IN APRIL
THE GOVERNMENT
ANNOUNCED
$3.7 BILLION
FUNDING TO REFORM
AGED CARE
WHAT DOES THIS MEAN FOR THE
280,000
AUSTRALIANS
WITH
DEMENTIA
AND THEIR
CARERS?
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It has been another good quarter for Alzheimer’s Australia and for us in NSW. Not only have we continued to deliver services to our many clients, we have also been active in our advocacy and political work. Both are essential if we are to prosper. On 20 April, the Federal Government announced major aged care reforms and its plan to tackle dementia. It seems clear that Prime Minister Julia Gillard and Minister for Mental Health and Ageing Mark Butler have listened to people with dementia and responded comprehensively.

Significantly, as part of ‘Living Longer, Living Better’ reforms, the government announced it would be seeking the agreement of Commonwealth, State and Territory Health Managers to add dementia to the existing list of National Health Priorities.

This is an outstanding result and affirms the value of our sustained political engagement strategy. We must now continue to keep up our momentum and fight for equitable funding for dementia research, which was not addressed.

Dr Richard Matthews AM has joined our Board. Dr Matthews was previously Deputy Director General of the NSW Department of Health and it was largely due to his efforts that we were able to move to the Gibson-Denney Centre. Our Board needs the balance Dr Matthews offers: a good appreciation of what dementia is and of the journey people make, along with suitable governance skills.

The Parliamentary Friends of Dementia meetings continue to prosper. People on both sides of State Parliament are champions for us and launch documents prepared by our excellent research staff.

This included the March launch of the discussion paper What Prevents People with Dementia Making Plans for their Future?. It urges consideration of competency and the realisation that people with dementia do not lose all capacity to plan for themselves when they are diagnosed.

Not only is this an important paper in itself, but it is in our new marketing colours and is most attractive. The high quality of this publication is a tribute to our staff and we are grateful to Carroll & O’Dea Lawyers who provided funding for AlzNSW to produce this important document.

The Memory Walk and Jog was on Sunday 6 May at the Bay Run in Lilyfield and was a great success. This is one of our major events for the year and we are thrilled by the support we received from the large number of people taking part, those who worked so hard to raise money, and our generous sponsors.

The Victor Fairfax Family Resource Centre has had necessary upgrades. The centre was built in 1994 and has done well until now. The refurbished centre was opened formally by The Hon. Andrew Constance MP on 21 March. He is the MP for Bega and is the Minister for Ageing and for Disability Services. That is, he is ‘our’ Minister. He did the job splendidly and spoke to many people at the event.

The Victor Fairfax Family Resource Centre has had necessary upgrades. The

CEO’S MESSAGE
RING THE CHANGES

I am pleased to be able to welcome you to another edition of In touch with the news that our campaign for better funding has been heard, following the Federal Government’s aged care reform announcement in April. It followed a big effort from staff, members and supporters around NSW and Australia, and we thank you all very much for lending your voice and support to our campaigns. It is only because so many of you were so willing to tell your stories that our campaigns were effective.

In short, the Federal Government has committed almost $270 million over the next five years to tackle dementia. Reforms include strengthening the community care system to help people with dementia stay at home longer, better support for timely diagnosis, improving the quality of dementia care, improving acute care services, support for people with younger onset dementia, and expanded support through the National Dementia Support Program, which will improve access to better services.

The reforms are a great start and show the government has listened to the issues, but we now need to keep up the momentum. We need to continue to advocate for better funding for medical research and to continue to make sure our voices are heard. Thank you once again for your support, and congratulations.

You can read more about the reforms and what you can continue to do to keep up the fight on page 10.

Thank you also to everyone who took part in the Memory Walk and Jog in Sydney on 6 May. It was our best yet with more than 1300 people taking part and $100,000 raised so far to help keep our Memory Van on the road.

It was a wonderful event and great to see so many people out supporting our cause. Thank you again! Thank you also to our generous corporate supporters – Bupa, KinCare and Guardian Funerals. There will be more Memory Walks in regional NSW in September. For more information about the walks in the Hunter, Illawarra, Port Macquarie and Tweed Heads, visit the Memory Walk website. You can read all about the Sydney event on page 15.

We also held a very successful Younger Onset Dementia (YOD) Forum in April to look at how services can be improved for people with YOD. This was held in partnership with the NSW State Government and we thank them for their ongoing support and recognition of such an important issue. You can find out more on page 8.

The Hon. Prof. Peter Baume AC, Chair, AlzNSW
The Hon. John Watkins, CEO, AlzNSW
**NO PLANNING FOR FUTURE CARE**

Less than one in five Australians has recorded their wishes for end-of-life care and only an estimated 55 per cent of people in NSW have a will, according to a report released by AlzNSW.

A staggering 49 per cent of Australians have not taken any action to prepare for the possibility they may lose the ability to make decisions.

The discussion paper, *What prevents people with dementia making plans for their future?* looks at why people with dementia avoid making arrangements for their future health and financial wishes.

The release of the report, at a NSW Parliamentary Friends of Dementia meeting at NSW Parliament House, comes as new figures show the extent of the looming dementia epidemic throughout NSW.

Estimates indicate that the number of people with dementia in NSW is set to soar from 95,000 in 2012 to more than 300,000 by 2050.

In light of this, explains CEO of AlzNSW The Hon. John Watkins, planning ahead and setting out our wishes about our health care and financial affairs is more important than ever.

“This is not a topic that we, as a population, generally like to talk about,” Mr Watkins says.

“And we know from our members that many don’t talk about it until it is too late. “But it is vital that we start to consider these issues so that, even if for no other reason, you can ensure that your loved ones know how you would like to be cared for should you find yourself in a position where you can no longer make decisions for yourself.

“However, not doing it can add stress and trauma at an already difficult time.”

Research conducted with AlzNSW consumer groups found that people did not make future plans because they:

- Did not understand the value of, or were unwilling to seek out information about, planning ahead.
- Did not know where to access relevant information.
- Had difficulty understanding the terms used in documentation.
- Did not receive support from GPs and other health professionals.

“These are consistent with what we hear from our clients and members in our day-to-day work,” Mr Watkins said.

The discussion paper sets out a series of proposals to address these issues, including recommendations for the Federal Government (see below).

The discussion paper also recommends that the NSW State Government clarifies confusion about the legally binding nature of Advance Care Directives and supports ongoing maintenance and upgrades to the ‘Planning Ahead Tools’ website.

Copies of the report and the related statistics can be found on the Alzheimer’s Australia website.


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**DRIVING ADVICE**

Life After Licences, which raises awareness about the need to plan ahead for retirement from driving and helps older people transition to non-drivers, visited Coffs Harbour on 22 March.

As part of Seniors Week, the Life After Licences stall was set up in the Palm Centre and provided information about transport options for those who no longer drive, as well as strategies and emotional support for managing the transition to non-driver.

Life After Licences is a group of representatives from AlzNSW, the Aged Care Assessment Team, Community Care Options and Community Transport, and provides services in the Coffs Harbour, Nambucca Heads and Bellingen areas.

**DEMENTIA DEATHS ON THE RISE**

Dementia and Alzheimer’s disease remain the third leading cause of death of Australians, behind heart disease and cerebrovascular diseases, according to new data released by the Australian Bureau of Statistics.

The data, contained in the report ‘Causes of Death, Australia, 2010’ has revealed that the number of people who have died from dementia and Alzheimer’s disease has increased from 3740 people in 2001 to 9003 people in 2010.

CEO of AlzNSW The Hon. John Watkins says this statistic can’t be ignored.

“We must act now before it is too late,” Mr Watkins said.

The report has found that dementia kills more people in Australia than lung cancer, diabetes and breast cancer. Alzheimer’s disease is the most common form of dementia.
Refurbishments and extensions to the Vincent Fairfax Family Resource Centre in North Ryde were officially opened recently by NSW Minister for Ageing The Hon. Andrew Constance.

The CEO of AlzNSW The Hon. John Watkins said the centre refurbishments are important for the delivery of vital support services for people living with dementia and their families. The refurbishments will help the organisation continue to deliver high-quality services to people in need.

“We operate counselling services, the National Dementia Helpline, diversional therapy, a dementia-specific library, support groups and early intervention groups from this centre,” Mr Watkins said.

“All of these are extremely important in helping people with dementia, their families and carers.

“On behalf of our clients and members, I would like to thank the State Government for supporting these refurbishments.”

The number of people with dementia in NSW is set to soar from an estimated 95,000 people to approximately 300,000 in the next 40 years.

Filming of a new DVD to raise dementia awareness started recently in Coffs Harbour. It will include three short scenarios outlining risk reduction and what to do if people are worried about their own or someone else’s memory. Special target groups are younger people and the local Aboriginal community.

The DVD will be in a loop mode so that it can be played in GP surgeries, Centrelink offices and pharmacies. Local people are volunteering their time to act in the DVD and the filming is being carried out by Steve MacDonald of Life and Times. The DVD will be available on the Alzheimer’s Australia website.

W: www.alzheimers.org.au

Coffs Harbour locals are volunteering their time to act in the DVD.
OBITUARY

JOHN CRAIG OAM

We note with sadness the passing of John Craig OAM. John was an active supporter of AlzNSW since his presidency with Sydney Rotary helped raise $210,000 towards building a Family Resource Centre in North Ryde. In 1993 John became a member of the Board of Directors and remained an active member until 2004, holding the positions of President and Vice President. He also chaired many committees.

John also negotiated funds for an innovative project to support people in the early stages of dementia, which has become the national Living with Memory Loss Program, funded by the Federal Government.

AlzNSW CEO The Hon. John Watkins said John was a wonderful man who had been a great supporter of Alzheimer’s Australia for many years.

"I first met John 15 years ago when I was the local MP, and was immediately struck by his compassion, decency and passionate support for people living with dementia and their carers," John said.

"That never wavered. His recent work with the AD-HOC group showed how caring and practical he was.

"That wonderful group, with its marvellous volunteers, provides a unique caring opportunity.

"He will be sadly missed."

NEW FILMS ON YOUTUBE

Two short films encouraging acceptance of dementia as a medical condition in Culturally and Linguistically Diverse (CaLD) communities are now on YouTube, and another is in production. Personal accounts of carers' experiences in their own languages, along with opinions of community leaders and health professionals, address myths about dementia and the importance of seeking local support.

"When I was little I used to call my Grandpa a lion," Anthony Yanghoubpour says in the film for Assyrian communities. "I still do."

Speaking about the project, Anthony says: "It’s been a privilege to have had the opportunity to honour my grandfather and encourage other young people not to be ashamed if this disease affects their family."

Carer Sarah Odisho hopes that more people will be able to recognise the signs of dementia and get their loved ones the help they need as soon as possible.

"If the community can watch this DVD and understand that dementia is an illness like any other, then some good will come out of what has happened to my mum," she says.

The language-specific short films for Croatian and Assyrian communities are approximately 15 minutes in length with English subtitles, and have already attracted domestic and international audiences. The Cambodian version is being developed and will be available soon.

The films were produced in partnership with Why Documentaries and the Multicultural Communities Council of the Illawarra, with thanks to the Commonwealth Department of Health and Ageing, and the NSW Department of Family and Community Services. Watch online or contact AlzNSW Library and Information Services for a copy.

W: www.youtube.com/user/AlzheimersAustralia E: nsw.library@alzheimers.org.au

FOCUS GROUPS

AlzNSW has held focus groups throughout the state to research transitions into residential aged care for people with dementia, particularly people’s expectations and experiences.

“We regularly hear from our members that moving into residential aged care is their most stressful and upsetting time,” says Brendan Moore, General Manager of Policy, Research and Information with AlzNSW.

The focus groups are part of a wider research project that will help AlzNSW advocate for better services, improve the practices of aged care workers and provide recommendations to the government about improving the experiences of people in the transition period. Focus group meetings have been held in Dubbo, Tweed Heads, Newcastle and Bankstown.

VOLUNTEERS AWARDED

AlzNSW congratulates 2012 Seniors Week Achievement Awards recipients Janet Godsell and Lois Allanson.

“This is a wonderful recognition of the dedication, compassion and care both women have shown for people with dementia, their families and carers, and we are proud to count them among our team,” AlzNSW CEO The Hon. John Watkins said.

Diversional therapist Janet Godsell has worked with people with dementia for more than 20 years and leads one of the longest running carer support groups for AlzNSW.

Singer and pianist Lois Allanson is a dedicated volunteer. She runs the Percy Street Singers group at AlzNSW’s Hunter Dementia and Memory Resource Centre in Hamilton.

Fifty-nine recipients in six categories were announced in March.
IN TOUCH WINTER 2012

ECOnOmiC and fisCal disastEr

For the first time, the World Health Organisation (WHO) and Alzheimer’s Disease International (ADI) have urged governments worldwide to make dementia a national public and social care priority.

The report ‘Dementia: A public health priority’ finds that the predicted increase of dementia from 35 million cases in 2010 to more than 115 million by 2050 will have huge economic and social costs on health systems around the world.

In Australia, the number of people with dementia is set to soar from an estimated 280,000 people to almost 1 million by 2050.

“Around the world a new case of dementia arises every four seconds. That’s a staggering growth rate, equivalent to 7.7 million new cases of dementia every year – the same size as the populations of Switzerland and Israel,” said Marc Wortmann, the Executive Director of ADI.

“The inappropriate use of antipsychotics to manage BPSD is widespread and should be a major concern for health services and policy makers,” Prof. Banerjee said.

“In 2011, the National Prescribing Service in Australia issued an official warning about the serious and potentially life threatening side effects of the medications.

“Yet they continue to be used as the first response to behavioural symptoms in many cases.”

Memory Vans

The AlzNSW Memory Vans have been on the road visiting Moss Vale, Great Lakes, Newington, Ingleburn, Campbelltown, Dubbo, Penrith, St Marys and Marrickville.

In each location, they reminded the public of the importance of ‘minding your mind’ and seeking medical help for memory loss – both keys to early diagnosis and better support.

ECONOMIC AND FISCAL DISASTER

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“Our current health systems simply cannot cope with the explosion of the dementia crisis as we all live longer.”

The report identifies priority areas of action that need to be addressed within policy and planning, including raising awareness, timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training, prevention and research.

Follow That Van!

To find out where the Memory Vans will be in upcoming months, visit the Fight Dementia website.
W: www.fightdementia.org.au

Invite a Memory Van to your community event by contacting Kim Wilson or Susan Newton:
Hunter and Mid North Coast: Contact: Kim Wilson
T: (02) 4962 7000
E: kim.wilson@alzheimers.org.au

Rest of NSW:
Contact Susan Newton
T: (02) 8875 4637
E: susan.newton@alzheimers.org.au

Obituary

Susan Sackville

AlzNSW CFO Sue Sackville passed away in April. Sue joined us in December 2005 and quickly became a key member of the team.

CEO The Hon. John Watkins says Sue was a great woman who valued relationships with staff and loved working at AlzNSW.

“She was a highly respected member of the Senior Management Team and a highly capable CFO,” John said.

“But there was so much more to her duties.”

Sue project-managed a number of significant and difficult proposals, including the purchase and development of the Hunter Dementia Memory and Community Centre, and the refurbishment and relocation into the Gibson-Denney Building.

“Her responsibilities were carried out with consummate skill, sensitivity to the needs of staff and deep commitment to people living with dementia,” John said.

“Sue also had a strong relationship with our Board. She was a wonderful colleague, and we knew that her husband, Ken, and their children, William, Sarah and Leah, were never far from her attention.

“Alzheimer’s Australia is a stronger, better and more caring organisation because of Sue. Her skills and hard work have brought benefit to thousands of people living with dementia and to their families and carers.”
A Younger Onset Dementia (YOD) forum was held on 18 April at the Mercure Hotel in Sydney and attracted so much interest that it was filled to capacity. A total of 140 people attended the forum, which was targeted at service providers working in the community with an interest in YOD. Of those who attended, 22 people were either living with YOD or caring for someone with the condition, and they were invited to actively participate in the forum and share their experiences.

The forum was officially opened by The Hon. Andrew Constance MP, Minister for Ageing and Disability Services, who has since announced a $1 million three-year pilot, to be delivered by Alzheimer’s Australia, that will provide 40 flexible, person-centred packages for people with YOD.

YOD refers to the occurrence of dementia in adults under the age of 65, and currently affects an estimated 16,000 people across Australia. AlzNSW Manager of Services Robyn Faine said people with YOD were often left behind because they are a small, but unique, group with a different set of needs.

“Existing support services are lacking when it comes to YOD, as these services are designed to accommodate older people and simply do not meet the specific requirements of those with YOD,” Robyn said.

“People under the age of 65 are often in part-time or full-time employment, and have dependent children. This means a diagnosis of YOD can have serious implications for the financial stability of a family, which is further exacerbated if the spouse of a person with YOD also gives up their employment to become a full-time carer. Furthermore, people who are diagnosed with YOD are more physically active than those over the age of 65, and research has shown that some forms of YOD, such as fronto-temporal dementia usually involve behaviours of concern which are heightened when the person is physically active.”

Having recognised that people living with YOD have this unique set of circumstances, which service providers must meet, AlzNSW has been working closely with the NSW Department of Ageing, Disability and Home Care on a research project to inform government policy regarding YOD services. The results of the research, being done in collaboration with UnitingCare Ageing and the Social Policy Research Centre at the University of NSW, will be delivered to the NSW State Government shortly.

The report, Service and Support for People with Younger Onset Dementia and their Families, is a result of extensive face-to-face interviews and online surveys conducted in both metropolitan and regional NSW. The data collected includes the perspectives of Culturally and Linguistic Diverse (CaLD) groups, Indigenous Australians and people with other diagnoses as well as dementia. AlzNSW hopes the results of the research will inform decisions regarding effective service delivery.

AlzNSW is encouraging policies directed at age-specific services, age-appropriate care options, age-appropriate community support, respite and long-term accommodation options, carer support and education programs, as well as
advocating personalised support packages to improve the quality of life of people with YOD.

Additionally, AlzNSW is considering ways to better tailor its own information, support and education services towards YOD. Already, AlzNSW has set up YOD specific community programs, support groups for the children of those affected by the condition, and a library blog where people can access information on YOD. The Living with Memory Loss program has also been customised for people living with YOD.

On top of this, AlzNSW believes there needs to be more education within the medical professions regarding YOD, as many people with YOD receive a delayed diagnosis due to symptoms being attributed to other conditions such as anxiety, stress, depression or, in women, menopause.

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**YOD EVENTS**

**ST GEORGE AND SUTHERLAND**

YOD Focus Groups have been held across the St George Sutherland region. A Younger Onset Dementia Working Group, an initiative that arose from the YOD Planning Meeting of Service Providers held in January 2012, will be chaired by the St George Sutherland Dementia Advisory Service. The St George Sutherland Region also hosted a Younger Onset Dementia Planning Ahead Forum on 22 May, which was identified as one of the priority needs by the local focus groups.

**COFFS HARBOUR PROJECTS**

A range of YOD projects is underway in the mid-north coast and Coffs Harbour region. Earlier this year, AlzNSW commenced a range of activities and outings for both people with YOD and their carers including cultural events, social outings, carers’ groups, shared meals and physical activities.

**YOUNGER ONSET DEMENTIA AND ME**

Does your mum or dad have younger onset dementia? Would you like to talk to other young people in similar situations?

The AlzNSW blog Younger Onset Dementia and ME is a place for young people to connect with others and to access helpful information. Visit the website to subscribe.

**PORT MACQUARIE MEETING**

The Port Macquarie Dementia and Memory Community Centre held its first meeting for people with younger onset dementia and their carers in the Port Macquarie and Kempsey shires on 4 April, with almost 30 couples attending. Pending a successful funding grant, the centre is also hoping to host a YOD Camp Retreat in the area.
Alzheimer’s Australia welcomes the Federal Government’s aged care reforms and its plan to tackle dementia. Ita Buttrose, President of Alzheimer’s Australia, said the government’s package showed that the Prime Minister and the Minister for Mental Health and Ageing Mark Butler, have not only listened to people with dementia, they have responded comprehensively to their priorities.

“Thousands have spoken out about the failings of the health and care system in relation to dementia; the government’s decisions are both a reward and a relief to those 280,000 Australians with dementia and their 1.2 million carers,” Ms Buttrose said.

“The centrepiece of the reforms from a consumer point of view is the strengthening of the community care system to make it possible for people with dementia to stay at home longer. This is central to any strategy for consumer choice, as is the emphasis in the reforms to empower consumers to have more say over the services they need, when they need them and who delivers them.”

The government’s proposals for tackling dementia address the key priorities in the Fight Dementia campaign, particularly: timely diagnosis, improving the quality of dementia care, improving acute care services, support for people with younger onset dementia, and expanded support through the National Dementia Support Program to improve access to better coordinated services.

“There remains a concern about increasing the level of investment in dementia research but this is an issue that Alzheimer’s Australia will be pursuing vigorously through the Minister’s review of scientific and medical funding in Australia,” Ms Buttrose said.

“It’s great to see a genuine focus on dementia in the aged care reforms. Dementia is getting the attention it deserves.” Ms Buttrose thanked Minister Butler for taking the dementia issue to Cabinet and getting a good result in a difficult budget.

The CEO of AlzNSW The Hon. John Watkins said he wanted to thank all those members who showed their support and helped in the campaign. “We could not have done this without you,” Mr Watkins said.

“Thank you to everyone who signed up as a Dementia Champion, who shared your stories, who wrote to your local MP or Senator, who marched on Parliament House in Canberra in October last year and who signed our Valentine’s Day cards.

“This has been a giant team effort and having so many people uniting to demand better services →

On 20 April the Gillard Government announced a $3.7 billion overhaul to the Aged Care System, specifically devoting money to dementia care and services.
CRUNCH THE NUMBERS

$1.9 BILLION
TO DELIVER BETTER ACCESS TO AGED CARE SERVICES

$1.2 BILLION
TO TACKLE CRITICAL SHORTAGES IN THE AGED CARE WORKFORCE

$80.2 MILLION
TO IMPROVE AGED CARE LINKAGES WITH THE HEALTH SYSTEM

$54.8 MILLION
TO SUPPORT CARERS

$268.4 MILLION
TO TACKLE THE NATION’S DEMENTIA EPIDEMIC

$192 MILLION
TO SUPPORT THE DIVERSE CARE OF AUSTRALIA’S AGEING POPULATION
and care for people with dementia made all the difference.

“Thank you again to you all.

“There is still, however, much to be done and we must continue to speak up for people with dementia, their families and carers and make sure our voices are heard.”

Research in dementia is important to reduce the future numbers of people suffering from dementia. Alzheimer’s Australia is still concerned about the very low investment in dementia research. This issue will be pursued through the Minister’s review of scientific and medical funding in Australia.

The reforms will be reviewed at the end of five years and the government has taken the view that the full impact of the reforms will take 10 years to work their way through the system.

The reforms are not just a question of funding; they are also about changing the way services are delivered.

WHAT DO THE REFORMS MEAN?

PEOPLE WITH DEMENTIA CAN STAY AT HOME LONGER

Strengthening the community care system is central to any strategy for consumer choice and avoids premature entry into residential care.

ADOPTING CONSUMER-DIRECTED CARE IN ALL CARE PACKAGES

This enables consumers to have more say about the services they need, when they need them and who delivers them.

EMBRACING THE PRINCIPLE OF SUPPLEMENTARY FUNDING

This will assist in meeting the extra costs of dementia care in both residential and community settings.

GREATER TRANSPARENCY IN THE QUALITY OF AGED CARE

Consumers are reassured through the independent Aged Care Financing Authority, the new Australian Aged Care Quality Agency, My Aged Care website and greater independence of the Aged Care Complaints Scheme.

PLAN TO TACKLE DEMENTIA

The government’s proposals for tackling dementia address the key priorities in Alzheimer’s Australia’s Fight Dementia campaign, particularly in respect of timely diagnosis, improved acute care services, improved support for younger people with dementia and an expansion of Dementia Behaviour Advisory Services.

THE CENTREPIECE OF THE REFORMS FROM A CONSUMER POINT OF VIEW IS THE STRENGTHENING OF THE COMMUNITY CARE SYSTEM TO MAKE IT POSSIBLE FOR PEOPLE WITH DEMENTIA TO STAY AT HOME LONGER.

STAY IN TOUCH

Keep up with Alzheimer’s Australia’s efforts by signing up as a dementia champion at the Fight Dementia campaign website, or join the conversation on Facebook and Twitter.

W: www.campaign.fightdementia.org.au
Facebook: www.facebook.com/fightdementia
Twitter: twitter.com/alzheimersaus
YOGA REDUCES STRESS

A US study of the impact of daily yogic meditation on the stress levels of family carers of people with dementia who experience depressive symptoms has found that the activity could significantly lower depressive symptoms and improve mental health and cognitive function.

For 12 minutes each day for eight weeks, half of the carers practised Kirtan Kriya meditation and the other half listened to relaxation music. Just over 65 per cent of the meditation group showed a 50 per cent improvement on the Hamilton Depression Rating Scale, compared to just over 31 per cent of the relaxation music group. This research involved a group of 39 carers, and the results are yet to be confirmed on a larger scale.


EYE TEST FOR ALZHEIMER’S

Researchers have developed a simple eye test that may be able to detect changes in the brain related to degenerative neurological diseases including Alzheimer’s. The test enables observance of the death of a single nerve cell in a living eye over hours, days, weeks and months. This direct observation of retinal nerve cell death is useful to help refine diagnoses and track disease progression.

Source: Cell Death and Disease (2010) 1, e3; doi:10.1038/cddis.2009.3

PARTICIPANTS WANTED: HEALTHY VOLUNTEERS

The Neuroscience Research Unit at the University of Technology, Sydney, needs healthy males aged 36-65 for a study that will assess the association between cardiovascular and brain cognitive functions to identify predictive markers of mild cognitive impairment. All procedures are non-invasive and will take approximately one hour. Contact Louisa Giblin for more information.

E: Louisa.Giblin@uts.edu.au
T: 0449 175 613

PARTICIPANTS WANTED: CARERS

Griffith University-based research into the health and wellbeing of carers of people with dementia will help increase community awareness of the experiences of carers and be used to support carers.

If you are a current or former carer of a family member, spouse or friend with dementia, visit the website or contact Dr Siobhan O’Dwyer to complete an anonymous survey or find out more.

W: prodsurvey.rcs.griffith.edu.au/dementiacaresurvey
E: s.odwyer@griffith.edu.au
T: (07) 3735 6619

DISCUSS THE SCIENCE

PHARMACOLOGICAL TREATMENT OPTIONS

Pharmacological treatments for memory loss approved by the Australian Government Pharmaceuticals Benefits Scheme fall into two main categories: cholinergic and memantine.

Cholinergic treatments offer some relief from the symptoms of Alzheimer’s disease for some people for a limited time. They include acetylcholinesterase inhibitors. These block enzymes that break down excess acetylcholine, a neurotransmitter involved in memory. Cholinergic treatments are approved for use by people with mild to moderate Alzheimer’s disease.

Memantine is the first in a new class of drugs that targets a neurotransmitter called glutamate, which is involved in learning and memory. Glutamate can be present in high levels when someone has Alzheimer’s disease. Memantine blocks glutamate and prevents too much calcium moving into the brain cells and causing damage.

Memantine is currently approved for use for people with high levels when someone has Alzheimer’s disease. There are currently no medications available that slow the progression of dementia. Cholinesterase inhibitors or memantine may help to alleviate some symptoms but they do not alter the course of the disease.
IN MEMORIAM DONATION
By making a donation in memory of a loved one you ensure his or her memory lives on by helping others. You can also celebrate the life of a loved one by asking for a donation to AlzNSW in lieu of flowers.

In memoriam envelopes can be made available at a funeral, church, wake or service where friends and family can make a donation to AlzNSW. A receipt will be sent to the donor and, with their permission, a letter will be sent to the family to advise them of the kind gift. The amount of the gift will remain confidential and gifts $2 and over are tax deductible.

E: nsw.fundraising@alzheimers.org.au
T: (02) 8875 4673

IN LIEU OF GIFTS
Planning a celebration? Instead of gifts, encourage your guests to make a donation to AlzNSW. Donations in lieu of gifts are a memorable way to celebrate a special occasion and will make a practical difference to people and families living with dementia. We recognise gifts with a receipt, acknowledgment and thanks.

E: nsw.events@alzheimers.org.au
T: (02) 8875 4626

SEND US YOUR STORY
Some members help our fundraising and awareness-raising efforts by sharing their stories of dementia, whether funny, tragic, empowering, uplifting, inspirational or sad.

If you would like to help our fundraising and awareness-raising efforts by telling your story, please contact Karen.

T: (02) 9805 0100

STAY IN TOUCH
If you are not already on our email database and would like updates about all the news on our upcoming events, please contact Emma.

E: nsw.events@alzheimers.org.au
T: (02) 8875 4626

BEQUESTS
As our population ages we need to extend our services to meet growing demand. Leaving AlzNSW a gift in your will can give us the long-term financial confidence to maintain and extend our vital support services, continue to educate carers and health professionals, and invest in research to stop this deadly disease.

A bequest could be a specified amount, a gift of a particular asset such as shares or property, or a share 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 practical. To find out more about how you can help AlzNSW by leaving a gift in your will, contact us.

T: (02) 9805 0100

COMMUNITY FUNDRAISING
Thank you to the supporters of our community fundraisers this year, who have helped raise funds and awareness.

• The Ray Webb Art Tour – Ray Webb
• Channel Ten Million Kilo Challenge
• Sydney Morning Herald Half Marathon
• Ken Lewis’s 60th birthday party
• Grand Order of the Night Owls’ Charity Boat Cruise – Amanda Whitfield
• Ongoing stall at Lawson – Jean Priest and friends
• Trivia nights, Kangaroo Valley – Ken Novich
• Macquarie Bank trivia night

If you are planning a fundraiser, contact our Community Events Team.

E: nsw.events@alzheimers.org.au
T: (02) 8875 04626

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MEMORY WALK AND JOG

A RECORD NUMBER OF PEOPLE TOOK PART IN THE 2012 MEMORY WALK AND JOG AT THE BAY RUN IN LILYFIELD ON SUNDAY 6 MAY.

With 1304 registered runners and walkers raising money to help people with dementia and another 100 or so volunteering, the annual Memory Walk and Jog in Sydney was a great success.

“It was a wonderful event and great that so many people got out to support people in need across NSW,” said CEO of AlzNSW The Hon. John Watkins. “Our fantastic supporters have already raised more than $100,000 to help people with dementia, their families and friends across NSW.”

All funds raised from this year’s Memory Walk and Jog will go towards keeping AlzNSW’s vital Memory Vans on the road.

Mr Watkins thanked the many supporters who had helped make the day possible, including the entrants, the volunteers and sponsors.

“I would like to particularly thank our primary supporter, Bupa, and the city supporters KinCare and Guardian Funerals,” he said. “We would not be able to put on an event like this and raise much-needed funds for people with dementia without such generous support.”

All 2012 Memory Walk and Jog events are proudly supported by Bupa.

Runners, joggers and walkers, including Superwoman and Al the AlzNSW elephant, did a lap of the beautiful Bay Run, raising funds to keep the AlzNSW Memory Vans on the road.

OUR FANTASTIC SUPPORTERS HAVE ALREADY RAISED MORE THAN $100,000 TO HELP PEOPLE WITH DEMENTIA, THEIR FAMILIES AND FRIENDS ACROSS NSW

REGIONAL WALKS

Hunter
Sunday 9 September,
Speers Point Park,
Lake Macquarie

Illawarra
Saturday 15 September,
Stuart Park, North Wollongong

Port Macquarie
TBA September,
Westport Park, Port Macquarie

Tweed Heads
TBA September,
Chris Cunningham Park,
Tweed Heads

W: www.memorywalk.com.au
THE ALZNSW EDUCATION PROGRAM OFFERS COURSES FOR CARE WORKERS, FAMILY CARERS AND VOLUNTEERS.

**FAMILY CARER EDUCATION**

**One-day carer course**
Forster 11 September
Wingham 14 November

**Two-day carer course**
Port Macquarie 12 and 19 July

**Three-day carer course**
Hamilton 6, 13 and 20 September
North Ryde 11, 18 and 25 September

**Four-evening carer course**
North Ryde 1, 8, 22 and 29 November

**Impact of Dementia**
Singleton 12 June
Raymond Terrace 18 July
Nelson Bay 15 August

**Sons and Daughters, Family and Friends**
North Ryde 12 June and 22 August

**Friends, Family and Neighbours**
Taree 5 June
Laurieton 10 July
Inverell 9 October
Lismore 23 October

**Activities for Family Carers**
Ballina 25 October

**CARE WORKER COURSES**

**Maintain Identity Workshop**
Hunter 11 July

**Impact of Dementia**
Maitland 1 August

**Below the Belt Issues**
Hunter 22 August

**Pharmaceutical and Non-Pharmaceutical Treatment for People Living with Dementia**
Hunter 12 September

**Living, Loving and Dementia**
Hunter 26 September
North Ryde 17 October

**Legal and End of Life Issues**
Hunter 10 October

**The three Ds of Dementia Care: Depression, Delirium and Dementia**
Hunter 14 November

**Palliative Care and Dementia**
North Ryde 19 June, 21 November

**Understanding Dementia**
North Ryde 17 July

**Communicating with a Person Living with Dementia**
North Ryde 17 July

**Experiencing Dementia**
North Ryde 15 August
Ballina 24 October

**Engaging People with Dementia in Activity**
North Ryde 15 August
Ballina 24 October

**Working with People who have an Intellectual Disability and Dementia**
North Ryde 19 September

**Managing Behavioural Symptoms of Dementia**
Taree 20 June
Port Macquarie 31 July
Coffs Harbour 15 August
Forster 23 October
Kempsey 7 November

**Assisting with Activities of Daily Living**
Inverell 10 October

**VOLUNTEER COURSES**

**Volunteer Education**
Taree 18 July
Kempsey 23 August
Port Macquarie 19 September
Forster 9 October

**Activities**
Inverell 10 October

**Dates and locations may be subject to alteration. Fees apply for some courses. For more information or to register for a family carer, volunteer for care worker course contact AlzNSW.**

**SUPPORT GROUP LEADERS’ WORKSHOPS**

**Introduction to Group Workshop Leadership**
Narrabri 6 and 7 August
North Ryde 23 and 24 August
Ballina 26 and 27 November

**Advanced Group Leadership**
North Ryde 15 and 16 November

**Loss and Grief in a Carer Support Group**
Queanbeyan 18 and 19 June
North Ryde 3 and 4 September

**Group Leaders’ Forum (for current, experienced group leaders)**
Narrabri 9 June
Penrith 16 July
Nowra 31 July
Newcastle 28 August
Queanbeyan 29 October
Orange 3 December

**For more information or to register, contact Monica Cole.**

**E:** nsw.education@alzheimers.org.au
**T:** (02) 8875 4682
**Q** WHAT IS THE MEDICATION FOR ALZHEIMER’S THAT I’VE HEARD PEOPLE TALK ABOUT?

A These medications, such as Aricept, can slow the progression of the dementia but will not change the disease process and will not prolong life. Results are usually modest at best – some people show little or no improvement – and it is good to have realistic expectations of the medications.

**Q** SHOULD I TELL SOMEONE THAT DAD HAS DEMENTIA AND IS STILL DRIVING?

A In all states and territories except WA drivers do have an obligation to tell the licensing authority of any medical condition that may affect their driving including diabetes, some heart conditions and dementia. A diagnosis of dementia does not mean that a person is immediately incapable of driving, but the licensing authority will recommend that your dad see a doctor or have a driving test to assess his abilities. A Helpsheet to guide you and offer suggestions that may help your dad through this difficult time is available on the Alzheimer’s Australia website or advice is available from the National Dementia Helpline.

**NEED ANSWERS?**

W: www.alzheimers.org.au
E: nsw.helpline@alzheimers.org.au
T: 1800 100 500

"Support at time of diagnosis helps you and your family to make sense of the diagnosis and the next steps.

2 Practical advice helps you minimise the impact of dementia.

3 Living with Memory Loss programs for people in early-stage dementia increase knowledge and confidence for managing memory loss.

4 Individual and family consultations help you plan for the future.

5 Education programs help you understand and live well with dementia.

6 Up-to-date information and resources about dementia and access to the members’ lending library keeps you and your family informed.

7 Connections with other people living with dementia enable you to share information and experiences.

8 Social and creative activities provide opportunities for meaningful participation.

9 Recommendations and advice about dementia support services in your area ensure suitable care.

10 Our provision of information to GPs and other health care providers helps them improve their care and support for you.

"Courses and special events increase knowledge about dementia risk reduction and treatments.

"AlzNSW campaigns rally the public and lobby the government to improve dementia funding and care.

CROSSWORD SOLUTION
The free activities in the Social and Therapeutic Activities program enable people living with dementia and their carers to engage in meaningful and therapeutic recreational activities, such as art, music, film and social gatherings.

Each activity helps to maintain quality of life by continuing people’s involvement in their own leisure activities, with an emphasis placed on strengthening social connections.

When a person is diagnosed with dementia, it can be a very isolating experience and there is a tendency to withdraw. “Our activities encourage people to stay connected socially, and decrease the chances of apathy and depression,” says Program Coordinator Denise Herman. “Creativity allows a person with dementia to express who they are and gives them a sense of purpose.”

Activities are run on a regular basis, including a workshop called ‘Colour – from Heart to Art’, where participants work with colour as a way of expressing themselves without the need for words. The group explores colours in its many different forms in a relaxed and comfortable environment. Long-term participant of the colour workshop Colin Roach was approached by the program to do a painting of the Vincent Fairfax Family Resource Centre. “It was a task Colin very proudly accepted,” says Denise, and the finished painting now hangs in the building.

‘Music for Recreation’ sessions are designed for people living with dementia – with or without previous music experience – and are planned with the specific goal of creating positive social experiences for participants.

Participants can also take part in the Movie Club, where everyone is able to discuss their favourite films, actors or actresses past or present, and recent movie releases, all while enjoying a fine afternoon tea.

‘Coming Together’ sessions provide a welcoming place for socialising, sing-a-longs, carpet bowls, games, or simply conversations over lunch, and the AD-HOC group meets monthly for barbecues, garden parties and a yuletide lunch.

For more information about Social and Therapeutic Activities throughout the state, phone the National Dementia Helpline.

T: 1800 100 500
WE OFFER OUR CONDOLENCES TO THE FAMILIES WHO HAVE LOST THEIR LOVED ONES. WE ALSO THANK THEIR FRIENDS AND FAMILIES WHO HAVE DONATED TO ALZHEIMER’S AUSTRALIA NSW.

Betty Ackroyd
Domenico Agostino
Elizabeth Mary Allen
Luciano Angeloni
Valda Heather Appleby
Jean Asimus
Emely Azzam
Keith Alan Bartlett
Ruby June Bell
Anna Maria Beltrame
Ronald Benham
Donald Berg
Donald Phillip Berriman
Keith Beverly
Walter John Bleazard
Colin Boag
Lindsay Bond
Betty June Bonfiglio
Colin Bora
Lionel Frost Bowen AC
Audrey Brew
Peter Brown
Maria Brownrigg
Enid Bucknell
Sydney John Byrnes
Jim Campisi
David George Chandler
Milton Chariton
Norma Lorraine Cook
Douglas William Cooper
Jocelyn Gregory Cope
Walter Leslie Craft
Ruth Creer
Cedric Thomas Davies
Marcia Davis
Shirley A Dubois
Albert George Evans
William Henry Bill Folkard
Giuseppe Fontana
John Frampton
Mannix “Max” Patrick Gallagher
Dianne Garrad
John Albert Giacomin
Robert (Bob) Thomas Gorman
Patrick Walter Goward
Ellen Griffin
Jean Hale
Maise Francis Harding
Ronald Lloyd Hawley
Reverend David Clifford Hayes OAM
Enid May Hewson
Dorothy Josephine Hill
David Hotten
Josephine Venus Hush
Philip Imison
Michael Jacob
Dr Archie Kalokerinos
Kassiani Kalpaxis
Lucy Kaye
Duncan Kentish
Sylvia Phylis King
Wilma Knithakis
Ross Donald Knox
Anastasia Kontakos
Father Johann (John) Krewenka OAM
Kevin Ramsay Lennon
Nona Anne Lenny (nee Willis)
Ann Sandra Leonard
Edna May Livingston
Judith Ann Lewis (nee Leaver)
Olve Lidgerwood
Kathleen Leah Litt (nee Beattie)
Francesca Lo Ricco
Rena Lorimer
Heather Mackay
Daniel John Marc
Luka (Charlie) Marsic
Donald Clive Masterson
Elar Mawad (nee Elias)
Joyce McGinley (nee Davies)
Wallace John Mclveen
Pietro Mercuri
Margaret Mitchell
Olga Moncada
Antonietta Montuori
June Heather Morgan
Ronald John "Ron" Morris
Munro Nola
Laurel May Murray
George Napper
Sebastiana Parisi
John Edward Lyle Patison
Jimmy Patton
Domenica Pennisi
Douglas Penny
Dorothy May Phillemore
Kenneth Albert Powers
Andrew Rallis
Meryl Elizabeth Randell
John Redmond
Grazia Antonia Riotta
Kathleen May Rohan
Winifred Agnes Rouse
Stella Sarna
Peter Palmer-Saville
Bartolo Sciacchitano
Frank Sharkay
Noel Southwell
Kevin Oswald Spooner
William Staff
Henrietta “Ettie” Ann Stewart
Michael Stylianou
Clive John Thompson
Roy James Thompson
Eva Titley
Mary Patricia Tuni
Theodore Evangelos Vanges
Nicola Verratti
Norma Annie Wainwright
Cecil Godfrey Walls
Leslie Norman Wearing
Irma Wiemann
Maisie Worth Wilson
Norma Woods
Robert Zarb
George Zavras

Alzheimer’s Australia 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 benefit.
Creating Moments of Joy: A Journal for Caregivers
by Jolene Brackey
When a person has short-term memory loss, his or her life is made up of moments. We are not able to create a perfectly wonderful day with those who have dementia, but it is absolutely attainable to create perfectly wonderful moments that put smiles on their faces and sparkles in their eyes, or trigger memories. This book includes useful tips to help make life run more smoothly. For example, if a person with dementia is capable of losing valuable jewellery but enjoys wearing it, keep the originals safe and give them similar non-valuable jewellery.

Burnout and Compassion Fatigue: A Guide for Mental Health Professionals and Care Givers
by Christine Florio
Mental health care providers are often so dedicated to helping others that they neglect to take care of themselves and risk the possibility of suffering emotional burnout. Christine Florio offers a comprehensive guide to learning about, preventing and treating burnout, compassion stress and fatigue. Clearly and compassionately written, Florio’s book defines the symptoms and suggests ways to decrease or avoid the conditions altogether.

The Reality Slap: Finding Peace and Fulfilment when Life Hurts
by Dr Russ Harris
The ‘reality slap’ is a rude awakening that creates a gap between what you have and what you want. The bigger the gap, the harder it is to bridge, but it is possible. Dr Harris offers real-life stories and simple exercises to help readers stop depending on things outside of themselves for validation and, instead, work on finding peace and fulfilment within. The acceptance and commitment therapy concepts will help all readers survive and thrive.

Transforming the Quality of Life for People with Dementia Through Contact with the Natural World: Fresh Air on my Face
by Jane Gilliard and Mary Marshall (eds)
This book demonstrates why we should provide opportunities for people with dementia to experience the great outdoors and gives voice to those who have felt the benefit of getting close to nature. The contributors explore different ways in which people with dementia can experience and interact with nature through farming, gardening and walking, and the book includes a chapter on the therapeutic, life-enhancing effects of activities with animals. The book includes descriptions of projects and initiatives from around the world that have revolutionised the everyday experience of people with dementia, and made a real difference to their quality of life.

CROSSWORD

Across
1. Knitting with hooked needle
6. Fluent & insincere
10. Banishment
11. Fireworks explosive
12. Rough (manner)
14. Moulds
16. Shaking in fear
18. Shouting
20. New Delhi natives
22. Contagious childhood illness
23. Undisguised (hostility)
25. Reclusiveness
28. Seek forgiveness
29. More independent
31. Washstand jug
32. Numb

Down
1. Restaurant cook
2. French yes
3. Dog-like predator
4. Yanking
5. Convent
7. Heavily loaded
8. 2nd largest UK city
9. Putter or iron (4,4)
13. Whiskers
15. Use ambiguous words
17. Sluggishness
19. Lazed
21. Recording period
22. Alleviate
24. Run off to marry
26. Small quarrels
27. Compulsion
30. Dwindle

Resources

AlzNSW Library
Library and Information Services Coordinator Michelle de Mari reviews new additions to the AlzNSW Library.

Books

Creating Moments of Joy: A Journal for Caregivers
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Crossword

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Need assistance? Not sure what you want? Ask the Library!
Monday to Friday 9am–4pm
E: nsw.library@alzheimers.org.au T: (02) 9888 4218

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

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

IN TOUCH WINTER 2012
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