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In Touch Winter 2015
The quarterly newsletter for members of Alzheimer’s Australia NSW

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The national Alzheimer’s Australia Board, of which I am the representative from NSW, meets face-to-face every six months to discuss issues that are important to the states and territories and the federation as a whole. At the last meeting, I was impressed with the strong sense of renewed energy from the board, which is working very well. As you may know, the national board appointed Carol Bennett as CEO of Alzheimer’s Australia in December 2014 and Graeme Samuel AC as the new National President in the middle of last year.

During the board meeting I participated in a discussion about the strategic direction of the federation. It is clear from the meeting outcomes that there is a strong degree of collaboration and cooperation between the board of directors, and the CEO management team. There is a great unity of purpose and strong alignment of views. We are in a very healthy position as a federation.

As an organisation we rely, to a large extent, on Government funding to deliver a wide range of high-quality services and supports. There will be increased scrutiny on costs by the Government, so it is no surprise that we face a range of challenges to our funding.

We are advocating very strongly for the continuation, and expansion, of funding to vital services – including the National Dementia Helpline, the National Younger Onset Dementia Key Worker Program and a wide range of funded services, as well as awareness and risk reduction campaigns.

In NSW, our board is in the process of renewal. In the last edition of In Touch I welcomed our latest board member, Dagmar Schmidmaier AM, who has now attended several board meetings.

In the coming months, we hope to announce another board appointment which will further strengthen the governance of our organisation.

Jerry Ellis AO
Chair, Alzheimer’s Australia NSW

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Jerry Ellis AO
Chair, Alzheimer’s Australia NSW

The Hon. John Watkins
CEO, Alzheimer’s Australia NSW
Lunch and Literature

Members of the Queanbeyan Carer Support Group enjoyed a literary lunch with Associate Professor Lee-Fay Low, Dementia Advisor Libby Smith and Queanbeyan City Council Mayor Tim Overall at the Queanbeyan Kangaroo Club in February.

Author of Live and Laugh with Dementia, Lee-Fay spoke about her book and her research into aged care facilities. She discussed valuing and empowering people with dementia, and shared activities to help engage people with dementia more effectively.

Libby discussed the Dementia Advisory Service working throughout South East NSW and the capacity to support people with dementia living in rural communities. Libby also spoke about raising awareness for dementia and participating in community education in local Government districts.

Queanbeyan City Council Mayor Tim Overall said he learnt a lot about dementia as a result of the event. He commented that he now realised how many areas of a person’s life are impacted by dementia, beyond just memory loss. Tim purchased a copy of Live and Laugh with Dementia, which he intends to donate to the Queanbeyan Library once he has finished reading it.

The event was made possible by funding through the Community Development and Support Expenditure scheme and Queanbeyan City Council.

Guests included service providers, ACAT representatives, a Parkinson’s Support Group, GPs and carers from towns across the southeast NSW region.

Consumer Summit

NSW Consumer Summit delegates Helen James (left), Graeme Noonan, Vicki Noonan, David Doig and Pauline Doig with Alzheimer’s Australia NSW Ambassador Ita Buttrose.

Fifty consumers attended this year’s Consumer Summit at Parliament House in March to represent the more than 342,000 Australians currently living with dementia. The consumers gathered to voice their needs to politicians and to insight action on dementia-related issues.

Alzheimer’s Australia National CEO Carol Bennett said the Summit was an important platform for consumers to advocate for themselves. “It provides an opportunity for consumers, as users of health and aged care services, to voice their concerns about ways to improve the system to better support their needs.”

“These improvements to our health system need to be addressed now so that our country has the ability to cope with the growing number of people with dementia,” she said.

The consumers presented a clear message to parliamentarians about the need for community awareness and programs to reduce the fear, stigma and social isolation that commonly follows a diagnosis of dementia.

They called for an expansion of the Younger Onset Dementia Key Worker Program to include people with dementia of all ages in order to help navigate the complex pathways to service provision that currently exist.

One of the NSW consumers living with younger onset dementia, Vicki Noonan, raised the urgent need for expanded dementia-specific services, particularly for those with younger onset dementia. “The community needs to understand that people with dementia have unique care needs. This is even more important for people like me who live with dementia and are under the age of 65,” she said.

UK Dementia Friends campaign advocate Gina Shaw, who also lives with younger onset dementia, discussed the outcomes of the program in the UK, which has generated much needed community awareness around dementia and has supported people with dementia by assisting them to live well in their communities.

Alzheimer’s Australia National President Graeme Samuel said it was critical to hear from those directly impacted about what is working and what is not. “Over the past two days we have heard from people who are at the coalface of navigating the support and services available for those living with dementia.”

Consumer Summit delegate Anne Pietsch said: “It has been heartening to know that we are being included in the conversation about decisions that will directly impact us.”

You can access the recommendations included in the presentation at the Alzheimer’s Australia NSW website. E: fightdementia.org.au/National-Consumer-Summit-2015-Communique
Welcoming over 1100 attendees from around the world, the 30th Alzheimer’s Disease International Conference, held in conjunction with Alzheimer’s Australia, was hosted in Perth during April 2015.

Delegates attended presentations relating to the latest developments in diagnosis, treatment and care, delivered from experts in the field.

Graeme Samuel, Alzheimer’s Australia National President, welcomed the delegates to Australia and the conference. In his opening speech he acknowledged the current $200 million investment by the Australian Government and hopes to see this funding increased in future years.

“Research in the areas of prevention, detection and potential treatments are vital, but just as important as building capacity in the research sector and bringing our best and brightest minds into the field,” he said.

A major highlight was Edie Mayhew and Anne Tudor who shared their experience of Edie’s journey from pre-diagnosis through to diagnosis with Younger Onset Alzheimer’s disease.

“Early detection and advice is very important” said Edie, after telling attendees it took more than five years from first noticing memory problems to receiving a proper clinical diagnosis from a neurologist. Other sessions looked at innovations in dementia care, dementia-friendly communities, education and awareness. One of the sessions focused on how far we have come over the past 30 years in the way of awareness, education and reducing stigma.

Glenn Rees AO, Chair of Alzheimer’s Disease International, congratulated Australia on the collaboration that exists between Australian Government departments, advocacy groups and consumers, who all work towards a common goal of helping those living with dementia.

Senator The Hon. Mitch Fifield outlined the major reforms the Australian Government has put in place, including a $50 million National Dementia Research Institute (NDRI). The NDRI is currently being established and will be focused on translating research into practice.

Dementia News has provided this coverage and more from the 30th Alzheimer’s Disease International Conference in Perth. For more research and news from the conference, please visit dementiaresearchfoundation.org.au

Alzheimer’s Australia staff attending the ADI Conference 2015 (top), art and engagement (bottom left) and Charlie the socially assistive robot (bottom right).
A lzheimer’s Australia NSW Senior Counsellor Helen Carswell asserts that specific and unique skills are required of counsellors when a dementia is involved. “All our staff are generalist counsellors, but they will provide support within the context of dementia, which makes quite a difference,” Helen says.

Discussing the counselling services that Alzheimer’s Australia NSW provides, Helen highlights the focus on flexibility that their guidance offers. “It is a free, short-term service that people can use as they need throughout their dementia journey. We work with people as things change for them at different times,” she explains.

Speaking to someone to debrief, unload and discuss future options can be helpful. From people living with dementia who are dealing with a recent diagnosis to families facing complex decision making – there are lots of ways that speaking with a support expert can help.

“It doesn’t have to be something ‘big’,” Helen explains. “If you just want to come and talk to someone, that’s what we’re here for – to listen and understand.”
“Everyone has their own morals, family values and judgements – so only the person can decide what is best for them. We can help them talk through some of the information, and explore some options, but ultimately only they will know what is best for them and their situation. Talking to someone who is not emotionally involved with you can help you to see things from a different perspective.”

Alzheimer’s Australia NSW has developed partnerships with a number of organisations including The Benevolent Society, UnitingCare, CatholicCare, South West Sydney Area Health, Dementia Care Services and Mt Druitt Community Health Services, which has allowed the expansion of face-to-face counselling services to Penrith, Waverley, Liverpool, Camden, Long Jetty, Mt Druitt, Blacktown and Wollongong.

“We really are grateful for the support of our partners and of The Ernest Heine Foundation, which generously supports services in Western Sydney,” Helen says.

“These partnerships have allowed us to offer help to a wider section of the community.” Alzheimer’s Australia NSW has a team of experienced counsellors who can offer face-to-face services at any of our sites. If you are unable to attend in person, they also have a telephone and Skype service.

Speaking to an Alzheimer’s Australia NSW counsellor can help you deal with issues that arise, including:

- Feelings that arise when diagnosis is given
- Improving and maintaining your general wellbeing and ability to cope
- Increasing your understanding of dementia
- Reducing stress and feelings of isolation
- Improving relationships with others
- Responding to difficult situations

“Speaking with someone over the phone can offer a level of privacy. People can call us and be totally anonymous; we don’t know them or their community,” Helen says.

“This can be constructive when seeking support.”

MORE INFO

To make an appointment to speak with a support professional, phone the National Dementia Helpline on 1800 100 500 and one of the Alzheimer’s Australia NSW counsellors will phone you back to arrange an appointment time.
Supporting Dementia in India

Just outside of Delhi, India’s bustling capital, is a residential care facility where more than 30 people who have dementia reside. Alzheimer’s Australia NSW Counsellor Katy Fitzgerald befriended them during a recent three-month visit.

Amid the chaos of the busy capital, time moves more slowly for the residents of the care home. Katy took time to walk with them, offering a reassuring hand to hold and a warm, friendly face.

“There was one Indian lady, I used to tell her she was my favourite and she’d laugh as we’d walk along,” Katy says.

Passionate about her work with Alzheimer’s Australia NSW, she returned from India to continue her role, working mostly with carers.

“With carers, so much of their energy goes on the person with dementia – I try to encourage people to put some of their energy on themselves,” Katy explains.

Her role allows her to step back and really listen to what a person is saying, allowing a person to find their own solution to their situation.

“I am inspired by the strength and courage of many of the people I see. Most of the time people are looking for a sounding board, validation and acceptance,” she explains.

“It is a privilege for us that they share their story with us. Our role is more to empower and enable people to see the situation more clearly.”

Overcoming Negativity through Specialist Support

Barry Ferranti enjoyed almost 20 years of happiness with his spouse before losing her to dementia.

When Alzheimer’s disease and vascular dementia entered their life, Barry knew he needed some help in dealing with difficult changes.

“I was caring for her at home, up until a time when it was no longer sensible or possible,” Barry explains.

When the time came, his partner was moved into residential aged care at Randwick. “As I have found out in discussions with others, virtually no one is prepared,” he added.

“The seriousness of the condition becomes apparent and, as it goes on, it is harder and harder to cope with.”

Educating himself about his partner’s dementia through the Alzheimer’s Australia NSW library and confidential counselling resources helped him greatly through those initial weeks and months. Barry found talking to his counsellor about what was happening eased the pressure. “She was one to whom I could talk easily about the situation,” he says.

“I’m pretty sure it helped me be more open and to see things in a different light.”

Barry urges others to overcome any negative feelings about seeking counselling support, as the benefits were instrumental in accepting and dealing with his partner’s diagnosis.

Alzheimer’s Australia NSW is expanding its program options to offer carers and people living at home alone with dementia the opportunity to participate in a new Personal Wellbeing Coaching Program.

This model of coaching is particularly helpful for carers and people who live alone with dementia in more geographically and socially isolated parts of NSW.

The innovative program is designed to be flexible, accessible and individualised, and can be delivered over the phone or via Skype.

A personal coach will work with participants over eight wellbeing sessions to help set goals and prioritise what matters most, build confidence to manage the impacts of dementia, plan for changes and achieve overall wellbeing.

The program is designed around the following topics:

• Staying positive
• Adapting to change and being resilient
• Physical wellbeing
• Sleeping well and relaxation
• Mindfulness and meaning
• Maintaining connections with friends and community
• Communication
• Eating for health and wellbeing
• Keeping the cognitive wheels turning
• Meaningful engagement

Participants can track their progress by completing tasks that utilise skills learned and move toward achieving their goals.

The coach is there to offer constructive and empowering feedback along the way.

Participants are also able to determine the times and frequency of the eight sessions.

The program has been designed to help build confidence in participants’ ability to improve their wellbeing and quality of life, empowering them to enhance their self-care skills, improve optimism and resilience, and achieve short- and long-term health and wellbeing outcomes.

Supporting Dementia in India

Katy walking with a new friend at the Faridabad care facility.

CASE STUDY 1

CASE STUDY 2

Personal Wellbeing Coaching Program

Cover Feature
You have been diagnosed with a dementia such as Alzheimer’s disease. Should you tell your family and friends? Will you risk being ostracised?

My strong recommendation is for patients and their family members to share the news. It’s time to vanquish the stigma surrounding the ‘D’ word.

Talk to your extended family. Tell them what is happening and suggest how they can help. Share the news, prevent isolation and allow others to show their support. For example, if you lose your driver’s licence, a friend can drive you to your golf game or accompany you to your weekly game of bridge.

Knowledge is power. Patients and family members should find out as much as they can about their particular dementia in order to compensate and cope.

Living with dementia can be stressful for patients and family carers. Many studies have shown that counselling for family carers can reduce depression, improve coping skills and help patients remain at home longer. People with dementia can benefit from talking about their fears and anxieties, and by sharing positive stories. Relating to others who are similarly affected is often more helpful than talking to family. People with dementia can do this through face-to-face or online support groups.

Research has been done into carer support. In one study, just five sessions of counselling over three months reduced carer depression significantly, compared to a control group where carers received general support only. Most impressively, depression scores in counselled carers continued to decline over the following two years, while depression scores in the carers who had not received counselling continued to rise.

Training programs for carers and patients have been shown to reduce distress and behavioural disturbances. These programs discuss effective communication skills, understanding behavioural changes and learning about ways to compensate.

Medical care of dementia is just one aspect of helping patients and their families. Counselling, sharing, learning and growing through the experience may be even more important.

Find out more about CHEBA at www.cheba.unsw.edu.au

Professor Brodaty is an honorary Medical Advisor to Alzheimer’s Australia NSW.
New research looking at almost 2 million UK medical health records has suggested that your BMI might be linked to dementia risk.

The results reiterate that being underweight could increase your risk of dementia, as previously stated on the Alzheimer’s Australia Your Brain Matters dementia risk reduction website.

Reported in the most recent edition of The Lancet Diabetes and Endocrinology, UK scientists assessed whether there is an association between BMI and the risk of dementia. They analysed data from 1,958,191 individuals (obtained from the United Kingdom Clinical Practice Research Datalink), which included people aged 40 years or older whose BMIs were recorded between 1992 and 2007.

A BMI is calculated by dividing weight in kilograms by height in metres squared. According to the Australian Government’s Department of Health website, a normal range BMI is considered to be between 18.50 and 25. However, caution should always be taken when using BMIs in health research as they can be influenced by a person’s age, gender and ethnicity.

In this latest study, the analysis showed that dementia occurred in 45,507 people of the total number of people analysed in this dataset. When compared to people who were within a healthy weight range (and BMI), underweight people had a 34 per cent increased risk of dementia. They also reported that people in the overweight or obese BMI range had a 29 per cent reduced risk of dementia compared to those within the healthy BMI range. However, this result should be taken with caution. Not only are there various scientific papers which contradict this current finding, but having a BMI of 25 or above could lead to other health conditions such as Type 2 diabetes, asthma, stroke, heart disease and respiratory disease.

The lead researcher on the study, Dr Nawab Qizilbash from the London School of Hygiene & Tropical Medicine, admitted the results were unexpected but still gave warning in a BBC News interview.

“You can’t walk away and think it’s okay to be overweight or obese. Even if there is a protective effect, you may not live long enough to get the benefits,” Dr Qizilbash said.

Suha Ali, Alzheimer’s Australia’s National Risk Reduction Manager, said that this data emphasises that if you are ever concerned about your weight you should speak to your doctor or a health professional to seek advice.

“As with all research, these results all form part of a larger puzzle. The evidence we have to date suggests that following a brain healthy life, which includes maintaining a healthy weight range, is the best strategy to reduce one’s risk of developing dementia,” Suha said.

The researchers now plan on undertaking further investigation to fully understand their results.

For more information on dementia risk reduction please visit the Alzheimer’s Australia Your Brain Matters website.
W: yourbrainmatters.org.au
TREATMENT FOR STROKE COULD DOUBLE AS AN ALZHEIMER’S DISEASE TREATMENT

Edaravone, a treatment that is currently used overseas for people who have had a stroke, has been shown to be effective in reducing key Alzheimer’s disease toxic markers and improving cognition in mice.

These results, recently published in Proceedings of the National Academy of Sciences (PNAS), came from a recent collaboration between scientists from the University of South Australia and the Third Military Medical University in Chongqing, China.

In their animal study, the researchers injected Edaravone into mice with Alzheimer’s disease. They found that it reduced the build-up and formation of two key Alzheimer’s disease toxic proteins, amyloid beta and Tau, by up to 50 per cent.

It was also shown to curb brain inflammation and preserve neuronal structures.

The same mice underwent a variety of memory tests, and demonstrated improvements in memory and learning capabilities.

Lead researcher Professor Xin-Fu Zhou, Research Chair in Neurosciences at the University of South Australia, says this is the first time that Edaravone has been shown to be effective in Alzheimer’s disease animal models.

“The drug can suppress the production of amyloid beta by inhibiting the amyloid beta production enzyme,” said Professor Zhou.

“Edaravone, a treatment that is currently used overseas for people who have had a stroke, has been shown to be effective in reducing key Alzheimer’s disease toxic markers and improving cognition in mice.”

For more information on current treatments available to alleviate the symptoms of Alzheimer’s disease, please call the National Dementia Helpline. T: 1800 100 500

DEVELOPMENT OF SPEECH-BASED SYSTEM FOR EARLY DETECTION OF ALZHEIMER’S DISEASE

Researchers from Spain have developed a speech-based technology system that could potentially analyse and detect the early signs of Alzheimer’s disease.

The development of non-invasive and simple techniques to detect and diagnose Alzheimer’s disease is an ever-growing field, particularly as there are few reliable methods currently available to detect the early signs of dementia.

It is vital that detection techniques are available as research is beginning to suggest that early treatment can stall the progress of dementia.

This new study, published in Alzheimer’s and Dementia, is based on the recordings of people’s voices. Known as ‘Automatic Spontaneous Speech Analysis (ASSA),’ the researchers have automated speech biomarkers that detect signs of the disease. For example, the pauses a person makes when trying to remember a word they want to say are measured and analysed.

“This project is very much in its infancy, with researchers planning on testing the system further. If trials are successful it is hoped that it could be used as another potential test to aid a pre-clinical Alzheimer’s disease diagnosis.”

Dr Karmele López de Ipiña, coordinator of the research group, said that the ASSA system is still being developed. However, it is hoped in time that the system will be ready to be used routinely.

“It also inhibits the Tau hyperphosphorylation which can generate tangles accumulated in the brain cells and disrupt brain functions.”

NEXT STEPS FOR THIS RESEARCH

Scientists plan on creating a tablet version of this treatment, as it is usually administered by injection. They hope that human trials could happen within two years.

Alzheimer’s Australia National CEO Carol Bennett said that all research looking at the effectiveness of drugs on Alzheimer’s disease pathology is welcomed and looks forward to seeing results from future clinical trials.

Carol told Channel 9 News: “It’s great to see that the research is part of a collaboration and is being undertaken in Australia. It just shows that we need to keep investing in our best and brightest Australian dementia researchers.”

“Edaravone, a treatment that is currently used overseas for people who have had a stroke, has been shown to be effective in reducing key Alzheimer’s disease toxic markers and improving cognition in mice.”

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A recent study titled ‘Reducing the prevalence of Alzheimer’s disease: modifiable risk factors or social determinants of health’ estimates that a 20 per cent reduction in dementia cases could save $570 million by 2020 and up to $8.3 billion by 2050. The paper calls for a continuation of Federal and State Government funding and increased investment in the Your Brain Matters risk-reduction program.

Evidence suggests that there are seven modifiable risk factors for dementia. Alzheimer’s Australia NSW CEO The Hon. John Watkins said the biggest of these risks factors is physical inactivity, followed by high blood pressure in mid-life.

“Disturbingly, a recent paper released by the Australian Institute of Health and Welfare found that more than half the Australian population is inactive. Other risk factors include obesity, smoking, depression, diabetes and cognitive inactivity or low educational attainment,” John said.

“If the government invested in addressing at least some of these risk factors across the population, we could reduce the numbers of people living with Alzheimer’s disease, the most common form of dementia, making substantial savings to the community.”

The paper put forward several recommendations to the Australian Government including:

• continued investment in the Your Brain Matters dementia risk reduction program
• identify opportunities to incorporate brain health messaging in other preventative health campaigns around smoking, obesity and diabetes
• State Governments should implement incentives for healthier dietary choices including taxes on foods known to increase the dementia burden
• prioritise research funding through the National Health and Medical Research Council (NHMRC) into encouraging the population to embrace dementia reduction behaviour, in particular for populations of social and health disadvantage

The paper focused on approximately 30 per cent of Alzheimer’s disease cases that are attributed to modifiable factors. Its content and recommendations may have implications for other types of dementia that are vascular in origin. It is important to establish that risk reduction is not a guarantee of prevention.

A full copy of the discussion paper, including all the recommendations, is available at fightdementia.org.au

For more information about dementia risk reduction strategies please visit www.yourbrainmatters.org.au

The paper calls for a continuation of Federal and State Government funding.

ONLINE PROGRAM TRIAL

Carers who would like to learn strategies to better manage common behavioural changes in dementia are invited to join the study of an online program.

The program is for carers of people with dementia and is a joint collaboration between Alzheimer’s Australia NSW, St Vincent’s Hospital, The University of Sydney and University of NSW.

The eight-week program is entirely online and consists of fact sheets or videos and worksheets. It is free and confidential, and carers can take part in the comfort of their home at a time that suits them.

Participants do not need high-level computer skills to take part. Participants will be recruited until Tuesday 30 June 2015.

If you are interested in taking part, please visit www.caretoons.com.au This study has ethics approval (HREC/LNR/15/SVH/21).

LIKE THIS RESEARCH UPDATE?

Stay up-to-date with all the latest in dementia and research news.

DEMENTIA DAILY
www.dementiadaily.org.au

ALZHEIMER’S AUSTRALIA NSW’S FACEBOOK
www.facebook.com/alznsw

TWITTER @AlzheimersNSW
Helpful Resources

Alzheimer’s Australia NSW has released two resources to support decision making for people living with dementia.

Brendan Moore, General Manager – Policy, Research and Information, Alzheimer’s Australia NSW

Preventing Financial Abuse

Financial abuse is the illegal or improper use of a person’s money or resources. People with dementia are increasingly vulnerable to financial abuse due to the gradual loss of ability to manage their financial affairs. Financial abuse can be accompanied by other forms of abuse, including physical, sexual and psychological exploitation.

Unfortunately, victims of financial abuse usually know the perpetrator. Research indicates that financial abuse of people with dementia is often perpetrated by family members or parties authorised to manage financial affairs. People with dementia are also at risk of being financially abused by friends, neighbours and other people that they trust. Although less common, financial abuse is also perpetrated by people who come into contact with the person with dementia and then seek to take advantage of their vulnerability.

The best way to safeguard yourself against financial abuse is to plan ahead and appoint someone to act as your financial Power of Attorney. A Power of Attorney document gives your authorisation for an individual or individuals to act on your behalf when you no longer have the capacity to manage your financial affairs.

The person you appoint as your attorney should be trustworthy, capable and financially literate. It is very important that you appoint someone who you trust will act in your best interests and who will not take advantage of their power.

Some forms of financial abuse are criminal offences and in these instances you should contact your local police.

Monday 15 June is World Elder Abuse Day. If you, or someone you know, have been abused you can contact the NSW Elder Abuse Helpline. T: 1800 628 221

Staying on the Move with Dementia

Alzheimer’s Australia NSW collaborated with the NRMA in response to members’ concerns about issues relating to driving and the various options available after making the transition to non-driver. The following presents some of the key messages in the publication.

- At some point, all people with dementia must stop driving.
- The law requires drivers to report permanent or long-term illness that may affect their ability to drive safely.
- Reporting the illness doesn’t necessarily mean that a driver’s licence will be taken away. A Medical Report Form will need to be completed, or a practical driving test may be requested.
- If a doctor is aware that a driver is continuing to drive and feels that their driving is a serious risk to themselves and other road users, the doctor is legally authorised to notify the RMS directly.
- It is important to engage people diagnosed with dementia who are able and who want to continue to drive in discussions about their driving soon after diagnosis.
- It is important that people with dementia and carers maintain their mobility and retain social contacts.
- Alternative transport options should be discussed and tried soon after the diagnosis, ideally before the person gives up driving.

To access a full copy of these papers, please contact nsw.resources@alzheimers.org.au or visit nsw.fightdementia.org.

Get in Touch

This article is the second in a series that will inform people with dementia, their carers and families about changes to aged care and dementia services. To suggest topics for discussion in future editions, contact Brendan Moore. E: brendan.moore@alzheimers.org.au

National Dementia Helpline

Alzheimer’s Australia NSW provides help sheets on a variety of topics, including driving. The National Dementia Helpline number is 1800 100 500.
CAFÉ CONNECT
Raymond Terrace
(Cups n Saucers Café)
12 June, 10 July, 14 August:
10am – 11:30am
Miriam Low (02) 4962 7000

Coffs Harbour
17 June, 15 July, 19 August:
10am – 11:30am
Marg Coutts (02) 6651 7101

Newcastle (Birdy’s Refreshments & Espresso)
16 June, 21 July, 18 August:
10am – 11:30am
Maitland (Maitland Park Bowling Club Bistro)
18 June, 16 July, 20 August:
11am – 12:30pm

Nelson Bay (Little Nel Café at The Nelson Resort)
11 June, 9 July, 13 August:
9:30am – 11:30am

Toronto (Toronto Workers Club)
25 June, 23 July, 27 August:
10am: 10am – 12pm

Warners Bay (Warners at the Bay)
3 June, 1 July, 5 August:
10am: 10am – 11:30am (02) 4962 7000

St George (Café Brasserie, Beverley Park Golf Club)
16 June, 21 July, 18 August:
11am – 12:30am

Sutherland Shire (Camelia Gardens Tea House)
23 June, 28 July, 25 August:
9:30am – 11am
Julie Sinnis (02) 9531 1928

Bundanoon
4 June, 2 July, 6 August:
10:30am – 12pm

Bowral
18 June, 16 July, 20 August:
10:30am – 12pm

Jane Bushell and Nina Eagle
(02) 4869 5651

COFFEE AND CHAT
Yass (Kaffiene Café)
15 June, 20 July, 17 August:
10am – 12pm

Merimbula (Dolphin Room, Club Sapphire)
9 June, 14 July, 11 August:
10am – 12pm

Cooma (Werri-Nina Centre)
23 June, 28 July, 25 August:
10:30am – 12:30pm

FORSTER YOUNGER ONSET DEMENTIA ACTIVITY AND SUPPORT GROUP
13 July
Harrington Breakwall Walk 10am, Lunch at Harrigans Irish Pub 12pm

10 August
Artisans on the Hill Gallery 11am, Lunch at Mondooks Garden Gallery and Café 12pm

Ellen Brown (02) 6554 5097

THE AGED CARE RIGHTS SERVICE PRESENTATION ON LEGAL ADVICE
Boorowa
9 June Boorowa Citizens Club 10am – 11:30am
Young
9 June Mercy Care Centre 2pm – 3:30pm

Harden
3 June: 10am – 12pm
Verity Jackson (02) 6452 3961

Batemans Bay (Batemans Bay Community Centre)
3 June, 1 July, 5 August:
10:30am – 12pm
Gaye Finch (02) 4474 3843

Crookwell and District
17 June, 15 July, 19 August:
10:30am – 12pm

Jane Bushell (02) 4869 5651

Port Macquarie
25 June, 23 July, 27 August
Port Macquarie Dinner Group
9 June, 11 August

Laurieton
26 June, 24 July, 28 August

City2Surf 9 August
Blackmore’s Sydney Running Festival
20 September
Lucie Barney (02) 8875 4625 lucie.barney@alzheimers.org.au

THE AGED CARE RIGHTS SERVICE PRESENTATION ON LEGAL ADVICE
Boorowa
9 June Boorowa Citizens Club 10am – 11:30am
Young
9 June Mercy Care Centre 2pm – 3:30pm

Harden
10 June Anglican Church Hall 10am – 11:30am

Yass Valley
10 June Ngunnawal Aboriginal Corporation 2pm – 3:30pm
Libby Smith (02) 6241 0881

Let’s talk about sex conference 2015
Relationships and Intimacy as We Age
Pullman on the Park, Melbourne 8-9 September 2015
Register today at www.itas2015.com
DEMENTIA ADVOCATES

ALZHEIMER’S AUSTRALIA NSW DEMENTIA ADVOCATES WORK TO RAISE AWARENESS ABOUT DEMENTIA IN THE COMMUNITY AND MEDIA.

I was with Maree through the initial stages of finding a correct diagnosis for her illness, which was a very challenging time in our relationship. Once the diagnosis was confirmed I journeyed with Maree through her loss of employment, changed relationships with our children and friends, and the personal changes Maree experienced transitioning from independence to almost total dependence on others for everyday living. I believe I have a great deal of carer experience to share with others as Maree and I continue our journey through coping with her dementia.

We received invaluable advice from Verity Jackson, the Dementia Advisor for Cooma and surrounding regions. Verity was very supportive and was always thinking ahead about the challenges of the next stage of the dementia and what they could be like. She encouraged me to become a member of the Southern NSW Consumer Advisory Group.

Through this group, and with the support of Cooma Challenge who provide extended day care support for Maree and a Home Care Package (Level 4) through the Monaro Home Nursing Service, I am still able to work part-time even though Maree is in the advanced stages of her dementia.

I have been blessed with wonderful community support for Maree and have gained skills that I use every day. Being a Dementia Advocate, I believe I can offer other carers support and advice in this challenging and fulfilling role. Hugh Mackay, in his book The Good Life, stresses that true happiness and joy can be found in the service of others. I have found Hugh’s words to ring true and have experienced real joy in caring for Maree and consider it a privilege to be her primary carer.

Q My husband has been diagnosed with Alzheimer’s disease and I have noticed a few differences in his abilities. Can you help me understand other changes we may face over time?

Changes in people with Alzheimer’s disease will differ due to the uniqueness of each individual and their life circumstances. A person’s abilities may change from day to day or even within the same day. What is certain though, is that the person’s abilities will decline over time.

A person will often use behaviour as a means of communication when their ability to articulate words is lost. It can be helpful to watch the person and interpret what they want through their body language, facial expression or tone. The lack of orientation to time and place will also become noticeable. Keeping things more visible, including signage around the home, can also be helpful to keep a person orientated and remain independent.

Q I care for my mother who has dementia. At times it can be difficult and a bit overwhelming. I often feel others don’t understand the challenges I face. What can I do to feel less isolated?

Finding out about dementia and the immediate help available is usually a priority soon after a diagnosis. Alzheimer’s Australia NSW can help you learn about what is happening, provide emotional support, information, education and counselling. Alzheimer’s Australia NSW can also link people to a number of support groups throughout NSW. Many people find comfort and practical assistance by attending these meetings with others who know what it is like to care for a person with dementia.

Our free specialist counselling service helps to support and assist those affected throughout the illness.

Q My father has just moved into residential aged care and this change has been particularly difficult for my mother. How can my mother maintain her caring role with my father no longer at home?

When a person with dementia moves into residential care, the role of families and carers does not usually come to an end. Meaningful visits are an important way for the person in care and their family to stay connected, with routine visits and one-on-one time being invaluable to the person in care. It’s advisable for your family to maintain a staggered visiting schedule rather than all visiting at once. Also, choose visiting activities that the person can participate in, such as going for a walk or using old photos as story prompts. When the person’s abilities have changed, a visit based on conversation alone can leave you and the person feeling unfulfilled.

To learn more about help and support, phone the National Dementia Helpline. T: 1800 100 500.

If you would like to be a Dementia Advocate please contact Jo-Ann Brown or visit the Fight Dementia website. T: (02) 9875 4636 | E: jo-ann.brown@alzheimers.org.au W: nsw.fightdementia.org.au/nsw/support-us/dementia-advocates-program

WINTER 2015 IN TOUCH
The Alzheimer’s Australia NSW Memory Van raises awareness of the importance of brain health and provides information on dementia for people living with dementia and their families, service providers and the community.

**MEMORY VAN**

- Jindabyne
- Dee Why
- Cooma
- Wollongong
- Orange
- Dubbo
- Cobar
- Bourke
- Broken Hill
- Walgett
- Coooma
- Wilcannia
- Port Macquarie
- Camden
- Camden
- Queanbeyan
- Nowra
- Newcastle
- Newcastle
- Newcastle
- Nowra
- Newcastle
- Newcastle
- Newcastle
- Newcastle

**THE VAN ALSO VISITED:**
- Bombala Delegate
- Bonnyrigg
- Mudgee
- Gilgandra

**EDUCATION**

**ALZHEIMER’S AUSTRALIA NSW COURSES**

The Alzheimer’s Australia Education Program offers courses for Care Workers, Family Carers and Volunteers.

**CARE WORKER COURSES**
- **Experiencing Dementia & Challenging Perceptions of Behaviour Associated with Dementia**
  - North Ryde: 25 June
  - Macksville: 30 June

- **A Positive Approach to Understanding Dementia, Effective Communication and Behaviour Changes**
  - Newcastle: 22 July

Discover the Person, Not the Disease and Communicating with a Person Living with Dementia

- **North Ryde**: 25 June

**FAMILY CARER EDUCATION**

**One-day Carer Education**

- Newcastle: 11 August, 27 October, 10 November

**Four-evening Carer Education**

- North Ryde: 2 June
- Camden: 15, 22, 29 June; 6 July; 12, 19, 26 October; 2 November

**GROUP LEADER WORKSHOPS**

**Introduction to Group Leadership**

- North Ryde: 20-21 July

**Advanced Group Leadership**

- Queanbeyan: 1 June
- Newcastle: 23 June
- Albury: 27 October

**Loss and Grief in a Carer Support Group**

- North Ryde: 7-8 October
- Newcastle: 24-25 November

For more information or to register please contact:
- T: (02) 8875 4640
- E: nsw.education@alzheimers.org.au

**Group Leaders’ Forum (for current, experienced group leaders)**

- Nowra: 16 June
- Newcastle: 4 August
- Port Macquarie: 25 August
- North Ryde: 8 September
- Queanbeyan: 9 November

For information contact Leanne Norman.
- T: (02) 8875 4682
- E: groupdevelopment.nsw@alzheimers.org.au
The progressive deterioration in cognitive functioning associated with dementia will often mean that a person with dementia will eventually need to scale back or cease paid employment.

This has considerable financial implications for the person living with dementia and their family, particularly for those with younger onset dementia who often have additional financial responsibilities such as supporting children, education and mortgage repayments.

People with dementia and their families often ask whether they have a right to access their superannuation early to assist with their financial situation, given that they have a terminal illness.

Superannuation and Dementia is a new resource launched by Alzheimer’s Australia to help people with dementia and their families better understand and navigate the puzzling maze that can be superannuation and dementia.

It provides an overview of some of the options that may apply to people with dementia who want to access their superannuation and how to make a complaint if you are not happy with how your superannuation provider and insurance company have responded to your claim.

There are several circumstances in which a person with dementia can access their super fund early. These include compassionate grounds, which covers medical treatment or transport, mortgage assistance, modifications to your home or motor vehicle, palliative care or funeral expenses for a dependant, and also severe financial hardship.

There are also circumstances in which people with dementia may be able to access funds through insurance provided as part of their superannuation. These circumstances include terminal illness, and total and permanent disability.

Consumers on the National Consumer Advisory Committee and the Alzheimer’s Australia Dementia Advisory Committee drove the development of this resource, which identifies superannuation as a priority topic for people living with dementia.

To access a copy of Superannuation and Dementia online, please visit fightdementia.org.au/sites/default/files/NATIONAL/documents/superannuation-and-dementia.pdf.

Please note: the purpose of this document is to provide general information only. Please see your financial advisor or legal professional to obtain financial advice. The information contained within this document is current as of March 2015 and is subject to change dependent on legislation and Government policy.
ART WITH AN OBJECTIVE
AWARDED AUSTRALIAN ARTIST WARWICK FULLER HAS AUCTIONED AN IMPRESSIVE SELECTION OF PAINTINGS TO RAISE FUNDS FOR ALZHEIMER’S AUSTRALIA NSW, FOLLOWING HIS EXPERIENCE WITH DEMENTIA.

OVERSEAS CHALLENGES
Take part in the adventure of a lifetime while raising funds for people living with dementia. You can trek, bike, climb, ski, sled and raft throughout the world!

A TREK TO REMEMBER – NEPAL
Remote trek in the Annapurna region to the base of Machapuchare.
• Date: 18th October 2015, 15 days

EVEREST BASE CAMP – NEPAL
Outstanding trek to the base camp of the world’s highest mountain.
• Date: April 2016, 17 days

KILIMANJARO – TANZANIA
Climb Africa’s highest peak, and the highest free-standing mountain in the world.
• Date: October 2016, 10 days

OPEN CHALLENGE
Choose your own adventure with our partner Huma and we will support you to reach your fundraising targets.

TO FIND OUT MORE, CONTACT ALZHEIMER’S AUSTRALIA NSW.
T: (02) 1300 636 679 E: nsw.fundraising@alzheimers.org.au

JOIN THE FIGHT
Here are a few of the ways you can get involved:
• Hold an event through our community fundraising program
• Become a regular giver as a Dementia Fighter
• Donate through your workplace
• Request donations in lieu of gifts for celebrations
• Leave a bequest
• Volunteer

BEQUESTS
To meet the growing demands for our services, please consider supporting us by leaving a gift in your Will. Anyone considering this should also consult a solicitor or a Trustee Company. For a confidential discussion, please contact Alzheimer’s Australia NSW’s Bequest Executive Karen Carran.
T: (02) 8875 4639
E: karen.carran@alzheimers.org.au
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.

A
Giuseppe Antonio (Tony) Agostino
Michael Richard Allen
Yves Appassamy

B
Norma Beryl Barry (nee Turk)
Bruce Charles Batterham
Elsie Patricia Bayly
Joan Beckett
Yvonne Tike Bennett (nee Lewis)
Charles Richard Broad
Douglas Norman Brown
Daphne Burton

C
Olive Mary Rosetta Cain
Grazie Capra
Maureen Lilian Carlsson
Maria Cassimatis
Peter Frederick Castor
Nicola Cimini
Arthur Clarence Cole
Chrysanthy Constantinou
Audrey Corbett (nee Greig)
Leslie James Crawford
Francis Joseph Crowe
Norma Cruikshank

D
Edward George Dawkings
Anastasia Del-Pin
Carmine Di lenno
George Albert Dimmock
Marie Therese Dixon
Sheila Donnelly

E
Barbara Evans
Joan Magdalene Everingham

F
Fioresta Falvo
Gladys Joyce Farrawell
Palma Finocchiaro
Betty May Fisher (nee Gunner)
Doris Fletcher
William Flint
Edna May Fromant

G
David George
Gina Greco

H
Roger Haggert
James Norman (Jim) Halloran
Marjorie Hawthorn
Dorothy (Dot) Hayman
Annie Henry
Adrian Hiser
Margaret Hodge
John Holmes

I / J
Reta Florence Ireland
Marie Jansen
Barry Johnson

K
Keith Kay
John Van Kerckhof
Stanislawa Kosel
Josephine Kranjic

L
Kathleen Ivy (Kay) Land
Marjorie Hamilton Lawson
Serafin Legovic
Noel Thomas Lowe

M
Ronald Stuart Mackenzie
Christine Mackie
Duncan Macrae
Ravni Maki-Vinikka
Lal Heather & Howard Martin
Margaret Innes Matthews
Anne Denise McGuinness
Filippos Minas
Dorothy Jenner Moore
Max Murdoch

N
Emerlda Mary Neal
Richard Sandys Cameron Newman
Kay Lucille Norman (nee Ingram)

O
M P O’Meara
Desmond Ostwald

P
Domenico Pietro Parisi
Eiba Piazza
David Herbert Pilgrim
Jean Isabel Plews
Patricia Mary Plummer

Josephine Beth Porter
Jean Pounder
Max Powell
Paul Prowse

R
Caterina Raffaele
Patricia Anne (Pat) Richardson
Kevin Lindsay Roberts
Elaine Pearl Roberts (nee Millington)
Patricia Rodden
Margaret Marion Rowe
Athanasia Rozos
Lila Daphne Ryman

S
James Frederick Salkeld
Thelma Constance Saville
Cleopatra Sclavos
Arthur (Jack) Severs
Caterina Sganga
Dr John Wentworth Shand
Zelda Joyce Sharman
Elma Beatrice Shaw
Raelene Joy Sheather
Kelvin James (Kel) Stein

T
Nancy Lorna Thomas
Ian Todd
Giovanni Tropea

W
Ted (Edward) Wagstaff
Charles William Weaver
Iris Mildred Westwood (nee Huntriss)
Lucy White
Ada Whitten
Joanna (Ann) Woodward
Carl Geoffrey Wyborn

Y
Alfred Edwin Yard

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 benefit.
LIBRARY RESOURCES

THE ALZHEIMER’S AUSTRALIA NSW LIBRARY OFFERS FREE LOANS OF BOOKS, DVDS AND OTHER RESOURCES TO MEMBERS THROUGHOUT THE STATE. HERE ARE REVIEWS OF SOME OF THE ITEMS AVAILABLE AT THE MOMENT.

BOOKS

Living your best with early-stage Alzheimer’s: an essential guide
Lisa Snyder
Snyder provides a thorough, practical guide on coping with diagnosis, managing symptoms, finding meaningful activity, planning for the future, maintaining important relationships, participating in research and much more. This book is a working guide to help people with Alzheimer’s disease feel empowered to move forward in life in light of this challenging diagnosis.

Boundaries: where you end and I begin
Anne Katherine
Boundaries separate us from others physically and emotionally. Katherine explains what healthy boundaries are, how to recognise if your personal boundaries are being violated and what you can do to protect yourself. For anyone who has walked away from a conversation, a meeting or social interaction feeling violated and not understanding why, this is a book that can help.

Taking care of parents who didn’t take care of you: making peace with ageing parents
Eleanor Cade
Caring for ageing parents is difficult. It’s exhausting, expensive, time-consuming and under-appreciated. What happens when adult children are asked to care for elderly parents who were abusive, neglectful or absent? Cade provides a compassionate and practical guide to facing the psychological and emotional issues that arise when caring for ageing parents. The result is a powerful guide to moving beyond feelings of anger, regret, and grief in order to build healthy new family dynamics based on decency and mercy.

Loving someone who has dementia: how to find hope while coping with stress and grief
Dr Pauline Boss
Offering research-based advice for people who care for someone with dementia, Boss explains how to manage ongoing stress and grief. The book outlines seven guidelines to staying resilient while caring for someone who has dementia, and discusses the meaning of relationships with individuals who are cognitively impaired and no longer as they used to be. Boss provides a way to embrace rather than resist the ambiguity in your relationship with someone who has dementia.

Don’t bite the hook: finding freedom from anger, resentment, and other destructive emotions (audio)
Pema Chödrön
Life has a way of provoking us with traffic jams, computer malfunctions, emotionally distant partners and crying children. Before we know it, we’re upset. Chödrön shows that it is possible to relate constructively to the inevitable shocks, losses and frustrations of life so that we can find true happiness. In this recorded weekend retreat, Chödrön draws on Buddhist teachings from The Way of the Bodhisattva to reveal how we can stay centred in the midst of difficulty, improve stressful relationships, step out of the downward spiral of self-hatred and awaken compassion for ourselves and for others.

LOANING ITEMS

These items and many more are available to members of Alzheimer’s Australia NSW, and can be picked up from and returned to local resources centres and offices. Resources can also be posted to you if you are unable to get to one of our library sites. Find a list of offices and resources centres on the Alzheimer’s Australia NSW website, and contact the library to borrow items.

W: nsw.fightdementia.org.au/nsw/about-us/contact-us
E: nsw.library@alzheimers.org.au
T: (02) 9888 4218

REVIEW AN ITEM

We’d love to hear what you think of the library resources. Submit a review and we’ll choose a few for publication in each issue. Post or email your reviews to Sonia Byrnes, including your full name and suburb. E: sonia.byrnes@alzheimers.org.au P: Sonia Byrnes, PO Box 6042, North Ryde NSW 2113