Dementia, the disease of the century

• Dementia Awareness Week 2009
• A day in the life of a Helpline Co-ordinator
• NSW parliamentary support
The latest estimates of dementia prevalence rates from Access Economics are truly shocking. Without a medical breakthrough, it is estimated there will be more than 1.1 million Australians with dementia by 2050, with around a third of these people living in NSW.

This is a deeply disturbing statistic – even more so when we think of how unprepared the health and aged care systems are for the dementia tsunami, which, I think is fair to say, has already arrived.

That figure is even more disturbing when it is broken down to show how many new cases of dementia there will be every week.

Currently, there are 1,300 new cases of dementia each week across Australia. But that is going to soar to 3,600 by 2030 and to 7,400 by 2050! This further strengthens our message that more needs to be done and it needs to be done now. For a more detailed breakdown of the report, see page 8.

In August, we had a very successful re-launch of the Safely Home program involving NSW Police Commissioner Andrew Scipione and Police Minister Tony Kelly during Missing Persons Week.

This year, Missing Persons Week’s national program focused on older people with memory problems, which greatly helped to highlight what can be a very distressing element of dementia. We are lucky in NSW to have the Safely Home program, which we run in partnership with the NSW Police.

Safely Home is a great program which helps minimise the risks and the dangers to people with dementia who wander.

It is important that families and carers and people with dementia prepare for such an event and use this program to help reduce the risk.

Finally, I would like to say how I am constantly struck by the unwavering compassion, care and love shown by carers of those with dementia. Living with dementia is a long and hard road and we will continue to do what we can to support you in this journey.

The Hon. John Watkins
Chief Executive Officer
Chairman’s message

Some interesting things are happening at Alzheimer’s Australia nationally. The National President Dr Marc Budge has made it known that he will stand down when his term ends in 2010. The job then is to find another eminent person to lead the organisation through a difficult and turbulent period.

The recruitment process will be managed very professionally by the national selection committee, having sought opinions on the attributes that such a person should display, and then going on to the method of canvassing persons and making a suitable appointment. NSW is represented on that committee and the NSW Board gets regular feedback. We are fortunate in this state to have a member of the Board in Dr Robert Yeoh who is not only on the Board of Alzheimer’s Disease International (congratulations to Robert for that) but was past National President in Australia.

Media coverage is widespread and good – it can only help

Robin Wirth has announced that ill health has forced her to resign from the Board and from the position of Vice Chairperson. She is a professional social scientist who brought those particular skills to her Board work. We thank her for her counsel over the years and for the extra jobs she has undertaken on behalf of people with Alzheimer’s disease. Now it is time for her to look after her own concerns and we wish her well in this.

New report from Access Economics has given us some new measures of risk for the whole community. There are already massive numbers of people with dementia in the pipeline and we do not think governments are planning seriously enough for that challenge.

From the Board

The quarterly newsletter for members of Alzheimer’s Australia NSW

CEO The Hon. John Watkins
Manager Marketing Communications Andrew Mills
Manager Policy & Information Lisa Langley
Manager Corporate Services Susan Sackville
Manager Fundraising & Community Relations Brian Daniels
Manager Services Emma Daniels
HR Development Manager Sal Moussa
Honorary Medical Advisors
Professor Henry Brodaty AO
Director, Dementia Collaborative Research Centre
Dr Helen Creasey
Senior Staff Specialist, Geriatric Medicine, Deputy Director of CERA
Dr Michael Valenzuela
Research Fellow in Regenerative Neuroscience, School of Psychiatry, University NSW

Articles in this publication provide a general summary only of the subject matter covered. Any person with dementia or a carer for a person with dementia should seek professional advice about their specific case.

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Alzheimer’s Australia NSW, PO Box 6042, North Ryde NSW 1670 Australia. Phone: (02) 9805 0100 Fax: (02) 9805 1665. Email: admin@alznsw.asn.au, www.alzheimers.org.au Registered as a Print Post Publication Number PP: 234077/00008 ISSN: 1038-7854

Contact In touch
If you’ve got a story to tell or have some news to report, contact Andrew Mills or Sarah Price on (02) 9805 0100. Or email amills@alznsw.asn.au or sprice@alznsw.asn.au

Published on behalf of Alzheimer’s Australia NSW by Mahlab Media www.mahlabmedia.com.au
Alzheimer’s Australia NSW, together with convenors The Hon. Dr Andrew McDonald and The Hon. Judy Hopwood, held a very successful NSW Parliamentary Friends of Dementia forum on 25 June – the first for 2009. Many MPs attended in between commitments in the House, along with members of the Board and Advisory Committee of Alzheimer’s Australia NSW.

At the forum, Alzheimer’s Australia NSW CEO The Hon. John Watkins called for a public health awareness campaign, which he said was critical to help stem the devastating burden of dementia, already the fourth highest cause of death in Australia.

“It’s not good enough that someone with dementia has to wait, on average, three years to get a diagnosis,” John said.

“The community needs to be much more aware of the warning signs so they can recognise when something might be wrong and go to their doctor to get help sooner. A diagnosis can also help give control back to people and allow them to plan for the future while they are still able to do so.”

### “The community needs to be much more aware of the warning signs”

The Speaker of the House The Hon. Richard Torbay opened proceedings, followed by the Minister for Ageing The Hon. Paul Lynch.

Dr Michael Valenzuela, one of Alzheimer’s Australia NSW’s medical advisors, talked about the importance of treating high blood pressure, which may help reduce the incidence of dementia by up to 50 per cent, and The Hon. Dr Andrew McDonald closed the event on behalf of the Health Minister The Hon. John Della Bosca.

A personal journey

A highlight of the forum was Ms Joan Jackman who gave a frank account of her and her family’s journey with dementia. Joan, who cares for her husband Michael who has been living with dementia for more than 15 years, told of the frustrations she, her husband and their two children faced in waiting six years from the onset of symptoms for a conclusive diagnosis of dementia for Michael, following several misdiagnoses.

Joan’s honesty in the recount of the challenges they faced and continue to battle on a daily basis was invaluable for all who attended.

Alzheimer’s Australia NSW very much appreciates the continued support of NSW parliamentarians, and in particular the co-convenors The Hon. Dr McDonald and The Hon. Judy Hopwood.

The next NSW Parliamentary Friends of Dementia forum will be held on 22 September 2009 during Dementia Awareness Week.
Making Memories Patchwork Quilt

The Making Memories Patchwork Quilt, a quilt built collaboratively by people from all over Australia to raise awareness of dementia and celebrate the importance of making memories, has been unveiled. The quilt is comprised of 50 patches, each representing a precious memory.

While 50 entries were selected to be included in the final quilt, three standout entries were identified by the competition’s judges and awarded prizes. ‘Rose’, by Joan Warren of Wallerawang in New South Wales, won the $750 craft voucher for first place, while ‘20th Wedding Anniversary’, by Annie Radomski of Darwin in the Northern Territory, won the second place prize, a $500 craft voucher. The prize for third place, a $250 craft voucher, was awarded to Pamela McIntyre-Smith of Petersham in New South Wales for her entry, ‘Memories – Mum at Narooma’.

The judging panel comprised two experienced quilters, Mary Hitchens of Victorian Quilters Inc and Ami Hillege from Southern Cross Quilters, as well as Margaret Cameron, a part-time quilter and helpline advisor with Alzheimer’s Australia.

“The power of the Making Memories Patchwork Quilt is that it will raise awareness of dementia and communicate the importance of precious memories in a creative, colourful, artistic and personal way,” Margaret said.

The Making Memories Patchwork Quilt Competition is supported by Novartis Australia.

Carers NSW Conference

Dementia is the ‘climate change’ issue of social policy with the nation not ready to cope with the huge increase in the number of people expected to develop the disease, said The Hon. John Watkins, CEO of Alzheimer’s Australia NSW, during a keynote address at the Carers NSW Biennial Conference in June.

John said Australia was not ready to cope with the impact the increasing prevalence will have, not just economically, but socially – and particularly on carers.

“Dementia is now the fourth leading cause of death in Australia and the ageing population will mean a predicted quadrupling in the number of people with dementia from 245,000 in 2009 to 1.13 million by 2050,” he said.

“A recent Access Economics report warned there would be a chronic shortage of more than 150,000 paid and unpaid carers by 2029.

“Whether you are caring for a loved one with dementia or working as a carer in a community or a residential care setting, it is clear that unless things change there will not be enough carers to go around. And we are simply not prepared.

“Without urgent action we will be overwhelmed and the results for individuals and their carers will be dark and dramatic.

“It’s the climate change issue of social policy. It is that big and far-reaching.”

Solution to crossword (page 20):
Supporting our work

City2Surf
A big thank you to all those runners who represented AlzNSW in this year’s City2Surf. We really appreciate all your fundraising efforts as well as all the time you spent training and preparing for the big day. This year our runners were kitted out in AlzNSW running singlets and caps and we think they looked great! We hope to see you again next year.

Christmas cards
AlzNSW will again be selling a selection of beautiful Christmas cards from early October. Your generous support will help us continue to provide free services for people living with dementia and their families. These cards are also a meaningful way for businesses to connect with clients and staff at Christmas time. There will also be an opportunity to send an online card to friends and colleagues. Please phone AlzNSW on (02) 8875 4625 for more information or to place an order.

Entertainment Books
These fantastic books providing an array of bargains will only be on sale until 30 October and would make an ideal Christmas present. Just call Chris on (02) 8875 4625 for an order form. The discounts in this book represent more than $15,000 in value.

Volunteers Recipe Book
It’s here! Our new Recipe Book, Recipes to Remember, contains over 150 recipes, including some mouth-watering starters, amazing mains and tempting desserts. These family favourite recipes have come from more than 50 of our volunteers and staff members. Recipes to Remember makes a wonderful gift and is only $9.95 (plus postage). Order your copy now by calling Chris on (02) 8875 4625.

Golfers turn out
Three fantastic golf days are supporting the work of AlzNSW this year. Two were already held on 11 and 13 August. The first, by the Soft Furnishing Industries and supported by Breville, was held at the Kogarah Golf Club. Despite the rain a great day was enjoyed and more than $7,000 was raised. The second was held at the Macquarie Links by Australian Federation of International Forwarders (AFIF). Following a magnificent day of golf, a spectacular dinner with Max Walker as MC and auctioneer raised around $20,000. Well done to these wonderful organisations and their supporters. The third, to be held on 15 September by Alliance e-Finance at the magnificent Pennant Hills Golf Club, is expected to raise around $20,000 to help support services for people living with dementia.

Thank you
A big thank you to all the members and friends of AlzNSW who have generously supported our appeals during the 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.

Our sponsors
We would also like to show our thanks to all the businesses and organisations who have supported us for our Dementia Awareness Week events. Special thanks go to Norfolk Island Tourism, BridgeClimb Sydney, Novotel Wollongong Northbeach, Taronga Zoo, EcoPoint Resorts, Toshiba, Cricket Australia, Parramatta Eels, Australia Post, Roche Group (Hunter Valley Gardens, Harrigans Irish Pub, Tempus Two Winery).

Who won the car?
The First Prize winner in the Community Chest Raffle of the Toyota Corolla drawn on 16 July was ticket number RCR 17 532: Mr J Riddell of Mirani, QLD. The winner of the AlzNSW Booksellers prize of a DVD player was ticket number RAR 23973: Mrs D Lee of Guildford NSW. Congratulations to the lucky winners.

Another chance to win!
A new Christmas Treasure Trove Raffle is being launched in late September and it is your chance to win a Toyota Yaris. Just call Christine Bauer on (02) 8875 4625 with your phone order. Tickets are still just $2 each and entries close 5 January, 2010. Good luck!
Dementia Awareness Week

Several activities and events are being organised to support Dementia Awareness Week.

Dementia Awareness Week for 2009 is upon us and there are several events planned in NSW and nationally to raise awareness about dementia and to raise much-needed funds to help Alzheimer’s Australia in its fight against dementia.

This year, Dementia Awareness Week runs from Tuesday 15 September to Friday 25 September.

Memory Walk
AlzNSW will hold its second annual Memory Walk in Sydney as well as in regional centres across NSW. Memory Walks will raise awareness and much-needed funds to support people and their families living with dementia.

In Sydney, the Memory Walk will be held at the beautiful and historic Parramatta Park on Sunday 27 September. Join us on the day and help raise $70,000 to increase our ability to provide face-to-face services, such as counselling, art and music therapy, education and professional training across NSW.

At the Sydney Memory Walk there will be plenty of food, entertainment and activities including a Memory Tree, where people can make a wish or write a memory about a person they know who has dementia. Memories will be written on paper leaves and added to the tree.

Come and join in the fun or sponsor someone to walk. To enter the Sydney Memory Walk go to www.memorywalk.com.au or call Kathryn on (02) 8875 4626 for more information or to have an entry or sponsor’s form posted to you.

Memory Walks are also being held in the following NSW regions (please note that dates for regional walks may vary):

- Orange: 20 September
  1800 052 222
- Armidale: 27 September
  (02) 6771 1146
- Bega: 27 September
  (02) 6492 6158
- Port Macquarie: 27 September
  1300 791 751

Professor Constantine Lyketsos
Professor Constantine Lyketsos MD, one of the foremost dementia experts in America, has been invited by Alzheimer’s Australia to speak in each capital city as a central figure in Dementia Awareness Week activities in 2009.

In NSW, Dr Lyketsos will present a lecture on Tuesday 22 September in the Theatrette at NSW Parliament House from 10.30 to 12pm. He will present a vision for world class dementia care and discuss:

- The economic and social significance of dementia worldwide
- Latest research into cause and treatment
- Identifying those most at risk of dementia
- Ways to improve the quality of dementia care.

Cost is $25 per person, $15 concession, or free to members of AlzNSW. Bookings are essential. For enquiries and registration, please call (02) 9805 0100 or email: education@alznsw.asn.au.

An active clinician, teacher and researcher, Dr Lyketsos is based at the Johns Hopkins University, America’s first research university. An expert in the care and treatment of patients with Alzheimer’s disease and related dementias, Dr Lyketsos has carried out pioneering work regarding epidemiology and treatment of neuropsychiatric features of Alzheimer’s disease.

He has been cited in ‘America’s Top Doctors’ and ‘Best Doctor in America’ and has authored more than 250 publications, book chapters, commentaries and guest-edited several journal special issues.

Dr Lyketsos’ time in Australia will culminate with a presentation at the National Press Club in Canberra on Wednesday 23 September.

Merchandise
For this year’s Dementia Awareness Week, Alzheimer’s Australia NSW has developed a great range of merchandise that will be for sale for a range of prices, starting from $1, to help raise funds to continue our work supporting people with dementia.

These include stress elephants in a range of colours, Forget Me Not seed stick booklets, elephant pins, maze pens, caps and stress brains.

These will be available at Memory Walks, AlzNSW Sydney and regional offices and on the AlzNSW Collection Day, which is on Friday 18 September in the Sydney CBD, North Sydney and Parramatta. For more information, call (02) 9805 0100.
Without a significant medical breakthrough, the number of Australians affected by dementia is expected to increase from 245,000 in 2009 to 591,000 in 2030 and again to a staggering 1,130,000 by 2050,” said The Hon. John Watkins, CEO of Alzheimer’s Australia NSW.

“Every week there are more than 1,300 new cases of dementia. By 2030 there will be more than 3,600 and by 2050, about 7,400 new cases each week. The dementia epidemic is here.”

The figures are contained in a report commissioned by Alzheimer’s Australia from Access Economics – ‘Keeping Dementia Front of Mind: Incidence and Prevalence 2009–2050’.

In NSW, Access Economics estimates there are 84,000 people with dementia, which is also projected to increase fourfold to 341,000 by 2050.

In 2009, there are approximately 24,000 new cases of dementia in NSW, which is projected to increase to 116,000 people a year by 2050.

Spiralling impact

In the report, Access Economics has warned that the accelerating growth in the number of people with dementia will have dire consequences for the Australian health care system and the quality of life of Australians. It highlights the spiralling social and economic impact of dementia on a health and care system already under growing pressure.

Report author Lynne Pezzullo, Access Economics Director and health analyst, said there was little recognition in the final report from the National Health and Hospital Reform Commission (NHHRC) of the challenge that the dementia epidemic represents to the health and care system.

“The Australian Government should keep dementia front of mind in considering its response to the NHHRC report,” Lynne said.

“Within our lifetime, neurodegenerative diseases, and in particular dementia, will replace systemic disorders such as cardiovascular disease and cancer as major threats to Australian health and quality of life.

“The direct care cost of dementia is already $5.4 billion. Dementia will become the third greatest source of health and residential aged care spending within two decades, costing one per cent of GDP.

“By 2060 the report estimates that spending on dementia will outstrip that of any other health condition. It is projected to be $83 billion (in 2006-07 dollars) and will represent around 11 per cent of the entire health and aged care sector spending.

“Managing the challenges presented by dementia will be the overwhelming priority of health care in the

The report: key findings

• Over 1.1 million Australians will have dementia by 2050 – 341,000 in NSW
• By 2020 there will be 75,000 baby boomers with dementia
• Dementia will account for 11 per cent ($83bn) of health and aged care spending by 2060
21st century and early decisions on the future financial provisioning of health and aged care are critical.”

There are currently 15,000 Australians under 65 years of age with younger onset dementia for whom there are few appropriate services.

The baby boomer bulge in the Australian population also means that the coming decade will see an acceleration of the impacts of ageing on dementia prevalence greater than seen in Australian history.

“The first baby boomers turn 65 in 2010 and there will be 75,000 baby boomers with dementia by 2020,” Mr Watkins said.

The report provides projections that highlight the importance of planning service delivery to ensure equitable access to dementia care for those in regional Australia, people from culturally and linguistically diverse (CALD) communities and those with younger onset dementia.

It is projected that the number of regional Australians with dementia will increase by over 350 per cent between 2009 and 2050, to 449,000 – nearly double the total number of Australians with dementia today.

“Every week there are more than 1,300 new cases of dementia. By 2030 there will be more than 3,600 and by 2050, about 7,400 new cases each week”

Finding a cure

Professor Henry Brodaty, Director of the primary Dementia Collaborative Research Centre at UNSW and former Chairman of Alzheimer’s Disease International, said there were now realistic prospects both of identifying people at risk of dementia earlier and of therapeutic interventions that will delay dementia or slow its progression.

“But if that is to become a reality then significantly greater investment is needed in dementia research,” Professor Brodaty said.

“To protect the health and care budget from a significant blowout in the decades to come, a dramatic increase is needed in dementia research now to identify therapeutic interventions that will prevent or modify the progression of dementia and to find the best methods of care.”

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New cases of dementia per week

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<th>Year</th>
<th>Cases</th>
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<td>2009</td>
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<td>2030</td>
<td>3,600</td>
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<td>2050</td>
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Number of Australians affected by dementia

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<thead>
<tr>
<th>Year</th>
<th>Cases</th>
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<tbody>
<tr>
<td>2009</td>
<td>245,000</td>
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<tr>
<td>2030</td>
<td>591,000</td>
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<td>2050</td>
<td>1,130,000</td>
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A day in the life of a...

Helpline Co-ordinator

Joy is the National Dementia Helpline Co-ordinator and Counsellor for NSW at Alzheimer’s Australia NSW’s Dementia and Memory Community Centre in North Ryde. The Helpline is there to support people with dementia, their carers and families, as well as people who are concerned about memory problems. Typically in NSW, the Helpline receives about 30 calls a day, although on a busy day that number can jump to about 45.

“They range from very simple queries, like can you tell me the phone number of some other services, or I’ve just heard something about Mind Your Mind, can you send me a booklet, to far more complex issues such as how to manage serious behaviour problems,” said Joy, who has been with Alzheimer’s Australia NSW for five years.

But even so-called simple calls are rarely quite so straightforward. “We talk to the caller about why they are wanting the booklet – are they worried about their memory or are they worried about someone else’s memory? Often, people are worried about their spouse and they will start to talk about behaviour problems they are worried about.”

What do counsellors do?
The role of the Helpline Counsellor, says Joy, is to provide information about dementia, to talk to callers about their concerns and how they might manage them and to help people cope with the rollercoaster of emotions that dealing with dementia often brings. The anonymous nature of the Helpline and the fact people can call and talk to someone when they feel like it add to the appeal of the service. “They feel comfortable ringing us because we listen to them and help them,” Joy said.

“It is great to be able to help people feel that they are not alone in their journey. It is important to provide the caller with relevant local service contacts. Another aspect is to empower the caller by helping them to identify the resources and skills they already have themselves.”

Also helping people to recognise and deal with the losses they have experienced and come to terms with the many changes going on in their lives is an important aspect of the job. “For example, maybe helping them come to terms with the fact that they can no longer rely on their spouse to do the things they used to do before,” Joy said.

“Feeling like I’m contributing to the way carers are able to manage caring for the person with dementia, and people with dementia being able to live their life as well as possible with this condition, is wonderful.”

Joy is the National Dementia Helpline Co-ordinator and Counsellor for NSW at Alzheimer’s Australia NSW’s Dementia and Memory Community Centre in North Ryde.

For Joy Dodd, being able to help carers and people with dementia live their lives as well as they can is the most rewarding part of her job.

“We can help callers identify the resources they already have”

National Dementia Helpline: 1800 100 500

The National Dementia Helpline provides phone support for people with dementia, their carers and families, as well as people who are concerned about developing memory problems. It is also used by service providers, community groups and students. It is a free and confidential service and is often the first point of contact made with Alzheimer’s Australia.

The Helpline was started in 1982 by a group of volunteer carers and the calls were diverted to their home phones. These days the service receives government funding and is staffed 9am to 5pm by counsellors with various professional qualifications and experience in dementia or disability services and a group of able (and award-winning!) volunteers.

This is backed up by an after hours service, which forwards any emergency calls to the Carer Respite Centre or the Dementia Behaviour Management Advisory Service.

All after hours calls are followed up early on the next working day. Calls to the National Dementia Helpline number are answered by the Alzheimer’s Australia state office in the caller’s home state. The Helpline in NSW handles between 300-400 calls a month covering a broad range of topics.

National Dementia Helpline: freecall 1800 100 500
Farewell, Pat

Everyone at AlzNSW was saddened by the sudden passing of our beloved Pat Dermody.

Pat began work at the Vincent Fairfax Family Resource Centre in North Ryde as a receptionist in November 2000, before moving to the AlzNSW head office at Macquarie Park in 2007 to provide reception and switchboard duties. A modest person, Pat would occasionally describe herself as “just the receptionist”.

But this was an understatement. For so many people faced with a diagnosis of dementia for themselves or a loved one, Pat’s voice or her face would have been the first contact they had in reaching out for support in living with this debilitating disease.

Her voice could often be heard as she talked and listened with patience, warmth and compassion to a person who had called for help or advice. Her concern was always genuine and she would go to some length to explain the services offered by AlzNSW and make sure that the caller was connected and introduced to the appropriate staff member.

A history of caring
All who have ever worked with Pat also know how energetic she was. She was never too busy to lend a hand. Pat was ever professional, and it was noted that her presence had made a palpable difference to the running of the whole AlzNSW head office.

There are so many words that could be used to describe Pat’s character: loyal; dependable; dedicated; kind; generous; and industrious. But all that said, Pat was first and last our friend. It was a shock to all when she was taken ill suddenly in late May. Pat passed away at her home on 19 June.

She is survived by her mother Barbara, her sons Ben and Jaiben, and her daughters Joanne, Sharryn and Kelly, and nine grandchildren. We find some comfort in the fact that we all had the chance to know Pat, who lived life to its fullest, gave the most of herself to help others, and was well-loved by all who knew her.

Pat, thank you for everything.

AlzNSW staff have contributed to a crystal rose bowl engraved with Pat’s name, along with a framed photograph, which has been placed at reception at the Vincent Fairfax Family Resource Centre in North Ryde.

New staff at AlzNSW

Welcome to the three newest members of the Services Team: Karen Jones, Shiva Otim and Denise Herman.

Karen has joined AlzNSW in the new role of Senior Counsellor, based at the Dementia and Memory Community Centre at North Ryde.

Shiva has joined AlzNSW as a Group Work Facilitator, based in our office at Macquarie Park.

Denise has joined the organisation as a Diversional Therapist and works out of the Dementia and Memory Community Centre at North Ryde.

Emma Bourne has also been appointed Manager of Services.

Emma has been with AlzNSW since December 2007 and, prior to her latest appointment, was the Manager of Helpline and Counselling.

Carers Needed for Study
Call for Research Participants

The School of Psychiatry, University of New South Wales (UNSW) is conducting a mail-based questionnaire study about Australian perceptions of disability associated with various diseases including dementia. As part of the study we would like to learn more about the perceptions held by those who have spent time caring for someone with dementia. If you would like to know more about participating in the study please contact the researchers directly using the details listed below. Places are limited. Participants will be reimbursed for their time.

Ms Cynthia Honan: c.honan@unsw.edu.au
Professor Gavin Andrews: gavina@unsw.edu.au
(02) 8382 1733
In person
Liz is one of many who has completed the program. Here, she sums up her experiences. “This program has been invaluable to me since Ted and I started the Alzheimer’s journey. In fact I could say, without a doubt, it has been life saving!

“The diagnosis of Alzheimer’s for my husband at age 49 was traumatic to say the least. Having the LWML group meetings to attend has been so helpful.

• It has provided me with a safe space to express what I was going through.
• I can also discuss things at the meetings free from guilt. Sharing anecdotes with family or friends leaves me with a sense of betrayal. Often, however, I don’t need to explain my situation with anecdotes during the meetings as the other members of the group just understand.
• Ted’s needs are also being catered for with the LWML program. He is still intelligent and very aware of his condition. His group has developed a camaraderie and from their laughing we can tell that they are having fun. He always seems brighter and happier after the meetings.
• One huge benefit was discovering other people who are going through exactly the same thing. We can laugh and cry together as we share stories. This is such a relief! We are not in this alone! I can then go home with renewed energy to face the next month.
• Having a trained facilitator running the meetings is vital. They are able to hear what is being said and pick up on an issue that’s really concerning someone and tease that out. They make sure everyone is included and heard.
• The LWML program provides a unique forum to feel heard, be encouraged, be supported and enable those caring for someone with this lousy condition to survive the journey.”

Anyone interested in finding out more about the program can call 1800 100 500.
Safely Home is a joint program of Alzheimer’s Australia NSW and the NSW Police which helps minimise the risk to people who wander.

The CEO of Alzheimer’s Australia NSW The Hon. John Watkins, along with NSW Police Minister Tony Kelly and the Police Commissioner Andrew Scipione, re-launched the Safely Home program during National Missing Persons Week in August.

This year’s National Missing Persons Week focused on dementia and memory loss with the theme ‘Not knowing is like living in darkness’, reflecting the experience of those left behind.

“Safely Home is a great program that provides peace of mind to people living with dementia and their families and carers,” John said.

“Wandering is common among people with Alzheimer’s disease and other forms of dementia and can be quite scary for people living with the illness and their families.

“Safely Home minimises the danger wandering can pose.” NSW Police Minister Tony Kelly sees the link between memory loss and missing persons as a growing concern.

“Every year in NSW almost 11,000 people will be reported missing to police with almost ten per cent experiencing a dementia-related illness,” Mr Kelly said.

“As Australia’s population ages, the issue of people with dementia or memory loss as a group at risk of going missing will become an increasing concern.”

Register with Safely Home
People who register with Safely Home will get a personalised stainless steel bracelet which is virtually impossible to take off without assistance.

This features a toll-free phone number and personal identification number, which is linked to the NSW Police Safely Home database, which police can access 24 hours a day, seven days a week.

Importantly, this database not only has a detailed description of the person and contact details, it also features previous residential addresses and places the person may visit.

How it works
This program can work in two ways. If someone finds a person who is lost, they can call the number on the bracelet, quote the personal identification number and the police can then make arrangements to get them safely home.

Secondly, carers can use Safely Home to start a search for the person with dementia by contacting their local police station and filing a Missing Persons Report. The police can then use the information on the database to help them in their search.

It’s important that families, carers and people with dementia prepare for such an event and use this program to help reduce the risk.

It costs $35 for AlzNSW members and $49.50 for non-members, plus a small ongoing annual administration fee ($10 for members; $15 for non-members).

Alzheimer’s Australia NSW would like to acknowledge the support of, and funding from, the NSW Police and Perpetual Trustees, who have both greatly assisted with the Safely Home program in the community.

Safely Home in action
Jenny and Robert Goff are one couple for whom Safely Home has given peace of mind. Robert, who has younger onset dementia, has gone wandering several times and been returned safely home thanks to the bracelet.

During one incident, Robert went missing for 22 hours. Jenny was manning a charity stall at Parramatta. She took her eye off him for a minute and he disappeared. He was found 22 hours later in Berala. A member of the public had seen him near a car and called the police, concerned he was about to break into the car.

The police came, saw the bracelet, realised he was not trying to steal the car and, through the database, were then able to contact Jenny and get him safely home.

Jenny says Safely Home gives her great comfort when Robert goes missing. “It does give you peace of mind and any time that Rob’s gone missing since he’s been in the Safely Home program, I just have that confidence that he’s going to be found and returned,” Jenny said.
### Professional Education

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### Family Carer Education

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All sessions are held at the Dementia and Memory Community Centre, Cnr Cox’s and Norton Roads, North Ryde. Refreshments are included. Gold coin donation at free courses would be appreciated.

For more information or to register, please call (02) 8875 4653 or email education@alznsw.asn.au

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**Intouch Spring 2009 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 _____________________________ □ 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 47
A new choir has formed for members at the Alzheimer’s Australia NSW’s Dementia and Memory Community Centre in North Ryde. Members met for the first time on 3 August.

The choir is open to anyone who loves singing; you don’t need any formal training or even to have sung previously – just come along and enjoy yourself. The best part is that there is no audition and morning tea is included.

Led by AlzNSW’s very own music therapist, Grace Chiundiza, and accompanied on the piano by Susan Newton, the choir was put through its paces with warm-up exercises and discussion about what songs to sing. Then came the big moment.

The choir featured solo singers, blended singing and harmonising – and that was just on day one.

Old favourites like Amazing Grace and Que Sera, Sera were sung, along with newer tunes, including Andrew Lloyd Webber’s Any Dream Will Do.

**Music for health**

Singing is an important activity and has the great potential to contribute to wellness and a quality lifestyle.

During one session, choir members learnt the benefits of correct breathing and posture, which translates into everyday lifestyle, not just when you sing.

Grace would love to see more people in the choir, which has been meeting each Monday between 10am and 12pm.

*For more information, please contact Yasmin Mody on (02) 9888 4237.*

“The choir has been making beautiful music – and it’s looking for new members!”

“Singing is an important activity and can contribute to wellness and a quality lifestyle.”
The Alzheimer’s Australia NSW Memory Van has been out on the road, heading all around the state to help raise awareness about the importance of brain health and dementia risk reduction. Staff have also been on hand to provide information about dementia.
The Hon. John Watkins, the CEO of Alzheimer’s Australia NSW, said the numbers of people diagnosed with dementia in Orange is expected to soar in the next 40 years.

John was in Orange in July to meet with the Alzheimer’s Australia NSW Orange Regional Consumer Committee, dementia service providers from the area, Federal Member The Hon. John Cobb MP and the CEO of the Orange Aboriginal Medical Service Jamie Newman.

“We are committed to hearing the issues and concerns of people living with dementia in regional NSW,” John said.

The Orange State Electorate is in the top third of electorates in NSW with residents who are over the age of 60.

Unlike other chronic diseases, there is, as yet, no cure for dementia.

“We need to tackle this problem now with better resources and more commitment to finding a cure,” Mr Cobb.

“It is so important that we do everything we can to help people who have Alzheimer’s disease and other dementias, as well as their family and friends.

“It’s not just those who live with this awful disease but their friends, families and carers who also need our support, especially in regional areas, where issues of distance make it so much harder to deal with.”

John said he was looking forward to further strengthening the ties between Alzheimer’s Australia NSW and other dementia service providers and stakeholders in the area, to help tackle the looming dementia tsunami.

“We need to tackle this problem now, with better resources and more commitment”

Carrie McGee from New York’s Museum of Modern Art (MoMA) will present MoMA’s landmark Art and Alzheimer program, with Adriane Boag, from the National Gallery of Australia (NGA) in Canberra, presenting the NGA’s Art and Dementia program.

For more details, log on to www.artsandhealth.org.au, email info@artsandhealth.org or telephone 0416 641 482.

www.alzheimers.org.au

‘Meet me at MoMA’

Alzheimer’s disease is a key focus at the forthcoming Art of Good Health and Wellbeing conference in Port Macquarie from 10-13 November.
Quality Support Groups Research Project

The third and final report of a five-year research project that looked at what comprises a quality support group is now available.

The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service to carers of people with dementia.

The findings were delivered at the 2009 Alzheimer’s Australia Conference in Adelaide in June.

Researcher Jo-Ann Brown, who compiled the report, said it was the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia.

“One of the core goals of the project was to articulate best practice guidelines that would underpin quality in a carer support group. “While our study specifically investigated dementia support groups for carers we believe that these guidelines have the potential to assist all types of support groups.”

Key findings
Significant findings are:
• The far-reaching benefits of support groups for carers who regularly attend.
• The enormous capacity for group members to provide mutual aid in support of each other in the safe and trusting environment of the carer groups.
• Carers come to a support group with one thing in common other than the fact they are caring for someone with dementia – all are experiencing some form of grief and loss.
• Qualitative findings suggest that grief and loss is the greatest cause of emotional stress for carers.
• Some carers reported the grief and loss felt at this time was equal to, or even greater than, the grief felt when the person with dementia dies.
• The skills of the group leader are paramount to the success of the group. A quality group is flexible and recognises that one size does not fit all.
• There were five distinct dimensions of grief and loss identified.
• This research reinforces other research that acknowledges the unremitting burden of dementia that leads to carers becoming demoralised, isolated and psychologically distressed.

Putting findings into practice
The research recommended extending the skills of all group leaders, and, as such, Alzheimer’s Australia NSW has developed a module for dementia support group leaders that aims to improve and enhance their skills around grief and loss in support groups.

The Quality Support Groups Research Project Phase III report is available now from AlzNSW for $15 for members and $30 for non-members (+ GST and postage). An A3 poster detailing the Best Practice Guidelines is included with the report. To order your copy, go to www.alz.seekbooks.com.au.
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.

Anna Maria Adema
Tony Antico
Nancy Margaret Armstrong
Gilia Bagoly
June Sylvia Bailey
Ngaere Bartley
Harry Frederick Bell
Beryl Enid Blake
Carl Bock
Frances Broom
Nancy Winifred Brown
Emma Bucciarelli
Daune Burke
Polyxeni Caracatsanis
Giuseppe Carbone
Therese Anne Carroll
Joan Olive Clark
James Army Connor
Christina Costa
Effie Coutinho
Connie Cucinotta
Keith Dawson
Joan Vivienne Deane
Luciano De Liseo
Patricia Carol Dermody
George R Dickson
Archibald James Dickinson
Marie Veronica Dransfield
Bruce John Ellis
Helen Therese Evans
Angelo Fabbro
Joyce Kathleen Fahey
Una May Farley
Daphne Fry
Colin Trevor Grainger
Helena Grant
Elsie Grierson
Concetta Grotta
Hilda Joan Hattersley
John Hayes
Marie Theresa Hickey
Reginald Andrew Hincks
Kenneth Thomas Hunt
Phillip R J Ibbott
Marion Grace Johnson
Alan Jones
John Jones
Bessie Jones
Simeon Kerameas

Victoria Audrey Kerslake
Lucy (Brown) Kirkwood
Katina Kostos
Eileen (Val) Lakeman
Hans La-Ramee
Bartolo John Lauricella
Claudia Leach
Charlie Lees
Margaret Lemon
Patricia Lenon
Mihaly Levia
Wendy MacGeachie
Maria Mackiel
Margaret McGurgen
Richard Andrew Menzies
Chrisanthy M Michalandos
Costas Morfitis
Maria Mower
Brenda Murlis
Francis Richard Neale
Pamela Elizabeth Newton
Elaine Joan Osborn
Soultana Papathomas
Beryl Parker
Ronald Pascoe
Cesare Pellicci
Maria Previtera
Royal Pullen

David Clifford Riggs
Rosemary Joan Saville
Charlie Signorini
Gladys May Sneddon
Veronika Sola
James (Jim) Somerset
Gladys Eleanor Stanford
Evelyn Edith Steadman
Maria Stellino
Doris Evelyn Stephens
Robert Sullivan
Len Tilley
Crescenzo Enzo Tomei
Annette Eileen Tracey
Harry Tuffy
Doreen Tyne
Rosa Ursino
Robert Byron Wade
Annie (Nancy) Ellen Weatherall
Mary Websdale
Stanley Whiffen
Colin Williams
Neville Williams
Joan Wotan
Margaret (Peg) Brown Wright

In touch Spring 2009

www.alzheimers.org.au
The CSIRO Healthy Heart Program provides a 12-week Complete Lifestyle Program (CLIP) for lowering cholesterol and blood pressure, reaching and maintaining a healthy weight, and improving mental wellbeing. This program complements the Alzheimer’s Australia Mind Your Mind program. This book is sponsored by Christian Brothers Oceania Province

The Anti-Alzheimer’s Prescription by Dr Vincent Fortanasce provides a straightforward lifestyle prescription for improving brain health. This book is sponsored by Christian Brothers Oceania Province

The Savages (DVD) Oscar-nominated screenplay by Tamara Jenkins introduces Wendy and Jon and their father Lenny, who has dementia. Wendy and Jon are suddenly forced to live together under one roof for the first time since childhood. This DVD is sponsored by Christian Brothers Oceania Province

I’m Still Here: A Breakthrough Approach to Understanding Someone Living with Alzheimer’s by John Zeisel details how caregivers can have a vibrant and meaningful relationship with people who have dementia. Four copies of this book are sponsored by a Library Patron

Creativity, Dementia and the Therapeutic Environment aims to explore the physical environment and the level of success of creative expression programs for people with mild cognitive impairment to moderate dementia. This book is sponsored by a Library Patron

If you would like to Sponsor A Book please contact the Library on 02 9888 4218.

Announcements

Special bookshop discount for members
Between 1-31 October, Alzheimer’s Australia Online Bookshop www.alz.seekbooks.com.au is offering a discount of an additional five per cent off the already discounted online price. When completing your purchase, enter ALZNSW2009 in the promotional coupon box.

Advance Workshop Notice
The very popular Writer’s Workshop with guest writers Elizabeth Bezant and Pamela Eaves will take place on Monday 9 November from 1.30 pm until 4 pm. The workshop will be preceded by the launch of Elizabeth and Pamela’s latest book, Caring Moments. To register an expression of interest to attend contact the Library.