are clear instructions on how to assess BPSD with useful tables on causes and aggravating factors. The assessor needs to identify contributing factors, decide which problem(s) to target and attempt to understand why the problem is happening to this person at this time.

Non-pharmacological treatment of BPSD should be tried initially. This includes changing the environment (e.g. moderating noise levels), increasing recreational activities and behaviour management interventions. Drug treatment is often not effective for BPSD; one trial showed that 5-14

people need to be treated for 12 weeks for one additional person to show benefit in aggressive symptoms associated with dementia.

The Guide gives information on drug selection, dosage, maintenance, monitoring and withdrawal if antipsychotics are required. It makes the important point that informed consent should be maintained, from the person with dementia if possible, or from other concerned people. This requires consideration of possible side-effects (including the increased risk of stroke). A section on adverse effects sets out the risks of prescribing antipsychotics in dementia.

There are special sections on Lewy Body Dementia and other drugs used to manage BPSD (mostly unproven and/or with worrying side-effects). Other conditions such as depression need to be treated.

The appendix contains an algorithm summarising best practice prescribing. The first box is:

"Work on developing a shared culture of care that supports best-practice antipsychotic prescribing".

This seems to me to be a vital first step. Residential care providers are slowly recognizing the need for a suitable environment, appropriate activities and trained staff to improve the quality of life for people with dementia. Hopefully this Guide helps to reduce the incidence and severity of BPSD and the reliance on medication.

The report is publicly available on:
www.bpac.org.nz/a4d or by calling 0800 bpacnz

*Dr Chris Perkins
Member, Alzheimers New Zealand Scientific and Medical
Advisory Group*

Emailing Alzheimers News

To reduce our carbon footprint, Alzheimers News can now be emailed out. If you would like to receive an emailed version of Alzheimers News, instead of a printed copy, please send your name and email address to:

nationaloffice@alzheimers.org.nz

Merry Christmas

Alzheimers New Zealand staff would like to wish everyone a very Merry Christmas and a happy and safe New Year. The office will close for the Christmas break on Friday 19th December 2008 and will re-open on Monday 5th January 2009





Alzheimers New Zealand

Making life better for all people affected by dementia
Kia piki te ora mo ngā tāngata mate pōrewarewa

Alzheimers NZ Inc. National Office



Postal Address:
PO Box 3643
Wellington 6140



Ph: (04) 381 2362



Fax: (04) 381 2365



Email: nationaloffice@alzheimers.org.nz
www.alzheimers.org.nz

Physical Address:
Level 3, Adelphi Finance
House,
15 Courtenay Place,
Wellington 6011

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email lucille.ogston@alzheimers.org.nz

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Ashburton

Ph (03) 308 0176
PO Box 305, Ashburton
ashburton@alzheimers.org.nz

Auckland

Ph (09) 622 4230
PO Box 24 237, Royal Oak, Auckland
alzheimers@alzheimers.co.nz

Canterbury

Ph (03) 379 2590
PO Box 32 074, Christchurch
admin@alzcanty.co.nz

Counties Manukau

Ph (09) 576 7776
PO Box 51 291, Pakuranga, Auckland
info@alzcm.org.nz

Gisborne

Ph (06) 867 0752
PO Box 1020, Gisborne
gisborne.alzheimers@xtra.co.nz

Hastings

Ph (06) 878 7502
PO Box 11-103, Hastings
hastings.alzheimers@xtra.co.nz

Manawatu

Ph (06) 357 9539
PO Box 527, Palmerston North
manawatu@alzheimers.org.nz

Marlborough

Ph (03) 577 6172
PO Box 4024, Redwood Village, Blenheim
alzheimersmarlb@xtra.co.nz

Napier

Ph (06) 834 0417
PO Box 4084, Marewa,
Napier
napier@alzheimers.org.nz

Nelson

Ph (03) 546 7702
Community Groups Centre,
50 Halifax Street, Nelson
nelson.alzheimers@xtra.co.nz

Northland

Ph (09) 438 7771
PO Box 1179, Whangarei
northland@alzheimers.org.nz

Otago

Ph (03) 471 6154
PO Box 5304, Dunedin
adards.otago@xtra.co.nz

Rotorua

Ph (07) 349 0053
PO Box 430, Rotorua
alzheimersro@xtra.co.nz

South Canterbury

Ph (03) 684 8824
PO Box 983, Timaru
southcanterbury@alzheimers.org.nz

Southland

Ph (03) 214 0984
Community House, 46 Kelvin St
Invercargill
alzheimers.southland@woosh.co.nz

Taranaki

Ph (06) 769 6916
PO Box 8303, New Plymouth central
adardstaranaki@globe.net.nz

Taupo

Ph (07) 377 4330
PO Box 595, Taupo
alzheimers.taupo@vodafone.co.nz

Tauranga

Ph (07) 577 6344
PO Box 15553, Tauranga
info@alzheimers.net.nz

Waikato

Ph (07) 839 2427
PO Box 5720, Hamilton
waikato@alzheimers.org.nz

Wairarapa

Ph (06) 377 0066
PO Box 865, Masterton
alzheimerswairarapa@xtra.co.nz

Wanganui

Ph (06) 345 8833
PO Box 7018, Wanganui
alzheimers.wang@xtra.co.nz

Wellington

Ph (04) 939 0133
55 Hutt Road, Petone, Wellington
wellington@alzheimers.org.nz

Whakatane

Ph (07) 308 0525
PO Box 13, Whakatane
alzheimerswhakatane@xtra.co.nz



Alzheimers New Zealand Board
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