



Dementia is starting to come out of the shadows

Page 4

'Mr Wonderful'

Page 9

Planning an enjoyable Christmas

Page 6



*Merry Christmas
and a happy New Year!*

Alzheimers News

Published four times a year by:

Alzheimers New Zealand

ISSN 1173 4361

Comments, letters and contributions are welcome but will be inserted at the editor's discretion.

Writer/editor (except where otherwise stated):

Kimberley Ebbett

kimberley.ebbett@alzheimers.org.nz

04 381 2363 / 027 619 1911

Next issue:

Deadline for copy: 18 February 2012

Permission should be sought from the editor before reproducing articles and the source must be acknowledged. The views stated in *Alzheimers News* are personal and do not necessarily reflect the views of Alzheimers New Zealand. Alzheimers New Zealand does not endorse any products or services.

Correction: September Edition (Issue 87)

The September edition of *Alzheimers News*, 25th Anniversary feature (pg 23), incorrectly names Lady Reeves in the caption of the photos. The correct name is June Lady Hillary. We apologise for any confusion this may have caused.



From the Editor

Welcome to the December edition of Alzheimers News.

In this issue we have some helpful tips for a stress-free Christmas.

We profile a novel therapy new to New Zealand that is proving to

be a successful communication tool and we investigate some exciting research projects.

From the team at Alzheimers New Zealand: we wish you a safe and enjoyable holiday season.

4Good!

Four kiwi blokes from Tauranga had an idea to set up a website where the public can donate just \$4 to the chosen charity of the month, simply and easily online! Genius!!

In October Alzheimers New Zealand was fortunate to be selected as the charity of the month and we have received many generous donations totalling \$648 from the website. Thanks 4good! To check out the website go to <http://4good.org.nz/>.

News

Alzheimers Wellington blown away by public generosity

This year it wasn't just the wind blowing our Wellington team away but the generosity shown by the public throughout their annual appeal.

Alzheimers Wellington raised an incredible \$38,000 in their September appeal which coincided with World Alzheimer's Day. This is the most they have ever raised in their 25 years of service and well over twice as much as they had expected.

220 enthusiastic collectors covered 23 sites around Wellington over two days. Alzheimers Wellington manager, Nigel Heard was overwhelmed both by the support from their members who collected and the public who gave so generously in a time of financial hardship.

"The annual appeal was a fantastic effort on behalf of a magnificent team made up of staff, volunteers and members. Thanks to the efforts of our new events group we doubled the number of sites this year and the public responded magnificently given the recession and the Canterbury earthquakes.

"For us the two days were as much about bringing dementia out of the shadows and raising our profile as they were about raising money. However the increased amount will certainly go a long way to assisting in our drive to deliver more targeted services to people with dementia in the Wellington region," he says.

Goodbye to a great patron

It is with regret that we announce the resignation of our long standing patron, June Lady Hillary. Lady Hillary has been a strong supporter of Alzheimers New Zealand and has been influential in increasing our profile in the community.

We extend our heartfelt thanks to Lady Hillary for her support.



Annelies Kamp, Alzheimers Wellington volunteer, collecting at the Wellington Railway station.

Battle of the brains

On World Alzheimer's Day local businesses and Alzheimers Auckland supporters came together for a lively battle of the brains raising a significant \$12,000 for the local organisation.

A quiz night was held at the Hilton Hotel. 270 past and present Alzheimers Auckland supporters enjoyed a great evening of famous Hilton hospitality, and the opportunity to test how well their brains worked!

The evening was thoroughly enjoyed by all who attended.

"There was a wonderful atmosphere with friendly rivalry and lots of fun and, of course, being social and keeping your brain active is good too. The night was a win win for us all." Says Alzheimers Auckland fundraising coordinator, Saatchi Goldwater.

One guest commented: "Alzheimer's is not an easy charity to sell, it's winter and there is the Rugby World Cup to compete with, but you still managed to get a full house and people to have a wonderful evening for a most

Hats ON to Marlborough and Canterbury

Staff and volunteers from Alzheimers Marlborough and Alzheimers Canterbury had a marvelous time in September celebrating Alzheimers Hat Week. This campaign, inspired by Timaru's vintage hat campaign in 2010, proved to be a fantastic way to spread the word about dementia, get younger people on board, and raise donations for the organisations.

Members of the community were sponsored to wear a hat for a week, with all shapes and sizes of hats emerging from wardrobes. The Marlborough team was particularly inspired by Witherlea Primary School's effort. "Every student and teacher came to school wearing their hats with such flair, ingenuity and enthusiasm" says Alzheimers Marlborough office manager, Linley Wetton. "It's not only about educating the children, but also their parents" she adds.

The event was far-reaching, with people on the West Coast taking part for Canterbury. One woman put up her own Hat Day street display in Hokitika and was featured in their local newspaper, raising \$400 for the earthquake-stricken dementia community. "We were so touched at the number of individuals who saw the posters, picked up the phone and asked for their Hat Week kit" says Alzheimers Canterbury volunteer co-ordinator, Heather

worthwhile cause."

Bupa Care Services came on board as the major sponsor, with other sponsors including Progressive Enterprises, Dilmah, Knight Coldicutt, McLeans, Christopher and Banks Private Equity and The National Bank.

Alzheimers Auckland is really looking forward to growing this event and hosting even more businesses next year. If you are keen to take part please contact Saatchi Goldwater or Rosemary Ledingham on 09 622 4230.



Alzheimers Auckland board chairperson Robert Turner welcoming guests.



Entertainer, Gary McCormick, supporting Hat Week

Reeves. "It was lovely to be able to offer a fun and creative project for people to participate in." Some participants in both Marlborough and Canterbury wore a different hat to work every day, including a sombrero and Swiss Army helmet.

The Hat Week and Cuppa campaigns combined raised \$12,000 for Marlborough and \$5,000 for Canterbury. This project has also strengthened the bond between the Marlborough and Canterbury teams and demonstrated wonderful collaboration.

World Alzheimer's Day

Call for early diagnosis and intervention in New Zealand attracts national media attention.

On 21 September you would have been hard pressed to find a newspaper in New Zealand without a story on dementia. Interest from our nation's media arose after the release of a press campaign from Alzheimers New Zealand calling for early diagnosis and intervention of dementia. The national press release was based on the World Alzheimer Report 2011 and revealed some confronting new statistics such as the number of potentially undiagnosed cases of dementia in New Zealand.

"Dementia is starting to come out of the shadows and this is where we intend to keep it."

According to the World Alzheimer Report 2011 only 40% of dementia cases are recognised and documented in countries like New Zealand, meaning 26,473 New Zealanders may have the disease but have not yet been diagnosed.

Without a formal diagnosis people living with dementia do not have access to treatment, care and organised support. This is clearly a major concern, given that New Zealand's population is aging and new cases of dementia and Alzheimer's disease are increasing relentlessly. This created a lot of media attention and Alzheimers New Zealand national director, Johan Vos, was interviewed on Television Three's Firstline news programme, as well as national radio stations: Radio Live, Newstalk ZB, Radio New Zealand and Radio Rhema.

The report was commissioned by Alzheimer's Disease International (ADI), and was the first comprehensive, systematic review of all of evidence on early diagnosis and early intervention for dementia. The report shows that there are interventions that are effective in the early stages of Alzheimer's disease, some



of which may be more effective when started earlier, and that there is a strong economic and social argument in favour of earlier diagnosis and timely intervention.

The World Alzheimer Report 2011 and the number of un-diagnosed cases of dementia in New Zealand was also covered by six national radio stations, two national television programmes, 13 national newspapers and 35 local newspapers and two medical magazines.

"The coverage we have received this year is significantly more than last year, showing that dementia is starting to come out of the shadows and this is where we intend to keep it," says Vos.

The World Alzheimer Report 2011 revealed the following:

- Failure to diagnose often results from the false belief that dementia is a normal part of aging, and that nothing can be done to help. On the contrary, the new report finds that interventions can make a difference, even in the early stages of the illness.
- Drugs and psychological interventions for people with early-stage dementia can improve cognition, independence, and quality of life. Support and counseling for informal carers can improve mood, reduce strain and delay institutionalisation of people with dementia.
- Governments, concerned about the rising costs of long-term care linked to dementia, should "spend now to save later." Based on a review of economic analyses, the report estimates that earlier diagnosis could yield net savings of up to \$12,000 for each person with dementia, potentially over \$31 million in New Zealand.

Local World Alzheimer's Day Events

World Alzheimer's Day activities across the country saw our local organisations engaging with their communities to raise awareness and promote their services. Some organisations incorporated their annual appeal activities into World Alzheimers Day events, receiving generous support and raising vital funds.

This page has a selection of pictures from some of these lively, informative awareness-raising local events.



Volunteers and past mayor of New Plymouth share a cuppa. Alzheimers Taranaki held a World Alzheimer's Day Cuppa for a Cause where they made \$240.00 over two hours.



Alzheimers Hastings held a popular golf day



A fantastic supporter of Alzheimers Marlborough at Witherlea School



Alzheimers Ashburton supporters enjoy a BBQ in the sun on World Alzheimer's Day picture taken by Ashburton Guardian



Alzheimers Marlborough were amazed by the efforts of Witherlea School, who raised \$334 towards their Hat Appeal.



Alzheimers Gisborne staff and volunteers were overwhelmed by the support they got for their World Alzheimer's Day awareness walk.

A warm 'thank you' to all of our volunteers, sponsors, committees, and supporters across New Zealand who helped to make these events so successful.

Christmas – tips to reduce stress

Christmas should be a time to enjoy family and relax. For people with dementia, their carers and families, it can be hard to cope with busier schedules, extra people around and the disruption of routine.

However, Christmas for your loved one with dementia does not have to be stressful with the appropriate planning.

Here is some helpful information to consider when planning an enjoyable Christmas for your loved one with dementia.

TRAVEL

Christmas is a time when many Kiwis travel to be with relatives in other parts of the country or even overseas.

Overseas travel is stressful for all people but may be more so for a person with dementia and their companion.

Here are some points to consider when planning air travel:

PLANNING THE JOURNEY

Make sure travel 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 no more than 3 hours time difference to prevent jet lag. It is best to travel during daylight. Plan to sleep at the destination and, if the GP recommends, have the person with dementia take hypnotic medication.

Ask for an aisle seat, close to the toilet if necessary, and if possible get on first and get off last.

AVOID "AIR-TERMINAL STRESS"

Make sure you have easy connections - avoid the need to rush through the airport - between flights and as few connections as possible. Do not travel with a group as it is difficult to keep up. Try to spend time in quiet parts of the airport, such as the business lounge or the chapel.

INFORMATION

The person with dementia should carry their own and 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. 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. This may require some education from healthcare staff before travelling. Common causes in this situation are dehydration, alcohol, lack of oxygen and sleep or sensory overload.

PEOPLE WITH DEMENTIA VISITING YOUR HOME

Here are a few tips to ensure your home is safe and welcoming for a person with dementia.

- Put labels on the bathroom door and on the person's bedroom door
- Leave the hallway and bathroom light on at night for accessibility
- Keep doors to busy streets locked: if the person with dementia wants to go for a walk, offer to accompany them

Consider anything special which might make life easier for the person with dementia, such as slip-proof mats and larger cutlery. Ask the person's

carer if you need to provide anything special and whether you will need to help them take medications

- Have a room in the house where people can get away from noise and large groups
- Make sure there is nothing to trip over in hallways or stairs

PREPARING FOOD

If you have prepared a meal for a person with dementia and they haven't eaten it, don't fret. It might be easier if you put small amounts of a variety of foods on the person's plate and offer them more when they have finished eating. Try not to make your guest the centre of attention in case they feel self-conscious. If the food is getting cold because they are eating slowly, offer to heat it. The person may find it easier to eat on their own, or with their carer. It might help to ask the person's carer if there are any foods their loved one has difficulty eating or doesn't like. Not everybody enjoys rich or spicy sauces or condiments, so serve these as an option.

Contact your local Alzheimers New Zealand organisation for tips about coping during the Christmas period and for their Christmas opening hours.

This article has been based on the Alzheimers New Zealand Information sheet *Travelling With Dementia* – to read the full sheet please go to www.alzheimers.org.nz/resources and the Alzheimer's Society of UK fact sheet, Festivals, holidays and celebrations – to read the full fact sheet go to www.alzheimers.org.uk/factsheet/455

VISITING A PERSON WITH DEMENTIA

By Donya Nee from Admatha Dementia Care
Visit our website for Donya's full article and more helpful advice www.alzheimers.org.nz

1. Be aware of common characteristics of the dementia type your loved one has.

- Being educated may help to relieve any feelings of fear that may exist for you.
- Be prepared to 'go along' with stories positively, rather than arguing with the person if their story doesn't seem logical or relevant.
- Remember the person may be at another time and place in their mind, and confused about who you are. As hard as this can be to accept, remember that their 'happiness in the moment' is what is important.
- Keep in mind that their unusual or 'out of character' comments or actions are a symptom of their dementia.

2. Be self aware.

What we are feeling and thinking is often more apparent to the person with dementia than any words we may use.

- Be in a positive frame of mind when visiting.
- Be prepared to laugh together!

3. Visit in pairs rather than alone.

- Don't hesitate to bring pets or children. It is also good for children to realize that dementia is not a scary thing.

4. Go at the person's pace.

People with dementia often need more time to respond.

- Use slow and gentle motions and make sure you have the person's attention.
- Sit at eye level with the person, use good eye contact.

5. Communicate with staff or carers.

- Try call before your visit. This is a good way to gauge how the person is doing, what time they are most alert and if they are even there!

6. Arm yourself with a 'visiting kit' of ideas and props for activities together.

7. Reminiscing

This is one of the most valuable and meaningful activities for a person with dementia, as often their long term memory remains intact.

- Bring the family photographs. This can trigger memory, which in turn empowers and validates the individual.

8. Learn to be comfortable and adaptable with silence and changes of mood.

Dementia can cause abrupt changes of mood and difficulty in communicating.

- Allow time, be patient.

9. Develop an 'end-of-visit routine'.

- Try to leave at meal times as the person is naturally interested in another activity.
- Ask a staff member or carer for help. They will be able to divert the person gently so that their mind is taken off any negative feelings when you leave.

10. 'Look after you'.

Ensure that you have support to help you process your feelings about the changes you are experiencing, and to arm you with knowledge about what to expect.

- Contact your local Alzheimer's organisation.
- Join a dementia awareness group.



Drama Therapy

Developed in the 1960's, Drama Therapy is an internationally recognised diagnostic and treatment model.

Qualified Drama Therapists are employed to work with a wide variety of people and issues.

In Drama Therapy, clients experience different feelings and emotions by acting out situations. They can experiment with feelings i.e. make them more or less intense. Forms of acting are improvisation; working with scripts, myths and fables; role-play; making up stories and situations; or using real life stories.

In Europe and the USA, Drama Therapy is successfully used in the treatment of dementia. One Drama Therapist and a consultant are planning on bringing this successful treatment to New Zealand and have set up the organisation Drama Therapy NZ.



Drama Therapist Linda French with life size puppets

Drama Therapy and dementia – seeing the results

Linda French and Bas van der Hoeven, Drama therapists from Drama Therapy NZ tell Alzheimers News about their experiences working with a community-based group for people with various degrees of Alzheimer's disease and dementia and the astonishing results the therapy had on the residents.

"Last year we spent one hour each week with a community group for a total of 10 weeks.

The group had people who had early to late

stage conditions. Some had relatively minor levels of impairment, whilst others were completely withdrawn and uncommunicative. One was considered to be very aggressive. Several found movement extremely difficult. Despite the considerable efforts of the staff, most stayed in their chairs and said or did very little.

All had interesting individual stories including some amazing and saddening war stories. Quiet exteriors hid passionate, intelligent, funny, caring people who had strong ideas and beliefs. All were still cared for at home, supported by family and other care-givers.

After a few weeks, people remembered we were coming; discussed what they had done; talked to each other, sometimes for the first time in a long while.

Initially, we did constructed plays with the residents but they needed a lot of help. These were often around shooting "baddies", and surviving attacks. They enjoyed using props after some initial hesitation. Everyone used the large puppets we brought along with imagination and energy, not usually seen.

However, by the end, they were leading the drama activities with their own ideas, participating, discussing, problem-solving. Stories became adventures, firm and positive.

The drama activities are based on their memories - the areas of their lives that are important to them and still vibrant. Using this information, their concerns can be accessed using play.

Communication becomes a non threatening activity. Anxiety and aggression are minimised as a result. Engagement with others becomes enjoyable not worrying. Gradually vocalisation and movement increase. Positive interaction between group members increases, problem solving re-starts. From passive onlookers, group members move to being active participants and leaders. One such story really demonstrates this shift in behaviour:

Mr B is Pacifica and had worked in the Public Service for many years. He had considerable difficulty walking, leaning heavily on a stick, someone supporting him. Despite memory issues, he had many interesting ideas and stories of work life. A leader in his community, he was cared for by his family.

He took part but only in a very quiet way. He always seemed interested and if he did take part had a wonderful creative streak and sense of fun.

He began to take more of a lead role. Things came to an amazing climax. At the end of a story he had created around him being a doctor saving the life of a mother and baby in a storm he announced he wanted to celebrate what we were all doing. He rose to his feet and without his stick or any other help performed a Haka learned in his island childhood. The power and the emotion in the delivery moved everyone."

If you would like to find out more about Drama Therapy please visit: www.dramatherapy.co.nz

Volunteer Profile 'Mr Wonderful'

Every morning the Alzheimers Napier team and members are greeted with a big smile and a "top of the morning to you." This warm greeting is delivered by their dedicated volunteer driver Bryan Wilson, who has been transporting members to and from the Mahana Club for over a decade.

Bryan also looks after the maintenance of all the vehicles and is always willing to help with any handy man jobs which crop up.

Nicknamed "Mr Wonderful", Alzheimers Napier staff say Bryan is always bright and cheerful and highly respected by the team.

"We value Bryan in our team and hope he stays with us for many more years to come. His sense of humour, warmth and affinity with our Mahana Club members and families is very special and appreciated by all who are privileged to know Bryan," say Alzheimers Napier manager Mairi MacInnes.



Bryan says his love of meeting new people and helping others is the reason he volunteers.

We say keep up the great work Bryan!

Bryan celebrating his 10 year anniversary as a volunteer for Alzheimers Napier

A sad goodbye to a very special person

Alzheimers Wanganui is mourning the loss of a special patron and advocate for the organisation. Margaret Story, who died recently at the age of 96, dedicated 25 years to making life better for people with dementia in Wanganui.

Her involvement began in 1986. When caring for her husband, she attended a lecture at the Wanganui hospital after which a staff member suggested establishing a support group for Alzheimer's carers. Margaret was involved from the outset. She traveled to other parts of the country where Alzheimers Societies had been established, to meet key personnel and soon ensured the groups were transformed from their informal beginnings to structured organisations.

In 1990, during her presidency, Alzheimers Society Wanganui was registered as an incorporated society. Margaret was later made a life member of the society and in 2004, she accepted the role of patron, a role she continued to hold until the time of her death.

Alzheimers Wanganui board chairperson, Margaret Campion says Margaret's support of the organisation was invaluable.

"She always took time to talk to people in need of support; remained up to date with developments of the society; supported public lectures and fundraising events and, until last year, regularly attended the organisation's Annual General Meeting."

"We owe a great debt to Margaret. We feel privileged to have known her and we will miss her greatly."



Margaret Storey, long term supporter of Alzheimers Wanganui, will be greatly missed.

A year of achievements

By *Alzheimers New Zealand national director, Johan Vos*

2011 has been a year our entire organisation should be very proud of. While it began so tragically, with the events in Christchurch that touched all of our lives, the hard work and commitment of our teams throughout the country has seen incredible milestones achieved in our twenty-fifth year.

In May we were all very pleased to hear the government's commitment to dementia with the announcement of \$44m of additional funding in the Budget. This was further supported by the Minister of Health, who confirmed his support of a nationwide awareness campaign with \$250,000 of funding. Our friends at Pub Charity also pledged their ongoing partnership to the Dementia Leadership Project and this awareness campaign, and an additional \$643,000 was granted.

Our profile in the community continues to grow with an increase in public seminars held locally and we are seeing a rise in local and national media coverage. I am sure that the launch of the national awareness campaign in 2012 will further heighten awareness of dementia and will go a long way to de-stigmatising all forms of dementia, as will our biennial conference Future Faces of Dementia, to be held in May.

On World Alzheimer's Day (21 September) we launched ADI's World Alzheimer Report 2011 that focused on the benefits of early diagnosis and interventions having health, financial and social benefits. In New Zealand we launched a unique website (<http://facesofdementia.alzheimers.org.nz>) sharing the experiences of those who have journeyed with dementia. This emotive view into the lives of those most affected by the disease further galvanizes our efforts to make life better for all people affected by dementia.

Finally, I would like to thank you for your continued support and interest and hope that you and your family have a safe and happy festive season.



Looking ahead

By *Alzheimers New Zealand chairperson Martin Brooks*

As we approach the holiday season I would like to reflect on the year that has been, and also look forward to and be excited about what lies ahead in the future.

Looking back, I think we can say that we have made some progress in our quest to increase the awareness of dementia both in government and in the community. However we still have some way to go. Even for some health professionals, dementia can be a subject that is not well understood. A recent experience of my own illustrates this: On World Alzheimer's Day I happened to go for a blood test. The phlebotomist asked what the date was, I answered: "September 21, World Alzheimer's Day". Her response was: "I hope I don't forget that!"

Although said as a joke I believe that it showed a complete lack of awareness of the disease and the affects that it has on anybody who has been touched by it.

Internationally we saw the release of the World Alzheimer Report 2011. This document is important in raising the global awareness of dementia. The United Nations summit on Non Communicable Diseases in September adopted a declaration that includes Alzheimer's disease as a major disease area. At last we are seeing that the World Health Organisation is starting to acknowledge that dementia is a serious disease.

Looking ahead to the next year, we have our biennial conference scheduled for May. This is an opportunity for us to really get our message across. An event such as this will allow us to increase exposure in the media both locally and nationally. We need to continue our work in our own communities, a strong local presence is critical to our overall success.

Finally on behalf of the entire Board of Alzheimers New Zealand I would like to take this opportunity to thank you for your continued support and hope that you all have a safe and happy holiday season.

Facing the future

By *Bupa Care Services CEO, Dwayne Crombie*



The immense relief from winning the Rugby World Cup and the resultant euphoria is slowly wearing off. We have also survived the "election season". The NZ Aged Care Association which represents many of the aged care providers kicked off its campaign with a highly emotive picture of four older people sharing the same bed. This got the message across in a rather simple way, if we don't plan, then beds for older people in future might be in short supply!

The most controversial issue during the campaign was the NZACA's call for the income and asset test threshold to be lowered from \$210,000 to \$150,000. This would have had the effect of reducing some of the government's current costs via the subsidy by making people pay privately. Thus some of government's funding could go towards raising the price to providers and encouraging new development. Despite the current threshold being extremely

generous by world standards, all of the political parties distanced themselves immediately from the call.

While it might suit the politicians to avoid the hard decisions, as a community we are going to face these decisions sooner or later. It is very clear we need to address them in a mature fashion to provide the security, safety and care that our older people so richly deserve.

On a more practical note, Bupa Care Services took the opportunity of another visit by Graham Stokes (Bupa's global expert on the care of people with dementia), and held three public meetings. These meetings were held in Auckland and Wellington and were solely for family and friends of those with dementia to hear first hand from Graham about some of the issues in caring for people with dementia and a chance to ask questions. We hope to hold more meetings next year.

Lastly I would like to wish everyone season's greetings and hope that you have the opportunity to be with family and friends during the Christmas and New year period.



United Nations recognises dementia

In the week of 19 September, the United Nations (UN) held only the second meeting in its history on a global health issue by convening a Summit on Non Communicable Diseases (NCD).

The final political declaration of the summit specifically recognised neurological diseases, including Alzheimer's disease and other dementias, as an important cause of morbidity that contributes to the global burden and that NCD prevention programmes and health care interventions provide equitable access to effective programmes on these illnesses.

Alzheimers New Zealand is excited by this recognition of Alzheimer's disease and other dementias as a burden on par with diabetes, cancer, lung diseases and cardiovascular disease.

"For countries like New Zealand that are part of the UN, this decision should result in strengthening policy initiatives that ultimately will result in improved services for all people affected by dementia, providing government will make the necessary investment" says national director, Johan Vos.

Alzheimers Disease International (ADI) reports that adding dementia considerations to the health planning effort at the World Health Organisation level is a major leap towards mobilising the imagination and resources of the public health community.

Marc Wortmann, ADI Executive Director, says: "I am very proud that Alzheimer's disease and other dementias are part of the Political Declaration that was agreed on during the Summit. This is a result of extraordinary public policy efforts of the entire Alzheimer's movement and dementia advocates in many countries."



Research

Sleep Solutions

Rosie Gibson is a Massey University Doctoral Candidate. She is researching ways to improve sleep for people with dementia living in the community, through working with them and their caregivers. Below she outlines the problem of sleep as well as the exciting research project which is taking place in Wellington.

Sleep is important for all of us, but as we get older it often becomes problematic. As we age, it is normal for sleep to become shallower and fragmented, with early morning awakenings, and often daytime sleepiness. Sleep disorders including snoring, insomnia or restless legs also become more common with age.

For those affected by dementia (such as Alzheimer's disease), sleep often becomes even more fragmented, and sleep timing more unusual than in healthy ageing. Some people also experience confused awakenings and wandering type behaviours in the night.

Family caregivers often have disrupted sleep as well. This may be due to having different sleep timing to those in their care, being woken or providing support in the night, or increased trouble getting to sleep.

Sleep disruptions have been found to contribute to problems with memory, mood and daytime functioning. Therefore managing sleep of people affected by dementia may have a significant impact on the waking symptoms of dementia, quality of life, and coping.

My research aims to:

1. Better understand dementia-related sleep problems of couples living in the community.
2. Assess whether strategies aimed at improving the sleep of those with dementia are feasible to use in the home.

Background of the project

We each have a circadian body clock in the brain, which is the pacemaker for daily rhythms of many bodily functions including the sleep/wake cycle, helping keep us alert in the daytime and asleep at night. With dementia, the body clock typically reduces in size and activity, and also becomes less sensitive to the cues that keep it in step with the day/night cycle.

The body clock is usually kept in step with the 24 hour day through light input via a special pathway from the eyes. Routine physical activity and socialising can also help. However for many people with dementia, time spent in bright light or engaged in activities is compromised.

This research is trialling techniques to boost the activity within the body clock of people with dementia. The study includes both people with dementia and their supporting partner, and involves home-based light therapy and physical activities to try and incorporate into the routine of those with dementia. Participating pairs will also be given a sleep information booklet.

What the project entails...

The study involves couples consisting of a person with dementia and their supporting partner. It takes a total of 6 weeks to complete, takes place in the home and involves routine tasks. Couples can enroll regardless of any work, club, or respite commitments.

- During the first week your sleep will be monitored. This involves wearing a small watch-like device on your wrist that measures movement, and keeping a sleep diary. We would also bring some questionnaires concerning sleep, mood and daytime functioning.



- For weeks 2-6 you will be provided with a light box and exercise program to try to incorporate into the routine of the partner with dementia when possible. You will also receive the sleep information booklet.
- During the final week of trialling the light and exercise you will be given the questionnaires and sleep monitors again to assess whether there have been any changes.
- At the conclusion of the sleep study you will be sent your sleep monitor reports. The final study results will be mailed to you when they become available.

In order to understand and manage dementia-related sleep problems Rosie needs more volunteers!

If you or your partner have Alzheimer's or other type of dementia and have troubled sleep, this project may be of interest to you!

She is looking for couples consisting of a person with dementia and their supporting partner who:

- Live in the Wellington region (including Hutt Valley and Kapiti Coast)
- Are aged 65 and over
- Are interested in improving their sleep

Rosie believes participants so far have found the study simple and rewarding. It all takes place in the home and you would have the right to withdraw at any time.

If you would like to ask any questions or have a study information pack sent to you please contact Rosie at the Sleep/Wake Research Centre:

Rosie Gibson
Free phone: 0800 SNOOZE (766693)
Phone: 04 380 0635
Email: r.gibson@massey.ac.nz

Funding dementia research

The Alzheimers New Zealand Charitable Trust is solely dedicated to dementia research. The Trust's primary objective is to support individuals and organisations who are providing medical and social research for the benefit of people (directly or indirectly) affected by dementia.

The closing date for the next funding round has been extended. Up to \$15,000 is available for research focused on the medical and social aspects of dementia. Any relevant topic will be considered. The closing date for applications is now Friday 27 January 2012. Applicants should follow the information provided in the document "Small Project Grants" available at <http://www.alzheimersresearch.org.nz>.

In 2010 an Alzheimers New Zealand Charitable Trust research grant of \$14,715 was awarded for the study *Sleep of older people with dementia and those who live them: Pilot of an intervention* (Miss Rosemary Gibson, Professor Philippa Gander, Dr Linda Jones and Professor Tony Dowell).

Tai Chi

Matthew Croucher, Susan Gee, Margaret Francis, Rachael Beever and Gillian Bastion (grant recipients in 2009) have completed their project "A settling effect at a difficult time of day. Does Tai Chi have beneficial effects on challenging behaviour in an inpatient psychogeriatric ward?" Matthew Croucher reports:

"The CDHB-hosted Psychiatry of Old Age Academic Unit recently evaluated the short-term effect of Tai Chi on behavioural disturbance in a dementia specialty inpatient ward. The Alzheimer's NZ Charitable Trust and the Canterbury Health Care of the Elderly Education Trust kindly gave grants to enable two summer studentships in 2009 / 2010 as well as equipment to assist with this research. A randomised controlled study was conducted comparing three conditions - standard care, music, and Tai Chi in the mid afternoon. This is a time of "sundowning" and increased frequency of challenging behaviours from some people with dementia. Although no difference between the conditions was found for direct observational measures of agitation or changes in emotion in the late afternoon, a combined measure of the use of non-scheduled psychotropic medication and use of physical restraint was slightly but significantly lower on Tai Chi days than on standard care days. The study has also provided valuable experience in the use of formal measuring tools for research into challenging behaviour so that advice can be given to future researchers. The findings have been presented at the 2010 "Change Champions" conference in Sydney and a formal journal article is being submitted to a health care scientific journal early in 2011."



Weight loss and Dementia



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

While much of the world focuses on the growing rates of obesity, for those with dementia unintentional weight loss is not uncommon and poses a real challenge for the people who care for them. Many factors play a role in this.

People with dementia can have higher energy needs if they are anxious and therefore restless or because they pace incessantly. If they don't match their increased energy needs with an increased calorie intake, they will experience weight loss.

Or weight loss may occur because a person's ability to eat enough is impeded. People with dementia can become distracted during meal times and not complete what is served to them. They may also forget how to use cutlery and attempt to eat inappropriate foods with their hands. Carers understandably lose their patience and eating opportunities are lost.

Many of these barriers can be overcome at least initially. For those who have higher calorie needs making porridge with milk instead of water and topping it with three tablespoons of runny cream doubles its calorie content. Serving simple desserts such as canned fruit and custard or milk puddings routinely and adding a scoop of ice cream provides extra calories which are easy to eat and are generally well liked.

Taking the opportunity to serve nutritious, calorie dense snacks between meals rather than just a cuppa and a biscuit also makes a difference. Some easy options include cheese and crackers (try spreadable cream cheese if slices of Cheddar or Edam are inclined to fall off), peanut butter sandwiches where the peanut butter is thickly spread and the crusts have been removed, slices of fruit loaf with a thick spread of margarine, an ice cream in a cone or a selection of dried fruits

Drinks also provide great opportunities to add additional calories. Make coffee, Milo and hot chocolate entirely with milk and once a day

serve either a milk shake or fruit smoothie which is fortified with whole milk powder (add two - three tablespoons of milk powder per 200mls of fresh milk).

If a person is easily distracted and inclined to get up from the table before they finish their meal, ensure their meal is set in front of them promptly when they sit down to eat and try sitting opposite them and eating your meal while they eat theirs. Your company may keep them seated for longer, they may copy your actions and it will be easy for you to offer verbal prompts in between your own mouthfuls.

Foods which one can eat using ones fingers are a way of providing nourishment whilst maintaining a degree of dignity amongst dementia sufferers who are still able to feed themselves but who can not manage using a spoon or fork. Toast with tasty spreads can replace cereals at breakfast, whole sandwiches or sandwiches which are cut into bite size pieces

“Many of these barriers can be overcome”

make an easy lunch option. However for variety consider cheerio's or pieces

of rolled luncheon, cubes of cheese or cheese on toast, little savouries, pieces of cold chicken or even omelette. At the main meal, potato wedges or large pasta spirals can replace mashed potato and rice and most meats, chicken and vegetables lend themselves to being cut into bite size pieces.

Bite size snacks are useful for many who are constantly on the move. Small bowls of such foods can be left out at a couple of locations. Put together mixes of bite size crackers,

pretzels, cereals such as Nutrigrain, dried fruit, even marshmallows and some squares of chocolate!



News around the World

Melbourne Brain Centre opens

The world's fifth largest brain research centre has opened in Victoria, Australia.

A \$225m(AUD) Brain Centre has opened in Parkville, Melbourne. It will host 700 staff, who will research various brain conditions including Alzheimer's disease.

Researchers from the Florey Neuroscience Institutes, The Mental Health Research Institute and Melbourne University's neuroscience department will work with clinicians from the Royal Melbourne Hospital and the Austin Hospital at the centre.

The federal government contributed AU\$77m towards the centre, the former Brumby government AU\$53m, and the remainder of funding was provided by the Myer and Ian Potter Foundations.

Millions for dementia research in UK

The UK government has announced an £800 million investment in health research over the next five years, including £18 million for dementia research.

Fight Dementia Campaign

Alzheimers Australia has launched the Fight Dementia campaign with the aim to get recognition of dementia as a health priority in the 2012 Federal Budget. Alzheimer's Australia is proposing that the Australian Government commit to an additional AU\$500 million over the next five years to promote greater awareness of dementia, improve the quality of care and act on positive solutions to reduce the future numbers of people with dementia.

To find out more about the campaign visit: <http://fightdementia.org.au>

82 year old tweets her experiences with Alzheimer's disease

An 82 year old American woman with Alzheimer's disease has begun tweeting her experiences and thoughts with the aid of her daughter. In just 140 characters she portrays the daily challenges of Alzheimer's disease and living in a rest home with emotion and humour. You can follow her here: <http://twitter.com/#!/MaryAgnesKelley>



Help us to help you

Alzheimers New Zealand and The University of Auckland have been working on two exciting new research projects, assisted by many local Alzheimers organisations.

The first project will assist carers when they talk with their General Practitioners (GPs) and practice nurses. Carers often are so involved with the person they are caring for that they may forget that they need assistance themselves. We are at present testing a list of things carers may wish to discuss with their GPs. These include: information, practical matters, personal health and well being and relationship issues. If you would like a copy of the list, or would like to make comment, email d.jorgensen@auckland.ac.nz or ask your local Alzheimers organisation. The next step will be to compile a complete list of information to assist GPs in their discussions with carers, for example where to access financial information, respite, or other support, etc.

The second project is an investigation to find out what is the best kind of support that will assist older people with dementia (aged 65+) to continue living at home. We are finding out what helps carers most and what, if anything, they feel would be of more assistance to them. We are at present recruiting carers to participate and hope by early next year that we will have 300. So far we have 82 carers interested in being interviewed. The interviewers are either talking to carers in their own homes or by phone depending on where they live. If you would like to be part of this study please either let your local Alzheimers organisation know, or email n.abdrabalanabi@auckland.ac.nz.

ADDITIONAL SYMPOSIUM FOR HEALTH PROFESSIONALS AND PEOPLE WITH DEMENTIA ENQUIRE TODAY!



FUTURE FACES OF DEMENTIA

CONFERENCE MAY 24 - 27, 2012
WELLINGTON CONVENTION CENTRE

THE CONFERENCE FOR
THE NEW ZEALAND
DEMENTIA COMMUNITY

IF DEMENTIA IS A PRIORITY TO YOU, THEN MAKE THIS CONFERENCE
YOUR PRIORITY IN 2012

SUBMIT YOUR ABSTRACT OR REGISTER ONLINE TODAY!

WWW.CONFERENCE.ALZHEIMERS.ORG.NZ

Thanks to our supporters and funders



0800 004 001
alzheimers.org.nz

facebook.com/alzheimersnewzealand



0900 4 1234 (\$20 donation line)

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



Alzheimers New Zealand – Level 3, Adelphi Finance House, 15 Courtenay Place, PO Box 3643, Wellington 6140
Phone 04 381 2362 Facsimile 04 381 2365 Email nationaloffice@alzheimers.org.nz Web www.alzheimers.org.nz
Charity registration CC21026 Member Alzheimer's Disease International