A little respect
Sir Michael Parkinson speaks out for dignity in dementia care

Space mission
New report finds 279,000 more care places needed

» Productivity commission briefing
» Clinical trials
» Support group leader forum
The Board has had a quiet quarter but the organisation has been humming along – a tribute to John Watkins and to an excellent senior management team.

It is good if things are quiet; policies are in place properly, investments are being watched closely, the achievement of our strategic plan is being followed and things generally are on track.

Productivity Commission

The biggest thing in the quarter was the release of the Draft Report of the Productivity Commission on Ageing in Australia (Caring for Older Australians).

It was generally welcome but we and the entire dementia community were disappointed that it did not specifically mention ‘our’ disease and did not deal with the coming tsunami of dementia in Australia.

Alzheimer’s Australia NSW (AlzNSW) has met with two Commissioners, Robert Fitzgerald and Sue Macri, to put forward our concerns, and subsequently invited both commissioners to come to an open forum hosted by AlzNSW.

The government has agreed that the final report will not come in until mid-year, which is too late for the Budget this year but in time for the next. Read more about the briefing on page 8.

Support groups

We are grateful for the support groups that exist in many parts of the state. They enable carers and patients to discuss and push for what is needed in their geographical area.

We have become aware that need for general dementia services is increasing most rapidly in the Tweed, on the Central Coast and in the Illawarra, and know that too many people are not getting service in western and south-western Sydney.

We intend to support the groups that do exist and push for new groups in other areas. We want a better availability of services, especially in areas where people are going to retire and where dementia is going to be increasing rapidly.

The Hon. Prof. Peter Baume AC
Chairman
We are very fortunate to have the support of Sir Michael Parkinson, who delighted a packed audience in February at a very successful fundraising lunch. In a heartfelt and thought-provoking speech, Sir Michael spoke about the importance of treating people with dementia with dignity, about his beloved mother, Freda, and her experience with dementia. We are lucky to have Sir Michael and our other Ambassadors who were also at the lunch to help us raise the very important issues of people with dementia in the wider community.

New government
We congratulate the O’Farrell Government on their success at the recent state election. In particular, we welcome Minister Jillian Skinner as the new Minister for Health and Minister Andrew Constance as the new Minister for Ageing. Both are long-term supporters of AlzNSW and we look forward to continuing a warm relationship with the new government.

Memory Walk
Thank you to everyone who participated in our recent Memory Walk, held in Sydney in May. It was by far our most successful yet, with record numbers of people walking and running and record funds raised. The new venue at Lilyfield proved to be a popular choice and the event proved how much support we have out there in the community as well as how much people are willing to help to support people with dementia and their families across NSW.

The Hon. John Watkins
Chief Executive Officer
Congratulations to the winners of the inaugural Bang the Drum competition.

Thank you to everyone who entered. The competition has proved such a success that we have decided to do it again, so help us bang the drum!

Email or post your entries:
E: amills@alznsw.asn.au
P: Andrew Mills, AlzNSW, PO Box 6042, North Ryde, NSW 2113

WINNERS

1ST: Al the Elephant’s visit to Afghanistan

2ND: Al visits Scott’s Hut on Ross Island, Antarctica

3RD: Al makes his way through the English countryside

A prize pack is on its way to the winner.
Documentary premiere

The Long Goodbye, a documentary featuring three families in different stages of dealing with diagnoses of dementia, recently premiered on ABC1.

The CEO of AlzNSW, The Hon. John Watkins, has congratulated and thanked those who took part in the documentary, The Long Goodbye, for their bravery, courage and generosity in sharing their stories.

The film, which was screened on ABC1 on 12 April, follows the lives of three families who are dealing with diagnoses of dementia.

“IT IS CONFRONTING AND HONEST, HEARTBREAKINGLY SAD, AND ALSO UPLIFTING AS IT REVEALS THE GREAT DEPTHS OF LOVE AND COURAGE THAT RESIDE IN ALL OF US,” MR WATKINS SAID.

“The documentary reveals many of the issues facing families confronted with a diagnosis of dementia: how it affects the individual diagnosed, the impact on families and relationships, the great sadness and loneliness it can cause, the most difficult decision to choose residential care, and the sheer exhaustion many carers experience. But it does so with great sympathy and affection for all involved.”

The Long Goodbye was launched by Mr Watkins at NSW Parliament House on Tuesday 5 April at an event attended by the families who took part in the film, director Kaye Harrison, producer Gina Twyble and the new NSW Minister for Mental Health and Healthy Lifestyles, The Hon. Kevin Humphries.

For more information about the film, visit The Long Goodbye website. W: www.thelonggoodbye.com.au

Save the date – Forget Me Not Again!

Forget Me Not (FMN) has announced its second annual cocktail fundraiser, FMNAgain, to be held on Saturday 24 September at The Pavilion, The Domain, Sydney.

Forget Me Not is the initiative of four young women who have seen dementia affect a loved one, and the disease has had a profound impact on their lives.

The FMN girls, Sophie Pieters-Hawke, Andrea Britz, Tess Paul and Annabelle Boyd Jones, are also the first Youth Ambassadors for Alzheimer’s Australia.

The first FMN cocktail night was held during Dementia Awareness Week in 2010, and raised more than $26,000 for the Hazel Hawke Alzheimer’s Research and Care Fund.

When the FMN girls do it all over again, they would love for you to join them and share the remembering!

For more information on tickets and donations, visit the FMN website. W: www.forget-me-not.com.au

NEW STAFF

Patrice Teakle has commenced at our North Ryde DMCC where she will provide administrative support to the Helpline and reception teams.

Samantha Joyce has commenced in the role of Dementia Support Worker in our Bega area supporting clients and carers on a casual basis.

Simon Crowson has taken up the new role of Corporate Relationship Manager to further develop our fundraising initiatives.

Ljubinka Brkic has been busy in her new role of Dementia Advisor within the Sutherland area.

Diana Waring has hit the ground running in the role of Volunteer Coordinator to establish our volunteer program.

Most recently, Kylie Sait has joined the Policy and Information team in the role of Research Project Officer and, last but definitely not least, Katy Fitzgerald has joined us part-time in a newly commenced Counselling service based in South-West Sydney.

VOLUNTEERS

Volunteering opportunities are available in our offices as well as at fundraising and other events across NSW. If you are interested in volunteering or would like more information, contact Diana Waring.

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

Keep Up!

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

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

John Watkins (second from left) and Diana Waring (far right) with Corporate Volunteers from Real Insurance.
AlzNSW has responded to increasing need on the mid-north coast, relocating to a larger office in Port Macquarie. The new, larger office was officially opened in March, enabling staff to better serve the increasing population with dementia in Port Macquarie and the Mid-North Coast.

“Port Macquarie state electorate is second only to Tweed in terms of the number of people with dementia in the area,” CEO of AlzNSW, The Hon. John Watkins says. “Currently, there are an estimated 1600 people with dementia in the Port Macquarie state electorate alone.

“Coffs Harbour is also in the top 10 of state electorates in terms of dementia prevalence, and is expected to stay there over the next 40 years, so it is more important than ever that we are prepared for this.”

Gary Thomas, AlzNSW’s Regional Coordinator for the Mid-North Coast, has encouraged anyone with memory loss concerns or concerns about dementia to drop in and talk to staff.

AlzNSW is grateful for the support of the State Government, which contributed to the cost of the new office.

To talk to a dementia advisor, access the library or talk to staff about concerns relating to memory loss, contact the Port Macquarie office, Monday-Friday 9am-5pm T: (02) 6584 7444

More information
Alzheimer’s Australia maintains a list of dementia projects and clinical trials in Australia. Projects range from short online surveys to brain scans and clinical trials of novel drugs.

This research may be instrumental in advancing dementia treatments and care, and improve outcomes for people with dementia in future generations. Before any project is listed by Alzheimer’s Australia, it is reviewed and must provide evidence of approval from an ethics committee.

For more information about current projects in Australia, visit Alzheimer’s Australia’s Projects and Clinical Trials website or subscribe to the clinical trials e-news.

W: www.alzheimers.org.au
E: trials@alzheimers.org.au

New Port Macquarie office

The recent launch of AlzNSW educator Elaine White’s book Dementia and Sexuality was a great success.

More than 50 local and interstate guests crowded into AlzNSW’s Hunter Dementia and Memory Resource Centre on Friday 25 March for the launch of Dementia and Sexuality: The Rose That Never Wilts, by AlzNSW educator Elaine White.

The book is a practical guide to dementia and sexuality, and Elaine hopes it will become an agent for change for readers.

Copies of Dementia and Sexuality sold out, and each guest received a beautiful bookmark on the day as a memento. The launch was a celebration of both a milestone in dementia care and a career full of achievements.

READ THE BOOK
Dementia and Sexuality can be borrowed from the AlzNSW member library and is also available for purchase.

Borrow
AlzNSW member library
E: lis@alznsw.asn.au
T: 02 9888 4218

Buy
W: www.careinfo.org
E: remi@hawkerpublications.com

National Dementia Research Forum

The fifth annual National Dementia Research Forum, hosted by the Dementia Collaborative Research Centres, is taking place in Sydney this September.

Keynote Speaker will be Dr Ronald C Peterson MD PhD, Director of the Mayo Alzheimer’s Disease Research Center, USA.

Closing Date for abstracts is June 30.

When: 22-23 September
Where: Wesley Conference Centre, Pitt Street, Sydney
W: www.dementia.unsw.edu.au
E: dementiacrc@unsw.edu.au

Developing new treatments

Research projects, clinical studies and clinical trials that provide hope of new treatments for Alzheimer’s disease and dementia depend on the involvement of people with dementia and their carers.

An early step in developing new treatments, clinical studies observe people in normal settings with less direct intervention than in clinical trials and may help identify new possibilities for clinical trials.

Clinical trials test interventions such as drugs or devices, as well as preventative methods and changes in diet or lifestyle. Drug testing is the focus of many clinical trials.

Currently in the USA, more than 90 drugs are in clinical trials for Alzheimer’s disease, and more are in the pipeline awaiting Food and Drug Administration (FDA) approval to enter human testing.

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Planning ahead

End-of-life planning is essential to ensure your wishes are carried out, writes Professor Colleen Cartwright in a new report commissioned by Alzheimer’s Australia.

Professor Colleen Cartwright, Director of the ASLaRC Aged Services Unit in the Health and Wellbeing Research Cluster at Southern Cross University, is the author of the new publication and seminar series on end-of-life planning for Alzheimer’s Australia.

Planning for the End of Life for People with Dementia: Part One was developed in consultation with members of the Alzheimer’s Australia National Consumer Advisory Committee (NCAC).

Talking points

The publication and seminar series discuss issues including palliative care, refusal of treatment, pain control, resuscitation, residential care, advance financial planning and enduring power of attorney.

They have been developed to advise people with dementia and their families and carers about the legal options available.

“Research has found that very few people want to leave such decisions to their family or doctor, with most preferring to make their own decisions,” Professor Cartwright said.

The Hon. John Watkins, CEO of AlzNSW adds: “It is hard to prepare for the future and even harder to know how to go about navigating legal, financial and care planning.”

Practical planning

Almost half of Australians have not taken any action to prepare for an event where they may lose the ability to make decisions.

NCAC member Liz Fenwick said the publication is an essential reference tool for people with dementia, as well as their families and carers.

“It was devastating to find how little I knew about the decisions that had to be taken when the time came to care for my husband,” Liz said.

“Most people expect people with dementia to be in aged care homes, but this is not always the case. Carers and families as well as the person with dementia need information in the early stages of the disease to prepare.”

Contact Alzheimer’s Australia for information on end-of-life planning.

W: www.alzheimers.org.au

T: 1800 100 500

Living with memory loss

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

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

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

Get involved

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

T: 1800 100 500

GET HAPPY!

More than 40 inspiring speakers and over 3000 delegates will explore human happiness at the 6th Annual Happiness and its Causes Conference in Brisbane from 16-17 June.

Nobel Peace Prize recipient His Holiness the Dalai Lama and leading humanitarian Matthieu Ricard will be in attendance.

Join the brightest minds in philosophy, psychology, science, religion and the arts to explore the age-old question: ‘how can we lead happier, more meaningful lives?’.

Alzheimer’s Australia members are eligible for a 10 per cent discount on conference registration. For the full conference program, details of the pre- and post-conference workshops or to reserve your place, contact conference organisers.

W: www.happinessanditscauses.com.au

T: (02) 8719 5118

PREMIER’S SENIORS WEEK CONCERTS

Christine Lovatt and AlzNSW staff and volunteers handed out puzzles and information during Seniors Week.

Over 30,000 seniors packed into the Sydney Entertainment Centre over two days for the Premier’s Seniors Week Gala Concerts.

Lovatt’s again provided thousands of puzzle books to give away at the AlzNSW stand with our information about the importance of brain health. The puzzles proved very popular and guaranteed a big crowd at our information booth.

Thanks Lovatts for your support.

FAREWELL

It is with sadness that we heard of the passing of Daphne Lamont, beloved wife of Jack Lamont, in March.

Jack has been a long-time supporter and volunteer for us here at AlzNSW and our thoughts go out to Jack and his family.
QUALITY ACCREDITATION

AlzNSW has received confirmation that our application for accreditation by the Quality Improvement Council has been accepted.

This follows three years of reviewing our systems and processes to ensure they comply with standards provided by the Quality Improvement Council, which focuses on activities of the community sector.

A team of independent auditors assessed our activities against the standards, finding that we met them all.

We were awarded with ‘Exceeded’ status for our work identifying need at all levels of the community. This accreditation reflects our good business practice and ensures our ongoing sustainability.

PRODUCTIVITY COMMISSIONERS’ BRIEFING

AlzNSW hosted a briefing of 150 aged care workers, members and the general public on the draft report Caring for Older Australians by Productivity Commissioner Robert Fitzgerald and Associate Commissioner Sue Macri in March.

Mr Fitzgerald and Ms Macri gave a briefing on key insights and findings from the report, and participants had the chance to ask the Commissioner and Associate Commissioner questions.

The draft report contains a number of proposed reforms to overhaul Australia’s aged care system.

The final report is due to be delivered to the Federal Government by mid-year.

Art exhibition

A unique exhibition featuring artworks from people with memory loss was held in Coffs Harbour in April.

An official opening ceremony for the Talking without Words exhibition was held in the North Coast Regional Botanical Gardens on Tuesday 5 April.

The artworks are a result of a joint project, managed by AlzNSW with the UnitingCare Ageing Social Support Monitoring Program and its Red Dove centre-based day care service.

The project was launched in July last year and runs weekly dementia-specific art groups in Coffs Harbour and Nambucca Heads.

AlzNSW Dementia Advisor Marg Coutts, who jointly runs the program, said visual art provides the means for people with dementia to express themselves without the need for words, logic or skill, and in a way that is completely individual.

“This is a space that people with dementia can access and in which they can find the kind of nourishment that promotes quality of life,” Ms Coutts said.

UnitingCare Ageing’s HACC Coordinator for the Mid-North Coast, Trudi McCaul, echoed these comments. “This is truly a place where clients can find connection where previously those connections may have been lost,” she said.

“Using their own choice of media they can express feelings they may have struggled to find the words for.”

The project was made possible through Home and Community Care, UnitingCare Ageing Red Dove Social Group and AlzNSW Dementia Advisory Service.

Thank you to John Myers, who donated $100 from sales of his new book WaKudo beyond Sudoku, to AlzNSW.

Thank you to John Myers, who donated $100 from sales of his new book WaKudo beyond Sudoku, to AlzNSW.
More care places needed: new report

Australia is facing a shortage of 279,000 aged care places by 2050, with dementia a key driver of demand.

Increasing rates of dementia will drive a 279,000-place shortfall in community and residential care by 2050, according to a new Access Economics report commissioned by Alzheimer’s Australia.

In NSW this will leave an estimated 95,200 older people without access to the aged care services they need.

The report, Caring Places Volume 2, uses projections based on current government policy to study how this shortage will impact on every federal electorate in Australia.

Reforming aged care

The report comes a month after the release of the Productivity Commission’s draft report on aged-care reform.

“The reform of aged care should recognise the extra demands that dementia care places on family carers, as well as the additional costs to service providers,” said AlzNSW CEO The Hon. John Watkins.

“A comprehensive plan is needed to address the dementia epidemic, which embraces aged care reform and ensures timely diagnoses.”

Aged care provider Bupa Care Services (BCS) is working in partnership with Alzheimer’s Australia to develop better treatment and management strategies for people with dementia.

“Although everyone desires to stay in their own home, our research reveals that caring for someone with dementia can be an overwhelming burden on the family,” BCS Managing Director Paul Gregersen said.

“We hope the government gives priority to funding dementia-specific aged care to meet the needs of our ageing population,” he said.

Creating places

Ita Buttrose AO OBE, President of Alzheimer’s Australia, said the number of Australians with dementia will grow to almost one million by mid-century.

“The Productivity Commission’s report made a great start in recommending entitlement to aged care, increased consumer choice and flexibility of services,” Ms Buttrose said.

“However, we were discouraged to see that not one of the 42 recommendations dealt specifically with dementia and we urge the Commission to make dementia care the highest priority as they finalise their deliberations.”

The report

Caring Places Volume 2 reports the numbers of additional aged care services that will be required across the states and territories, as well as Commonwealth electoral divisions and Aged Care Planning Regions.

The full report is available from the Alzheimer’s Australia website. W: www.alzheimers.org.au

CRUNCH THE NUMBERS

ACCORDING TO THE ACCESS ECONOMICS REPORT, NSW WILL FACE A SHORTAGE OF 95,200 AGED CARE PLACES IN 2050

SHORTAGES WILL BE FELT MOST IN MID AND FAR NORTH COASTAL REGIONS, WITH ELECTORATES IN THOSE REGIONS PROJECTED TO FACE 4 OF THE TOP 5 SHORTAGES:

PATERSON: 2943
LYNE: 2878
RICHMOND: 2777
COWPER: 2678

ROUNDING OUT THE TOP 10, GILMORE WILL FACE A SHORTAGE OF 2590, FOLLOWED BY PAGE: 2431
DOBELL: 2311
SHORTLAND: 2259
EDEN-MONARO: 2222
CHARLTON: 2208
Well-loved international media identity Sir Michael Parkinson CBE called for spending on dementia research to be dramatically increased and spoke about the importance of treating people with dementia with dignity in a heartfelt, powerful and thought-provoking speech at an Alzheimer’s Australia NSW event.

Sir Michael, who is an Honorary Ambassador for Alzheimer’s Australia NSW, was speaking at a sold-out fundraising lunch on 25 February at NSW Parliament House.

Sir Michael’s mother had dementia and he has been a passionate advocate for better care for people in hospital and in aged care facilities, most recently as the National Dignity Ambassador for the British Government’s Dignity in Care Campaign.

**Spending**

During the address, in which he spoke about his beloved mother Freda and her experience with dementia, Sir Michael also spoke about the need for more spending on dementia research.

“You could spend as much, of course, on dementia research as you do on cancer research. You could spend as much as you do on heart research,” he said.

“In England, I think there’s something like 50 million pounds spent on dementia research and 580 million on cancer research.

“I’m not denying cancer research is important but this seems to be disproportionate, given what we’ve been talking about today – a growing problem that we don’t actually seem to recognise in terms of research and finding a cure for this disease.

“It’s an indication that again we’re paying lip service to it but in the end nothing practical is done,” he said. “But the ultimate must be a cure. We know the only way around that is money.”

**Dignity in care**

Sir Michael also spoke of the need to treat older people with much more dignity and respect.

“We treat old people as unworthy of our time and consideration,” he said. “If we treated young people the way we treated old people, there’d be an outcry, a revolution, and quite rightly so. In Britain, a campaign called Dignity in Care was started that changed those kinds of attitudes towards that person in that bed, that person in that corner, that decrepit soul.

“I think that maybe when I was growing up society demanded you had a greater respect for older people than occurs today. So while we’re talking about changing culture within the care service, I think we also need to change the culture within our society.
“Can we really expect staff to don a different set of values when they put the uniform on? If the rest of us, the rest of society, don’t appear to value older people, why should they?

“When we consider how we can improve the way older people are treated in general, we should look not only at nurses and care workers, but I believe at ourselves. We should ask ourselves, why are we so terrified of growing old?

“Why do we neglect old people, shove them in the corner and expect them to die without making too much fuss about it? Why does the media, at worst, ignore old people, and, at best, patronise them? Why is media skewed towards the notion that the only people worth attracting, worth bothering with, are aged between 18 and 34?

“When we close our eyes to the older generation, consigning them to the footlocker of priority where they can curl up quietly and die, we overlook the relationship between young and old.

Positive ageing

“What I believe, and what I have come to understand through my work as Dignity Ambassador, is that the growing problem of dementia – the dementia catastrophe as it was being called in Britain earlier this week – cannot be seen in isolation from the greater overall problem of how, as a society, we treat old people. Our indifference to a valuable, wonderful asset is as wasteful as it is insulting.

“We need to celebrate the business of growing old instead of fearing it. The wisdom, the experience and maturity should be seen as a valuable asset, and not a sad decline. I mean we’re all going to get there, so let’s do everything we can to enjoy the journey.

“Let’s promote the thought: it’s better to travel in style, than in fear. Let us also find inspiration, as I did, and comfort in the words of Henry Wadsworth Longfellow who said: ‘Age is opportunity no less than youth itself, though in another dress. And as the evening twilight fades away the sky is filled with stars invisible by day’.”

The lunch was generously sponsored by Bupa Care Services Australia and generously supported by Guardian Funerals and NRMA Motoring & Services. This is an edited version of Sir Michael Parkinson’s speech.
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<th>LOCATION</th>
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<tr>
<td>Hunter</td>
<td>Understanding confusion in the older person</td>
<td>22 June</td>
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<td>Dementia Causes and Treatment</td>
<td>15 July</td>
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<td>Effective Communication</td>
<td>10 August</td>
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<td>Pharmaceutical and Non-Pharmaceutical Treatment options for people living with dementia</td>
<td>14 September</td>
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<td>Assisting with Activities of Daily Living</td>
<td>6 October</td>
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<td>North Ryde</td>
<td>Depression and Dementia</td>
<td>1 September</td>
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<td>Lightning Ridge</td>
<td>Insight into Dementia</td>
<td>9 June</td>
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<td>Broken Hill</td>
<td>Concluding the Dementia Journey: a palliative approach to end of life care</td>
<td>27 June</td>
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<td>North Coast</td>
<td>Understanding and Responding to behavioural symptoms</td>
<td>29 June</td>
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<td>25 May; 2 and 9 June</td>
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<td>3 Day Carer Course</td>
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<td>3 Day Carer Course</td>
<td>8, 15 and 22 September</td>
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<td>Sons and daughters - Understanding and Responding to behavioural symptoms</td>
<td>6 July</td>
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<td>Broken Hill</td>
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<td>Nelson Bay</td>
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<td>1 Day Carer Course</td>
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<td>Dementia and Depression - Port Macquarie</td>
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<td>Sons and Daughters - Yamba</td>
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<td>Friends and Neighbours - Coffs Harbour</td>
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<td>2 Day Carer Course - Port Macquarie</td>
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<td>Effective Communication</td>
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<td>Lightning Ridge</td>
<td>Volunteer Education</td>
<td>8 June</td>
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<td>Broken Hill</td>
<td>Insight into Dementia - volunteers and personal care workers</td>
<td>28 June</td>
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<td>North Coast</td>
<td>Volunteer Education - Coffs Harbour</td>
<td>26 July</td>
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<td>Volunteer Education - Ballina</td>
<td>7 September</td>
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<td>Volunteer Education - Forster</td>
<td>13 September</td>
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<td>Volunteer Education - Gloucester</td>
<td>24 November</td>
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<tr>
<th>LOCATION</th>
<th>WORKSHOP</th>
<th>DATE</th>
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<tbody>
<tr>
<td>Lightning Ridge</td>
<td>Mind your Mind</td>
<td>8 June</td>
</tr>
<tr>
<td>Broken Hill</td>
<td>Mind your Mind</td>
<td>28-June</td>
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</tbody>
</table>

For more information or to register for Support Group Leader workshops, contact Monica Cole  
T: 02 8875 4682

For more information or to register for Care worker workshops, contact Gail Longhurst: (02) 9805 0200 or education@alznsw.asn.au

For more information or to register for Family Carer Education workshops, contact Gail Longhurst: (02) 9805 0200 or education@alznsw.asn.au

For more information or to register for Volunteer Courses, contact Gail Longhurst: (02) 9805 0200 or education@alznsw.asn.au

For more information or to register for Community Awareness workshops, contact Gail Longhurst: (02) 9805 0200 or education@alznsw.asn.au

For more information or to register for Support Group Leader workshops, contact Monica Cole  
T: 02 8875 4682
10 ways AlzNSW can help you

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

How we help Les

Les Medo was diagnosed with Alzheimer’s disease in 2008. An accomplished cornet player, Les is now an active member of the Music for Recreation Group at AlzNSW’s Dementia and Memory Community Centre in North Ryde. “Playing is his whole life, really,” Les’s wife Gloria says. “It’s the only thing he has that he’s in charge of. It’s the one independent thing he has. He just loves playing and enjoys being able to play there.”

Get involved

The Music for Recreation Group meets weekly. No musical experience is required; the aim is to connect on a different level. If you would like to come along and explore your inner rhythm and have some fun, contact AlzNSW on the National Dementia Helpline. When: Mondays 2pm-4pm Where: Dementia and Memory Community Centre, North Ryde T: 1800 100 500 An interpreter service is available
Carer support groups
Support groups for carers of people with dementia are throughout NSW, but what do they do?

Carer support groups offer opportunities for carers of people living with dementia to come together to support each other.

Each group is led by a professional worker or a trained volunteer. Leaders are not current carers, but have knowledge of dementia and experience in dementia-related services.

Carer support groups meet regularly (usually once a month but can be weekly in some instances) for about two hours during the day or evening. Group members come from all walks of life. They are of all ages, cultures, genders and care situations.

Some groups are time-limited – they meet for a set number of sessions – while other groups are ongoing.

There are different kinds of carer support groups. Some are primarily social, while others offer emotional support or provide information and education. Other groups offer a mixture of these elements.

Purpose
In support groups, carers share and discuss their experiences, and assist each other, enhancing the wellbeing of the carer and the person with dementia.

Each support group provides a confidential and respectful forum for carers to share their stories.

Groups also offer practical and emotional assistance, stress relief, a sense of belonging, and opportunities for problem solving, as well as reducing feelings of isolation.

To find your nearest carer support group or to obtain support, information, education and counselling, contact AlzNSW through the National Dementia Helpline.
T: 1800 100 500

Carer feedback quotes courtesy of Quality Support Group Research Project Phase II (Brown, 2007).

(It helps) that others are in the same situation, and the ability to share and help each other, and also to be able to laugh at some aspects of the situation.

The group gave me an insight into how to preserve relationships and understand what was happening.

(The group has given me) experience in coping personally and coping with each stage of dementia, emotional support, and total honesty from others in the group at each stage (of) crisis.

Carer feedback quotes courtesy of Quality Support Group Research Project Phase II (Brown, 2007).
What happens when you take ten carer support group leaders, mix in two hours of education and a generous slice of supervision, add a splash of creativity and spread evenly over a whole day of networking?

The AlzNSW Group Leaders’ Forum is a one-day opportunity for carer support group leaders to reflect, learn and share in a relaxed and creative environment, so they can continue doing the wonderful jobs they do.

The first two Group Leaders’ Forums rolled out in Queanbeyan and Seven Hills have been a resounding success, with more to be delivered throughout NSW in 2011.

See the training calendar on page 12 to find upcoming Carer Support Group Leaders’ Forums and Group Leadership Workshops near you and register today.

Group Leaders’ Forum

Location of groups throughout NSW
- Carer Support Groups led by AlzNSW staff, volunteers and regional partners
- Social groups led by AlzNSW staff, volunteers and regional partners
- Carer support groups run by other leaders whose groups are registered on the AlzNSW database

The AlzNSW Memory Vans have been clocking up the kilometres travelling around NSW to raise awareness of dementia and risk reduction.

To find out where the Memory Van will be in coming months, contact AlzNSW.

To invite a Memory Van to a community event in the Hunter or Mid North Coast regions, contact Kim Wilson, or contact Susan Newton if your event is in other parts of NSW.

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

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

Resources

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Rest of NSW: Susan Newton
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Supporting our work

Events around the state raise funds for AlzNSW.

Memory Walk and Memory Jog
For this year’s annual fundraiser, a record number of people walked and ran the beautiful Bay Run at Leichhardt Park on Sunday 15 May. PJ Lane was the face and MC of this year’s event. It was a great day enjoyed by the almost 900 participants (double the number who attended last year) and raised much-needed funds for vital support services in NSW.

Thank you to all who attended, raised funds and supported our participants, and a big thank you to our fantastic volunteers, without whom this event would not be possible. There will be a full report of the event in the next edition of In touch.

We are still holding regional walks in the Illawarra, Broken Hill and Port Macquarie during Dementia Awareness Week, 16-26 September. W: www.memorywalk.com.au

Entertainment Books
2011 Entertainments Books are on sale now. Enjoy great savings on restaurants and more while supporting the work of AlzNSW. Order from the Alzheimer’s Australia website or contact Chris. W: www.alzheimers.org.au T: (02) 8875 4625

Gift cards
Our new gift cards are now on sale, with all proceeds going to AlzNSW. Four different designs have been chosen from Making Memories Patchwork Quilt competition, and a pack of 12 is just $9.95. Contact Chris to order. T: (02) 8875 4625

Climb Kilimanjaro!
We are pleased to welcome three new members of the AlzNSW Climb2Remember team: Mel Cox, Fiona Kendal and Matt O’Hara.

We are so lucky to have such a great team willing to give up time and a whole lot of energy to raise money and awareness for AlzNSW.

Spaces are filling up for our first charity challenge, Climb2Remember, a 13-day adventure heading to Mt Kilimanjaro in September 2011.

Challenge yourself and your friends to join us on the great heights of Mt Kilimanjaro. You will not only experience the adventure of a lifetime, you will also be helping AlzNSW by raising funds through sponsorship.

Visit our Facebook and Twitter pages for all the latest updates. To get involved in this once in a lifetime adventure or to sponsor a participant, visit the Climb2Remember website. W: www.inspiredadventures.com.au/climb2remember

Christmas cards
Christmas Cards are coming soon. They are made from certified sustainably managed forests and recycled content. Watch this space!

Community fundraising
Planning a fundraiser in your local community? We can guide and support you to organise morning teas, lunches, market stalls, kitchen teas and more. Contact Chris to find out more. T: (02) 8875 4625
Bequests
With our ageing population the number of people who will need the services of AlzNSW is increasing dramatically.

Making a provision in your will to AlzNSW will ensure that we will be able to offer the same level of support in the future as we do now.

How to make a bequest
Simply make a will or update your existing will (you should check to see if it is out of date) and include a bequest to AlzNSW.

A bequest could be a specified amount, a gift of a particular asset (such as shares or property) or a share of the residue of your estate.

You should always seek the services of a solicitor or trustee company to prepare your will to ensure that it is correctly drafted and is practical in meeting your wishes.

More information
To find out more about how you can help AlzNSW through your will, or how your gift may be recognised appropriately, please do not hesitate to contact AlzNSW.

T: (02) 9805 0100

Support opportunities
We have a number of opportunities for businesses to partner or assist us in our fundraising ventures. Our events include Dementia Awareness Week activities, the Memory Walk, seminars, corporate golf days and more.

We are also seeking donations of high-level auction items and raffle prizes for community-driven fundraising events.

To support the work of AlzNSW, please contact the fundraising team.

T: (02) 9805 0100

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

We also extend our gratitude to our regular pledge supporters who donate on a monthly or quarterly basis; knowing we have your support allows us to better plan our service delivery.

Win a car!
The Community Chest Raffle is running again and it is your chance to win a new Toyota Yaris.

Tickets are still $2, and booksellers will be in the running to win the best bookseller’s prize.

Last sale of tickets will be Wednesday 6 July, and the raffle will be drawn on 20 July.

For tickets or more information, contact Chris at AlzNSW.
T: (02) 8875 4625

Graeme Samuel lunch
We are looking forward to this month’s lunch with Graeme Samuel, Chair of the Australian Competition and Consumer Commission (ACCC).

With the recent announcement that Mr Samuel will be retiring from his position with the ACCC, this event is one not to be missed.

Where: NSW Parliament House, Sydney
When: 30 June, 12 - 2.30pm
Tickets: (02) 8875 4626

1ST STREET IS PROUD TO ANNOUNCE A NEWLY FORMED PARTNERSHIP WITH ALZHEIMER’S AUSTRALIA.

At 1st Street we place a high level of importance on supporting the community around us. Dementia has such a widespread effect and we feel that it is our duty to get behind an organisation that impacts the same community we deal with every day. In doing so we will donate a percentage of each loan we sign and fund a community support group for Alzheimer’s Australia NSW.

1st Street has satisfied and delighted clients with our results over the years and this success has led to numerous accolades. 1st Street was recently ranked 1st in the Australian Elite Business Writers Awards and recognised by the Commonwealth Bank for being one of the largest residential loan writers in Australia.
Policy and Research at AlzNSW is coordinated by Lisa Langley (Manager Policy and Information) and Jo-Ann Brown (Research Officer). As part of the Policy and Information Unit, Lisa and Jo-Ann research dementia-specific social policy issues, write submissions to government inquiries, write and disseminate discussion papers, organise public forums such as the Planning Ahead Forums, conduct dementia-specific program evaluations and provide advice to staff members about current trends and statistics regarding dementia.

Lisa and Jo-Ann both have tertiary qualifications in policy, advocacy and applied social research and, together, they are able to combine their skills to contribute to the integral work of the organisation as the peak body for those living with dementia.

Keeping policy appropriate
Much of the work Lisa and Jo-Ann undertake is based on the AlzNSW Consumer Engagement Strategy. This strategy underlies the eight regional consumer committees around NSW and ensures that policy and services for people with dementia and their carers are informed, appropriate and effective.

Lisa and Jo-Ann are proud to report that their paper promoting this best practice model for consumer-driven policy and service delivery has been accepted for presentation at the inaugural Consumers Reforming Health Conference, to be held in Melbourne in July.

“Our work is very important to the organisation,” Lisa explains. “Our link to the people we represent through the regional consumer committees lends strength and credibility to our policy development.

“Both Jo-Ann and I are passionate about ensuring the voices of people with dementia and their carers are reflected in AlzNSW policy and submissions to government.”

Rewarding social research
“I have been in this role for eight years now and I have seen social research grow to become an important part of the organisation across the board,” says Jo-Ann. “For instance, within the fundraising department, the importance of measuring social impact is increasing and the evidence that our unit can provide often makes all the difference to a tender.

“To be able to see the results of our research grow to become a successful AlzNSW service or policy change that may assist people with dementia and their carers is a wonderful reward.”
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.

Shirley Ethel Alderton  
Agatha Arena  
Robert Atkins  
Gladys Clara Baldwin  
Alison Balfour  
Violet Mavis Bartlett  
Eric Bedelis  
Guido Bortoli  
Noel William Bradshaw  
Alian Thomas Brooks  
Antonio Bruzzano  
Marjorie Cain  
Lorna White Carter (nee McKimm)  
Betty Chater  
Marie Clarke  
Mrs Cleef  
Mary Kathleen Compton  
Maureen Corrigan  
Kevin Joseph Cowls  
John Crabb  
Keith Austin Cross  
Hilda Olympia De Freitas  
Joyce Emily Dibb  
Lynne Joy Dunn  
Eileen Eleanor Emerton (nee North)  
Tom Fallance  
Patricia Fennel  
Alan Franks  
Norma Jean Gardner  
Dante Ghirardello  
Frank Edward Giddey  
Henry Gill  
Carole Mary Glover  
Gerda Frieda Goldhahn  
Pamela Elaine Goode  
Dr Charles Paul Grima  
Elsie Hafey (nee Maxwell)  
Jerry Hay  
Nouhad Isaac  
Eva Antoinette Jany  
Heather Jones  
William James Kelly  
Jim Kirby  
Angela Koutoulogenis  
Malcolm Eager (Dusty) Lambert  
Daphne Lamont  
Peter Copland Lloyd Jones  
Valda Grace Lloyd  
Richard Loughlin  
Colin Andrew Matheson  
Wendy Joan May  
Alma Elizabeth McCloy  
Donald Gordon McKenna  
Peter William McLaren  
Vince Meaney  
Betty Mills  
Harry Monk  
Frances Ann Musgrove  
Betty June Myers  
Teresa Natoli  
Margaret Nell Marge Naylor  
Eileen Barbra Nicholas  
Levena Muriel Palmer  
Vincenzo Parisi  
Margaret Peterson  
Matilde Pigliacampo  
Robert Ainslie Richardson  
Kathleen Philomena Rowlands  
Edith Mary Ryan  
Carmen Santiago  
Edwin Murray Saxby  
Dorothy Esther Seguna  
Fiore Simeone  
Roderick Newham Simpson  
Nancy Stewart  
Audrey Strambi  
Elizabeth Tonkin  
Pamela Watson  
Bruce Webb  
Lillian Elsie White  
Barry Willmott  
Betty Valda Wright  
Antun Zivkovic  

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

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

**Strengthen your mind program**
by Kristin Einberger and Janelle Sellick
Become an instant expert with research on brain health and memory. Learn about and practise mental activities with fun, interactive games, exercises and quizzes.

**Be with me today: a challenge to the Alzheimer’s outsider (DVD)**
by Richard Taylor PhD
Richard Taylor was diagnosed with dementia when he was 58 years old. In this documentary, Richard speaks for a person-centred approach to care.

**Coping with grief**
by Mal and Dianne McKissock
This little gem of a book helps readers through the grieving process. Easy to read and understand, it helps readers comprehend what they, their family or friends are going through.

**The little book of conflict transformation**
by John Paul Lederach
This clearly articulated book offers a hopeful and workable approach to conflict resolution.
The author discusses ways to end something destructive and replace it with something desired, and how to deal with both immediate crises and long-term situations.

**Is dementia a bigger word than cancer?**
by Ross Colquhoun
This book aims to prepare people for dementia. It clearly explains what patients might expect and what they can do.
Early diagnosis, it argues, provides many benefits.
It can allow patients a say in their care before memory loss progresses, and early interventions can delay onset or slow progress.

**Stressed carers study for dementia conditions**
- Are you a carer for a family member or relative who has a dementia-related condition?
- Are you aged 18–80 years, and currently feeling stressed or upset?

**If YES...** we are seeking volunteers to take part in a psychological study in the treatment of anxiety and depression in carers.
The program consists of eight individual therapy sessions held at Macquarie University. The therapy is free for eligible carers.

For further information, please contact: Dr Maria Kangas (Centre for Emotional Health) and her team on (02) 9850 4082/9850 8599, or email maria.kangas@mq.edu.au