What price health?

Baroness Susan Greenfield calls for more funding for dementia research

10 ways we can help

» Younger onset dementia
» Record-breaking Memory Walk
» Support groups
» Campaigns
It was really good to see the Queen’s Birthday Honours list and it was especially delightful to see the name of Professor Maree Gleeson there. Maree is one of the Directors of Alzheimer’s Australia NSW (AlzNSW) and is a source of good advice and good sense; we like to think that some of her award is for her service to this organisation. Maree’s award will soon be conferred by our Patron the Governor of NSW Marie Bashir.

Retiring Directors
Maree is also now standing down as a Director of AlzNSW, and we are very grateful for her wonderful contribution to the Board.

Robert Yeoh will also retire from the Board at the upcoming AGM. Robert’s position is a little different in that he is also a member of the Board of Alzheimer’s Disease International.

Robert has been a Chairman of AlzNSW as well as National President of Alzheimer’s Australia. We thank him for his wonderful, lengthy contribution and wish him well.

Our brand
We have a really exciting new marketing strategy. It has been developed by Interbrand, coordinated by Andrew Mills from AlzNSW. Congratulations to AlzNSW. 

Publicity
Our new National President Ita Buttrose AO OBE has been working hard on wonderful publicity in the short time she has been in the position. For example, at the National Conference she got a lot of publicity with some necessary and forthright speeches. She comes from the Advisory Council in NSW and people should be aware of the high quality of the people who sit on that Council and assist us under the chairmanship of Barbara Cail.

The Productivity Commission Report has now been released. It is of great importance to us. Six months ago, the Draft Report did not mention dementia very much. We thought this was an enormous oversight, as ageing in Australia is associated with dementia far too often.

It is necessary that opinion leaders understand just how serious the dementia challenge is and the report of the Productivity Commission is a perfect opportunity for this. We held a function for the commissioners a couple of months ago and emphasised the importance of dementia.

Many of our activities are important but are not what any government funds us for, so we have to pay for them out of monies that you help us raise. The activities are vital for our success and must go on in spite of a lack of government funding.

One such activity is planned for later this year: to provide the many first-time NSW parliamentarians with electorate-specific information about the impact dementia will have on their own constituencies.

Events and speakers
Baroness Susan Greenfield, a neuroscientist from Oxford University, has been an exciting and welcome visitor. She spoke to dementia specialists in Sydney, visited every state and territory and addressed the National Press Club.

See page 8 for more information about Baroness Greenfield’s visit.

We also had a successful lunch with Graeme Samuel AC in Parliament House on 30 June. Graeme, whose brother is Vice-President of Alzheimer’s Australia, spoke emotionally about his mother’s dementia, and we all enjoyed his talk.

The Hon. Prof. Peter Baume AC Chairman
It is my privilege in this edition of In touch to thank a wide range of people who, by their compassion and talents, make life better for those living with dementia as well as their families and carers.

Congratulations to Professor Maree Gleeson, one of our Directors, for her well-deserved OAM. Our Directors do a wonderful job, all in a voluntary capacity, and we thank them most sincerely for it.

Memory Walk
A big thank you to everyone who took part in our all new and improved Memory Walk and Memory Jog in May.

The changes that were made, including the move in the location and the time of year it was held, all helped us to have our best Memory Walk yet, raising $110,000.

More Memory Walks will be held in regional NSW during Dementia Awareness Week in September. You can read all about them on page 4.

Dementia Awareness Week
Again this year, there is a lot of activity happening in Dementia Awareness Week, running from 16 to 26 September. We are particularly pleased to have Professor Ron Petersen, Director of the Mayo Alzheimer’s Disease Research Centre in the United States, who is renowned as the ‘godfather of Mild Cognitive Impairment’, on a national speaking tour for Alzheimer’s Australia.

Having speakers of the calibre of Professor Petersen and neuroscientist Baroness Susan Greenfield, who was here in July, helps us get dementia onto the wider public agenda and keep our members up to date with the latest developments in research and treatments for dementia.

You can find out more about Dementia Awareness Week and Professor Petersen’s visit on page 4.

Farewell
Finally, thank you and farewell to Jill Faddy, an AlzNSW volunteer for more than 25 years. Our volunteers are invaluable and we would not be able to help as many people as we do without them.

On behalf of the organisation, thank you Jill for your many years of wonderful service, and thank you to all our volunteers for your tireless work and support. Read about Jill and some of our many volunteers on page 12.

The Hon. John Watkins
CEO
Dementia Awareness Week

AlzNSW events will raise the profile of dementia during DAW.

Dementia Awareness Week (DAW) is happening again this year from 16-26 September and there is again a wide range of activities planned.

We are happy to announce that the NSW Government Department of Human Services (ADHC) and HACC are once again providing funding for our extensive range of initiatives, which include World Alzheimer’s Day on Wednesday 21 September, a statewide media campaign, a public seminar with Professor Ron Petersen, Memory Walks, Memory Van visits and more.

MEDIA CAMPAIGN
The media campaign will feature our Community Service Announcement (CSA) titled ‘There’s a difference’. The CSA is aimed at people who have legitimate concerns about memory loss and memory related symptoms. It recommends consumers phone the National Dementia Helpline to discover a world of understanding, information and support.

The campaign will run on a major commercial network across metro, regional and rural NSW, and can be watched on YouTube.

W: www.youtube.com/ watch?v=JBOuoMsdKmA

PROFESSOR PETERSEN SEMINAR
Professor Ron Petersen is the Director of the Mayo Alzheimer’s Disease Research Center and the Mayo Clinic Study of Ageing in the USA and has authored more than 300 peer-reviewed articles on memory disorders, ageing and Alzheimer’s disease.

He will be speaking at a free AlzNSW public seminar in Sydney on Monday 26 September, perfect for carers, medical and healthcare professionals, and anyone involved in dementia care or education.

When: Monday 26 September.
Morning tea and registration from 9.30am; seminar 10am – 11.30am
Where: Strangers Dining Room, NSW Parliament House
E: reception@alznsw.asn.au
T: (02) 9805 0100
Bookings are essential.

MEMORY WALKS
The Sydney Memory Walk was held in May and was a great success, raising over $110,000 and there are more to come around the state during Dementia Awareness Week.

Broken Hill: 11 September
Illawarra: 17 September
Port Macquarie: 18 September
Albury: 24 September
Tweed: 25 September
Hunter Community Walk with Amanda Percival: 17 September
W: www.memorywalk.com.au

PREVENTION AND TREATMENT SEMINAR
AlzNSW will be holding a free public seminar during DAW, where Scientia Professor Henry Brodaty AO, Director of the Primary DCRC at the University of NSW, and Professor Nicola Lautenschlager, Professor of Psychiatry at the University of Melbourne, will discuss the prevention and treatment of dementia. The seminar will be chaired by Alzheimer’s Australia President Ita Buttrose.

When: Wednesday 21 September 6-7.30pm
Where: Wesley Conference Centre, 220 Pitt St, Sydney
W: www.dementiaresearch.org.au
E: dcrc@unsw.edu.au
T: (02) 9385 2702 or (02) 9385 2585

YOD EVENT
A Younger Onset Dementia function with Professor John Hodges will be held at Noah’s on the Beach on Monday 19 September for health professionals, GPs and specialists.

E: shelley.horne@uchunter.org.au
T: (02) 4908 0217

OTHER EVENTS
AlzNSW initiatives also include Memory Van visits to selected regional areas, a street banner campaign in the City of Sydney, a Memories Service at Christ Church Cathedral in Newcastle on Sunday 18 September and ‘Morning Tea’ grants for statewide Carer Support Groups.

Once again, we’ll ask the dementia advisers and Carer Support Groups to distribute ‘Worried About Your Memory?’ brochures to small clinics and pharmacies.

Join us this September by getting involved in any way you can to help us spread the word!

Al the Elephant hit the streets to raise awareness of dementia prevention and treatment during last year’s DAW events.
Plan ahead

AlzNSW Planning Ahead Forums promote the importance of being prepared.

A recent Pfizer Health Report found 49 per cent of Australians have not taken any measures to plan ahead in the event of losing their ability to make decisions due to illness.

According to the report, most people have clear ideas about what they would like to happen if they were terminally ill even though they have not documented their wishes.

To explain the importance of planning ahead, AlzNSW is holding two forums with NSW Health, generously sponsored by Carroll and O’Dea Lawyers.

The forums will describe in simple terms the legal instruments available and what people need to do.

Speakers will include Professor Colleen Cartwright, international expert in ageing, ethics and medical decisions at the end of life; Imelda Dodds, CEO of the NSW Trustee and Guardian; and The Hon. John Watkins, CEO of AlzNSW.

Smithfield RSL Club: 5 October
South Tweed Sports Club: 8 December
RSVP: AlzNSW
E: admin@alznsw.asn.au
T: (02) 9805 0100

Volunteer program awarded

Bega-based dementia volunteer program recognised in the Health Excellence Awards.

Bega Hospital’s Person Centred Dementia Volunteer program has been recognised in the Southern NSW Local Health District Excellence Awards.

Established by AlzNSW Bega office Regional Manager Barbra Williams and Dementia Delirium Clinical Nurse Consultant Cath Bateman two years ago, the program aims to improve the emotional wellbeing of patients and reduce their risk of adverse outcomes.

Taking out top gong in the Volunteer Service Category and Highly Commended in the Chief Executive Officer category, the program was recognised for its contribution to improved emotional care and safety for patients and support to staff.

It has now been included in the NSW Dementia Services Framework 2010-2015 as an example of existing good practice in hospital care.

Have your say

Join a Regional Consumer Committee.

We are committed to ensuring the voices of our consumers are heard and our policies and programs reflect the needs of those we represent.

We have developed a network of regional consumer committees throughout NSW to consult with people living with dementia, their families and carers.

The AlzNSW Consumer Committees in Sydney, Newcastle, Wollongong, Port Macquarie, Armidale, Orange and Wagga Wagga meet twice a year, and committees in Bega and Cooma meet annually.

Committees discuss important policy issues and contribute to both state and national policy development.

HOW TO JOIN

For more information or to join a committee contact Jo-Ann Brown.
E: jbrown@alznsw.asn.au
T: (02) 8875 4636

BANG THE DRUM!

Al the Elephant scales the heights of Mt Kilimanjaro with Julie and her daughter Lauren.

Keep sending in your entries for the second Bang the Drum competition!

Post: Andrew Mills, AlzNSW
PO Box 6042, North Ryde, NSW 2113
Email: amills@alznsw.asn.au

Café Connect provides opportunities for people with dementia and their carers to socialise and share ideas.

The Connections Café in Warners Bay has been such a success in reducing social isolation that it has changed to a larger venue. The Warner’s Bay group now meets at Ducks Crossing at Eleebana. There are also several Café Connect groups throughout NSW, so check the dates below and come along.

Toronto
When: fourth Thursday of each month
Where: Toronto Workers Club
Contact: Clare Coyle
T: (02) 4962 7000

Warners Bay
When: first Wednesday of each month, 10am
Where: Warners Bay
Contact: Bev Watson
T: (02) 4962 7000

Caringbah
When: 27 September, 25 October, 22 November
Where: Camellia Gardens Tea House, Caringbah
Contact: Julie
T: 0418 815 041
Gold coin donation appreciated.
Early support

The early stages of dementia can be difficult, but both the patient and their loved ones can find support in AlzNSW’s Living with Memory Loss program (LWML).

LWML is for people in the early stages of dementia and their carers, and people with memory loss can also attend alone.

Groups talk about symptoms and diagnoses, adapting to changes, research and new drug treatments, practical strategies for coping with memory loss, relationships, looking after themselves, planning for the future, community services, legal issues, and where to find more help.

To find out about upcoming LWML sessions, contact AlzNSW on the National Dementia Helpline.

T: 1800 100 500.

Dementia and sexuality

Congratulations to Elaine White, AlzNSW Educator and author of Dementia and Sexuality: The Rose that Never Wilts, which was glowingly reviewed by Alzheimer’s Scotland.

BORROW THE BOOK
E: lis@alznsw.asn.au
T: (02) 9888 4218

BUY THE BOOK
W: www.alz.seekbooks.com.au
T: (02) 8206 9035

Identification

The NSW Photo Card is a voluntary identity card for people who do not hold a current NSW driver licence or other form of photo identification.

The Photo Card application form is available from any motor registry, or can be downloaded from the RTA website.

Administration fees may be waived for eligible pensioners, including war widows.

Contact the RTA to find out more.

W: www.rta.nsw.gov.au
T: 132 213

Member discounts

AlzNSW members are eligible for discounted registration for the Mind and its Potential Conference in Sydney.

The Mind and its Potential Conference will bring 40 amazing speakers to Sydney in November, including creativity guru Dr Edward de Bono, inventor of mind mapping Tony Buzan and Oxford University neuroscientist Baroness Susan Greenfield.

Topics of discussion include: how we learn, how we should teach, how to overcome adversity and disability, and different ways of living our lives.

Alzheimer’s Australia members and affiliates are eligible for a 10 per cent discount on conference registration.

When: 7-8 November
Where: Sydney Convention and Exhibition Centre
W: www.mindanditspotential.com.au
T: (02) 8719 5118

KOREAN VISITORS

A delegation from the Yuhan Institute of Health Medicine and Welfare in Seoul, Korea, visited the Vincent Fairfax Family Resource Centre in North Ryde in June to learn about the services offered by AlzNSW, including the National Dementia Helpline, the library, counselling, and early intervention programs.

VETERANS’ BENEFITS

Changes to how links between medical conditions and military service are assessed may mean more veterans with Alzheimer’s disease are eligible for benefits.

In 2010, the Repatriation Medical Authority updated its Statement of Principles (SOP), used to establish a connection between a medical condition and military service to determine a person’s eligibility for benefits, for Alzheimer’s disease.

The SOP for Alzheimer’s disease provides a list of factors, at least one of which must exist to suggest a link between Alzheimer’s disease and the military service rendered by the person. If you or your spouse is or was a veteran with Alzheimer’s disease, you may be eligible for additional benefits.

Contact the Department of Veterans’ Affairs or your local ex-service organisation for advice.

W: www.dva.gov.au
T: (02) 8719 5118

The SOP is available from the Repatriation Medical Authority.
W: www.rma.gov.au
Art Xpress in the Hunter

The Hunter Dementia Memory and Resource Centre is now running weekly art sessions for people with dementia, including younger onset dementia.

Art Xpress in the Hunter is a dementia-specific art therapy program that encourages people with dementia to engage in creative expression in a safe, supportive environment.

Each week, the Percy Street Centre’s meeting room is transformed into an artist’s studio with relaxed, fun atmosphere, and a group of people with dementia, including people with younger onset dementia, meets for art therapy sessions.

A growing body of research literature has found the use of creative therapies can exercise and increase cognitive skills. Art therapy also encourages self-expression and provides social interaction for people living with dementia.

While the idea of participating in an art therapy session can be overwhelming for some at first, the program focuses on the strengths and abilities of its members and, with a little encouragement, their reluctance is often replaced with enthusiasm.

The measure of success is in the positive outcomes for the participants, with none more obvious than the delight they express as their creative skills are developed.

Come along

Where: Dementia Memory and Resource Centre in Newcastle
When: Tuesdays, 10am-12pm
T: (02) 4962 7000

STAFF NEWS

Welcome to Verity Jackson, who has commenced with us in Cooma in the role of Dementia Advisor. Also, big thanks to Kirsty Perry and Faye Cavdarski, who have been very cheerfully providing administration and reception support for the past few months at the Dementia and Memory Community Centres at North Ryde and Port Macquarie.

CONGRATULATIONS

Congratulations to Professor Maree Gleeson, one of AlzNSW’s Directors, who received an OAM in the Queen’s Birthday Honours for her contributions to medicine, education and professional associations.

DONATION

The Dementia Care Volunteer Program at Coffs Harbour Base Hospital received generous donations of $150 from the Coffs Harbour Ex-Services Sports Touring and Classic Car club, and $200 from St Nic’s Craft Group.

They will be used to fund activities for the program, which is jointly managed by AlzNSW and the Mid-North Coast Local Health Network.

Keep up!

Get all the latest news from AlzNSW on Twitter and Facebook, and see event photos on Flickr.

Facebook: facebook.com/alznsw
Twitter: twitter.com/alznsw
Flickr: flickr.com/photos/alznsw

ART XPRESS IN THE HUNTER

AlzNSW Ambassador PJ Lane is again hosting Memory Lane, a wonderful night of entertainment in honour of his father, the late, great Don Lane.

This year’s show will feature such stars as Rhonda Birchmore, Verity Ballard-Hunt (aka Mary Poppins), David Harris, Alan Jones and comedian Darren Carr, and all proceeds will go to AlzNSW.

When: Monday 24 October
Where: State Theatre, Sydney
W: www.thememorylaneconcert.com.au
T: (02) 9373 6655
Funding for dementia research is woefully inadequate, giving researchers little chance of finding answers, a leading neuroscientist has warned.

Baroness Susan Greenfield, Professor of Synaptic Pharmacology at Oxford University, is one of Britain’s foremost neuroscientists and heads a multidisciplinary research group that investigates neurodegenerative disorders.

In Australia in July on a speaking tour for Alzheimer’s Australia, Baroness Greenfield said more effective approaches for treating the debilitating condition could be found, but only with appropriate funding.

Level the playing field
“There is an inexplicable and disturbing disparity in funding for research between dementia and other chronic conditions,” Baroness Greenfield said.

“In Australia, dementia research receives approximately $20 million – a little more than four per cent of the total amount spent on research for all chronic diseases – despite the fact that it is already the third leading cause of death in this country.

“In comparison cancer research receives $144 million annually while $97 million per annum is spent on researching cardiovascular disease. The situation is similar in the UK where dementia receives only about five per cent of total research funding compared with the 70 per cent that cancer research receives.

“Yet by 2060, spending on dementia is set to outstrip that of any other health condition in Australia.

“Without appropriate funding for dementia research, too many parents and grandparents will be lost to a condition for which more effective answers can be found. We can beat dementia. Governments are just not trying hard enough.”

A numbers game
An estimated 269,000 Australians have the condition, a number that is expected to soar dramatically to almost one million by 2050 as the population ages. Currently, there are approximately 1500 new cases of dementia each week.

The Hon. John Watkins, the CEO of Alzheimer’s Australia NSW, said decisions taken in the 2011/12 Federal Budget had resulted in the government taking a step backwards rather than trying harder to beat dementia.
“The Dementia Initiative, which has provided thousands of people with dementia and their families and carers with invaluable support and services since 2005, will dry up by June 2013,” John said.
“Unless it is replaced, this will leave Australia unprepared to deal with the dementia epidemic coming its way.
“This year’s Budget decisions have resulted in a loss of guaranteed funding for key programs for addressing the staggering increase in the number of people with dementia in the next 40 years.
“This has been a major disappointment to the already one million Australians who care for people with dementia.

Solutions
“The government needs to introduce its own comprehensive and funded plan to address dementia when it responds to the Productivity Commission’s forthcoming report on Caring for Older Australians.
“Initiatives are desperately needed to provide dementia care services, achieve timely diagnosis of dementia, make hospitals safer places for people with dementia and increase funding for dementia research.
“Dementia is core business in aged care and without a funded dementia plan the reform of aged care will just not make sense nor will it be successful. We need a commitment for appropriate funding to address this looming epidemic before it’s too late.”

Spreading the word
Baroness Greenfield travelled around Australia to talk about the current approaches for treating dementia, the future of dementia treatments and research strategies that may lead to a dementia-free life.
“We will only be able to achieve a new era of dementia reduction and prevention with more money for research,” she said.

The Baroness started her national speaking tour at a public seminar at NSW Parliament House in July. National President Ita Buttrose AO OBE was the MC for the event.
NSW Health Minister The Hon. Jillian Skinner also spoke at the seminar, along with AlzNSW Honorary Medical Advisor Professor Henry Brodsky.

Missed the talk?
To watch Baroness Greenfield’s address to the National Press Club, visit the Alzheimer’s Australia website.
W: www.alzheimers.org.au

MEMORY VANS’ TRAVELS
The AlzNSW Memory Vans have been clocking up the kilometres travelling around NSW to raise awareness of dementia and risk reduction.
To find out where the Memory Vans will be in the coming months go to www.alzheimers.org.au/nsw
To invite a Memory Van to a community event, contact AlzNSW.

Hunter and Mid North Coast: Kim Wilson
T: (02) 4962 7000
E: kwilson@alznsw.asn.au

Rest of NSW: Susan Newton
T: (02) 8875 4637
E: snewton@alznsw.asn.au

www.alzheimers.org.au
A record number of walkers and fun runners took part in the Sydney Memory Walk and Memory Jog at the Bay Run in Lilyfield on Sunday 15 May.

Alzheimer’s Australia NSW Ambassador PJ Lane, who was the MC for the event, said 967 people registered to take part in the walk and fun run.

“It was fantastic to see so many people out on such a beautiful day in support of people with dementia,” PJ said.

The hundreds of runners and walkers have also helped raise $110,494 – a record amount for the Memory Walk and Memory Jog.

The CEO of Alzheimer’s Australia NSW, The Hon. John Watkins, said it was a wonderful event that helped raise much-needed funds for people in need across NSW.

“Our wonderful supporters have raised a record amount that will provide much-needed support and education to people living with dementia, their families and carers,” John said.

“Thank you to everyone who took part and helped make this our most successful Memory Walk and Memory Jog yet.

“And a very special thank you to our top five teams and top five individual fundraisers for their fantastic effort.”
NEW RESEARCH PROJECT

AlzNSW has teamed up with the University of NSW and Uniting Care Ageing for a new study of services and support for people with younger onset dementia, their families and carers.

The new collaborative research study will canvass participants from metropolitan, regional and rural areas. It will include face-to-face interviews and surveys with people with YOD and their family/carers about their good and bad experiences regarding accessing services, their pathway to diagnoses, their social support requirements and respite services.

The findings will inform policy and service change to increase quality of life and community living standards, ensure a smooth pathway of service and support, and prevent premature entry into residential care.

Inspiring change
Professor Brian Draper and Dr Adrienne Withall from the Dementia Collaborative Research Centre at UNSW recently won funding from the National Health and Medical Research Council for a study to determine accurate information about the numbers of people affected by YOD, their different conditions, their experiences and those of their family members.

The results of the study will inform service planners about the health and support service needs of younger persons with dementia and their carers, and improve training.

The study is a collaboration between researchers at UNSW, the University of Sydney and the Prince of Wales, St Vincent’s, Sutherland and Port Kembla hospitals.

More information:
W: www.inspiredstudy.org
E: inspiredstudy@unsw.edu.au
T: (02) 9385 2617

New YOD blog
Does your mum or dad have YOD? Are you looking for information on YOD? Would you like to talk with other young people in similar situations?

The AlzNSW blog Younger Onset Dementia and Me is a place for young people to connect with others, be listened to and find information.

Contributors must be over the age of 18, have a parent with YOD and agree to the terms and conditions. Check out the blog and contact Helen Carswell for more information.

W: youngeronsetdementiaandme.blogspot.com
E: hcarswell@alznsw.asn.au

NEED TO KNOW
Younger onset dementia, also known as early onset dementia, is dementia with onset before age 65. The numbers of people with early onset dementia seem to be increasing, however there is little known about this group.

Get involved
If you are a person with YOD, a carer or family member who would like to participate in the study please contact Jo-Ann Brown.
T: (02) 8875 4636
E: jbrown@alznsw.asn.au

If you would like to talk to someone about YOD, phone the NSW National Dementia Helpline: 1800 100 500

If you would like to talk to someone about YOD, phone the NSW National Dementia Helpline: 1800 100 500
How does retired clinical psychologist and committed volunteer Jill Faddy describe her quarter-century with AlzNSW?

“It’s been the ride of my life,” she says. “Seeing how AlzNSW has grown has been wonderful.”

Jill’s involvement with AlzNSW started when she was caring for her mother with dementia in 1982, the year the organisation started. Jill joined up and attended the Randwick Botany support group as a carer.

About two years later, she was asked to be the support group leader, a post she will have held continuously until her retirement from the group in September this year. Jill has also been a Director of AlzNSW from 1983-2005 and was president from 1986-88.

Lending support

The time has come for Jill to retire as support group leader. Jill remembers what she has enjoyed most about leading a carer support group: “Seeing people recognise that they are not alone with this, that they have the support of the other people in the group.

“They can also learn how to cope with living with a person with dementia, so they can become skilled carers and be able to learn how to look after themselves as well.”

Jill said some of the biggest challenges were helping carers to try to step back when facing a stressful situation and work out how to best deal with it, as well as deal with their own feelings.

“You feel terrible and you feel hopeless, especially with some of the challenging behaviours,” Jill said.

“You’re trying to understand what a person struggling with dementia is trying to communicate. It’s as though you’re both speaking different languages.

“If you step back and try to understand where the person with dementia is coming from, you can help the person with dementia feel understood and valued.”

Future leaders

Jill also has sage advice for future support group leaders: “Learn as much as you can about dementia and how to facilitate support groups.

“Listen hard before you say anything. And get support from other group leaders and professionals; it gets a bit stressful if you try to wing it alone.”

While Jill, who is a life member of AlzNSW, may be retiring as leader of the support group, she is not retiring from her association with the organisation. “I think AlzNSW is a magnificent organisation,” Jill said. “Because dementia is the ‘growth industry’ we’d rather not have, more needs to be done in research as well as in how to cope with it.”

Congratulations

Long-time and dedicated AlzNSW volunteer Dorothy Webb has been nominated for the City of Ryde 2011 Volunteer of the Year Award.

Congratulations to Dorothy, and thank you for all your work.

Thanks

Thanks to all our dedicated volunteers; we would not be able to do what we do without you! If you would like to volunteer, contact Volunteer Coordinator Diana Waring.

E: alzvolunteer@alznsw.asn.au
T: (02) 8875 4631

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THE RIGHT ANSWERS

Families, friends and carers of people diagnosed with Alzheimer’s disease and dementia often have many questions. In each issue of In touch, AlzNSW offers answers.

Q What’s the difference between Alzheimer’s disease and dementia?
Alzheimer’s disease is actually a form of dementia. It can be helpful to think of dementia as an umbrella term for more than 100 known conditions, including Alzheimer’s disease, Vascular dementia, Dementia with Lewy bodies and Frontotemporal dementia.
Dementia is the term used to describe the symptoms, such as changes in memory, intellect, rationality, social skills and physical functioning. There are many different causes of dementia and Alzheimer’s disease is the most common type, accounting for between 50–70 per cent of all dementia cases.

Q Dad tells different stories to different people. Does the dementia cause him to lie?
Dementia causes gaps in people’s memories, sometimes described as blank sections. When a person who has dementia is talking about something, or asked a question, and hits one of those blank sections, he or she will often invent to fill in the gap. This is called ‘confabulation’. In your dad’s case, it allows him to maintain his self-esteem by not appearing as if he ‘has no idea’. This story may then change when he talks to another person because the memory of what he said the last time has gone.

When you are talking to your dad, stay calm and allow plenty of time for him to respond. Don’t argue and feel that you have to make him see the truth. Think of it from his perspective and always aim to maintain his dignity and self-esteem.

Need answers?
Send your questions to Helen Carswell or phone the National Dementia Helpline.
E: hcarswell@alznsw.asn.au
T: 1800 100 500
Ways AlzNSW can help
AlzNSW is here to support people with dementia, their families and carers. Let us count the ways!

1. Support at time of diagnosis helps you and your family to make sense of the diagnosis and the next steps.
2. Practical advice helps you minimise the impact of dementia.
3. Living with Memory Loss programs for people in early-stage dementia increase knowledge and confidence for managing memory loss.
4. Individual and family consultations help you plan for the future.
5. Education programs help you understand and live well with dementia.
6. Up-to-date information and resources about dementia and access to the members’ lending library keeps you and your family informed.
7. Connections with other people living with dementia enable you to share information and experiences.
8. Social and creative activities provide opportunities for meaningful participation.
9. Recommendations and advice about dementia support services in your area ensure suitable care.
10. Our provision of information to GPs and other health care providers helps them improve their care and support for you.

To find out more, contact AlzNSW on the National Dementia Helpline. The National Dementia Helpline is an Australian Government Initiative. An interpreter service is available. T: 1800 100 500

How we help Gordon
Gordon has frontotemporal dementia (semantic dementia) so he has trouble with comprehension and language, and there are also behavioural changes.

“He can’t remember meanings of words; he can’t remember faces,” says his wife Helen. “He’ll call milk water, for example. If I mention my brother, he has no idea who he is until he sees him. He’s in a totally different world.”

Gordon comes to the AlzNSW ‘Colour from Heart to Art’ sessions, and Helen says he loves it. “He can go in there and express his creative side in safety and he doesn’t have to communicate with anybody. It just gives him so much pleasure. I can’t put a value on it.”

Art therapy programs are run in Sydney and regional areas, and no prior experience is necessary! Contact AlzNSW on the National Dementia Helpline to find your nearest session. T: 1800 100 500
Life support

Events around the state raise funds to help AlzNSW improve dementia services.

City2Surf
Thank you to everyone who took part in the City2Surf for AlzNSW. About 70 people took on the challenge of the popular annual event as part of AlzNSW’s Memory Joggers team and we’ll have a full wrap-up of their run in the next edition of In touch.

Blackmores Running Festival
It’s not too late to join the Memory Joggers team who are running in the Blackmores Sydney Running Festival on Sunday 18 September.
Our fantastic volunteers will be stationed at Bradfield Park to help the Blackmores team with registration before the race and the AlzNSW banners will be flying, so come and visit us at the registration desk.
After the race, join the team to wind down at theWoolloomooloo Bay Hotel from 11am.
A huge thank you to the team and all its supporters! If you haven’t joined yet and would like to participate, please register on the Sydney Running Festival website and join the Memory Joggers Team.
W: www.sydneyrunningfestival.com.au

Raffle winners
Another successful Rotary Community Chest Raffle was drawn at the Burwood RSL on 20 July, and the winner is now the owner of a brand new Toyota Yaris.
1 Toyota Yaris.
Winner: J Barratt, Cook
2 $1000 worth of jewellery.
Winner: C Norman, Maryborough
3 Netbook Computer.
Winner: J Pambris, Flynn

Thank you
We extend a big thank you to all the members and friends of AlzNSW who generously supported our appeals last 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.

Events newsletter
The fundraising team is proud to announce the first events e-newsletter, Events Buzz@ Alzheimer’s Australia NSW, which is being sent out to our ever-growing email database.
This fortnightly e-newsletter will keep you up to date with all the upcoming fundraising events, news about our wonderful fundraisers and ways you can get involved.
If you don’t already receive our e-newsletter, get in touch to sign up so you don’t miss out on our next exciting event!
E: events@alznsw.asn.au

At 1st Street we place a high level of importance on supporting the community around us. Dementia has such a widespread effect and we feel that it is our duty to get behind an organisation that impacts the same community we deal with every day. In doing so we will donate a percentage of each loan we sign and fund a community support group for Alzheimer’s Australia NSW.
1st Street has satisfied and delighted clients with our results over the years and this success has led to numerous accolades. 1st Street was recently ranked 1st in the Australian Elite Business Writers Awards and recognised by the Commonwealth Bank for being one of the largest residential loan writers in Australia.

www.alzheimers.org.au
### Care worker workshops

Fees apply. Contact Gail Longhurst: (02) 9805 0100 or education@alznsw.asn.au

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>WORKSHOP</th>
<th>DATE</th>
<th>COST</th>
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<tbody>
<tr>
<td>Hunter</td>
<td>Pharmaceutical and Non-Pharmaceutical Treatment options for people living with dementia</td>
<td>14 September</td>
<td>$25</td>
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<td></td>
<td>Assisting with Activities of Daily Living</td>
<td>6 October</td>
<td>$25</td>
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<td>Legal and Ethical Issues at End of Life</td>
<td>3 November</td>
<td>$25</td>
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<td>Bathurst</td>
<td>Person Centred Care and Communicating with People Living with Dementia</td>
<td>12 September</td>
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<td>Bega</td>
<td>Living, Loving &amp; Dementia</td>
<td>18 October</td>
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<td>Batemans Bay</td>
<td>Living, Loving &amp; Dementia</td>
<td>19 October</td>
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<td>Queanbeyan</td>
<td>Living, Loving &amp; Dementia</td>
<td>20 October</td>
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<td>Mudgee</td>
<td>Living, Loving &amp; Dementia</td>
<td>7 November</td>
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<td>Dubbo</td>
<td>Living, Loving &amp; Dementia</td>
<td>8 November</td>
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<td>Parkes</td>
<td>Living, Loving &amp; Dementia</td>
<td>9 November</td>
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<td>Bathurst</td>
<td>Living, Loving &amp; Dementia</td>
<td>10 November</td>
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<td>Nowra</td>
<td>Person Centred Care and Meeting Hygiene Needs at Home</td>
<td>11 October</td>
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<tr>
<td>North Ryde</td>
<td>Engaging People with Dementia in Activity</td>
<td>22 September</td>
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<td></td>
<td>Experiencing Dementia - Person Focused Approach to Understanding Behavioural Symptoms of Dementia</td>
<td>24 October</td>
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<td>North Coast</td>
<td>Behavioural Symptoms - Taree</td>
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<td>Activities - Taree</td>
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<td></td>
<td>Behavioural Symptoms &amp; Activities - Taree</td>
<td>14 September</td>
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<td></td>
<td>Dementia and Depression - Coffs Harbour</td>
<td>24 September</td>
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<td></td>
<td>Experiencing Dementia - Port Macquarie</td>
<td>11 October</td>
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<td>Experiencing Dementia &amp; Behavioural Symptoms - Port Macquarie</td>
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### Family Carer Education

Workshops are free. Contact Gail Longhurst: (02) 9805 0100 or education@alznsw.asn.au

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<th>WORKSHOP</th>
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<tr>
<td>Hunter</td>
<td>3 Day Carer Course</td>
<td>8, 15 and 22 September</td>
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<td>Sons and daughters - Coping with Grief and Loss</td>
<td>16 November</td>
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<td>Nelson Bay</td>
<td>3 Day Carer Course</td>
<td>21, 28 September and 5 October</td>
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<td>Bathurst</td>
<td>1 day Carer Course</td>
<td>14 September</td>
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<tr>
<td>Penrith/Regentville</td>
<td>3 Day Carer Course</td>
<td>11, 18 and 25 October</td>
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<td>Nowra</td>
<td>1 day Carer Course</td>
<td>18 October</td>
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<tr>
<td>St George's Basin</td>
<td>1 day Carer Course</td>
<td>27 October</td>
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<td>Moss Vale</td>
<td>2 Day Carer Course</td>
<td>28 October and 4 November</td>
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<td>North Ryde</td>
<td>3 Day Carer Course</td>
<td>6, 13 and 20 September</td>
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<td>Friends</td>
<td>26 October</td>
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<td></td>
<td>4 Evening Carer Course</td>
<td>1, 8, 15 and 22 November</td>
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<tr>
<td>North Coast</td>
<td>Sons and Daughters - Ballina</td>
<td>7 September</td>
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<td>Friends and Neighbours - Coffs Harbour</td>
<td>20 September</td>
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<td></td>
<td>Sons and Daughters - Casino</td>
<td>16 November</td>
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<td></td>
<td>Sons and Daughters - South Tweed</td>
<td>17 November</td>
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<td>1 Day Carer Course - Taree</td>
<td>22 November</td>
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<td>1 Day Carer Course - Laurieton</td>
<td>23 November</td>
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<td></td>
<td>2 Day Carer Course - Port Macquarie</td>
<td>15 and 22 September</td>
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### Volunteer courses

Workshops are free. Contact Gail Longhurst: (02) 9805 0100 or education@alznsw.asn.au

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<tr>
<td>Hunter</td>
<td>Effective Communication</td>
<td>9 November</td>
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<tr>
<td>Bathurst</td>
<td>Volunteer Education</td>
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<td>North Coast</td>
<td>Volunteer Education - Ballina</td>
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<td>Volunteer Education - Forster</td>
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<td>Volunteer Education - Gloucester</td>
<td>24 November</td>
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### Community Awareness Programs

Workshops are free. Contact Gail Longhurst: (02) 9805 0100 or education@alznsw.asn.au

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<thead>
<tr>
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<tr>
<td>Bathurst</td>
<td>Mind your Mind presentation</td>
<td>13 September</td>
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### Support Group Leaders’ Workshops

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<tr>
<td>Advanced Group Leadership</td>
<td>North Ryde</td>
<td>28 and 29 November</td>
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<tr>
<td>Grief, Loss &amp; Dementia for Support Group Leaders</td>
<td>Seven Hills</td>
<td>7 and 8 November</td>
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<td>Group Leaders’ Forum (for current, experienced group leaders)</td>
<td>Fairfield</td>
<td>7 October</td>
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<td>Bingara</td>
<td>27 October</td>
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For more information or to register for Support Group Leader workshops, contact Monica Cole T: 02 8875 4682
Change in 2012

The 2011 Federal Budget was a great disappointment, with no new funding and the termination of a major dementia initiative. But Alzheimer’s Australia is fighting for more from the 2012 Budget, and you can pitch in.

The 2011 Federal Budget was a severe disappointment to people with dementia and the families and carers who support them. There was no new funding to combat the dementia epidemic and the Australian Government terminated the dementia initiative ‘Making dementia a national health priority’, which means the loss of guaranteed funding for essential programs and support services for people living with dementia.

There are currently 269,000 Australians with dementia and 1500 new cases of dementia every week. By 2050 there will be nearly one million people with dementia.

Alzheimer’s Australia’s Fight Dementia Campaign will seek Federal Government recognition of dementia as a health priority. Action is needed to tackle dementia in the 2012 Federal Budget.

The campaign

Alzheimer’s Australia’s Fight Dementia Campaign has identified five priority areas for additional funding over the next five years to be addressed in the 2012 Federal Budget. These priorities are to:

• promote awareness and understanding of dementia
• achieve timely diagnoses of dementia
• provide quality dementia care in community, residential and acute care settings
• make people aware they may be able to reduce the risk of dementia
• invest in dementia research to reduce future numbers of people with dementia

For this to be achieved, we urgently need the Federal Government to commit to at least an additional $500 million over the next five years.

How to make it happen

Alzheimer’s Australia needs wide community support in the fight against dementia and to make dementia a health priority. The best way is for people with dementia and their families and carers to tell their stories so people better understand dementia.

1. Sign up as Dementia Champion
   Visit the campaign website to register your support.
   W: www.fightdementia.org.au

2. Tell your dementia story
   Stories should be no more than 500 words in length and will be shared with the community through the campaign website and the media. To share your dementia story, contact Tegan McGrath.
   E: tegan.mcgrath@alzheimers.org.au
   T: (02) 6254 4233

3. Join the Fight Dementia March
   The Fight Dementia March will be held at Parliament House in Canberra on Thursday 13 October. We need you to take part and to encourage as many people as you can to also join. Register your interest in marching by contacting Alzheimer’s Australia.
   E: fightdementia@alzheimers.org.au
   T: (02) 6254 4233

4. Talk to your MP
   Write to your Federal Member of Parliament to tell your story of living with dementia and ask for their support for dementia funding in the 2012 Budget. Seek a meeting with your MP to explain the issues in more detail and encourage your MP to become a Dementia Champion and join the Fight Dementia March on 13 October. Visit the House of Representatives section of the Parliament of Australia website for a list of all Australian MPs and their contact details.

   If you would like any more information about the campaign or would like to help, please contact Diana Waring.
   E: dwaring@alzns.w.org.au
   T: (02) 9805 0100

WITH YOUR SUPPORT, ALZHEIMER’S AUSTRALIA WILL PUT DEMENTIA BACK ON THE POLITICAL AGENDA IN 2012.
A day in the life of...
AlzNSW Educator Michelle Basic

As AlzNSW’s Educator with our Culturally and Linguistically Diverse (CaLD) project, Michelle Basic is involved in making sure that dementia awareness, risk reduction strategies and carer education reach into the CaLD communities of NSW.

“There are approximately 117 languages spanning 200 cultures spoken as the main language in NSW homes, and the total number of people in NSW who don’t speak English at home is approximately 1.2 million,” Michelle says.

“Some communities have no word for dementia, so the condition is not openly discussed or understood. Bringing contemporary information to these communities is very rewarding.”

On the mark
The courses Michelle writes and delivers must be useful, meaningful and relevant to encourage early diagnosis and the uptake of services to better support both people living with dementia and their families.

“In light of the prevalence prediction figures for the next few decades, it is extremely important to raise the profile of dementia,” Michelle says.

“The CaLD Project and I as an English-only speaker are indebted to the enthusiasm of bilingual volunteers who have worked alongside me to make certain that written information, visual material and general dialogue is palatable and of interest to the individual communities.”

Visual aid
To support communities where there is stigma and misinformation about dementia, Michelle is producing DVDs to demonstrate that dementia is a medical condition that should not carry with it shame and social ostracism.

“Over the past few months I have been working closely with the Croatian and Assyrian communities, and the filming of DVDs for these two communities has just commenced,” Michelle says.

“The DVDs feature doctors, allied health professionals, community workers and carers of that culture, speaking directly to their communities, giving factual information and very personal accounts of dementia. The DVDs will be distributed widely with the aim of demystifying dementia, promoting acceptance and steering communities to avenues of assistance.”

The DVDs will also have English subtitles, making them a useful, ongoing resource for educators, the wider community and for families who have younger family members who may only speak English.

Community engagement
“I’m continually impressed by the strength of the many families I’ve met, and particularly by the generosity of carers, who already have a heavy workload, who have embraced the opportunity to defy cultural stigma and appear on the DVDs with the simple, unselfish aim of helping others in their communities,” Michelle says.

“Every day of my working life is different and it continues to be a privilege to be welcomed with great warmth into the many communities I have spoken with. I’m enjoying something of a cultural and food safari around which the confounding subject that is dementia can be put into better perspective.”
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.

Alzheimer’s Australia NSW would like to acknowledge and thank the families and executors of the recently received bequests from which people with dementia, carers and their families have received lasting benefits.
What’s new on the bookshelf...

...with AlzNSW Library and Information Services Coordinator Michelle de Mari

Hearing the Person with Dementia: Person-centred Approaches to Communication for Families and Caregivers
by Bernie McCarthy
Advocating a person-centred approach to dementia care, the author describes techniques for communicating with people who can no longer speak or move easily and strategies for communicating more effectively in specific day-to-day situations. Exercises encourage the carer to reflect on their learning and apply it to their own circumstances. Guidelines for creating a life story with the person with dementia as a means of promoting good communication are also included.

The Grey Cat
by T oryn Chapman
Jillian Barrett has cared for her mother Elizabeth, who has Alzheimer’s disease, for five years. At Elizabeth’s hospital bedside, Jillian relives those difficult years spent trying to accept her mother’s increasingly cryptic behaviour. What she can never know are the experiences in a Depression-era orphanage that, 70 years ago, shaped her mother’s life and to which she has been looking back.

The Senior Moments Memory Workout: Improve your Memory and Brain Fitness Before you Forget!
by Tom Friedman
Acute absentmindedness, fuzzy thinking, head-scratching confusion: these are just a few symptoms of the dreaded senior moment. The Senior Moments Memory Workout features a collection of engaging quizzes, puzzles, brainteasers and memory challenges to keep memory loss at bay, as well as sound advice and historical anecdotes to reassure people with memory loss they’re not alone.

Need assistance; not sure what you want? Ask the Library!

Hours: Monday to Friday 9am–4pm
T: (02) 9888 4218 E: lis@alznsw.asn.au

Keep up to date with all new items in the Library, including books, DVDs and journal articles by visiting the Library News blog.
W: www.alzheimersnswlibrary.blogspot.com

Choose from more than one million general titles, as well as a wide range relating to dementia and Alzheimer’s disease, at the Alzheimer’s Australia Online Bookshop.
W: www.alz.seekbooks.com.au
T: (02) 8206 9035

Alzheimer’s Australia Online Bookshop provides an easy way to purchase resources relating to dementia and Alzheimer’s disease, as well as more than one million general titles.
W: www.alz.seekbooks.com.au
T: (02) 8206 9035

Sudoku
Fill the grid so that every column, every row and every 3x3 box contains the numbers 1 to 9.

Rating: ★ ★ ★ ★ ★

Solution on page 12

FREE PUBLIC SEMINAR
ALZHEIMER’S & YOU
PREVENTION AND TREATMENT OF DEMENTIA

When: 21 September, 6–7.30pm
Where: Wesley Conference Centre, 220 Pitt Street, Sydney (between Market St and Park St)
Enquiries and RSVP:
E: dcrc@unsw.edu.au
T: (02) 9385 2585
T: (02) 9385 2702

Chair: Ita Buttrose AO OBE President of Alzheimer’s Australia

Presenters:
Scientia Professor Henry Brodaty AO Director of the DCRC, University of NSW
Professor Nicola Lautenschlager Professor of Psychiatry, University of Melbourne