In touch
The quarterly newsletter of Alzheimer’s Australia NSW

Issue 69 Winter 2009

• Music therapy works its magic
• A carer’s story: living with dementia
• Day in the life of a dementia advisor

Dementia epidemic
Carer shortage looming
In touch
The quarterly newsletter for members of Alzheimer’s Australia NSW

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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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From the Board

Vice Chairperson’s message

My introduction to dementia was 20 years ago. My husband, two children and I went to live with my grandmother who had mid-stage dementia. She lived in an area where she was isolated, she was a wanderer, and constantly complained that my husband was stealing her food. This is where my journey with dementia started.

Over the next 18 years I worked for different community-based organisations and was lucky enough to be able to use and build on my own personal knowledge of dementia, to develop programs that provided care in the home to people who had different types of dementia. In 2001, I was voted onto the Board of Alzheimer’s Australia NSW. The past eight years have been an interesting journey and over this time I have worked with some very talented staff and seen the organisation grow with new facilities including Port Macquarie and Newcastle, as well as a host of new services and programs up and running.

Responding to your needs
Alzheimer’s Australia NSW is, and needs to be, an organisation that, while keeping its overall dementia focus, changes its strategic focus as needed. This does not mean that it changes its client base, just that, as time passes, people need different things from our organisation. The Board and staff are always aware of the most important stakeholders, those people living with dementia, and in order to make the organisation responsive to you and your needs, you need to be able to communicate easily with us. There are a number of ways that this can be done. I am very aware that it is not easy to get to our offices but, at the end of every phone, there is someone who knows what you are talking about and can steer you in the right direction to get support or to give support.

Group support
We now have a number of Consumer Advisory Committees that you can become a member of. There are a number of carers’ groups who are affiliated with Alz NSW. The Helpline is there for you, whenever you need it.

The education section has programs in most areas of the state and I would encourage you to go along, just to learn something new or to re-hear something you know but might have forgotten. It is also an opportunity to talk to our education staff.

Good luck to all of you.

Robin Wirth
Vice Chairperson

CEO’s message

The recent release of the Access Economics report ‘Making Choices – Future Dementia Care’ is a startling reminder of the huge challenge we face in coming years.

The projections of the rapidly increasing numbers of people that dementia will hit in the coming decades, and the social and economic implications this will have, only serve to strengthen our resolve to keep up the important work we are doing and to continue to ensure our voices are heard.

A more comprehensive summary of the report can be found on page 8 of this issue of In touch.

As part of our work in continuing to spread the message, the Alzheimer’s Australia NSW Memory Van has been on the road, recently taking in Dubbo, Wellington, Mudgee, Narromine, the Orange area and Bathurst. By all accounts it was a highly successful trip and allows us to continue to get important information about dementia, including ways to reduce risk, to people living across the state.

Alzheimer’s Australia NSW staff have also been out and about in Sydney to raise awareness, with a stall at both the 2009 Premier’s Seniors Week Gala Concerts in March and at the Royal Easter Show in April. They were great events and served to spread our message even further.

The national conference was held in June. Congratulations to our staff – Policy and Information Manager Lisa Langley, Research Officer Jo-Ann Brown, Specialist Group Worker Lyndell Huskins and Dementia Education Support Person Sally Prowse – who presented at the conference.

Our second Parliamentary Friends of Dementia forum occurs on 25 June. This is a great way to engage with key decision-makers with whom we hope to continue to work to address the dementia tsunami coming our way.

Finally, we have had some great feedback about the new look In touch, which is a very valuable way to engage with our members.

I hope you continue to enjoy reading about the great work that is happening across your organisation.

The Hon. John Watkins
Chief Executive Officer
It is critical that Alz NSW be accessible to the widest possible audience in order to increase awareness of dementia and the work of our organisation. Participation at the Seniors Week concerts gave us direct contact with around 36,000 senior citizens during the event on 16 and 17 March. This was the first time we’ve participated in this event, and we distributed around 20,000 pieces of information as well as answering innumerable questions about memory loss.

Macquarie University
Alz NSW was recognised by Macquarie University for its continuing involvement and support of its Social Science Research Internship Program where selected students participate in ‘real life’ research practice, under the guidance of our staff.

Affordable Aged Care Seminar: Commercial Law Association
Alzheimer’s Australia CEO John Watkins was invited to chair the Affordable Aged Care Seminar. The theme of the seminar was ‘Current Issues, Innovative Solutions and the Role of Insurance’. The seminar was held at Gadens Lawyers on Thursday 7 May. Federal Minister for Ageing Justine Elliot attended the seminar as well as several highly respected legal professionals.

The well-attended seminar provided an excellent opportunity to highlight some of the key issues concerning aged care funding and explore some of the strategies that may assist in ensuring affordable and sustainable aged care solutions.

The organiser of the seminar, Max Wilson, CEO of the Commercial Law Association of Australia Ltd, said:

“The role of the chair is critical in linking sessions and highlighting key points. Your insightful comments and chairing of the sessions added greatly to the seminar’s success.”

John Watkins and Federal Minister for Ageing Justine Elliot.

Solution to crossword (page 20):
**NSW Companion Card**

The NSW Minister for Disability Services, Paul Lynch, has launched a new Companion Card program that allows people with a disability to take their carers on public transport and to events for free.

“The card recognises that a carer is vital for people with a profound or severe disability and provides equal access to services and facilities,” Minister Lynch said. He said about 240 businesses had signed up to offer benefits for Companion Card holders.

Alzheimer’s Australia NSW CEO John Watkins said the new card was a welcome step forward for people with disabilities, including dementia, and those who care for them. “We applaud this initiative,” said John. “Anything that encourages and allows greater engagement in society for people with disabilities, and, in particular dementia, is to be supported.”

To check eligibility or to obtain an application form, people interested can call 1800 893 044 or go to the National Disability Services NSW home page at www.nds.org.au/nsw/index.html.

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**Chinese New Year**

John Watkins joined members of the ACCA Ming Shi Chinese Dementia Respite Day Care Centre to celebrate Chinese New Year at the Vincent Fairfax Family Resource Centre (North Ryde) in late January.

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**Sydney Royal Easter Show**

Alz NSW joined the Seniors Village at the Sydney Royal Easter Show on 12 and 13 April 2009. Around 10,000 seniors visited the event over these two days and were able to collect information or ask questions. This was another first for Alz NSW.

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**Dementia now fourth highest cause of death in Australia**

The Australian Bureau of Statistics’ (ABS) latest report found deaths from dementia have more than doubled in the past decade. In 2007, 5.3 per cent of all deaths were from dementia, up from 2.6 percent in 1998.

Dementia is now the fourth highest cause of death in Australia (previously ranked seventh). Heart disease, stroke and lung cancer remain the top three.

“This is a startling finding and demonstrates the growing momentum of this condition in Australia,” The Hon. John Watkins, CEO of Alzheimer’s Australia NSW, said.

“The ABS statistics highlight the critical need for immediate action into planning for the significant health, social and economic impacts on Australian society these dementia figures represent,” John said.

“Now is the time to take a long-term view and plan for the future of aged care and dementia care services in Australia,” he added.

“An increase in funding for medical research is now also urgently needed to ensure adequate prevention measures and even a cure for dementia,” John said.

He said the direct economic cost of dementia and cost of dementia care combined is currently $7.3 billion*.


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**Volunteer winners**

Congratulations to the Alz NSW Dementia Helpline Volunteers (some of whom are pictured with Alzheimer’s Australia NSW Manager Services Emma Bourne), who have been named the 2009 City of Ryde Volunteer Group of the Year. Congratulations also to the Alzheimer’s Disease Help Our Carers (AD HOC) volunteer group, who received a certificate for their great work.
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Alzheimer’s Australia NSW.
We are also looking for people who are interested in volunteering on the day.
Contact Kathryn Gibb on kgibb@alznsw.asn.au or on (02) 8875 4626 to be registered as a volunteer.

Memory Walk 2009
Our Memory Walk is on again! This year’s event will start at 8.30am on Sunday 27 September at the Bowling Green, Parramatta Park with a choice of either an easy 2km or 5km walk.
We are currently planning for live music, great food and drinks and lots of family fun including a jumping castle and face painting for the kids.
Thanks to everyone who attended last year and we hope to see you all back again, enjoying our brand new location. So reserve the date and encourage your family and friends to join us for the Memory Walk.

Alliance e-finance Golf Day
Alliance e-finance is again supporting Alzheimer’s Australia NSW through its annual Charity Golf Day on Tuesday 15 September 2009, at Pennant Hills Golf Club, Copeland Road, Beecroft. Registration is at 10am, with a late breakfast, followed by the tee-off.
The event will conclude with an auction of sporting memorabilia and other donated items and close at around 6pm. If you want to organise a team of 4 people you are welcome to participate. Contact Coralie Hicks on (02) 8875 4652 for details.

Supporting our work

Blackmore’s Sydney Running Festival
At Alzheimer’s Australia NSW we are very excited to have been chosen as a supporting charity for the Blackmore’s Sydney Running Festival in 2009.
This event will take place on Sunday 20 September and we encourage all our supporters to get outside, get active, fundraise and have fun! It’s a great way to Mind your Mind.

Perhaps you can encourage family and friends to be involved or maybe sponsor someone who is walking or running.

Get involved
Register now at www.sydneyrunningfestival.com.au to take part in the Blackmore’s Sydney Running Festival and follow the links to find out more about how you could raise funds and support Alzheimer’s Australia NSW.

Entertainment Books
These are still on sale and provide a fantastic array of bargains and discounts. They make a wonderful, present or family gift and you are helping us raise valuable funds.
Just call Christine Bauer on (02) 8875 4625 with your phone order or go to our website – the

Upcoming events

Masquerade Ball
12 September 2009
Roma Reception Centre, Liverpool. Organised by the Knights of Malta in support of Alz NSW.

National Dementia Research Forum
24-25 September 2009
The Dementia Collaborative Research Centres (DCRC) will be holding a National Dementia Research Forum at Wesley Centre in Sydney. For further information, contact the centre on (02) 9385 9060 or email dementiarc@unsw.edu.au

Mind and its Potential conference
2-3 December 2009
This conference is supported by Alzheimer’s Australia and will be held at the Sydney Convention & Exhibition Centre. For further information, visit www.mindanditspotential.com.au or contact Laura Tait on tel: (02) 8719 5118; fax: (02) 9798 9413; or email: conferences@vajrayana.com.au
Fundraising news

Discounts in this book represent $15,000 in value.

The Sun-Herald City to Surf
Participants in the 2009 City to Surf on Sunday 9 August can again be sponsored to raise money in support of Alzheimer’s Australia NSW. Encourage your friends and family who run in the City to Surf to check out our website www.alzheimers.org.au and follow the fundraising links to set up their own sponsorship page.

For details call Kathryn on (02) 8875 4626.

Our sincere thanks
The economic situation is biting all sectors of our community and Alzheimer’s Australia NSW is not exempt, with our fundraising income being affected.

We do however sincerely thank our dedicated and committed members, pledge supporters and friends who continue to generously support our work.

Government does provide some of the funds we need to deliver direct services but it is only with the generosity of the broader community that we are able to maintain the current level of our services.

Funds are always required to expand our services due to the unmet need in the community. Knowing we have your support allows us to better plan our service delivery.

Pledge-giving is a convenient way to support Alz NSW and it helps us by reducing the number of appeal letters we need to send. For details about becoming a pledge supporter, call Coralie Hicks on (02) 8875 4652.

Courses

Alzheimer's Australia NSW Group Work Skills Workshops 2009

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Please note: These dates and locations may be subject to alteration

For further information please contact Monica Cole on tel: (02) 8875 4682; email: mcole@alznsw.asn.au

www.alzheimers.org.au

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New savings scheme recommended to combat dementia epidemic

A savings scheme, on top of the current superannuation scheme, is essential to cope with the predicted rapid increase in the number of people with dementia in Australia, according to a new report.

The devastating report by Access Economics also forewarns of a chronic shortage of more than 150,000 paid and unpaid carers for people with dementia by 2029, unless there are major policy changes or a significant medical breakthrough.

The report, commissioned by Alzheimer’s Australia, also recommends increased investment in dementia research and prevention, and greater promotion of dementia risk reduction so as to capture huge potential savings by delaying the onset of the disease. The report reiterates the massive size of the problem. Currently, there are 230,000 Australians diagnosed with dementia. That is projected to increase to 465,000 in 2030 and even further to an astounding 730,000, or more, by 2050.

Lynne Pezzullo, a director of Access Economics, said providing quality care for those with dementia was the immediate priority in the next two decades.

“But in the longer term, investment in research is the key to prevention and effective treatment of dementia,” she said. “Adequate financial provisioning for quality care services requires a rethinking of high care capital financing mechanisms today, hand-in-hand with the gradual introduction of savings vehicles over the longer term.”

Alzheimer’s Australia NSW CEO The Hon. John Watkins said an equitable funding scheme, for example, the suggested savings scheme, an additional Medicare levy, or changes to superannuation provisions, must be investigated urgently so we can cope with the huge financial impact dementia will have on the Australian economy.

“These provisions will enable Australians to provide for quality care and appropriate residential care options with well-trained staff for those people who are living with dementia,” John said.

“Australia already spends $94 billion, or about 9 per cent of GDP, on health and aged care services. That is projected to increase to $246 billion or 12.4 per cent of GDP by 2032/33.” John said action was urgently needed. “The nation is not prepared for the dementia tsunami that is about to hit us,” he said.
“Looking at these future projections, the current health care system will be unable to cope with the looming dementia crisis. There needs to be a quantum shift in the awareness of dementia and that has to be backed up by adequate government support.

“Unless that happens, the projected chronic shortage of carers means we are going to condemn thousands of Australians to abject poverty in their older years.”

The report, ‘Making Choices, Future Dementia Care: Projections, Problems and Preferences’, has predicted a shortfall of 58,887 full-time equivalent dementia care staff and 94,266 unpaid family carers by 2029.

The latest Australian Bureau of Statistics figures have found that deaths from dementia and Alzheimer’s disease have more than doubled in a decade and that it is already the fourth leading cause of death in the country, behind heart disease, stroke and lung cancer. Access Economics has also previously forecast that dementia will become the leading disability burden in Australia by 2016.

The report authors have called for a ‘fundamental rethinking’ of the delivery of care for people with dementia, so that it involves a mix of community and residential care services that is driven by the needs of the person.

John Watkins said the issue could not be ignored. “The health system is barely addressing the needs of people with dementia and their families now,” he said. “The problem is only going to get much worse.”

1 National Health and Hospitals Reform Commission (NHHRC), Interim Report, February 2009

ABC coverage of the report.

Making Choices, Future Dementia Care: Projections, Problems and Preferences
This report, by Access Economics, identifies eight key issues with recommendations that need to be addressed to ensure the future care of Australians with dementia and the people who support them.

Planning aged care and dementia services
Dementia-specific community and residential care services need to be included in a review of planning for aged care.

The balance of community and residential care services
Introduce consumer-directed models of care to allow people to choose a mix of community and residential care services to best meet their needs. Reform community care and ensure an increase in community and residential care services for people with dementia to meet projected demand, with enhanced consumer choice.

Information and consumer support
Expand and enhance access to information and carer support through the National Dementia Support Program and the Commonwealth Respite and Carelink Centres.

Quality dementia care
Extend access to dementia training for formal and family carers promoting person-centred dementia care, and increase delivery of Certificate IV and Diploma in Dementia Practice.

Workforce options for carers
Improve access to long day respite care and provide greater workplace flexibility for carers.

Special needs groups
Give higher priority to providing dementia services to five groups that are particularly disadvantaged in accessing dementia care, including: younger people with dementia; Indigenous people; people from culturally and linguistically diverse backgrounds; those with dementia and psychiatric issues who fall between the aged care and mental health systems; and those in rural and remote areas.

Research
Continue to expand investment in dementia research and prevention and promote awareness of dementia risk reduction.

Develop new financing mechanisms
Introduce new financing mechanisms, like dedicated Healthy Ageing Savings Accounts (HASAs) for aged care, in addition to superannuation.
ElderClowns (SMILE) study: Humour therapy in residential care

The Dementia Collaborative Research Centres are about to embark on an exciting new study involving humour therapy in residential care.

SMILE is a randomised controlled trial of a humour therapy program in residential aged care. Thirty-six RACF units will be involved in total, with 50 per cent randomly chosen to receive the full humour therapy intervention, and 50 per cent randomly chosen to be the control group and receive delayed LaughterBoss training. The study will be running between 2009 and 2011.

ElderClowns will be visiting intervention units for two hours every week for 12 weeks and will be interacting with and entertaining residents and staff with stories, jokes, mime, songs and in other ways. Two staff volunteers from each unit will attend one-day training to take on the role of LaughterBosses and bring humour into the facility routines. It is hoped that the ElderClown visits and LaughterBosses will increase resident engagement whilst improving quality of life and mood and decreasing behavioural disturbance.

Both high-level and low-level residential care facilities within the greater Sydney area are welcome to participate. More than one unit from a facility can participate, however the unit cannot share staff with another participating unit, to prevent leakage of the intervention. Units which have a majority of non-English speaking residents are not suitable for this current study.

For more information, please contact Dr Belinda Goodenough at the Dementia Collaborative Research Centre, University of New South Wales – email: b.goodenough@unsw.edu.au

DCRC National Dementia Research Forum

Hosted by the Dementia Collaborative Research Centres (DCRCs), the Annual National Dementia Research Forum will be held at the Wesley Conference Centre in Sydney on 24-25 September 2009.

The theme of the forum is ‘Translating Research into Practice’ and there will be an emphasis on how lessons from academia can translate into best practice at the clinical coalface. The forum will showcase the latest research in diagnosis, treatment and management of dementia, as well as providing updates on drug treatments, prevention of dementia and maintaining quality of life with dementia.

This unique event will bring together a diverse group of participants, including health professionals, aged care workers, researchers, clinicians, service providers, carers and people with dementia.

The Hon. Justine Elliot MP, Minister for Ageing, will open the forum.

There will be presentations by prominent local and international keynote speakers on a wide range of topics.

Providing Dementia Care in the Community: an Evidence-based Approach
Professor Constantine Lyketsos
Elizabeth Plank Althouse Professor
The Johns Hopkins Bayview Medical Center, USA

Dementia in Indigenous People
Professor GA (Tony) Broe
Senior Principal Research Fellow and Professor of Geriatric Medicine
University of New South Wales

Knowledge Translation in Dementia
Dr Sue Phillips
Executive Director
National Institute of Clinical Studies

Advances in Drug Treatments of Alzheimer’s disease
Associate Professor Michael Woodward
Director, Aged and Residential Care
Austin Health

To register and for more information please visit the DCRC website: www.dementia.unsw.edu.au

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

UNSW
THE UNIVERSITY OF NEW SOUTH WALES

Research News
Alzheimer’s Australia NSW in partnership with Alt Beatty Consulting have been contracted by the NSW Department of Ageing, Disability and Home Care (DADHC) to undertake a needs analysis project in the Metro South Region. The project will look at:

- The distinct characteristics of each dementia specific HACC service model in each LPA.
- The needs of people with dementia and their carers at each stage of the disease.
- The capacity of the service system to respond to these needs into the future.
- Indicators that trigger the need for higher support.
- Innovative models of service and their associated costs.

Consultations with service providers, people with dementia and carers, and other interested stakeholders across the Metropolitan South Local Planning Areas (Inner West, South West Sydney and South East Sydney) will occur between May and August 2009.

An issue paper will be available for each consultation, and is tailored for the participants: service providers; people with dementia and their carers; people from culturally and linguistically diverse backgrounds, and Aboriginal people.

If you would like further information about this project, wish to participate in a consultation, or make comment on the issues papers, please contact the Project Coordinator, Nicky Hayward-Wright, Alzheimer’s Australia NSW on nhayward@alznsw.asn.au or (02) 9888 4244.

Quality Support Groups

The Alzheimer’s Australia National Conference in Adelaide provided an opportunity to present the findings from phase III of the Quality Support Groups Research Project.

Research Officer Jo-Ann Brown presented a paper on the most significant findings from the project. These included the significant capacity of mutual aid between members of a carer support group as well as the profound impact of grief and loss on a carer and how the regular attendance at an ongoing support group can relieve some of their emotional stresses. Recommendations from the report were given in the presentation and included the importance of group skills training for leaders, acknowledging carer diversity and the reduction of stigma associated with dementia. Best practice guidelines for a quality support group were formulated as part of the project.

Group leader training program

In the spirit of good research to practice Lyndell Huskins, Specialist Group Worker, also presented a paper on the group leader training program she has developed following the research findings from the Quality Support Groups Research Project. It was recognised in the research data that an indicator of quality in a group is often the way in which the group deals with the grief and loss experiences of its members. Lyndell’s paper reflected this and discussed the need to extend group skills training for leaders. She then outlined the Grief and Loss module that Alzheimer’s Australia NSW has added to its suite of training units for leaders in the Group Development Unit.

Chinese Dementia Awareness Campaign

A CALD partnership project between Australian Nursing Home Foundation (ANHF) and Alzheimer’s Australia NSW for a Chinese Dementia Awareness Campaign has commenced. The project will entail:

- Four Chinese-speaking seminars/workshops to promote better community awareness and understanding of dementia and support services.
- Radio program by geriatricians and aged care professionals to be broadcast on SBS and ethnic media (2CR) and edited as audio tracks to be uploaded on ANHF websites and Alzheimer’s Australia website, or dubbed onto audio CDs when needed.
- Articles on dementia printed in ethnic newspapers.
- A Chinese information booklet for carers of people with dementia will be compiled and will include information on dementia, support services, looking after oneself and articles on caring experiences based on interviews of carers.

All resources will be kept at So Wai Dementia Education and Resource Centre at Burwood and a copy of each resource at Alzheimer’s Australia NSW Library & Information Service.

For further information about this project contact Brigit Tam, ANHF on (02) 8741 0214 or Nicky Hayward-Wright, Alz NSW on (02) 9888 4244.
A carer’s story

Darrell Bailey talks about life as a carer for his wife who has Alzheimer’s disease.

Recently I read a magazine article titled ‘Living With Dementia’. To me, the co-authors seemed to paint a rather rosy picture saying that living with dementia provides opportunities to enjoy that life (obviously with the availability of support services) and that living in the moment is fine, as long as the ‘moment’ is positive and stimulating – or at the very least, not stressful.

These authors in the article seemed to imply that support was readily available upon demand. I differ with the above view, and what follows is part of my daily experience as a carer and, although my role is a willing one, I find rare enjoyment and quite a bit of stress.

The path my wife and I walk is not one we expected to travel. We have to accept what comes each day. We cannot change our circumstances, so we adapt and make it as easy as we can. Most importantly, we do not look for, nor do we expect, pity or sympathy. We know and see others whose circumstances are worse than ours.

In December 2001, my wife was officially diagnosed with early memory loss, or Alzheimer’s disease, or dementia, whichever description is used. However, symptoms started to manifest about 1994 and our (then) GP would not agree there was anything amiss with my wife’s memory and behaviour.

It began with little lapses in memory and behaviour which have become Big Things over time. My wife has lost skills and talents and today she can do almost nothing beyond the basic tasks of eating and sleeping. It has become my responsibility to do all the tasks around the home – prepare meals, laundry, house-cleaning and so on. Each day one must expect the unexpected, and planning ahead is vital. A carer must think for two people (and particularly the one with dementia).

We’ve re-arranged our methods of paying bills and household expenses. For example, electricity, gas, council and water rates. Also the shopping schedule.

We’ve dealt with wills, powers of attorney, guardianship, funerals, signatories to financial accounts and advance care directives.

I have arranged short-term ‘in-house’ respite if I should suffer a sudden illness, or another emergency. We’ve had to deal with ‘busybodies’ regarding my wife’s odd behaviour and comments. We have been shunned by some relatives and friends and have withdrawn from some groups to which we belonged and served for years. We are no longer useful or usable.

We have moved on from the bitterness and anger and now feel only sadness – not for ourselves, but for those who cannot understand. They have not walked in our shoes and cannot comprehend. Sometimes we get upset when people express pity or sympathy. We feel it is rather hollow and consider the expressions to be patronising.

In the years following my wife’s diagnosis there have been just three offers to stay with my wife while I have a break of a few hours to have some time and space for myself. We no longer travel, except for the occasional day coach trip. My wife is quickly confused and disoriented once we leave familiar places. She forgets the day and date. She misjudges the time of day and cannot read an analogue or digital clock face. I now do all the driving.

We’ve had trouble with side-effects from medications, such as diarrhoea, fatigue, leg cramps, hallucinations and weakness, to name a few. My wife cannot handle...
a cordless telephone, nor can she read a telephone directory. So if I have an accident at home, and our neighbours were unavailable, she would be unable to call for help.

We’ve lost part of our lives together. We cannot work as a team as we did when raising our family. We’ve lost friends. We’ve lost some enjoyable and meaningful roles in our (now former) social circles. We do not go out much, but on rare occasions we enjoy the company of caring and understanding friends.

We do not ask people to our home for lunch or dinner because my wife’s anxiety levels would begin about two days before any visit and then would reach maximum when the event occurred.

She can no longer use her sewing machine, nor follow a knitting pattern, let alone manipulate knitting needles.

I have lost my confidante. We cannot talk over those issues which daily enter our lives because loss of brain cells means her rational thinking and expression are impaired. I realise my role is to be more understanding, patient, tolerant, forgiving and aware. We have some occasional ‘blow-ups’ and express our frustrations. But it is not the person, it is the disability which is the cause.

I have come to know I should look after myself. If I get sick or taken out then I cannot help her or myself, and a crisis would occur. It is good to find someone who listens and understands. Sharing one’s fears, frustrations, hopes, joys and sorrows is a very good form of therapy for the carer. And support groups help considerably.

Take a break. Make that possible. It is not selfish, but pragmatic. Occasionally, a carer needs some personal space and time to recharge the batteries. It is good, too, for the person with dementia to be away sometimes from the carer.

Carers live daily with the knowledge of the prospect and inevitability that the cared-for will ultimately move from home into residential care. And this conflicts with my marriage vows that I would care for my wife in sickness and health, in good times and bad times. It is extremely difficult to reconcile this covenant with what must be done when I can no longer carry out my carer’s role.

I am reluctantly and slowly preparing for these eventualities, and I am aware I should follow my head rather than my heart when the hard decisions have to be made.

Darrell is a member of Alzheimer’s Australia NSW and is involved with the Hunter Dementia and Memory Resource Centre. The views expressed by contributors to this newsletter are not necessarily shared by Alzheimer’s Australia NSW.
For dementia counsellor Kath Readford, there is no such thing as a typical day.

Kath, a dementia counsellor with Catholic Health in Dubbo, looks after carers of people with dementia – be they at home or in a care facility. While based at Lourdes Hospital, in Dubbo, Kath could be out on the road visiting carers in any of the 11 local government areas that she covers, ranging from Cobar in the west, to Coonabarabran on the eastern edge, down to Mudgee, back to Dubbo and all places in between.

Or she could be in the office talking to up to seven carers either in person, or over the phone, working with the area’s Aged Care Assessment Team, working with the visiting psychogeriatrician or with the various support groups she runs for carers.

Adapting to change
While no two people are the same, sleepless nights and incontinence continue to be common issues raised by carers. Changed behaviours and personalities are sometimes problems for family carers.

“People not being the same, easy-going personality that perhaps they once were.

“Or the continual asking of the same question – that’s often very tiring for carers.”

Not surprisingly, Kath loves her job.

“Particularly the clinics, because it’s a multidisciplinary team and working with the specialists is particularly helpful, both for the carers and staff alike,” she said.

Kath believes carer support groups are also of huge benefit to carers.

“They’re often a very good way of supporting carers, letting them know they are not alone,” she said.

“And carers learn other tips and strategies from each other, as well as from health professionals.”

Working with other services
Kath is the sole dementia counsellor in her area, which she describes as “a bit of a challenge at times”!

“I appreciate being able to work with the aged care assessment team as well as the team from the Commonwealth Respite and Care Link Centre,” she said.

“It’s helpful being able to work with the range of support services because we’re all trying to help the carer and their family. I’d like to think that for the future, we will have more community awareness services, particularly in the smaller towns. It’s so important for early assessment, referral and diagnosis.”

Kath Readford worked with Alz NSW staff during the Memory Van’s recent highly successful trip to Dubbo, and has had a long association with the organisation through training programs, research and the group development unit.

Farewell to Karen Black
Karen Black has departed from Alz NSW after five years of service to prepare for the birth of her second child. Karen is well-known to many due to her tireless efforts as Community Relations Coordinator, responsible for arranging many events, seminars, and the Memory Van. We wish Karen and her new baby good health and plenty of rest!
New staff at Alz NSW

Mid North Coast
Catherine Cahill, Dementia Advisory Services (DAS)
At last we have Catherine Cahill on the Alz NSW team. After three years operating as a ‘regional partner’ to Alz NSW Catherine has joined the team as a Dementia Advisor on the Mid North Coast in the Nambucca Valley, Coffs Harbour, Bellingen and Dorrigo areas.

Catherine has worked in the community care sector since 2002. Her various roles have included coordinating centre-based day programs, social support services and various activity groups. Catherine has experience in training volunteers for Neighbour Aid support programs and facilitating dementia carer support groups.

Catherine’s interests include tennis, walking and yoga. Her many clients are very pleased to learn of her return to the DAS role.

Alz NSW is pleased to have Catherine as part of the team.

Talavera Road
Shannon Davis, Community Relations and Volunteer Coordinator
Shannon Davis joins us to fill the gap left by Karen Black. Shannon’s role has been expanded to include both Community Relations and Volunteer Coordination to ensure that we are well placed to maximise the wonderful support provided by volunteers to our great organisation.

Sarah Price, Marketing & Communications Coordinator
Sarah Price will be well known to readers of the weekly newspaper. We are very pleased to have Sarah join the Alz NSW team as the full time Marketing and Communications Coordinator who will assist us to raise the profile of dementia and our organisation.

North Ryde
Denise Herman, Diversional Therapist
Welcome to Denise, who joined Alz NSW in May as a Diversional Therapist. This position is responsible for planning, developing, promoting and evaluating evidence-based activities for people living with dementia and their family and carers. Activities may be social, recreational or therapeutic, such as music therapy and outings.

Bega – Barbra Williams wedding
We are thrilled to report that our Bega-based Dementia Advisor, Barbra Williams, married Peter Gibbs on Saturday 28 March at Kianinny Resort, Tathra.

Congratulations to both Barb and Peter and family on this happy occasion.


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Memory Van tours Central West NSW

The Alzheimer’s Australia NSW Memory Van got loaded up and hit the road in May, taking in Wellington, Mudgee, Narromine, the Orange area and Bathurst in its travels.

The Memory Van is a mobile education resource that travels statewide to help raise awareness of the importance of brain health and dementia risk reduction.

It provides communities with information designed to help educate and assist people living with dementia, their carers and health professionals and is fully equipped with Help Sheets, Fact Sheets, DVD and video resources and a Nintendo Brain Game.

Staff from Sydney met up with regional staff for the tour, which generated great interest from the communities and local media, with stories on the van and its message in newspapers, on television and the radio.

We hope to be able to continue to spread the message with more regional tours in the near future.

Regional wrap up

Strong attendance at the ‘Mind your Mind’ seminar.

Bega Dementia: Delirium hospital volunteer pilot program

Alzheimer’s Australia NSW has been working in partnership with Greater Southern Area Health Service (GSAHS) in the Bega Valley to establish this research project to investigate the health and social benefits of volunteers spending time with patients who are admitted to hospital with dementia and/or delirium.

Barbra Williams, the Dementia Advisor from our Bega Valley and Eurobodalla Dementia Advisory Service, has been working closely with Cath Bateman, Dementia – Delirium CNC (Acute) GSAHS to get this program underway.

Following an extensive process to get ethics and research approval, Cath and Barbra were thrilled to recruit 12 quality volunteers who, now that they have completed their training program, will be commencing in the Bega Hospital on 4 May to begin working with assigned patients.

The results

The data for this research project will be collected from May – November 2009 and will then be available for review once it has all been evaluated.

Both Barbra and Cath will be spending a lot of time over the next few months working with the volunteers and patients at the Bega hospital and are also pleased to have the support of Ass Prof Mike Bird and Psychologist Katrina Anderson (from GSAHS Aged Care Evaluation Unit) as associate researchers. It is anticipated the findings from this research project will be available in approximately April 2010.

Record turnout for Hunter fundraiser

Challenging economic times appear to see many people wanting to get out for a night of fun to help a worthy cause. And this would appear to be the case with the Hunter’s trivia fundraiser on Friday 1 May.

The Hunter Dementia & Memory Resource Centre’s staff organised a trivia night in the Starlight Room of Wests Leagues Club in New Lambton. The Club was very generous in donating the room, and an audio visual technician and equipment.

The challenge initially was: “Can we find enough people who want to play trivia to make this auditorium, with a seating capacity of 490, look reasonably full?” As the day got closer, it became obvious that the challenge was not whether there would be sufficient participants but whether the auditorium would be big enough.

Mark Priest and Diana Golvers of Quizmasters generously donated their professional services and expertise on the night, and many Hunter businesses donated prizes and gift vouchers.

The evening raised over $7,000 for the Centre and its services. The Newcastle team is already looking to making the 2010 event better but perhaps not ‘bigger’.
Bega Cheese donation helps fund dementia work in Bega

The chief executive officer of Alzheimer’s Australia NSW, the Hon. John Watkins, travelled to Bega in May to accept a donation worth more than $13,500 from Bega Cheese. “I would like to thank the staff at Bega Cheese, and, in particular, the Chairman Barry Irvin, for this generous donation,” John said. “It is particularly welcomed as it comes at a time when the incidence of dementia is set to rise rapidly.

The donation will be used to pay for office equipment at the Dementia and Memory Community Centre, Bega. It will also go towards funding two Healthy Ageing Community Information days, which will include Alzheimer’s Australia’s highly successful Mind Your Mind program – a community education program which outlines brain-healthy habits you can adopt to help reduce your risk of developing dementia. The days will be held in the Bega Valley and Eurobodalla local government areas.

The money was raised at the annual Bega Cheese charity auction, which is held during the Bega Cheese Corporate Event dinner every March. Bega Cheese Chairman Barry Irvin said Bega Cheese was very aware of its important role in the community and of the many challenges faced by rural communities in providing appropriate care and services for those with dementia.

Pictured above: (L–R) Mayor of Bega Valley Shire Council, Cr Tony Allen, CEO of Alz NSW John Watkins and Barry Irvin, the Chairman of Bega Cheese.

New signage improves awareness

Being seen is a critical element in helping to improve the visibility of our cause, and our services. Good signage is a fundamental part of improving directions and access. Strong branding communicates who we are and what we do.

Over the past few months Alz NSW has been actively seeking opportunities to help put us more clearly on the map – be it directional street signage at key intersections to help visitors find our centres, or improved facility signs, to build awareness.

See left for a few examples across the region – more will follow.

Alz NSW and Rotary at the races

For the past decade, the Rotary Club of Newcastle has been a major driving force in working to raise funds to assist in the establishment of the Hunter Dementia & Memory Resource Centre in Newcastle.

Newcastle club members annually organise a Race Day for charities throughout the Hunter. Once again this year, Alzheimer’s Australia NSW and in particular, the Hunter Resource Centre, was chosen as one of the recipients of funds raised by Rotary on Anzac Day at Newcastle’s Broadmeadow Race Course.

Included amongst the Rotarians attending were a number of returned servicemen who had, along with many others, already joined in the numerous Anzac Day dawn services held in Newcastle and surrounding regions.

Representing Alz NSW was the Fundraising and Community Relations Manager, Brian Daniels, and the Hunter’s Community Development Officer, Beverley Watson. Both agreed that a great day was had by all and plans are afoot to utilise the funds raised towards the establishment of a Men’s Shed at the Centre.

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The FlashID Community Support Program

FlashID International Pty Limited, PO Box 94, Bundanoon, NSW 2578
Music Therapy Program was a wonderful experience!

Fourteen people from the Hornsby Ku-ring-gai area were privileged to participate in a wonderful eight-week Music Therapy Program held in March and April in the McQuoin Park Community Hall, Waitara.

Co-ordinated by Grace Chiundiza, Music Therapist with Alzheimer’s Australia NSW, and organised by Mary Clifton, Dementia Advisor for Hornsby Ku-ring-gai, the two-hour sessions were attended by clients, staff and volunteers of Catholic Healthcare’s Chantal Dementia Day Cottage.

Singing ‘hello’
By the time of their second visit, it was lovely to see the smile on participants’ faces as they recognised the opening melody of the ‘Hello’ song Grace sang to the group every week, identifying each person by name and signalling the commencement of the session. A special farewell song at the conclusion of each session provided cues to the group that the session was coming to an end.

The program evolved over the course of the eight sessions, with Grace incorporating new songs, different percussion instruments and easy-to-follow seated movement each week, to meet the needs, preferences and musical tastes of individuals within the group.

Remembering old favourites
Most group members, aged in their 70s and 80s, knew many of the songs by heart and needed no prompting or song lyrics to help them join in – the playlist included wartime songs, romantic songs from the 30s, 40s and 50s, sorrowful Irish laments, and several Australian folk songs. The beautiful Amazing Grace was a particularly apt favourite for the group.

A couple of men in the group brought their own musical instruments, one a trombone, the other a harmonica, to demonstrate their perfectly retained musical skills, and provided flawless performances!

Some group members, who now find speaking quite difficult, were also observed singing some old familiar tunes without any trouble – truly remarkable.

Walking frames and sticks were set aside at the end of morning tea, as a space was cleared to dance in a circle to a range of songs – Wimaway, Kiss Me Goodnight Sergeant Major, Ain’t She Sweet and many others…

On completion of the Hornsby Ku-ring-gai program, a second six-week series was delivered in the Ryde Hunters Hill area, organised by local Dementia Advisor Roxanne Chant who reported that the reaction of her younger group to the program was just as positive, so we would both like to recommend this worthwhile program.

Mary Clifton
Dementia Advisor, Hornsby Ku-ring-gai

For more details about the Music Therapy Program, please call Alz NSW’s Diversional Therapist, Grace Chiundiza on 9888 4206 or email gchiundiza@alznsw.asn.au

Members of the Hornsby Ku-ring-gai Music Therapy Group enjoy one of the sessions.

[Images of participants enjoying the sessions]
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.

Alan Angus
John Lindsay Armitage O.A.M.
James 'Jim' Bell Armstrong
Rev (Canon) Ernest Bailey
Clarissa Baldwin
Keith Robert Barcham
Giuseppe Bardetta
Joseph Barilla
Herbert Becker
James Armstrong Jim Bell
Laura Eleanor (Betty) Brown
Olga Carmody
Lilian Cassar
Michellina Cecere
Ketty Christou
John Matthew Collins
Valerie Corbett
Reginald Frank Craft
Herbert Frederick Crampton
Patrick John Crimmin
Myrtle Elsie Davies (nee Diller)
Geoffrey John Dean
Mary Dempsey
Joyce Docherty (nee Forbes)
Brian Francis Dodd
Eileen Dodd
Mavis Lena Epple
Mary Elizabeth (Bette) Epps
Giovanni Fabbro
Gwendoline Fahey
Mary Margaret Faine
Diana Finlayson
Jan Furness
Motoko 'Peggy' Gleeson
Thomas Dixon Glenn
Mavis Gray
Keith Hazeltine Greenwood
Carmel Halpenny
Allan Charles Harford
Gordon Augustus 'Bud' Harley
Neville John Higgs
Ivy Huddy
Graham Hutchings
Albina Kersul
Ida Siebrigje Kramer
Rosy Lane
Neil Leonard Lawrence
William (Vasilis) Lazaris
Sarina Rita Leonardi
Mario Mower
Chrissafis Mandalidis
Kevin Robert Morgan
Lois Noreen Morris
Doreen Munro
Jean Alice Newlyn
John Oliver
Jenny O'Toole
Francesco Pace
Valma Passmore
Katerina Paternoster
Winifred (Pinky) Pink
Efisio Piras
Graham Porter
Katherine (Kitty) Potts
Frances Reid
Iris May Reynolds
Margit A Santo
Warwick Andrew Schurr
Rosa Sciaccicita
Henry (Harry) Sergent
Constance Grace Adelaide Shanley
Joan Sheldon
Dr Kurt Singer
Judith Slatyer
Ury Stafford
Eric Stephens
Norah Patricia Stewart
Gordon Stockley
Reginald (Reg) Stonestreet
Alfred Rylance (Alf) Styles
John Sunderland
Adriaan Terpstra
Violet Ivy Thomas
Leonardo Villa
Mrs D M Walker
Milton Walmsley
Tom Ward
Marianne Sophie Weil
Mavis Weir
Joan Whiteley
Angela Margaret (nee Bradley) Wild
Yvonne Wilks
Roy Wilson
Ian Withycombe
Olga Wroe
Ivan Zivkovic

www.alzheimers.org.au
What’s new on the bookshelf...

By Nicky Hayward-Wright

Following is a small selection of new resources for loan to members. A member service offered by the Library & Information Service is free postage of library books and DVDs; so you don’t need to come into the library, the library can come to you!

Coach Broyles’ Playbook for Alzheimer’s Caregivers: A Practical Tips Guide is based on Coach Broyle’s philosophy of doing things with his wife Barbara, rather than for her. Coach Broyle approached Alzheimer’s disease much like he approached an opponent on the field; he had a solid game plan and a dedicated team. This book also has an accompanying Pocket Reference of Tips and Strategies. Both titles are available online at www.alzheimersplaybook.com in a range of languages. An audio edition is available in English and Spanish.

Aniseed Balls, Billy Carts, and Clotheslines – An ABC of Growing Up in the Thirties book and 7-CD talking book set is the recollections of Roly Chapman about growing up in Auchenflower, Brisbane in the 1930s. His anecdotes cover topics from ‘dunny men’ and the Ekka, to cracker night, nicknames, and war. This useful reminiscing tool is recommended for family carers, diversional therapists and recreational officers.

Bathing Without a Battle: Person-Directed Care of Individuals with Dementia 2nd Edition is an update of its popular predecessor. It offers an individualised, problem-solving approach to bathing and personal care of a person with dementia. This book is recommended for carers in the home and in care facilities.

Sponsored books

If you would like to Sponsor A Book please contact the Library on (02) 9888 4218. We would like to thank Jilly Faddy OAM for sponsoring the following books:

The Long Good Night by Daphne Simpkins is an uplifting story of hope from a daughter’s perspective. Drawing on the experience of caring for her father, Daphne discusses the difficulties of parent care, reflects on the power of family, and provides humorous anecdotes of daily life at home as snapshots of ageing; all of which combine to provide a memoir about love rather than an elegy about a disease.

The Alzheimer’s Action Plan: The Experts’ Guide to the Best Diagnosis and Treatment for Memory Problems is a useful guide for people recently diagnosed with mild cognitive impairment or dementia, and their carers.

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; www.alz.seekbooks.com.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

Books for pleasure and learning…. visit the Alzheimer’s Australia Online Bookshop which offers over a million general titles and a wide range of dementia-related topics to purchase: www.alz.seekbooks.com.au

Crossword

Across
1. Infusing
6. Factual
10. Lordly
11. Atomised
12. Bridge fee booth
14. Say
16. Knot-shaped biscuit
18. Became less drunk, ... up
20. Infested
22. Of the sea
23. Eighth, ..., tenth
25. Zooming (past)
28. Careless
29. Swedish prize benefactor
31. Castrate (horse)
32. Unrelenting

Down
1. Taverns
2. Cry
3. Just right
4. O-O in tennis (4,3)
5. Nieces & ...
7. Adjust (clock)
8. Finished creation (3,7)
9. Debatable
13. Excessively fat
15. Assigning
17. Critical time (4,4)
19. Quarrel (3-2)
21. Not any place
22. Narcotics
24. Himalayan land
26. Areas
27. Congeal
30. Group, ... Gees