Driving change
AlzNSW dementia and driving discussion paper makes an impact

Support group study
AlzNSW research at international conference

• Diversional Therapist Denise Herman
• Memory Van’s travels
• Fundraising highlights
• Latest news

WIN
Toyota Yaris!
p15
It has been an important three months for Alzheimer’s Australia NSW. First, we moved premises. We got the wonderful building on Macquarie University campus due to significant support from NSW Health – so thank you to that body. The campus is a lovely place to be and we are so lucky to be part of it.

The move was complete on 19 March and credit goes to many in the organisation for a well-conducted move. There was maximum efficiency and minimum disruption. Our thanks go especially to Sue Sackville who oversaw things so well, and to a special committee (and to Alistair Bell for his leadership) that conducted the exercise with efficiency and aplomb.

The move has been very successful and very well received. Staff members have been universally positive, and we no longer pay dead rent for the building at Talavera Rd, although there are residual expenses associated with ‘making good’ there.

By having all our staff together we may gain significant efficiencies. We are paying rent to NSW Health for the building on Macquarie campus but are getting a rental subsidy too. So financially the move has been very good. Our two buildings are now next to each other, so our Sydney-based staff is in one area – no more ‘us’ and ‘them’.

If we add the cash benefits from the move to the benefits that have flowed from the improvement in the share-market, we will be in a better position to help people with dementia in 2010-2011 than we were a year ago.

We came through the GFC well – John Watkins did wonders to almost maintain previous employment levels in AlzNSW while delivering a good and agreed budget outcome. If we add substantial bequests which are coming, our capacity to work for people with dementia is increasing.

While we expect Alzheimer’s Australia Research and the cooperative research centres to do all basic research (and we transmit all monies given for research to them) we undertake social research involving political matters, such as the NSW dementia prevalence rates with individual electorate profiles for politicians, or involving our important consumer network.

We used consumer input to help us put together an important document on ‘driving and dementia’ which was launched at the NSW Parliamentary Friends of Dementia meeting at Parliament House in April.

This is a fraught subject and the paper will be an important contribution to the debate. The State Government indicated that the paper will be important.

**International conference**

I went to Wellington in early May to give two speeches about the disease to the Annual Conference of the New Zealand association. Great support was received from within AlzNSW in the preparation of these speeches.

**News from the Board and states**

We now have a new Vice-Chair of the Alzheimer’s Association in NSW, John Morrison. John has been on the Board now for seven years and is an accountant. We are lucky to have him and welcome him to this position.

Three of the CEOs from other States have resigned but there is no link between the three resignations. The Victorian and Queensland CEOs have resigned from full-time positions to go to part-time positions, thus effecting sought-after lifestyle changes, and the CEO from the ACT has resigned to follow her husband to the USA.

Recruitment is underway in all three jurisdictions and we are doing whatever they ask to assist them.

**Professor Peter Baume AC**

Chairman
A major feature of this issue is coverage of the launch of a very important discussion paper on driving and dementia at our twice-yearly NSW Parliamentary Friends of Dementia meeting in April.

Driving is a significant and difficult issue for many of our members and we are encouraged by the wide-ranging support we have received for the paper.

In particular, The NSW State Government announced at the launch the formation of a working party, which will include the RTA and AlzNSW, to look at all 13 of the recommendations.

We will continue to work hard with the relevant stakeholders on this vital topic. You can read more about the discussion paper and the launch on page 8.

We have also been lobbying our NSW-based federal Members on your behalf as the nation prepares for another federal election, expected later this year. In letters to all NSW-based federal MPs, we have continued to highlight the importance of making dementia a priority in the health and aged care reform agenda of the government.

We have called on all federal parliamentarians to urgently commit to improved services, increased funding and better planning to deal with the impending dementia epidemic. We will continue to raise this issue at every opportunity in the coming months.

I am pleased to report that the move of AlzNSW’s administration from Talavera Road in Macquarie Park to Cox’s Road, North Ryde, next to our Dementia and Memory Community Centre, is now complete.

Thanks to hard-working staff and volunteers, the move went very smoothly and we are already reaping the benefits of having our Sydney staff located on the one site.

I wish you all the best and assure you that our members are at the forefront of our thoughts and in whatever we do at here at AlzNSW.

The Hon. John Watkins
Chief Executive Officer
Café Connect in the Hunter

The inaugural gatherings of the Hunter Centre’s Café Connect were held in April at both the Swansea and Toronto RSL Clubs.

The Cafes provide opportunities for people with a diagnosis of dementia and their carers to get together and share information and ideas over morning tea or coffee, as well as to enjoy social contact, fun activities and great speakers.

Upcoming Cafes
Swansea RSL Club
Time: 10am-12 noon
Dates: 10 June and 8 July

Toronto RSL Club
Time: 10am-12 noon
Dates: 24 June and 22 July

Contact
Clare Coyle T: (02) 4962 7000

Members honoured at Seniors Awards

AlzNSW congratulates members John Craig OAM and Bruce Vitnell, who have been honoured with a 2010 NSW Seniors Week Achievement Award.

NSW Minister for Ageing The Hon. Paul Lynch announced the winners at a ceremony in Sydney to mark the start of Seniors Week.

AlzNSW CEO The Hon. John Watkins said Mr Craig and Mr Vitnell had both made enormous contributions to AlzNSW in a voluntary capacity.

“Mr Craig and Mr Vitnell have given a lot of time, expertise and valuable assistance to the organisation and they are highly deserving of being recognised so appropriately,” John said.

“We are very lucky to have them as part of Alzheimer’s Australia NSW and very grateful for all the work they have done for the organisation.”

Support for new site

State Member for Ryde Victor Dominello MP presented CEO of AlzNSW The Hon. John Watkins with over $17,000 to support the relocation of AlzNSW to Building 21 on the Macquarie Hospital site. AlzNSW gratefully acknowledges this much-needed support.

Creative Connections on ABC1

The Creative Connections Art Program at AlzNSW’s Dementia and Memory Community Centre at Port Macquarie has hit the national spotlight, courtesy of the ABC1 Art Nation program.

The Creative Connections program, which is in its fourth year, was featured in a segment about the benefits of art therapy for people living with dementia.

AlzNSW Dementia Advisory Service (DAS) and qualified arts therapist Marg Couatts was also featured in the segment explaining the benefits of such programs.

It was an excellent program and highlighted the great work which is carried out by AlzNSW across the state.
Staff changes

We bid a fond farewell to Emma Bourne, Manager Services, who has finished up with AlzNSW to pursue further study. We thank Emma for the great contributions she has made and wish her all the best in her studies and other professional pursuits.

We also warmly welcome Robyn Faine, who has joined us as the new Manager Services. Robyn has come to us from MS Australia and we are lucky to have her on board.

We look forward to continuing the great services our team delivers to people with dementia and their carers throughout NSW.

We have also welcomed several other staff who are already making a great contribution to the organisation. Melanie Hillman, Martine Woodhill and Sandy Murphy have joined the team at North Ryde. Melanie joined in a new role, Business Development Officer/Administrator, and Martine and Sandy are providing valuable administrative assistance.

Bev Primrose joined the team at Bega as a Dementia Advisor, while Pam Turpin and Julie Sinnis are working in the Sutherland area as Activity Group Leader and Project Officer for a Dementia Café pilot.

Nicole Cornish joined the Port Macquarie team as a Dementia Advisor and Clare Coyle joined our Hunter office as a Project Officer for a Dementia Café pilot.

Finally, welcome back to Kaylene Parker, who has rejoined the team at Port Macquarie as a Group Work Facilitator.

Welcome, everybody. It is great to have you all on board.

Young people say ‘we care’

Four Sydney women have banded together to start an Alzheimer’s disease fundraising and awareness-raising venture, Forget-Me-Not, which aims to engage young people in the dialogue surrounding Alzheimer’s disease and dementia.

Their first initiative will be a cocktail event during Dementia Awareness Week, on 25 September at the Museum of Contemporary Art, Circular Quay, and they expect to attract approximately 250 young people.

The Forget-Me-Not team includes Sophie Pieters-Hawke, granddaughter of Hazel Hawke.

“Some people think that because we’re young, we don’t care about issues of ageing and changing,” Sophie says.

“But we do. Many young people are affected in some way, usually as grandchildren of those who have been diagnosed with Alzheimer’s disease or dementia.

“Forget-Me-Not is all about saying we care about those we know who are diagnosed, and we care about the prospects of a cure.”

All funds raised by Forget-Me-Not will be donated to the Hazel Hawke Alzheimer’s Research and Care Fund, which is overseen by Alzheimer’s Australia.

The event is not only about raising money. It aims to get peers talking to each other about their experiences, and to raise awareness about Alzheimer’s disease and dementia, particularly younger-onset dementia.

Members of AlzNSW will be there on the night to provide information about the organisation and their support services.

Visit the Forget-Me-Not website for more information, to get involved, or to purchase tickets to the cocktail event on 25 September.
W: www.forget-me-not.com.au

AlzNSW partnership trains volunteers

A new dementia volunteer program at the Port Macquarie Base Hospital is now underway, with the first batch of volunteers having completed their training and started in the ward.

Hospitalisation can be difficult for people with memory problems, and the Dementia Care Volunteer Program aims to improve the quality of life for patients with dementia in an acute-care environment.

The program is jointly managed by Margaret Allen, from AlzNSW, and Collette Scott, from the Mid-North Coast Area Health Service.

Margaret explains that the program aims to support older people in hospital who have dementia. “Similar programs run in other areas have shown that older people in hospital who are experiencing dementia or other memory and thinking problems are showing improved outcomes when supported by a volunteer,” Margaret says. “ Volunteers are able to provide one-on-one support and engagement in activities which assists those experiencing dementia, or who have memory and thinking problems, to feel more relaxed.

“This, in turn, improves their wellbeing during the term of their hospital stay. The program also aims to prevent problems for patients at risk of developing confusion during their hospital stay.”

Volunteers offer a few hours each week to the program, with flexibility over the specific times and days.
Bang the Drum for dementia

AlzNSW is launching a fun promotion called Bang the Drum, and is inviting you to help us to build awareness and visibility of dementia and our organisation.

To spread the word, send us a photo (digital or print) featuring a piece of AlzNSW merchandise from somewhere in Australia or anywhere in the world.

It could be a photo of someone wearing a ‘Memory Walk’ cap while out fishing or climbing Mt Kilimanjaro, you could take our little elephant with you on holiday or even be captured on film reading In touch in a public place.

In each edition of In touch we’ll feature a selection of photos taken by our members, friends and staff, all banging the drum for dementia.

The promotion will run for the next 12 months and we’ll announce the overall winners in the Winter 2011 issue of In touch. Good luck!

To enter: email or post your entries to Andrew Mills.
E: amills@alznsw.asn.au
P: Andrew Mills, Alzheimer’s Australia NSW, PO Box 6042, North Ryde NSW 2113

Seminar: Ethics in care

Internationally renowned UK-based Professor Julian Hughes will be speaking at a seminar on ethics in dementia care in Sydney in June.

Professor Hughes is a respected authority on ethical decision making in dementia care, including end of life issues.

Entry is free for AlzNSW members, but bookings are essential.

Where: Jubilee Room, NSW Parliament House, Macquarie Street, Sydney
When: Thursday 17 June 10.30am-midday
Cost: members free; non-members $15
RSVP: by 14 June
T: (02) 9805 0100
E: education@alznsw.asn.au

AlzNSW working with the State Government

The NSW Departments of Health and Ageing, Disability and Home Care have been working with AlzNSW to plan services for people with dementia and their carers through the development of the NSW Dementia Services Framework 2010-2015.

The Framework seeks to improve the care experience for people with dementia, as well as their carers.

It will describe the services required for keeping healthy, getting a diagnosis, living with dementia, obtaining more support, managing illness, managing behaviour and personality changes, transition to residential care, and care at the end of life.

The pathway will be used to guide the work of government, service providers and nongovernmental organisations (NGOs).

The NSW Dementia Policy Team consulted with the AlzNSW Regional Consumer Committees across NSW in March and April.

The objective of the consultations was to learn more about consumers’ experiences and how services can be improved to better meet their needs.

AlzNSW is pleased to have been able to offer our members the opportunity to provide feedback on the new Framework, so that it can best reflect the needs of the people it serves.

Solution to crossword (page 17):

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Bang the Drum for dementia

The Memory Walk cap in Fiji
New AlzNSW resources

The AlzNSW library blog is full of the latest news on dementia from our journal and library resources.

The blog, Library News, alerts you to new journals that Alzheimer’s NSW subscribes to, with abstracts of all articles, book reviews by health professionals, and new books, DVDs and kits.

To register for email alerts, visit the blog or phone the library.
W: alzheimersnswlibrary.blogspot.com
T: (02) 9888 4218.

AlzNSW speaks carers’ languages

Education and training sessions for carers of people with dementia have been translated and run in Korean, Serbian, Japanese and Afghani languages for the first time in the Northern Sydney region.

The sessions covered topics including understanding dementia, communication and behavioural symptoms, understanding accommodation options, planning ahead and caring for yourself.

AlzNSW and the Northern Sydney Commonwealth Carer Respite Centre jointly conducted the sessions.

Mind your Mind in the Hunter

The first of 19 free Mind your Mind presentations running in the Hunter region this year have been completed.

AlzNSW and the Department of Veterans’ Affairs have joined together to offer presentations of the Alzheimer’s Australia national dementia risk reduction program.

The presentations are open to people of all ages.

For more information about upcoming seminars, contact AlzNSW Hunter DMRC.
T: (02) 4962 7000
E: hunter@alznsw.asn.au

Retreat for people with dementia

Local organisations in Ryde have combined to run a retreat for people with dementia.

The retreat revolved around Alzheimer’s Australia’s Living with Memory Loss program – an early intervention program for people diagnosed with dementia.

The program involved a total of seven sessions over a four-week period, including the weekend retreat, and it was held in April and May. It was open to people in the early stages of dementia who live in the Ryde local government area, as well as their carers. Thirteen people participated in the program.

Participants found out more about dementia, met and talked confidentially with others in similar situations, focused on maintaining and enhancing their skills and abilities, and explored ways of managing the illness now and into the future. Other activities included a trivia night, a movie night and a card-making afternoon.

Thanks to North Ryde RSL, Ryde-Eastwood Leagues Club and the City of Ryde, whose generosity made this retreat-style program possible.

Living with Memory Loss and other programs for people with dementia are available throughout the state from AlzNSW.

More information can be obtained through the National Dementia Helpline.
T: 1800 100 500.

Open Day

The AlzNSW Dementia and Memory Community Centre at North Ryde is holding an Open Day on Tuesday 22 June.

The centre will be open to the public to showcase the various services available, including the library, diversional therapy and the multisensory room.

The Open Day will also host the east coast launch of the new book by Elizabeth Bezant and Pamela Eaves, Caring Moments, and a talk by the authors.

Where: Vincent Fairfax Family Resource Centre, North Ryde
When: 10am–1pm
T: (02) 9805 0100
The NSW State Government has announced the formation of a working party to look at the recommendations from an AlzNSW discussion paper on driving.

The discussion paper, Driving and Dementia in NSW, launched on 21 April during AlzNSW’s twice-yearly NSW Parliamentary Friends of Dementia meeting, has found there is little clear, accessible information about the rights and responsibilities of a driver after a diagnosis of dementia.

In NSW, there are more than 90,000 drivers over the age of 80 and dementia impacts on one in four people over the age of 85.

Improving services
The paper found that current driver testing regimes for people with dementia and transport alternatives for a person with dementia who can no longer drive are inadequate, explained The Hon. John Watkins, CEO of AlzNSW.

“We need better, more appropriate testing regimes, better information about the rights and responsibilities of a person with dementia in regard to driving, and better transport options for a person with dementia and their carers for when they are no longer able to drive,” John said.

“We also need better support for the transition from driver to non-driver.

“Current protocols, testing regimes and availability of information of the rights and responsibilities of a person with dementia with regard to driving need to be improved and, given the numbers of people with dementia are set to rise dramatically, this needs to be done urgently.”
the complexity of the issue is that dementia is an unpredictable illness, and a person’s cognitive capacity can vary from day to day.

“There has been research to suggest that drivers with dementia may pass a driving test under controlled conditions but may be unsafe in an uncontrolled environment when they must rely on their own cognitive abilities.”

There are 13 recommendations in the discussion paper, which include better driver testing regimes for people with dementia; better, clearer and more accessible information about the rights and responsibilities of drivers after a diagnosis of dementia; better transport alternatives for people who have a diagnosis of dementia; better support for people transitioning from driver to non-driver; and the introduction of programs that better enable earlier diagnosis of dementia.

Government support

Speakers at the launch of the paper said that given the projected large increases in the number of people with dementia in NSW, it was a timely discussion, and the State Government confirmed that the RTA will be working with AlzNSW on some of the key recommendations (see box, right).

AlzNSW Honorary Medical Advisor Professor Henry Brodaty also spoke at the launch of the discussion paper, as did AlzNSW member and carer Joan Jackman.

The discussion paper includes results of a survey of members of Alzheimer’s Australia NSW.

There are an estimated 257,000 people with dementia in Australia today, and approximately a third of those are in NSW. The number of Australians with dementia is expected to increase to 1.13 million by 2050.


Full Text: Read the full discussion paper on the AlzNSW website W: www.alzheimers.org.au Click on NSW and follow the links to publications.
This is about my husband Michael, a healthy, active, life-loving man who loved and participated in many sports including running and cycling long distances. Michael also loved the independence and freedom of driving. He was the family expert on cars, and our chief driver and expert navigator for all family excursions and journeys.

Around 1996, some subtle changes in Michael’s character became noticeable. He seemed to lose interest in the activities and pursuits that usually gave him so much enjoyment, he had less initiative for things that needed doing around the house, his normal drive and enthusiasm around work waned, and he generally seemed to have less volition. We sought help.

After several misdiagnoses, in 2001 Michael was diagnosed with younger onset fronto-temporal dementia. We were fortunate to have an excellent medical manager who had finally diagnosed the inexplicable changes we were experiencing in Michael.

He carefully explained the condition to us, including all the things Michael could continue doing in this early stage of the condition. Importantly, he emphasised there is life after a diagnosis of dementia. He advised us to organise enduring power of attorney, and for Michael to discontinue driving.

The diagnosis was devastating. The implications for our family were incomprehensible. There would be many changes ahead of us. Michael had already had to cease employment and had subsequently picked up a large range of domestic responsibilities while I continued to work full time as the family breadwinner.

This role transition had been difficult, but we had all adjusted. Importantly, he emphasised there is life after a diagnosis of dementia. He advised us to organise enduring power of attorney, and for Michael to discontinue driving.

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“Over the next four hours, the kids and I hunted everywhere. He finally arrived home, in the dark, with two tired and relieved dogs.”

Michael continued driving, just for the time being, while he was still so good. About six months later, I received a call at work. Michael had locked himself out of the car and lost the keys at a reserve about eight kilometres from home. He had our two dogs with him. Wait there, I instructed, I will come and get you. When I finally arrived, about an hour later, he and the dogs were gone. The locked car was still there.

Over the next four hours, the kids and I hunted everywhere. He finally arrived home, in the dark, with two tired and relieved dogs, having walked the eight kilometres. He had forgotten my instruction to stay put and misjudged the situation. Fortunately, he did manage to find his way home.

But then he began having difficulty finding his way around local suburbs and familiar streets. He would forget what was needed to keep the car operating well, like petrol, and he gradually seemed less sure, less confident on the road.
Hard decisions
We became more alert to his performance. He had a near-miss at a red light with our son in the car. Then, early one Sunday morning, when driving our daughter to her then casual job, running late and in haste, he went straight through a red light at a local intersection. Fortunately, there was no accident. No one was hurt.

We made a family decision that it was no longer safe for Michael to drive. This was 18 months after his diagnosis. This was very hard on Michael. It resulted in the loss and compromise of more roles, and changes to the nature of his contribution to the family.

In the wisdom of hindsight, we had made a mistake. Our view now is that Michael should have stopped driving 18 months earlier than he did, when we were advised to do so. With early stage dementia, it was an accident waiting to happen – to him or to anyone else during that period.

Complex issues
When we had the initial diagnosis of dementia, we failed to consider and accept that dementia is a chronic, progressive condition. You don’t know how it is going to manifest for you, what capacities you will lose and when you lose them. Indeed, your capacities can even vary daily and within the day.

Obtaining a driver’s licence is, for all of us, a right of passage in our personal development in our transition from adolescence to adulthood. It opens the doors to adulthood, to freedoms, to personal independence.

For Michael, not being allowed to drive was a huge blow. Did it bring huge adjustments and some hardships for us as a family? Yes, it did. But this issue is a public safety issue. It is about all of us as road users.

In the interest of the person with dementia, their family, and the public the issue of driving and dementia deserves urgent attention. The discussion must include what transport alternatives for people with dementia are, and need to be, to support their living a full and quality life.

The key recommendations in the discussion paper – more effective driver testing for people with dementia, our legal obligations being clear, and improved transport alternatives – need to be considered by the whole community now.

Progressing this issue is our collective responsibility.

In concluding, I would now like to acknowledge my husband Michael, who continues to deal with what this condition brings with great courage. He is our inspiration.

Editor’s note: This is an edited version of Ms Jackman’s presentation at the launch of the Driving and Dementia in NSW Discussion Paper at the NSW Parliamentary Friends of Dementia meeting. This reflects Ms Jackman’s personal experience and opinions.

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Instrument donation
North Ryde’s music therapy program has received a donation from the Primary Club of Australia for instruments and equipment.

About $8000 has been donated for new instruments for the music therapy program at the Dementia and Memory Community Centre at North Ryde.

The grant, from the Primary Club of Australia Inc, has enabled the purchase of a new keyboard, drums, shakers and more.

AlzNSW music therapist Grace Chiundiza said the grant was a huge boost to the program, which was a popular form of diversional therapy with clients.

“Music therapy provides moments when individuals develop relationships and express themselves in ways they may not be able to express using words alone, in a supportive and non-threatening environment.”

Gloria Medo, who attends music therapy with her husband Les, said the sessions were always a lot of fun. “It lifts the spirits,” Gloria explained.

Ern Isles agrees: “There’s a real sense of fellowship.”
AlzNSW research on the international stage

The results of a groundbreaking study on support groups were recently presented to an international conference.

Results from an Australia-first study were presented in Greece to the 25th International Conference of Alzheimer’s Disease International. The research, which looked at what comprises a quality support group, is the first comprehensive study of ongoing support groups for carers of people with dementia in Australia.

Conducted by AlzNSW, the study found great benefits of support groups to participants, and that grief and loss have an enormous impact on the health and wellbeing of a carer of a person with dementia.

The grieving process can begin for a carer of a person with dementia at the time of diagnosis, the research found, with some carers reporting that the grief and loss felt at this time was as much as, or even more than, the grief felt when the person with dementia died.

Importance of support
The CEO of Alzheimer’s Australia NSW, The Hon. John Watkins, said the Quality Support Groups Research Project is significant because it highlights what an undervalued and important resource good support groups are for carers of people with dementia.

“Because of the ageing population, dementia is a growing concern for the entire community, with more than 1.13 million Australians projected to have the illness by 2050,” John said.

“That means more than one million families – husbands, wives, sons, daughters and friends – will be caring for a loved one with dementia and they need to be supported as much as the person living with the illness does.

“Caring for someone with dementia is a 24-hour-a-day, seven-

“More than one million families – husbands, wives, sons, daughters and friends – will be caring for a loved one with dementia”
The Hon. John Watkins
“[Our support group has] built friendships that are indescribable – we can laugh and cry together about anything. We’re all travelling a journey together.”

Leah Hardaker

day-a-week job. The unpredictable nature of the illness as it progresses, and the challenges that brings, can be very isolating, which is where the strength of a good support group comes in.”

About the project
More than 350 people across NSW took part in the Quality Support Groups Research Project, including leaders of the groups and carers who had attended them.

The research project was conducted over five years and was presented to the International Conference of Alzheimer’s Disease International in March by report author and AlzNSW research officer Jo-Ann Brown.

Jo-Ann said those who took part in the research believed a major benefit of their support groups was that they reduced the feelings of isolation which so many felt.

“The participants frequently said that support groups were so important, not least because they found others who knew exactly what they were going through,” she said.

“That common understanding and that sense of belonging was cited time and again throughout the research as being invaluable for the support group members.”

Leah Hardaker has been part of a support group for carers of people with dementia for the past 15 years and has found it life changing.

“We decided from the beginning that we would stay together as a support group for as long as any one of us was still caring for our partner. The pact was made because we realised how important it is to support one another,” explained Leah.

“It’s built friendships that are indescribable – we can laugh and cry together about anything. We’re all travelling a journey together.”

The Quality Support Groups Research Project has also identified best practice guidelines for support groups and, as a result of the research, AlzNSW has developed a workshop for dementia support group leaders that aims to improve and enhance their skills in helping group members with grief and loss.

Full text: A copy of the full report is available through the AlzNSW online bookshop. www.alzheimers.org.au
Supporting our work

Events around NSW raise funds for the work of AlzNSW.

**Memory Walk**
Save the date! The 2010 Memory Walk will be held again in the beautiful and historic Parramatta Park on Sunday 26 September. We are currently planning for live music, great food and drinks and lots of family fun including a jumping castle and face painting for the kids.

Thanks to everyone who attended last year and we hope to see you all back again. So reserve the date and encourage your family and friends to join us at the 2010 Memory Walk.
*When: Sunday 26 September  
Where: Parramatta Park*

**Blackmore’s Sydney Running Festival**
AlzNSW is excited to announce that we have again been chosen as an official supporter charity for the Blackmore’s Sydney Running Festival in September.

There are four events giving people of all ages and abilities the once-a-year opportunity to run, jog or walk over the famous Sydney Harbour Bridge and finish at the equally iconic Sydney Opera House.

Register now at www.sydneyrunningfestival.com.au to take part in the Blackmore’s Sydney Running Festival and follow the links to find out more about how you can ‘run for a cause and run for free’, which will support the work of AlzNSW.
*When: 19 September  
Where: Sydney  
Information: www.sydneyrunningfestival.com.au*

**Sydney City2Surf**
Participants in the 2010 City2Surf on 8 August can again be sponsored to raise money in support of AlzNSW.

Encourage your friends and family who run the City2Surf to support our work by setting up their online fundraising ‘hero’ page.
*When: 8 August  
Where: Sydney  
Information: Contact Coralie  
T: (02) 8875 4652*

**AlzNSW Christmas cards**
AlzNSW Christmas cards will be available again this year.

There will be a great selection of cards on offer and the order form will be available in the next issue of *In touch*. 
*Information: Watch this space!*

**Thank you**
We extend a big thank you to all the members and friends of AlzNSW who generously support our appeals each year.

We also extend our gratitude to our regular pledge supporters who donate on a monthly or quarterly basis. Knowing we have your support allows us to better plan our service delivery.
Rob Lundie
Inspired Adventures Mt Kilimanjaro participant

Charity Challenge – Climb Kilimanjaro!
AlzNSW, in conjunction with Inspired Adventures, is about to launch our very first charity challenge. Challenge yourself and your friends to join us on the great heights of Mount Kilimanjaro; you will not only experience the adventure of a lifetime, but will also be helping AlzNSW by raising funds through sponsorship. Our first trip will be heading to Mt Kilimanjaro in September 2011.
Information: Contact Tristaine Scott T: (02) 9262 9880 E: tristaine@inspiredadventures.com.au

Partnership opportunities
We have a number of opportunities for businesses to partner or assist us in our fundraising ventures.
- Our events include Dementia Awareness Week activities, the Memory Walk, seminars, corporate golf days and more.
- We are also seeking donations of high-level auction items and raffle prizes for community-driven fundraising events.
- If your company or business wants to support the work of AlzNSW, please contact Brian Daniels, Manager Fundraising.
Information: Contact Brian Daniels T: (02) 9805 0100

In Touch Winter 2010 appeal
☐ I would like to provide support for the work of Alzheimer’s Australia NSW
Name: ______________________ Address: __________________________________________
Postcode: ____________________
Ph (daytime): __________________ Mob: __________________ Email: ___________________
Please accept my tax deductible donation of $_______ (Donations of $2 and over are tax deductible)
Debit my ☐ VISA ☐ MasterCard ☐ Amex OR
I would prefer to support Alzheimer’s Australia NSW on an ongoing basis, please charge $_________ to my credit card per month until notified.
Credit Card No. __________________________ Expiry Date ____ / ____
Signature __________________________ OR ☐ I have enclosed my: Cheque/Money Order
☐ Please send me information about Wills and Bequests
Alzheimer’s Australia NSW, PO Box 6042, North Ryde NSW 2113
Tel: (02) 9805 0100, Fax: (02) 8875 4665 Web: www.alzheimers.org.au
ABN 27 109 607 472

In Touch Winter 2010

WIN!
A Toyota Yaris

Want a new car? A new Community Chest Raffle has now been launched, and it is your chance again to win a Toyota Yaris valued at $25,000.
Tickets are still just $2 each and, if you sell a book of tickets you could also win the booksellers’ prize!
Enter: call Chris with your phone order.
T: (02) 8875 4625

Fundraising news

Entertainment Books
The 2010-11 book is available now! They make a wonderful gift for family members, friends or valued clients. The coupons in the book represent fantastic value for money with over $15,000 dollars in discounts – including 5 per cent discount on your groceries at Coles supermarkets for a whole year!
Information: Contact Christine T: (02) 8875 4625

Rob Lundie
Inspired Adventures Mt Kilimanjaro participant

WIN!
A Toyota Yaris

Want a new car? A new Community Chest Raffle has now been launched, and it is your chance again to win a Toyota Yaris valued at $25,000.
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Enter: call Chris with your phone order.
T: (02) 8875 4625
### Professional Education

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>WORKSHOP</th>
<th>COST</th>
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<td>Newcastle</td>
<td>Tackling Incontinence in Dementia</td>
<td>$25</td>
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<td></td>
<td>Understanding Grief and Loss</td>
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<td>Dementia and Medication</td>
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<td>Living, Loving and Dementia – Keeping people connected: assisting with Activities of Daily Living</td>
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<td>26 Oct</td>
</tr>
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<td></td>
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<td>Environment – Coffs Harbour</td>
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<tr>
<td>New England</td>
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<td>$40</td>
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<tr>
<td></td>
<td>Activities – Armidale</td>
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<tr>
<td>Far North Coast</td>
<td>Experiencing Dementia and Behavioural Symptoms – Grafton</td>
<td>$70</td>
<td>21 Oct</td>
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<td>ADL’s and Dementia and Disabilities – Goonellabah</td>
<td>$70</td>
<td>3 Nov</td>
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<td>ADL’s – Goonellabah</td>
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<td>Dementia and Disabilities – Goonellabah</td>
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<tr>
<td>Shoalhaven</td>
<td>Person Centred Approach to Behavioural Symptoms / Effective Communication / Engaging the Person with Dementia in Activity – Bomaderry</td>
<td>$70</td>
<td>14 Oct</td>
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### Family Carer Education

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>WORKSHOP</th>
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<tbody>
<tr>
<td>North Ryde</td>
<td>Sons and Daughters</td>
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<td>23 Jun</td>
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<tr>
<td></td>
<td>Understanding Grief</td>
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<td>21 Jul</td>
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<tr>
<td></td>
<td>Managing Behavioural Symptoms</td>
<td>Free</td>
<td>23 Jul</td>
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<td>Liverpool</td>
<td>Family and Friends – Liverpool</td>
<td>Free</td>
<td>20 Oct</td>
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<td>Mid North Coast</td>
<td>Sons and Daughters – Kempsey</td>
<td>Free</td>
<td>28 Jun</td>
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<td></td>
<td>Sons and Daughters – Coffs Harbour</td>
<td>Free</td>
<td>1 Jul</td>
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<td></td>
<td>Two-day Family Carer Education – Macksville</td>
<td>Free</td>
<td>7 &amp; 14 Jul</td>
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<td>Sons and Daughters – Wauchope</td>
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<td>25 Oct</td>
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<td></td>
<td>Family Carer Education – Coffs Harbour</td>
<td>Free</td>
<td>10 Nov</td>
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<tr>
<td>New England</td>
<td>Family Carer Education – Armidale</td>
<td>Free</td>
<td>11 Oct</td>
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<tr>
<td>Far North Coast</td>
<td>Family Carer Education – Grafton</td>
<td>Free</td>
<td>9 Aug</td>
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<tr>
<td></td>
<td>Sons and Daughters – Ballina</td>
<td>Free</td>
<td>17 Aug</td>
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<td></td>
<td>Sons and Daughters – Tweed Heads South</td>
<td>Free</td>
<td>18 Aug</td>
</tr>
<tr>
<td>Shoalhaven</td>
<td>Two-day Family Carer Education – Nowra</td>
<td>Free</td>
<td>10 &amp; 17 Aug</td>
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<tr>
<td></td>
<td>Sons and Daughters – Bomaderry</td>
<td>Free</td>
<td>14 Oct</td>
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### Volunteer Courses

<table>
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<tr>
<th>LOCATION</th>
<th>WORKSHOP</th>
<th></th>
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</tr>
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<tbody>
<tr>
<td>Mid North Coast</td>
<td>Interacting with the Person with Dementia – Port Macquarie</td>
<td>Free</td>
<td>21 Jul</td>
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<td>Interacting with the Person with Dementia – Kempsey</td>
<td>Free</td>
<td>22 Jul</td>
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<td>Interacting with the Person with Dementia – Coffs Harbour</td>
<td>Free</td>
<td>7 Oct</td>
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<tr>
<td>Far North Coast</td>
<td>Interacting with the Person with Dementia – Tweed Heads South</td>
<td>Free</td>
<td>19 Aug</td>
</tr>
<tr>
<td>Illawarra</td>
<td>Interacting with the Person with Dementia – Dapto</td>
<td>Free</td>
<td>14 Jul</td>
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</table>

For more information or to register, contact Monica Cole. T: (02) 9805 0100 E: mcole@alznsw.asn.au

### Support group leader workshops

<table>
<thead>
<tr>
<th>WORKSHOP</th>
<th>DATE</th>
<th>LOCATION</th>
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<tr>
<td>Introduction to Group Work Leadership</td>
<td>28-29 June</td>
<td>Ballina</td>
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<td>13-14 September</td>
<td>Central Coast</td>
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<td>29-30 November</td>
<td>Penrth</td>
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<tr>
<td>Advanced Group Leadership</td>
<td>2-3 August</td>
<td>Tamworth</td>
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<td>12-13 August</td>
<td>Nowra</td>
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<td>26-27 August</td>
<td>Wagga Wagga</td>
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<td></td>
<td>28-29 October</td>
<td>Ballina</td>
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<td></td>
<td>8-9 November</td>
<td>North Ryde</td>
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<tr>
<td></td>
<td>22-23 November</td>
<td>Orange</td>
</tr>
<tr>
<td></td>
<td>9-10 December</td>
<td>Fairfield</td>
</tr>
</tbody>
</table>

For more information or to register, contact Gail Longhurst T: (02) 9805 0100 E: education@alznsw.asn.au
Dementia is now the third leading cause of death in Australia, according to a new report from the Australian Bureau of Statistics. *Causes of Death, Australia, 2008*, released in March, found that deaths due to dementia and Alzheimer’s disease more than doubled over the past 10 years. This has seen deaths from dementia and Alzheimer’s disease overtake trachea and lung cancers as the third leading cause of death in Australia. Heart disease remains as the leading cause of death in Australia, followed by stroke. More information: www.abs.gov.au

**Leading causes of death**

<table>
<thead>
<tr>
<th>1999</th>
<th>2003</th>
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</table>

- Brown: Ischaemic heart disease
- Pink: Stroke
- Red: Dementia and Alzheimer’s disease
- Green: Diabetes
- Blue: Colon and rectum cancer
- Orange: Chronic lower respiratory disease
- Black: Trachea and lung cancer
- Circle: Dementia and Alzheimer’s disease surpasses trachea and lung cancer

**Crossword**

**Across**
1. In the first place
6. Highlander
10. Crawl
11. Agricultural workers (4, 5)
12. Recreation period
14. Dislodge
16. Spotty disease
18. Toy dog (4, 3)
20. Systems
22. Lifting weight
23. Misbehaves, ... up
25. Inability to hear
28. Spitefulness
29. Photographs bones (1, 4)
31. Trade
32. Astounding

**Down**
1. Black and white ocean mammal
2. Wrath
3. Intimate
4. Matters
5. Pantries
7. Defeated soundly
8. Stylishly
9. Tattier
13. Dog restraint
15. Diversions
17. Woolly pelt
19. Pines and palms
21. Most depressed
22. Thrashes (5, 2)
24. Country, ... Rica
26. Actress, Cynthia ...
A day in the life of...

a Diversional Therapist

At the North Ryde DMCC, Denise Herman sees activity participants connect with their creativity and make empowering decisions.

A lzNSW Diversional Therapist Denise Herman is passionate about the importance of diversional therapy for people with dementia.

“The most important part of attending diversional therapy activities is it provides the person with dementia a safe environment to make decisions and make choices,” Denise said. “This is very empowering for a person with dementia.”

“I find that people with dementia often feel as though their individuality is taken away from them and everyone else is making decisions for them. Attending activities gives the person with dementia self-esteem and confidence and puts them back in touch with the person they were.”

Denise works out of AlzNSW’s Dementia and Memory Community Centre at North Ryde in Sydney. Diversional therapy activities run at the centre by the team include discussion groups for men, movie and popcorn sessions, bus trips, Memories of Me sessions and colour expression, where participants work with colour to create art including paintings, pictures or cards. The sessions last up to two hours and carers can also join in.

Expanding the program

As well as running the programs at the centre, the team has developed programs – which encompass creative arts, music and rhythm sessions – for community centres. These are already in demand and being delivered by the team at a centre in Sydney.

“To me, activities such as ours should be a part of everybody’s day,” Denise said.

“As human beings, our life has never just been about work only. We go to work but we always put time into ourselves through our sport or other pursuits, like music or reading or art. That should not be taken away from a person with dementia.

“If you take that out of our life, you’ve got a life that is empty. It is every individual’s right to be able to make choices and decisions, it’s just not right to take that away from the person with dementia.”

Denise also believes that everybody is creative on some level. “It’s just so important for a person to stay connected with what they used to do, even if it’s not at the same level,” Denise said.

“To see a person with dementia connect with their creativity and know that what they are doing is worthy is rewarding.

“When a person connects with an activity, there is just that moment where their thought process is so in tune with what they are doing, it’s almost as if the dementia doesn’t exist.”

For more information about therapeutic and social activities at your local centre, contact the National Dementia Helpline. T: 1800 100 500.
In memoriam

We offer our sympathies to the families who have lost their loved ones. We also thank the friends and families who have donated to Alzheimer’s Australia NSW in their memory.

Joseph Henry Ainsworth
Anita Aldred
George Anastasiou
Jeanette Anderson
Doreen Marie Arnold
Barry (Thomas) Ashe
Meri Bagnall
Daisy Barwick
Noel Arthur Beckett
Shirley Loreen Beggs
Emilio Benivento
Mekhael Doumit Boueiri
Ralph Bryant
Cyril Thomas Burke
Joyce Chopping
Andrew Christofis
Freda Margaret Cole
Norman Collins
Carmela Colosi
Jenny Coombes
Alma Corcoran
Marjorie Joan Cross
Edna Roseina Crow
Fred Crutchley
Douglas Gordon Bruce
Cumming
Kenneth Richard Cush
Marie Joyce Davidson
Ilse-May de Jong
Stephanie Demkiw (nee Paslawsky)
Debe Diab
Leo Diestel
Douglas Dimmack
Elaine Addison Doolan
Avril Driver
Lorna Ebsworth Dunbar
Marie Carmel Dunn
Elizabeth Joan Eliasson
Yvonne Farrugia
The Hon. William Kenneth Fisher AO, Q.C.
Hilton Alexander Forbes
Dulcie Fouracre
Alfred Franks
Norma Georgina Garland
Edna Eileen Glover
Bryan Graves
Bobby Gribble

Carolina Gurrieri
Harriet Hardyfenwick
Peter Hawes
Denis Hoctor
Donald Norman Hoffman
Jean Irwin
Kathleen (Kay) Francis Jarvis
Winifred Melinda Keating
Marjorie Joyce Keeley
Roland Kerr
Leo King
Henry Thomas Leader
Edith Eliza Lenthall
Robert Leonard
Catherine Lewis
Anne Lewis
Mary Lindfield
Elspeth Beth Macqueen
Besse Maskill
Joyce May
Bob McCartney
Leo Francis McMahon
Colin James McNeill
Patrick Melican
George Simpson Michie
Ruth Moffat
Elizabeth (Bette) Newby
Edith Minnie Parsons
Barry Neal Parton
Norman Kenneth Pease
Connie Philipson
Joyce Phillips
Noelene Pidcock
Vincenza Pignetti
Francesca Pipitone
Angelo Franco Porcella
Edith Ellen Price
Mieps Pritchard-Jones
Olive Pugh
Leo Rasmessun
Peter Retter
Hazel Rhodes
Joan Margaret Robinson
Luigia (Louisa) Ronchin
Michael John Ryan
Vittorio Sain
Neville Salkeld
Walter Santomaggio
Prof Graeme Schofield

Barry Scott
Alexander Collin Scott
Perce Searant
Mavis Searle
Judith Sheppard
Judith Simpkins
Rosario Spata
David Stanmore
Gwen Sutton
Ching Yung Tang
Pauline Tomlinson
Heather Ure-Smith
Elaine Wallington
Joy Helen Webb
Mark Wilkinson
Helen Wolfe
Jean Yates
Allan Edward Yeaman
Remembering Home: Rediscovering the Self in Dementia
By Habib Chaudhury
A wonderful book! Place and time as the taproots of memory are beautifully demonstrated in this book, which also offers strategies for health care professionals and activity staff members in bringing place and home into their programmed activities and conversations with older adults who have dementia.

To sponsor a book please contact the Library: (02) 9888 4218.

What’s new on the bookshelf…

The Alzheimer’s Project
HBO
The Alzheimer’s Project consists of four films. Momentum in Science is a prime-time state-of-the-science report, featuring 25 leading scientists, which reveals the most cutting-edge research advances.

Three additional prime-time specials – The Memory Lost Tapes, Grandpa, Will You Remember Me? with Maria Shriver; and Caregivers – capture what it means to experience the disease, to be a child or grandchild of one who lives with dementia, and to care for those who are affected.

Alzheimer’s is an irreversible and progressive brain disease that slowly destroys memory and thinking skills. Since advancing age is the strongest risk factor for Alzheimer’s, as the baby boom generation reaches retirement in 2011, the number of those affected will soar.

Hard scientific inquiry is demonstrating that there are a number of ways we can improve our chances of remaining cognitively vital throughout a long life.

The Selfish Pig’s Guide to Caring
By Hugh Marriot
Millions of people provide unpaid care for disabled or elderly relatives, friends, or neighbours. Their job is long, lonely and hard, with limited support and no formal training. As a result, carers suffer damage to their physical and mental health.

Though carers by definition are anything but ‘selfish pigs’, they are also liable to feelings of guilt that are often brought on by fatigue and isolation. This guide is designed to provide support for carers of every variety and air commonly ignored topics that arise when providing care.

Humorous and uplifting in tone, this is the perfect resource for coming to terms with caring for someone in the grip of a debilitating disease.

Looking for Lionel: Coping with Dementia
By Sharon Snir
A searingly honest and inspirational memoir of how dementia changed a family in ways they never could have imagined. Looking for Lionel is a warm, insightful memoir about how dementia entered Sharon Snir’s family and left them struggling with fear and sorrow. As Sharon shares her inspirational story, she invites you into her world of laughter and tears. Written for family and friends of those with the disease, it helps readers regain their courage and find the joys of relating in the here and now.

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Need assistance; not sure what you want? Then ask the Library!
Hours: Monday to Friday 9am–4pm;
T: (02) 9888 4218; E: lis@alznsw.asn.au
Library News keeps you up to date with new items in the Library: www.alzheimersnswlibrary.blogspot.com
Alzheimer’s Australia Online Bookshop offers over a million general titles and a range of dementia-related topics: www.alz.seekbooks.com.au
Alzheimer’s News features latest research, care practices and more: www.alznews.blogspot.com

…with AlzNSW Library and Information Services Coordinator Michelle de Mari