Dementia Awareness Week
Memory Walks and other highlights around NSW

- A carer at 17 years old
- AlzNSW support services in practice
- Report on dementia: NSW coast hardest hit
Staff are recovering from a very busy and enjoyable Dementia Awareness Week (DAW), when so much was done to raise awareness about dementia around NSW. Activities included Memory Walks, public seminars, barbecues and much more.

During the week, we also released a new report from Access Economics detailing estimates of dementia prevalence rates for every state electorate across NSW. This report, which you will find in more detail on page 18, was officially released during our NSW Parliamentary Friends of Dementia event where politicians were given individual packs with prevalence rates from now until the year 2050 for their state electorate.

This successful event was very well attended by many state politicians who were extremely interested in the predicted enormous increase in dementia prevalence rates across NSW. We will continue to advocate strongly on your behalf with more events like these planned for 2010.

Another significant event during this year’s DAW was the launch of the new Safe2Walk device in NSW at the Sydney, Bega and Port Macquarie Memory Walks. The device, which is a GPS personal alert and location service, was developed by our sister organisation in Western Australia and was launched there earlier this year. It has already been very well received in NSW in the short time since the launch and has received a lot of interest from our members, the general public and the media. You can read more about Safe2Walk on page 17.

Finally, I would like to say thank you all for your support during my first year as CEO. I have enjoyed getting to know you and continue to marvel at the great work that is done by our staff and at the endless dedication, care and support of our members as we all work to navigate the often difficult dementia road.

I wish you all the best for the upcoming festive season and hope it is a safe, enjoyable and restful time. I look forward to seeing you again in the New Year.

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

There are signs that the economy is improving; we see share prices rising (and therefore our portfolio looks better than it did) and interest rates are rising (and so our income from cash is rising too). Readers will know that this investment income is untied money and allows us to do important things we would not otherwise be able to do. Most of our government money, welcome as it is, is tied to specific functions – so we use it solely for those functions.

We are lucky to have the Investment Advisory Committee which worries about AlzNSW and our investments. Because it worries, we are in a position to support staff better and to give a greater financial support to our CEO so that he can plan services as he wishes. The committee meets regularly and works with dedicated officers to get us the best possible returns from the stock market. At the same time it worries about the safety of investments and walks the narrow line of balancing safety with good returns.

Memory Walks

The Memory Walk in Sydney was well attended and a great success. The Parramatta Park location was an advance on the location we had last year. The turnout was excellent and the opportunity was taken to demonstrate some Safe2Walk devices. Organisation of the event was excellent and is a tribute to the many staff who did so much. The walk was easy enough and AlzNSW made some money from the sponsorships. But most of all it was a good day and we had a lot of fun just meeting people and being there. The feedback from the activities has been very good.

During Dementia Awareness Week, we had a great speaker in Professor Constantine Lyketsos. He was very easy to listen to and had a message of knowledge and hope for the large audience. The professor also got some very good media exposure which was a plus for our clientele.

New appointments

Robin Wirth has left the Board and we all wish her well as she battles ill health. We have a vacancy for a Deputy Chair and are looking at filling the position now.

Recently elected to the Board of Alzheimer’s Disease International, Dr Robert Yeoh AM was once President in NSW and then was National President in Australia. We congratulate him on his new position and wish him well in the important work he does for us all.

Data on dementia

Our Board is very committed to Alzheimer’s disease and to NSW where so many more people are going to be affected by dementia and where the services we can offer are going to be more urgently needed. In this respect, the most recent report of Access Economics paints a dismal picture of the numbers of people for whom we will have to advocate in the next decades. The numbers are enormous and worrying. We have been able to extract electorate-specific data for NSW and will make sure that local MPs know just how many in their own electorates have dementia now and will have dementia in the future.

Professor Peter Baume AC
Chairman
Calling all songsters

Staff at the Hunter Dementia and Memory Resource Centre are putting the call out for songsters to join a choir. Having already enlisted the help of a choirmaster, the centre is now looking for recruits.

People who have dementia, their family and friends are all welcome. Even those who have no connection to someone with dementia but who want to try singing for health and wellbeing in a fun and friendly atmosphere are welcome to join.

Musicians who would like to contribute time and expertise or those who don’t think they can sing but can play along with small percussion instruments are also invited to come along. People with English as a second language are especially encouraged to join in.

There will be no auditions and singing ability is optional. However, a sense of humour is essential.

Contact Deanna Sue on (02) 4962 7000.

In other Hunter news...

The staff at the Hunter Dementia and Memory Resource Centre are planning to build a Men’s Shed. But they need help.

If you, or someone you know, can help by providing time, resources or materials to build this much-needed workspace it would be greatly appreciated.

For more information, please call Julie Broadbent on 0408 439 094.

‘Maintaining Your Memory’ seminar and Chinese expo

How we can keep our brains healthy and free of dementia was the theme of ‘Maintaining Your Memory’, a free half-day dementia seminar and expo attended by more than 160 Mandarin speaking members of the Chinese community in October at Chatswood.

Dr Ernest Tam, Senior Staff Specialist Physician and Geriatrician at Ryde Hospital spoke about the difference between normal memory changes as we age, and the more serious memory loss caused by dementia. He also advised people about what to do if they notice significant changes to their memory and other symptoms of dementia.

Dr Michael Valenzuela, Research Fellow from Prince of Wales Hospital and AlzNSW Honorary Medical Advisor, presented findings from his book It’s Never Too Late to Change Your Mind. His key message: keep a check on your blood pressure and, if it’s high, get proper treatment to lower it. He also recommended three key lifestyle measures – keep cognitively active (particularly by learning something new and challenging) and keep socially and physically active!

Both presentations were translated into Mandarin by Yan Wang, Dementia Service Team Leader with the Australian Chinese Community Association (ACCA).

A joint initiative between ACCA and the Dementia Advisors under the auspice of Catholic Community Services, this event was generously supported by Willoughby City Council, and funded by the Department of Ageing Disability and Homecare, under the auspice of AlzNSW.

Southern Sydney Koori Expo

On the beautiful shores of Gunnamatta Bay, the Dementia Advisor from the St George and Sutherland Shire, Sue O’Brien, was part of the Southern Sydney Koori Interagency Expo and Information Day held in September.

Organised by the GNARRA Aboriginal Project, the event was designed to be an information day about services that assist the local community. Other participants included Centrelink, the ATO, Law Access NSW, Community Transport, Jannali Neighbour Aid, aged care providers and Sutherland Carer Support Services. Those who attended also received some cultural training and enjoyed Aboriginal art demonstrations.

There was entertainment, morning tea and a barbecue. The local Koori radio station was also there, which was a great addition to the day that drew about 100 people from the local community.
Emily Wilkins from Macintyre High School in Inverell created a tribute to her grandmother for her HSC art project. Called ‘Fragmented Memories’, Emily said the piece aimed to explore the world of someone with Alzheimer’s disease “who has lost the ability to distinguish between past and present, dream and reality”.

“She can no longer fathom all the complexities of her environment. To express this, I have created a seemingly haphazard and incomplete scene, partially immersed in shadow.

“The audience can experience the emotional chaos of not knowing what is real and what is contrived by the trauma of this disease,” she said.

“The work is also a tribute to my family history, particularly the enigma of my grandmother,” Emily added.

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Port Macquarie donation

Butterfly Beauty at South West Rocks has treated carers on the Mid-North Coast to a pampering session. Jeannine Douglas from the beauty salon donated six vouchers for members of the South West Rocks Carer Support Group.

One was drawn out of a hat each month, with the winner treated to a session at the salon. Margaret Allen from the AlzNSW DMCC at Port Macquarie said the vouchers were a wonderful gesture and were very gratefully received by the winning group members.

“Jeannine called me one day and said she was aware that there were lots of people in the community who were living with dementia and that she knew it was not an easy path for carers,” said Margaret. “So she wanted to do something special for them.”

(lr) Pam Hughes from South West Rocks Carer Support Group and Jeannine Douglas.
AlzNSW Memory Walk goes global

In October, Joe Jefferson, Ian Craig, Richard Fetherston and Andrew Thompson summited Mt Kilimanjaro, Tanzania, resplendent in their AlzNSW Memory Walk hats.

The climbers were sponsored by family and friends in their quest to reach the top. They donated the money raised to AlzNSW, charities in the UK and an orphanage in Tanzania.

Win movie passes to Bright Star

AlzNSW is pleased to be the nominated beneficiary for an exclusive NSW Seniors Card member screening of Bright Star.

From award-winning director Jane Campion, Bright Star tells the story of first love between romantic English poet John Keats and the girl next door, the stylish, headstrong Fanny Brawne (played by Abbie Cornish).

A big thank you to NSW Seniors Card for their support.

Free passes

Hopscotch Films is offering AlzNSW members 20 double passes to see Bright Star when it opens in Australian cinemas from 26 December. Any member can enter – you do not have to be a NSW Seniors Card holder.

Thanks to Hopscotch Films for the passes.

How to enter

Just fill out the coupon below and post it back to:

Bright Star Movie Competition
Alzheimer’s Australia NSW
PO Box 6042
North Ryde NSW 2113

Entries close by 15 December 2009.

The competition will be drawn on 17 December and the winners will be notified with their tickets by mail.

Bright Star movie competition

Name: _______________________ Address: _______________________________________________
Postcode:  ____________________ Ph (daytime): ___________________ Mob: ___________________ Email: ______________________
AlzNSW member number: __________________________________

Raising our profile

AlzNSW sought the support of high profile Australians to raise awareness of Alzheimer’s and dementia.
## 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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**By Lisa Langley**

AlzNSW is committed to ensuring the voices of people living with dementia are heard and wants to be sure that the organisation’s policies and programs reflect the needs of those living with dementia and their carers.

To ensure consultations with consumers remain ongoing, AlzNSW has formed a network of regional committees around the state to meet with consumers on a regular basis.

Since 2006, regional committees have been established in Armidale, Bega, Newcastle, Orange, Port Macquarie, Sydney, Wagga Wagga and Wollongong. The committees meet twice a year to provide input on social research surveys, feedback on important policy issues and to raise issues that are important for their local areas.

These regular meetings have been complemented by a series of ‘town hall’ meetings, where stakeholders in the area have the opportunity to meet with AlzNSW CEO The Hon. John Watkins to discuss issues faced locally.

Where possible, the committees are supported locally by regional Dementia Advisors, with the AlzNSW Policy Manager providing management and coordination of the committees and integration of the committees’ work into policy and practice.

Liaison with National Consumer Committee through the National office and development of new committees is also managed by the NSW Policy Manager.

The regional groups represent an ongoing way for AlzNSW to interface and communicate with its consumer base around NSW. This approach to consumer engagement is unique to NSW. No other state is approaching its consumer engagement in quite this way.

The ultimate purpose is that it positions AlzNSW as the preferred provider of consumer information to inform government policy and programs around dementia and ensures consumer feedback is effectively gathered and integrated into the policy, advocacy and service development for the organisation.

For more about consumer committees in your area, please contact the NSW Policy Manager Lisa Langley on (02) 8875 4681.

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www.alzheimers.org.au
Alliance e-finance Golf Day

The Alliance e-finance Golf Day took place on 15 September at the beautiful Pennant Hills Golf Course. We would like to thank the team at Alliance e-finance for making this day a great success, as well as the 80 golfers who played, our volunteers and, of course, all the fantastic sponsors. The Golf Day raised over $22,000 – an incredible result.

Knights of Malta Masquerade Ball

The inaugural Knights of Malta Masquerade Ball was held in 2008. It was such a great success that it will now be held on a yearly basis. This year, the ball was attended by 220 guests who helped to raise significant funds for the chosen charities, one of them being AlzNSW. It was a fun night and everyone is already looking forward to next year’s event!

Blackmore’s Running Festival

Our heartfelt thanks go out to all the runners and walkers who represented AlzNSW in the Blackmore’s Sydney Running Festival. AlzNSW was chosen as a supporting charity this year and had a promotional marquee at the end of the race. There was a fantastic response with more than 70 people running on behalf of our organisation, raising almost $20,000 for AlzNSW. We hope to be back, bigger and better, next year so keep an eye out for the Memory Joggers.

If you are interested in running on behalf of AlzNSW please contact Kathryn on (02) 8875 4626.
There’s a new way to celebrate the life of a loved one and also support AlzNSW. Living Years recently launched an online memorial website where family and friends can create an interactive page dedicated to acknowledging that special person.

What is Lifebook?
This page is called a Lifebook, where photos, thoughtful comments, stories, eulogies, videos and more can be shared on a dedicated memorial homepage. As more people visit and share, the story becomes a rewarding, multi-faceted tribute.

Support AlzNSW
In acknowledgement of the work of Alzheimer’s Australia, Living Years will donate $10 for every paid Lifebook (with a one-year minimum sign-up) created through www.livingyears.com/alzheimers. This $10 will go to Alzheimer’s Australia Research. You can also choose AlzNSW to receive in memoriam donations in memory of your loved ones.

A Lifebook online page is simple and easy to create and will give you a lifetime of memories to share and cherish.

For more information about how to set up a Lifebook please phone Coralie, AlzNSW’s Development Officer, on 02 8875 4652.

Mulbring to Maitland Walk
On Saturday 26 September, Amanda Percival, her family, friends and supporters walked from Mulbring to Maitland in honour of her late father, the Reverend Ernest Bailey. Forty-six fit and enthusiastic walkers took part in the 24km event. We would like to thank Amanda for all her amazing efforts on behalf of AlzNSW, and Michel’s Patisserie in Maitland for their fantastic contribution and support of the first ever Mulbring to Maitland Walk.

Small world ~ no small wonder
It’s a world away, yet close at hand.
A refreshingly different place and experience that far surpasses its size.
The World of Norfolk. Yours to explore
www.theworldofnorfolk.com.au
Win a Corolla!

The Christmas Treasure Trove Raffle is now on and it is your chance to win yet another Toyota Corolla Yaris Auto valued at $25,000. Just call Chris on (02) 8875 4625 with your phone order, or Chris can arrange tickets for you to on-sell. Tickets are still just $2 each and entries close 8 January 2010. Good luck!

Thank you

AlzNSW extends a big thank you to all the members and friends 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.

In touch Christmas 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 _______________________ OR ☐ I have enclosed my: Cheque/Money Order
☐ Please send me information about Wills and Bequests
Alzheimer’s Australia NSW, PO Box 6042, North Ryde NSW 2113 Tel: (02) 9805 0100, Fax: (02) 8875 4665
Web: www.alzheimers.org.au
ABN 27 109 607 47
As a Dementia Advisory Service (DAS) working out of AlzNSW’s Dementia & Memory Community Centre at Port Macquarie, Margaret Allen’s days could never be described as typical.

“As a DAS, we provide information, education and support to people living with dementia, which covers a whole range of activities,” she said. “We not only provide services to people at the varying stages of the dementia, we also assist those with memory concerns and undertake community awareness programs.

“Clients tend to maintain contact with AlzNSW throughout the course of their illness because of the individualised ‘whole of life’ approach that is provided.”

A varied role
Margaret’s job is made up of many and varied components – from working with committed volunteers; facilitating support groups; responding to referrals, which includes making home visits; increasing community awareness of dementia and risk reduction; running DMCC activities, and working on the Living With Memory Loss Program to forging collaborative relationships with other service providers.

The geographic area that the Mid-North Coast team covers is big enough to encompass eight local government areas, from Woolgoolga in the north, to Hawks Nest in the south. But for Margaret, the best part of the job is working with clients.

“It’s being allowed to share the journey with people,” she said. “From pre-diagnosis through to the advanced stages we are able to provide care, support and information, which is greatly appreciated. Once people know they are not alone, you see their relief; they think they’re alone and suddenly they realise they are not.”

Giving support
Being able to connect carers together is one of the most satisfying aspects of the role,” said Margaret. “It facilitates carers looking after each other, reduces stress and isolation and helps develop lasting friendships.”

According to the latest projections from Access Economics, the Mid-North Coast is going to be among the worst hit in terms of dementia prevalence in the next 40 years, which means local AlzNSW staff will be working hard not just to provide support and information for the community, but also to make sure the issue is kept front and centre in people’s minds.

“In the coming years, we’ll be right in the heart of it,” Margaret said. “Keeping dementia on the agenda, so that people remain aware of the epidemic, and lobbying for funding, will be a big challenge. We could not do this if it were not a team effort – we are already at saturation point with all of our services.”

But it is a challenge Margaret is looking forward to and one that brings its own rewards.

“The good thing about the job is the remarkable people that you meet”

People Dementia Advisory Service at the Dementia & Memory Community Centre, Port Macquarie
Clare Lutton was 12 years old when she first noticed the changes in her mother. They were subtle, like difficulty cooking dinner and forgetting to pick Clare up from places. Clare thought her mum’s behaviour was a little odd, but she adapted.

“I was at an age when she should be doing all that for me; she should be remembering to pick me up and she should be cooking dinner,” said Clare. “I was the centre of her universe and not knowing how to do things properly for me – and not knowing why – was really hard for her.”

But instead of just being a small hiccup in their lives, the situation slowly became worse. “Initially, Mum’s decline was so gradual that I didn’t realise how much our roles as mother and daughter had changed,” said Clare, now 23.

**Difficult diagnosis**
Following several misdiagnoses, including depression, Clare’s mother was eventually diagnosed with younger onset dementia. Clare was 17, her mother just 49.

“That’s when it started to get hard because I wasn’t doing it because I was helping her out but because I had to,” Clare said. “The caring duties I had been carrying out unfazed for years became incredibly hard because they were a constant reminder that Mum had dementia and, more importantly, that...it was just going to get progressively worse.

“That was scary for both of us – it was emotionally exhausting.”

Clare’s teenage friends understandably had no experience or knowledge of the disease; and her mother didn’t talk about the diagnosis with her friends. “She isolated herself. So it really felt like it was just her and me,” Clare said.

Following the diagnosis, her mother’s condition went downhill quickly. “She became so frightened and stressed. She was unable to comprehend what was happening to her – Alzheimer’s wouldn’t let her,” said Clare.

**The journey**
A talented rower with the ACT Academy of Sport, Clare had been offered nine full scholarships to several US universities including Boston University. But she made the difficult decision to stay in Canberra and be with her mum.

“I wanted to be around, it was a
stretched out goodbye,” she said. “I don’t regret it but when I was in the thick of it, it was really hard to say no to those opportunities.”

Clare did eventually move out of the family home to salvage the mother-daughter relationship. “Living together just crossed too many lines,” said Clare. “When I moved out, she could get help with showering, dressing and ironing and I could still pop over every day and cook dinner and spend time with her. But it meant I still had the space to be my age and she could still be my mum.”

“It’s been heartbreaking to watch my beautiful Mum – someone so successful, determined and kind – slowly slip away,” Clare said. “When Mum’s having a bad day, it’s hard and sad because I realise how quickly she’s deteriorating.

“And when Mum’s having a good day, it’s bittersweet because I remember the person she used to be and that makes me miss her.

“When I’m having a bad day, I want to call Mum and chat but I can’t. And when something good happens, or on birthdays, I wish she was there.”

“Then I feel an immense sadness because I know how much she would want to be there for me because being my Mum meant everything to her.”

Clare is a member of AlzNSW. For more information about the Daughters and Sons group, please call AlzNSW on 1800 100 500.

“People
New staff members at AlzNSW
Welcome to our newest team members. Kaylene Parker joined AlzNSW’s Mid-North Coast Dementia & Memory Community Centre in the role of Group Work Facilitator/Educator. She has a wealth of experience in the provision of services for people with dementia and their carers, and was recently recognised for at the Kempsey District Business Awards.

Lynne Dunbar has joined our DMCC at North Ryde as a Group Work Facilitator and Counsellor. Naj Hadzic will be working on the Dementia Action Plan project on the Mid-North Coast. A warm welcome to all our new staff.

Carers use of respite services
We believe carers are the best people to tell us about the things that make it difficult or easy to use respite services.

The University of Wollongong and AlzNSW want to find out more about the factors that influence carers’ use of respite services. Research will also inform development of services so that carers can be better supported in their role.

University of Wollongong research associate Lyn Phillipson has developed a survey to find out about the use of respite services by carers. The survey is anonymous and takes about 20 minutes to complete.

For a copy of the survey please contact Lyn Phillipson on (02) 4221 5106 or email her at lyn_phillipson@uow.edu.au

New beginnings
Clare has since moved to Sydney for a fresh start where she has a job that she likes and is enjoying her life in the city. She visits her mother in Canberra regularly and phones her often.

Her mother is happy and being well looked after, said Clare. “She’s got people around her all the time and the nursing staff love her. Last night I tried to call her and she wasn’t there – the nurse said she’d gone to a concert!”

Clare is now in a ‘daughters and sons’ support group with AlzNSW. It has helped her come to terms with her mother’s illness, which is something she is now able to speak openly about with her friends.
Dementia Awareness Week 2009

September was a very busy month with Dementia Awareness Week underway across NSW. There were Memory Walks, community seminars, movie days, street stalls, open days, commemoration services, public barbecues and much more.

The message was also spread throughout the wider community with media coverage of various events and issues throughout the week, and beyond, in newspapers, on radio and on television news bulletins across NSW.
Memory Walks

As part of Dementia Awareness Week, Memory Walks across NSW drew record numbers.

Sydney
Despite the windy conditions, the Memory Walk in Sydney was a great success. Walkers enjoyed music from the NSW Police Band and the Bright Stars Choir as well as lots of other entertainment and activities including the Taronga Zoomobile and stalls from Creative Memories and Friends and Family of the NSW Missing Persons Unit.

The 2009 Walk took place in the beautiful Parramatta Park and we would like to thank the Parramatta Park Trust for their support of our event. The walk was officially opened by the Lord Mayor of Parramatta, Councillor Tony Issa OAM. We also would like to thank our VIPs – AlzNSW Advisory Council member Ita Buttrose and Federal Member for Bennelong Maxine McKew for being so generous with their time and support.

TV appearance
We had our first live television experience with Tim Bailey’s Weather on Channel 10 News, which helped promote the Memory Walk in the week leading up to the event. Thanks to all our volunteers and The Kings School students for coming along to the filming.

We also launched Safe2Walk, a GPS personal alert and location service, with the support of Alzheimer’s Australia WA. Safe2Walk was also launched at the Bega and Port Macquarie walks.

Around NSW
Memory Walks were held across NSW in Bega, Orange, Armidale, Umina, Fingal Bay, Port Macquarie and Wollongong. It’s great to see how the event is growing in many local communities. Our oldest walker was Monica Roche, age 94, who walked in Umina.

Port Macquarie, in association with the Port Macquarie Triathlon Club, ran their first ever ladies fun run as well as their Memory Walk. The fun run was a great success with more than 140 women taking part.

A special mention must go to Peninsula Village in Umina, Harbourside Haven in Fingal Bay and the Illawarra Ethnic Community Council who all held their first Memory Walks this year. Great work everyone!

Thanks so much to all our staff, volunteers, sponsors and walkers across NSW for making the 2009 Memory Walks a great success – we could not do it without you!

Raffle winner at Sydney Memory Walk
Congratulations to our lucky first place raffle winner, who is jetting off on an amazing seven night holiday to Norfolk Island, with thanks to Norfolk Tourism.
Dementia Awareness Week

In Sydney, as well as the Memory Walk, Dementia Awareness Week (DAW) was marked by the inaugural AlzNSW Badge Day, where staff and volunteers hit the streets to sell elephant pins, squeeze elephants, Forget-Me-Not seed sticks and squeeze brains to morning commuters in North Sydney and the Parramatta and Sydney CBDS.

There was a public lecture by Alzheimer’s Australia guest Professor Constantine Lyketsos, one of the foremost dementia experts in America. The talk by Professor Lyketsos, who was also featured in an interview on the ABC’s 7.30 Report and who spoke at the National Press Club, was a highlight for many who attended.

A NSW Parliamentary Friends of Dementia event was also held during DAW. At the event, which was very well attended by many NSW parliamentarians, AlzNSW released a new Access Economics report which detailed dementia prevalence rates and predictions for every state electorate in NSW (page 18).

Managing the practical challenges of caring for someone with dementia was the theme for ‘The Dementia Adventure 2009 – facing the practical challenges’ the fourth one-day symposium organised by the Dementia Advisors of Northern Sydney. This was held at the Epping Club as part of DAW and was attended by more than 170 participants who were treated to a fantastic line-up of speakers presenting on topics that covered dementia from top to bottom.

In other regions...

**Armidale**
A Mind your Diet barbecue at the local Armidale mall received a great response. Local Mayor Peter Ducat (right) and NSW Member for Northern Tablelands The Hon. Richard Torbay MP helped out.

**Bega**
The Bega Valley and Eurobodalla shires celebrated DAW with two Movie Magic events, a street stall, a World Alzheimer’s Day Celebration Service and the Memory Walk.

**Hunter**
The Hunter Dementia and Memory Resource Centre opened its doors at the start of DAW and dozens of people took part in a barbecue, health checks and learnt how to reduce the risk of developing dementia.

There was also the annual Celebration of Life Remembrance Service for World Alzheimer’s Day; and staff battled dust storms to deliver seminars for the community and allied health professionals in the Upper Hunter.

**Sutherland Shire & Illawarra**
In the Sutherland Shire and the Illawarra there were several Mind your Mind seminars, information days and the Memory Walk.

**Port Macquarie & Coffs Harbour**
On the Mid-North Coast, an education seminar was held at Coffs Harbour; while in Port Macquarie and beyond there were river cruises, lawn bowls, a barbecue day, a bus trip, and the Memory Walk and Women’s Fun Run.

**Orange**
In Orange, DAW was celebrated by a Memory Walk and a tree planting ceremony in the Orange Botanic Gardens. There was also a gathering of the Canowindra support group where members indulged in brain healthy food, took a food quiz and listened to a talk by dietitian Julie Middleton.
A personal alert and location service for people with dementia was launched by AlzNSW at the Sydney, Bega and Port Macquarie Memory Walks in September, and later in Orange and Newcastle.

Safe2Walk is an easy-to-use GPS and mobile phone device that has been designed to reduce the risk of people with dementia going missing.

The CEO of AlzNSW The Hon. John Watkins said ‘wandering’ (the term used for people with dementia who may wander from their usual environments) was quite common amongst people with Alzheimer’s disease and other forms of dementia.

“It can be quite scary for people living with the illness and their families,” John said. “In NSW, 11,000 people are reported missing to police each year and almost 10 per cent of those are experiencing a dementia-related illness. Sadly, some of these people never return home.”

The Safe2Walk device
The device can be worn around the neck on a lanyard or clipped to a belt and has a GPS function on it that updates the location every 60 seconds. Carers can then log on to a secure, easy-to-use website and see where the person wearing the device is.

“Safe2Walk may help minimise the danger wandering can pose and can help provide much-needed peace of mind,” said John.

There is also a simple mobile phone component to the device, which is operated by one button and holds up to three pre-programmed telephone numbers. If the primary carer’s phone number is busy, it will automatically divert to a second or third nominated carer. The phone also has an auto answer feature.

Walking with confidence
John said the Safe2Walk service will help reduce the burden on carers while promoting the wellbeing of people with dementia. “It’s all about empowerment and helping maintain independence, so people with dementia can go walking with greater confidence,” John said. “This decreases the likelihood of premature admission into residential care or the need for hospitalisation.”

John, along with AlzNSW’s Advisory Council member Ita Buttrose, and Federal Member for Bennelong Maxine McKew, demonstrated the Safe2Walk device during the Memory Walk in Sydney. “We need to do what we can now to try to minimise the impact it will have,” said Ms McKew.

For more about Safe2Walk, contact AlzNSW on 1800 100 500 or visit www.safe2walk.com.au
Australians retiring to the coast will drive a rapid increase in dementia up and down the NSW coastline, said the CEO of AlzNSW, The Hon. John Watkins.

“That means a heavy burden of community care, aged residential care, service delivery, respite and support services for people with dementia will fall on regional NSW which, generally, does not receive the same level of service as the city,” John said.

**Projections**

“The Tweed, Wyong, Port Macquarie, Bega, Myall Lakes and South Coast electorates are now in the top 10 state electorates for dementia prevalence in NSW and are expected to remain in the top 10 by 2050.

“Without a significant medical breakthrough, the number of people with dementia in NSW is expected to quadruple from about 84,000 people today, to 341,000 by 2050. Nationally that figure is expected to exceed 1.13 million by 2050.”

In the Sydney metropolitan area, the report suggests that western and south-western areas will be hardest hit. The state electorate of Camden leads the way with a more than 800 per cent increase in dementia prevalence expected by 2050.

The Access Economics report, ‘Projections of dementia prevalence and incidence in NSW: 2009-2050’, has been commissioned by AlzNSW. It was officially launched at a
briefing to NSW parliamentarians at NSW Parliament House.

John said that the ageing population meant every state electorate in NSW could expect to experience significant growth in the number of people with dementia. “The state electorate with the least number of people with dementia in 2050 will still have more than that with the most number of people this year – there are no winners,” he said.

“Dementia is the disease of this century and it is going to have a huge impact on the health and social welfare system,” John said. “We need urgent action now to plan for its impact.”

Planning ahead
NSW Deputy Premier and Minister for Health, Carmel Tebbutt, said the report would assist in the planning of dementia-specific services through metropolitan and regional NSW.

“It is important to know where the growth areas will be so we can continue to plan for services in the areas of greatest need,” Ms Tebbutt said.

The NSW Minister for Ageing and Disability Services Paul Lynch said that as the population ages, it was vital to know where the dementia burden was going to fall. “It is important to plan now for the impact the ageing population will place on the community,” Mr Lynch said.

Funding needed
John said funding was urgently needed for more services and to fund more research to find a cure for dementia, or to delay the onset of the debilitating condition. “We also need to ensure the planning for future service delivery is based on where the burden is going to fall,” he said.


For the full report, please visit our website at www.alzheimers.org.au and go to NSW. Please note the figures in this report are based on the ABS 2006 Census. Some state electorate boundaries have since changed.

Key findings
- Regional NSW will be worst hit by the dementia epidemic
- Sydney’s west and south-west to bear the brunt of dementia growth in the metropolitan area.
- The number of people with dementia in NSW to hit 341,000 by 2050.

Prevalence of dementia in NSW: 2009-2050

<table>
<thead>
<tr>
<th>Rank in 2050</th>
<th>Rank in 2009</th>
<th>State Electoral Division by prevalence</th>
<th>Cases in 2050</th>
<th>Change (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>Tweed</td>
<td>7,451</td>
<td>363.4</td>
</tr>
<tr>
<td>2</td>
<td>79</td>
<td>Camden</td>
<td>6,641</td>
<td>871.5</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>Wyong</td>
<td>6,236</td>
<td>380.3</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>Port Macquarie</td>
<td>6,154</td>
<td>330.2</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>Bega</td>
<td>5,830</td>
<td>340.9</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>Myall Lakes</td>
<td>5,801</td>
<td>320.9</td>
</tr>
<tr>
<td>7</td>
<td>20</td>
<td>Port Stephens</td>
<td>5,372</td>
<td>419.8</td>
</tr>
<tr>
<td>8</td>
<td>51</td>
<td>Maitland</td>
<td>5,291</td>
<td>493.9</td>
</tr>
<tr>
<td>9</td>
<td>7</td>
<td>South Coast</td>
<td>5,186</td>
<td>315.3</td>
</tr>
<tr>
<td>10</td>
<td>11</td>
<td>Coffs Harbour</td>
<td>5,142</td>
<td>366.5</td>
</tr>
</tbody>
</table>
Barry Fegan’s diagnosis of younger onset dementia in 2005 brought with it a mix of emotions for wife Christine and their family. There was relief that they could finally put a name to the symptoms that had been affecting Barry for several years. But there was also the shock of what it meant and what was going to come next.

“Between all those years, we knew that there was something seriously wrong,” Christine said. “All our family was saying there was definitely more to this than just him forgetting a few things.”

And while it was good to finally know there was a reason for the changes in Barry, the diagnosis of dementia was still distressing, not least because they didn’t know anything about the illness.

“Most people, unless they are connected to somebody that they know with the diagnosis, don’t know anything about the disease,” Christine said. “But at least we knew what was going on so that we could find out what the next step was to take…at least we could move forward and find out how we could live with this.”

Barry’s specialist had recommended the couple call the National Dementia Helpline to get linked in with support services and find out more about the illness. Through the Helpline, which is operated in NSW by AlzNSW, the couple was then referred onto a Living with Memory Loss program.

“That was wonderful, it was so
How we helped Barry and Christine

National Dementia Helpline

The Helpline provides telephone 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, students and the general public. The free and confidential service had 6956 contacts in the last financial year. This includes emails and letters as well as calls from carers, people with dementia, the general public, service providers and students.

Living with Memory Loss Program (LWML)

LWML is an early intervention program for people in the first stages of dementia and their carers. It is run in small groups for two hours over seven weeks and provides people with dementia an opportunity to discuss their condition, gain mutual support from peers, make plans for the future and learn strategies for coping with change.

Carer Support Groups

Education and support is available through more than 200 support groups throughout NSW, who generally meet monthly.

Library

The Library supports people with dementia, carers, health professionals and community care workers by providing access to quality dementia-related health information and resources. There is an extensive collection of books, videos and DVDs.

The online knowledge centre includes the library catalogue, reading lists and current awareness news services.

Informative,” Christine said. “The participants got to know each other and we could talk about common issues.”

After the seven-week program, those in the group continued to see each other through monthly follow-up meetings. Being in an environment where everyone was going through the shared experience of dementia greatly helped the couple.

“When I was told the diagnosis, it came like a bombshell,” Barry said. “That’s when my new life started and I realised that I had to go on and adjust.” Christine went on to say that each month when “Barry comes out of that meeting, he’s positive. He feels like he’s done something really productive.

“[In the group] we have really relaxed with each other which has allowed us to open up,” she added.

Carer support group meetings are a great comfort for Christine.

“Certainly, the fact that I didn’t feel alone was huge,” she said. “I think it was a relief knowing there were so many people out there that were in the same situation, and being able to talk about any issues without feeling uncomfortable about it.”

Christine also finds the AlzNSW resources in the library valuable.
and the couple has enjoyed outings organised by staff at AlzNSW’s Dementia & Memory Community Centre at North Ryde.

Barry and Christine have now signed up with Safe2Walk – a new GPS personal alert and location service for people with dementia that was recently launched in NSW.

“I don’t think that the average person has any idea of how caring for someone with dementia is really a 24 hour a day, seven day a week job,” Christine said. “It’s difficult in many ways, but now I don’t feel that I’m the only one out there doing it; I feel so much more comfortable about it knowing that, for instance, it doesn’t matter if we’re late for anything.”

Christine adds that her mindset has completely changed. “Now it’s a matter of – this is how it is and this is how we have to cope with it.”

For Barry and Christine, the support available through AlzNSW has been just as valuable as that provided by the medical profession. “The doctors can only go so far,” Christine said. “If we only had them, I would be at a huge loss.

“As the illness progresses, I know that I can ring AlzNSW and they will help me with the next step.”

**Activities**

AlzNSW provides social support through activities and outings including edible art, choirs, discussion groups for men, movie days, support groups run by carers, art therapy, day trips and music therapy.

**Regional Dementia & Memory Community Centre and regional support services**

Support services are available through our Regional Centres, Dementia Advisory Services and partnerships in Bega, the Hunter region, Coffs Harbour, Port Macquarie, Orange, Armidale, Wingecarribee and the St George and Sutherland areas.

**Other ways AlzNSW can help:**

**Counselling**

The AlzNSW Counselling Service has been operating for many years and has proven to be a valuable source of support for families across NSW living with dementia. It is available to all families who are living with the day-to-day challenge of dementia.

Counselling is conducted either at our Dementia and Memory Community Centre in North Ryde or over the telephone for those people in regional and remote areas. It is free of charge and operates during business hours. Counselling is also available at some of our regional centres and through AlzNSW regional partners.

For anyone interested in accessing the service please contact the National Dementia Helpline on 1800 100 500.

**Memory Van**

The AlzNSW Memory Van is a mobile education resource that travels statewide to help raise awareness on the importance of brain health and dementia risk reduction. It provides communities with information designed to help educate and assist those living with dementia, their carers and health professionals.

**Education services**

Education Services supports the learning needs of family carers in metropolitan and rural areas throughout NSW. In the past calendar year our team has travelled throughout NSW providing education to hundreds of families.

Our carer education is flexible and designed to meet the needs of various caring situations. Programs vary from one, two and three-day courses, to presentations for sons and daughters, sessions for family and friends, and a range of talks by invitation from facilities and community groups.

For more than 10 years, we have also provided accredited and customised programs for professional care workers. Interactive workshops and experiential program delivery aim to assist workers to provide quality care in residential care, community service and in-home environments.

Our staff also runs community awareness activities such as the national dementia risk reduction seminars Mind your Mind.
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.

Irene (Rene) Ashton
Una Beattie
Kevin Frederick Bennett
Agnes Bissett
Donato Bove
Patricia Anne Brown
Winifred Bunt
Margaret Burke
Francis Robert Byrne
Francesco Careddu
Norma Elaine Clarke
Eileen Mary Cola
Mary Connor
Valerie Mavis Coulls
Allen Cragg
Josef Jan Czamara
Bettye Denovan
William John ‘Bill’ Devenport
James Dennis Docherty
Teodor ‘Tommy’ Duma
Bernard Joseph Ernst
Dennis Hall Fawcett
Margaret Gavin (Mickey)
Rita May Haines
Maurice Alexander Harris
Keith Stanley Ibbotson
Ivy Winifred Johnston
Daniel Kirkland
Harold Lonergan
Floriana Lucchini
Stephen Noble Lundy
Neil Ewart Mannell
Vincent John Massey
Thelma Margaret Meagher
Anthony John Merton
Bronislaw (Bruno) Nowak
Wilton James O’Neill
Leo Carson Pinkevitch
Dorothy Annie Elizabeth Prince
Mary Reilly
Joan Marie Stark
Mabel Sunn
Alice Ethna Sykes
Joseph ‘Joe’ Sykes
Lance Humphrey Turner
Caterina Votano (Ardino)
Patricia Margaret Wheeler
Sylvia York
Resources

What's new on the bookshelf...

**Don't Breathe a Word** is aimed at readers aged 10 and above. The story is about the everyday life of an 11-year-old mixed with the challenges of living with and caring for someone with dementia. Teachers' notes are available from www.mariannemusgrove.com.au

This book is sponsored by the Cameron Family

**Caregivers in Drowning in a Sea of Cognitive Challenges** is recommended for the health professional. The book looks at what happens to caregivers both emotionally and physiologically as a consequence of the responsibilities and challenges of the caring role.

This book is donated by Jackie Wesson (Occupational Therapist)

**A Caregiver's Training Manual for the Elderly: Alzheimer's and other dementia** provides practical advice for any caregiver on how to instruct a person with dementia on daily tasks such as dining, bathing, grooming, dressing and toileting.

The following two unpublished stories have been donated by the authors and are available to borrow from the Library or read online through the Library catalogue https://catalog.nsw.alzheimers.org.au/liberty3/opac.htm

**Extract from my diary October 1998 – June 2007: My thoughts on living with my partner [John van Rossum] who has Alzheimer's disease** by Ina Leeflang

**Does it Last Forever? An Australian Carer's Perspective** by Gloria Forrest

**New to the Alzheimer’s Australia Online Bookshop:**

**Read a Bit! Talk a Bit!** is a new series of 10 activity books intended for people with dementia and Alzheimer's. The books start with a short article or story for the participants to read, followed by 15 to 20 questions for the facilitator to ask. Also by the same author is the yellow book of 250 pictures, **Lost Words**. All books are available from the library to borrow.

Announcement

**Writers' Workshop 2010**

The very popular Writer’s Workshop, with guest writers Elizabeth Bezant and Pamela Eaves, is now planned to take place in early 2010. The workshop will be preceded by the launch of Elizabeth and Pamela’s latest book **Caring Moments: The Carer’s essential, everyday handbook on dementia and Alzheimer’s**. To register an expression of interest to attend the launch and the workshop contact the Library on 02 9888 4218 or email lis@alznsw.asn.au

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

Hours: Monday to Friday 9am–5pm; tel: (02) 9888 4218; email: lis@alznsw.asn.au

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

Visit the Alzheimer’s Australia Online Bookshop which offers over a million general titles and a range of dementia-related topics: www.alz.seekbooks.com.au

Access latest research, care practices and more by visiting Alzheimer’s News at www.alznews.blogspot.com

Crossword

<table>
<thead>
<tr>
<th>Across</th>
<th>Down</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. One at a time</td>
<td>1. Support, ... with</td>
</tr>
<tr>
<td>6. Brush &amp; ...</td>
<td>2. Don't move, stay ...!</td>
</tr>
<tr>
<td>10. Loved foolishly, ... on</td>
<td>3. Mountain range top</td>
</tr>
<tr>
<td>11. Decorates</td>
<td>4. Treacle sweets</td>
</tr>
<tr>
<td>12. And so on (2,6)</td>
<td>5. Lassos</td>
</tr>
<tr>
<td>14. Eagle's nest</td>
<td>7. Additional</td>
</tr>
<tr>
<td>18. From Madrid</td>
<td>9. Rented vehicles (4,4)</td>
</tr>
<tr>
<td>20. Continually (2,3,2)</td>
<td>13. Jewelled crown</td>
</tr>
<tr>
<td>22. Deadly game, ... roulette</td>
<td>15. Softness</td>
</tr>
<tr>
<td>23. Equine beast</td>
<td>17. Damaged (stockings)</td>
</tr>
<tr>
<td>28. Fanatic</td>
<td>21. Sitting on eggs</td>
</tr>
<tr>
<td>29. Sleeps lightly</td>
<td>22. US property agent</td>
</tr>
<tr>
<td>31. Foam</td>
<td>24. Deemed</td>
</tr>
<tr>
<td>32. Attackers</td>
<td>26. Sea rhythms</td>
</tr>
<tr>
<td>33. In current state (2,2)</td>
<td>27. Animal exhibition</td>
</tr>
</tbody>
</table>

SOLUTION ON PAGE 17