ON THE MOVE

IMPORTANT INFORMATION TO GET YOU WHERE YOU NEED TO GO

POLICY UPDATE • EDUCATION • FUNDRAISING • NEWS
IN TOUCH
The quarterly newsletter for members of Alzheimer’s Australia NSW
CEO
The Hon. John Watkins AM
General Manager Services
Susan McCarthy
General Manager Policy, Research and Information
Brendan Moore
General Manager Human Resources and Volunteering
Annelise Coghlan
General Manager Marketing and Communications
Andrew Mills
General Manager Media
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General Manager Fundraising
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Chris Champ
Honorary Medical Advisors
Professor Henry Brodaty AM
Professor Bryce Vissel
Dr Craig Blain
Garvan Institute of Medical Research
Lynne leader with a Macquarie University Sydney
Chair, Alzheimer’s Australia NSW
Paul Robertson AM
Rebecca Zeadally
Director, Telco Together Foundation: Senator the Hon. Jordon Steele-John, PR
Chairman, Social Ventures Australia: Ron Samson
Chairman, St Vincent’s Health Australia Limited and
St Vincent’s Health, NSW: Paul McGurk
BRIEF BIOGRAPHY OF PAUL ROBERTSON
Paul is a former executive director of Macquarie Bank with extensive experience in banking, finance and risk management. Paul’s other current directorships and interests include:
Chairman, St Vincent’s Health Australia Limited and
Chair of Trustees of St Vincent’s Hospital, Sydney:
One of the 20 largest private companies in Australia, this
organisation helps to create better education and employment
opportunities for disadvantaged Australians by bringing the
best of business to the social sector.
Chairman, Social Ventures Australia: This organisation
helps to create better education and employment
opportunities for disadvantaged Australians by bringing the
best of business to the social sector.
Chairman, Director, Financial Markets Foundation
for Children: This foundation raises funds for the health
and welfare of children in Australia. It is chaired by the
RBA governor and directors, including the CEOs of four
major Australian banks.
Director, Telco Together Foundation: This is a
telecommunications industry foundation seeking to make a
difference in disadvantaged communities.
CEO’S MESSAGE
I am both humbled and delighted to be joining the board of Alzheimer’s Australia NSW as your new chairman. This is indeed an exciting time for us, and I’m fully of optimism for our continued success in driving policy change and service improvements for people living with a diagnosis of dementia, their families and their carers in NSW. I wish to express my gratitude and respect for our past chairman, Jerry Ellis AO, and board members past and present for their outstanding contribution to the organisation, which is in great shape.
Over the years, I have had a strong interest in health issues for Australians, both young and old, and a passion for helping disadvantaged people. Like so many others, we have had dementia in our family and have felt its devastating effects firsthand.
I believe it is critical that we continue our push for improved awareness and access to appropriate services. Not only is dementia a whole-of-government issue, but it is a whole-of-society issue. Dementia touches every corner of Australia, yet I am also amazed at the grace and resilience of our consumers and their carers in dealing with life’s challenges. The compassion and professionalism of the organisation and its staff is well recognised and enriches the lives of those that it touches. I look forward to working with John Watkins AM and the entire team at Alzheimer’s Australia NSW, and I invite you to let us know where we can do better.
Paul Robertson AM
Chair, Alzheimer’s Australia NSW
WELCOME
Transport plays an important role in helping people to stay connected, and at Alzheimer’s Australia NSW we understand the significant impact living with dementia can have on access to transport.
The latest dementia prevalence rates show that the number of people with dementia across NSW is now an estimated 115,000. This number is projected to increase to more than 129,500 by 2020 and 272,000 by 2050 if no cure is found. These figures tell us that dementia is an issue that will continue to increase exponentially and highlights the fact that good transport options will only become more crucial. Alzheimer’s Australia NSW is committed to ensuring the transport needs of people living with dementia are met. If you have been diagnosed with dementia and you need help with the early stages of dementia we encourage you, your families and carers to plan ahead and consider your needs regarding mobility and transport.
In 2016, we will also continue to advocate for a dementia strategy across NSW that will see improved support for people who are living with dementia, including initiatives in health, housing and other services.
ALZHEIMER’S AUSTRALIA NSW IS COMMITTED TO ENSURING THE TRANSPORT NEEDS OF PEOPLE LIVING WITH DEMENTIA ARE MET.
We will strive to ensure that people living with dementia continue to be enabled and empowered. We will engage with the NSW Government to ensure comprehensive action continues to be taken to provide the best possible care and fight this disease.
This year, we also welcome a new chairman, Paul Robertson AM, who brings a wealth of talent and experience to the role. Paul replaces Jerry Ellis AO, whom I would like to thank for the significant contribution he has made to Alzheimer’s Australia NSW over the past three years. I wish him all the best for the future.
The Hon. John Watkins AM
CEO, Alzheimer’s Australia NSW
Chris Barton will walk from Wollongong to Sydney on 3 April, Sydney on 1 May, Albury Wodonga on 22 May up to help beat dementia. Doris says. For a good cause and to raise awareness about dementia, as he has been affected by Alzheimer’s disease. “This terrible disease has sadly affected two of my family members: my nanna, who has now passed away, and my auntie Marylyn, who is currently going through it,” he says. “I wanted to attempt a My Memory Walk that replicates the difficulties that someone who has Alzheimer’s disease has to go through on a daily basis, including the feelings of isolation and personal challenge. “The walk I have designed is not part of an organised group, but rather a personal, solo journey with the help of a small support crew to guide me, walk with me and help me if and when needed. “I also wanted to attempt this journey in the hope that both my personal and business networks would get behind me and understand how important this is to me so that I can raise important funds to fight Alzheimer’s disease.” For more information visit: https://reg.memorywalk.com.au/my/ 

ILLAWARRA MEMORY WALK & JOG RAISED MORE THAN $37,000, WHICH WILL GO TOWARDS VITAL SUPPORT FOR PEOPLE LIVING WITH DEMENTIA IN THE ILLAWARRA REGION.

‘MY MEMORY WALK’

On 30 April, Chris Barton will walk from Wollongong to Sydney approximately 80km through some rugged coastal terrain to raise funds through My Memory Walk & Jog, a new fundraising initiative involving personal challenges for those unable to attend specific events. Personal challenges, sponsored by family and friends, can be created to complete a certain distance.

Doris says he will be completing the arduous walk all in one day because he is passionate about raising money to fight dementia, as he has been affected by Alzheimer’s disease. “This terrible disease has sadly affected two of my family members: my nanna, who has now passed away, and my auntie Marylyn, who is currently going through it,” he says. “I wanted to attempt a My Memory Walk that replicates the difficulties that someone who has Alzheimer’s disease has to go through on a daily basis, including the feelings of isolation and personal challenge. “The walk I have designed is not part of an organised group, but rather a personal, solo journey with the help of a small support crew to guide me, walk with me and help me if and when needed. “I also wanted to attempt this journey in the hope that both my personal and business networks would get behind me and understand how important this is to me so that I can raise important funds to fight Alzheimer’s disease.” For more information visit: https://reg.memorywalk.com.au/my/

DIY MEMORY WALK & JOG

If you don’t have a Memory Walk & Jog near you but want to get involved, you can host your own event. Alzheimer’s Australia NSW’s DIY team will provide you with all the materials and support you need to create a successful and fun event for your community. You can set up a DIY fundraising page and share it with your community, friends and family via email, Facebook or Twitter so they can donate directly to you.

PORT MACQUARIE DEMENTIA AND MEMORY COMMUNITY CENTRE

Alzheimer’s Australia NSW’s upgraded Port Macquarie Dementia and Memory Community Centre (DMCC) was officially opened in February. A big “Thank you” to The Hon. John Akaka MLC and The Hon. Leslie Williams MP who helped us officially open the centre and to St Agnes’ Parish for their support. The relocation and upgrading of the DMCC was funded by a NSW Government grant.

WANTED: PARTICIPANTS FOR RESEARCH PROJECT

People living with dementia throughout New South Wales are invited to participate in a research project conducted by Alzheimer’s Australia NSW. The project aims to gain an understanding of what it means to live well with dementia, to find out what service providers could be doing to improve quality of life for people with dementia, and to identify strategies and good practice to ensure people with dementia get the most out of support services so they can lead the best life possible. The research findings and recommendations will be reported in an Alzheimer’s Australia NSW discussion paper, as well as journal articles and conference presentations. The work will also be incorporated into the ongoing policy and advocacy activities of Alzheimer’s Australia NSW.

If you have any questions, you can contact Marija Stupar, Research and Policy Officer, at marija.stupar@alzheimers.org.au or (02) 8876 4621.

THE KIDS4DEMENTIA SERIES

The stars of the Kids4Dementia video series, in which children and grandchildren of people living with dementia speak about their experiences, were treated to an afternoon tea at NSW Government House. They and their families were hosted by the Governor of NSW, His Excellency General The Honourable David Hurley AC DSC (Ret’d), who is the Patron of Alzheimer’s Australia NSW, and his wife, Linda Hurley. The Kids4Dementia series was launched during Dementia Awareness Month this past September. To view, visit: www.dementiaday.org.au/videos

MEMORY VAN SPONSORED BY NRMA

Throughout February, the Alzheimer’s Australia NSW Memory Van hit the road in northern NSW thanks to NRMA, whose support enabled us to conduct this vital tour. The van visited locations including Armidale, Inverell, Tweed Heads, Banora Point, Brunswick Heads, Tenterfield, Casino, Warialda, Lismore, Ballina and Alstonville, Glen Innes and Ocean Shores. The Memory Van is a mobile information service packed with helpful resources about memory concerns and maintaining good brain health. This service is useful for people who want information and advice about dementia, or for people who are interested in learning about Alzheimer’s Australia NSW’s support and education services. For more information, please contact Paddye Parnell: T: (02) 8876 4609 E: Paddye.Parnell@alzheimers.org.au

KIDS4DEMENTIA

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You can help us by completing a brief survey about your experiences and opinions.

To learn more, please see the Community Events Calendar on page 17.

To find out more, visit: https://www.surveymonkey.com/r/lwwdexpressionofinterest

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For people living with dementia and their carers, access to reliable and safe transport helps to maintain social connections and a reasonable quality of life. The issue of driving can become complex and emotionally fraught for all involved. A need exists to ensure the person with dementia remains independent and able to drive for as long as it is safe. However, it is also essential that appropriate support and information on alternative transportation options are available to make the difficult transition to non-driver as smooth as possible.

The Australian Institute of Health and Welfare estimates that 80 per cent of people living with dementia in the community will require assistance with transport by 2031. The potential impact of unreached needs for transport are social isolation, feelings of frustration and reliance on caregivers for basic needs. Some symptoms of dementia, such as memory loss, difficulty performing certain tasks and language problems, can lead to frustration and reliance on carers for basic needs.

Dr Helen Feist, Acting CEO of the Centre for Road Safety, notes that improved mobility provides older people with a sense of independence and control over their lives. “It gives them autonomy, as well as feelings of active citizenship and belonging,” she says. “These issues are critical to people’s wellbeing in later life. As Australia’s population ages, the ability to engage independently with the community through adequate and reliable transport is becoming more imperative.”

The transport needs of people with dementia vary with the stage and type of dementia. Individuals diagnosed in the early stages are generally capable of maintaining their regular activities for a limited period; many continue to drive and are capable of using public transport for some time. However, Alzheimer’s Australia NSW CEO, the Hon. John Watkins AM, says that as the condition progresses, carers tend to carry the main responsibility for meeting transport needs. “And this can be a daily stress for them,” he says.

In research conducted by Alzheimer’s Australia NSW, people with dementia and carers said that transport needs to:

- Involve people trained in dementia awareness and management;
- Provide escorts, especially for people who do not travel with a carer;
- Provide ‘door-to-door’ or ‘door-through-door’ service, rather than ‘curb-to-curb’;
- Involve no waiting; Be flexible; and Be available at short notice.

Driving
At some point, all people with dementia must stop driving. This point will vary depending on the symptoms experienced and how rapidly they progress. Any driver diagnosed with dementia has a legal obligation to report to Roads and Maritime Services (RMS) in NSW. This does not automatically mean that their licence will be taken away, but they will need their doctor to complete a Medical Report Form. They might also be required to have a practical driving assessment conducted by an occupational therapist. If they continue to drive despite a doctor’s advice and are involved in a crash, they could be prosecuted and their car insurance might be invalid.

Trevor Crosby, 67, was diagnosed with dementia two years ago. In December, he successfully passed a driving assessment conducted at the request of his neurologist. The test involved a series of reaction, retention and road-rules scenarios. Trevor will take a similar driving test every six months.

“I would recommend not to resist doing the tests once your specialist or GP recommend them,” Trevor says. “I can’t imagine the terrifying effects one would experience if they were involved in any sort of accident. Play it safe and act on qualified advice as soon as it is suggested.”

Bernard Carlon, Executive Director for Road Safety at Transport for NSW (RTA), says driving is a complex task that requires attention, memory, judgement and the ability to plan. “Dementia, particularly when it advances, can diminish the skills needed to drive to the point where it becomes unsafe,” Bernard says. “If you have been diagnosed with the early stages of dementia, we encourage you, your family or carers to plan ahead and consider your mobility and transport needs.”

For more information visit: http://www.transport.nsw.gov.au/customers/taxis/ttss

Taxi Transport Subsidy Scheme
The Taxi Transport Subsidy Scheme (TTSS) provides subsidised travel for approved participants to travel by taxi at half fare with up to a maximum subsidy of $30 per trip. This is available to people who are unable to travel on public transport without the assistance of another person. Each application is reviewed by Transport for NSW’s independent medical assessor. Aged, invalid, blind or other pensioners do not automatically qualify for participation in the TTSS, and participation is not means-tested.

The NSW Government has implemented an incentive payment for drivers of wheelchair-accessible taxis to improve the accessibility, reliability and response times for TTSS participants who require a wheelchair at all times for travel.


Community Transport Organisation
Across NSW, community transport groups provide assistance for people to continue living an independent life. Community transport groups provide not-for-profit passenger transport services that cater to the needs of individuals and their carers who cannot make use of existing private or mainstream public transport, or where public transport services are not available.

For more information visit: http://www.cto.org.au/

Other alternatives are covered in Staying on the Move with Dementia, available at NRMA offices, by phone at 131122 or online at: www.mynrma.com.au/living-well-navigator/getting-around/staying-on-the-move-with-dementia.htm

ALTERNATIVES
Public transport is a great alternative to driving. But if that’s not an option, there are two other main alternatives: the Taxi Transport Subsidy Scheme (TTSS) and the Community Transport Organisation (CTO).
ACCESSIBILITY TRANSPORT ADVISORY COMMITTEE

Barry Freeman represents Alzheimer’s Australia NSW on Transport for NSW’s Accessible Transport Advisory Committee (ATAC), which is a forum for identifying and considering opportunities and barriers in the current transport system. Barry worked as a chemical engineer and in the private sector prior to his wife, Joanie, being diagnosed with Alzheimer’s disease.

“I needed to care for her full-time. Our experience with dementia has involved me as a full-time carer for four years until there became the need for residential care because of Joanie’s deteriorating health as well as my own, to a degree,” Barry says. “I’m still involved with her most days of the week to give her outings and in the current transport system.”

“Barry says transport is critical for those with dementia, and certainly their carers, as there are many needs for travel within the caring role. “Examples are medical appointments, respite from home care, and just the enjoyment of going somewhere for a movie, a show, the beach or the country. It all is necessary to maintain some quality of life,” he says.”

“The ATAC committee meetings are very interesting in terms of understanding what Transport for NSW is doing with various forms of transportation. It also gives various interest groups a real opportunity to input their concerns and needs about the relevant planning that goes on in the development of new and existing transport initiatives.”

“The committee has the opportunity to really influence the final outcomes of these projects. I know that Transport for NSW values the input they get from ATAC, and I’m sure we make a difference for those with challenges in situations in their lives, ensuring their needs are more effectively understood and catered for.”

APPS

Accessibility apps are designed to provide better services and information for people with a disability to confidently use public transport in NSW. Three apps are available to download on the iTunes and Google Play platforms, and several other accessibility apps are currently in development and will progressively be released, the NSW Government says. abil.io (example below) helps users with limited mobility access public transport. Users can plan their trip in real time and be provided with comfortable walking distances that avoid significant uphill or downhill slopes and stairs. Information is also provided on internal routing in stations, proximity to accessible parking and ground services. Trip plans are automatically updated if services are delayed or cancelled, so users can easily navigate around any issues.

The app uses real-time information to provide routes that cater to the individual user’s accessibility needs. When accessible routes are provided, it lists nearby bus stops, train stations and stops that are flagged as not wheelchair friendly. It even alerts customers if a selected station has a short platform and advises which carriages to board. The app can also be customised based on personal walking speed and maximum distance to travel.

Stop Announcement is for people with vision impairment who need help navigating on public transport. It features a clear, high-contrast display and is designed to work with the Android accessibility feature TalkBack, to provide prompt, easily audible announcements as users arrive at bus stops, train stations, ferry wharves and light rail stops.

For more information visit: www.transportnsw.info/apps

INDIVIDUALISED FUNDING AND TRANSPORT

Planning for Transport in Self-Directed Care is a new information booklet about transport options included under the self-directed care models through the Federal Government’s National Disability Insurance Scheme, home care packages and the State Government program Living Life My Way. Not only does it set out transport options that are available for people with dementia, but it also aims to help people understand the value of transportation in maintaining connections and social engagements for those affected by a dementia diagnosis.

“It is important to ensure that people with dementia are valued and respected community members, experiencing a fulfilling range of life opportunities and choices,” says Minister for Ageing and Minister for Disability Services The Hon. John Ajaka, MLC.

“The resources are a reminder for people to think more about transport when considering care, says Alzheimer’s Australia NSW CEO The Hon. John Watkins AM.”

“Transport initiatives can lessen the impact for a movie, a show, the beach or the country. It all is necessary to maintain some quality of life,” he says. “The ATAC committee meetings are very interesting in terms of understanding what Transport for NSW is doing with various forms of transportation. It also gives various interest groups a real opportunity to input their concerns and needs about the relevant planning that goes on in the development of new and existing transport initiatives.”

“The committee has the opportunity to really influence the final outcomes of these projects. I know that Transport for NSW values the input they get from ATAC, and I’m sure we make a difference for those with challenges in situations in their lives, ensuring their needs are more effectively understood and catered for.”

The National Dementia Helpline is available 9am to 5pm, Monday to Friday.

T: 1800 100 500

E: helpline.nsw@alzheimers.org.au

MAINTAINING MOBILITY

For most people, mobility is key to maintaining a good quality of life. Mobility equals freedom, flexibility and independence. What if you could not go shopping, see your doctor, visit family or meet with friends? For many people, driving is the preferred transport option.

But what if you have a medical condition that interferes with your ability to drive? National medical guidelines state that a person is not fit to hold an unconditional licence if the person has a diagnosis of dementia. This does not always mean giving up driving immediately, but eventually they will have to stop driving because dementia involves a gradual decline in cognitive and physical ability.

Once dementia is diagnosed, the driver must notify Roads and Maritime Services (RMS) within two weeks in NSW. Otherwise the insurer might not provide cover and the driver might be liable for any accidents. There is no need to notify the insurer of the condition if the person is legally able to drive and has met their responsibility of notifying the licensing authority. If in doubt, it is best to check with the insurance company.

Early diagnosis can smooth the transition to not driving. Community mobility assessment and planning includes family support, accessing public transport and use of the Taxi Transport Subsidy Scheme (TTSS). Resources are available to support retirement from driving through Alzheimer’s Australia1-4. Losing the ability to drive is traumatic for anyone and can lead to enormous family tension. A planned approach can lessen the impact.

Special thanks to Beth Cheal, Rehabs on the Road, for her advice and recommendations. Find out more about CHEBA at www.cheba.unsw.edu.au. Professor Brodaty is an honorary medical advisor to Alzheimer’s Australia NSW.

3 Alzheimer’s Australia https://fightdementia.org.au or 1800 100 500
TESTING THE WATERS
COULD A URINE TEST ASSIST IN DIAGNOSING DEMENTIA?
AMERICAN SCIENTISTS ARE WORKING ON IT.

There have been some promising advancements in the area of dementia diagnosis over the past few years, but now American scientists have added another interesting prospect to the mix: a urine test. In one study published in the journal *Scientific Reports*, scientists found that a specific odour signature appears in the urine of mice before the onset of Alzheimer’s disease brain pathology, suggesting that it might be possible to diagnose the disease through urine.

To get to this conclusion, the scientists collected urine from mice that were modified to develop biomarkers associated with human Alzheimer’s disease (such as toxic amyloid proteins), as well as mice that were considered cognitively healthy (i.e. the control group).

The urine was then analysed using a chemical-based lab test known as an odour cross-habitation assay. Results suggested that the urine of the mouse group with Alzheimer’s disease produced specific urinary odour profiles that could be distinguished from those of cognitively healthy mice.

“While this research is at the proof-of-concept stage, the identification of distinctive odour signatures might somehow point the way to human biomarkers that identify Alzheimer’s at early stages," says study leader Dr Daniel Wesson, a neuroscientist at Case Western Reserve University School of Medicine in the US.

Identification of an early biomarker for Alzheimer’s disease could potentially allow doctors to diagnose the disease before the onset of brain deterioration, which would also pave the way for impending treatments to slow progression of the disease.

Scientists now hope to continue developing this test to further identify and characterise the odour signatures in humans.

RESEARCHERS STUDYING THE EFFECTS OF MICROGLIAL CELLS SUGGEST THAT REDUCING THEIR NUMBER MIGHT SLOW DISEASE PROGRESSION.

Reductions in brain inflammation could halt some of the memory and behaviour deficits seen in those with Alzheimer’s disease.

In this study, published in the journal *Brain*, researchers specifically looked at microglial cells, which constitute about 10 to 15 per cent of total brain cells. While the role of microglial cells in Alzheimer’s disease onset and development is still up for debate, it is suggested that reducing their numbers could slow down disease progression.

During this study, the researchers at the University of Southampton, UK, used tissue samples from post-mortem brains with and without Alzheimer’s disease. They found that the number of microglia were higher in the brains of those with Alzheimer’s disease, and the activity of the molecules regulating the numbers of microglia also correlated with the severity of the disease.

What does this all mean? Well, based on these results, the researchers hypothesised that blocking excess microglial cells in the brains of those with Alzheimer’s disease might slow down and even stop the disease from progressing.

Researchers tested mice genetically modified to develop Alzheimer’s disease. They gave some of the mice an oral dose of an inhibitor called CSF1R that blocks microglia from developing. They found that this inhibitor could in fact prevent the rise in microglial activation and partially prevent the pathological progression of Alzheimer’s disease, which was seen in untreated mice.

In addition, the inhibitor prevented the loss of communication points between the nerve cells in the brain associated with Alzheimer’s disease, and the treated mice demonstrated fewer memory and behavioural problems when compared with the untreated mice.

Dr Diego Gomez-Nicola, lead researcher on the study, said that these findings are as close to evidence as they can get to show that this particular pathway is active in the development of Alzheimer’s disease.

“The next step is to work closely with our partners in the industry to find a safe and suitable drug that can be tested to see if it works on humans,” he says.
RAISING THE BAR FOR RETIREMENT VILLAGES

AS THE NUMBER OF INDIVIDUALS LIVING IN RETIREMENT VILLAGES GROWS, A NEW GUIDE AIMS TO SET HIGH STANDARDS FOR OPERATORS.

Throughout 2015, eight businesses in Port Macquarie, NSW, were recognised as working towards being dementia-friendly:

- Coast Front Realty
- St Agnes’ Parish
- Silver Service Hire Cars
- Settlement City
- MBC Recruitment
- Top Spot Café and Cakes, Laurieton
- Café Buzz, Port Macquarie
- The Fat Fish Beachfront Bistro, Bonny Hills

The Port Macquarie Dementia Community Support Alliance has also approved action plans for Holdsworth Community Centre, Gaden Community Café and Woollahra Community/ Woollahra Council in Sydney.

Numerous businesses in the Port Macquarie-Hastings area continue to register their interest in the dementia-friendly communities initiative, with local business plans currently under review by the local Dementia Community Support Alliance.

Other communities within NSW are now seeing the achievements being made in the Port Macquarie-Hastings area, and they are looking to Alzheimer’s Australia NSW for guidance and support in their own dementia-friendly community endeavours.

Dementia Mates, a part of the dementia-friendly community initiative, fosters a relationship between volunteers and people living with dementia, and it is continuing to gain traction within the community. To date, the volunteer social engagement program has recruited numerous volunteers who have since started some beneficial friendships with people living with dementia. The project aims to reduce social isolation, and it will ensure people living with dementia in the community continue to enjoy social interactions and engagement with activities.

Port Macquarie has also been fortunate to be one of only two areas involved in the pilot program of a primary school dementia program. Kids4Dementia will be piloted in Term 1 of 2016 at two Catholic Year 4 and Year 5 primary school classes in Port Macquarie.

Local MP Leslie Williams and Alzheimer’s Australia NSW Regional Manager – North Coast Gary Thomas established the Port Macquarie Dementia-Friendly Community project in 2012. A steering committee has been involved in developing and driving the Dementia-Friendly Community project since 2012 with a committed Port Macquarie Dementia-Friendly Community project officer in place during 2015.

If you would like more information on how your business could work towards being dementia-friendly, please contact Kara Nicholson, Dementia-Friendly Community project officer, on 02 6584 7444 or via email at kara.nicholson@alzheimers.org.au

A new standard of support for people living with dementia in retirement villages will be set as the result of a joint project between Alzheimer’s Australia NSW and the Property Council of Australia.

With the number of Australians living in retirement villages expected to more than double in the next decade, a new specialist guide, The Dementia Guide for the Australian Retirement Village Industry, will help operators make responsible decisions about support and care levels provided across Australia’s 2200 retirement communities.

The guide gives expert guidance to owners about services and design features including health and wellbeing staff, in-house home care, carer support and respite, technology for monitoring and community connection, assisted living and serviced apartments that help people with dementia to live independently for longer, and advice on when dementia is going to become more prevalent in our communities, as the number of people diagnosed will only grow.

“We are pleased to have produced this guide in partnership with the Property Council, and we are confident it will help retirement village operators respond better to this growing challenge,” Brendan says. “There will be greater clarity for residents and prospective residents around the level and types of support they can expect to receive in their village. Older Australians are looking for this type of support, including people with dementia.”

The Dementia Guide for the Australian Retirement Village Industry is available at www.retailliving.org.au/research

A new guide for the Australian Retirement Village Industry aims to set high standards for operators.

Q&A

My wife who has dementia seems to have gone downhill quite quickly. She’s very confused and disoriented. What should I do?

Sometimes a rapid deterioration in a person’s functioning indicates an acute medical condition, such as an infection. It is important to seek medical advice as soon as possible because the problem can often be easily treated. Sometimes it can be hard for someone with dementia to let you know the exact problem, but a visit to their GP should be the first step.

My mother has been diagnosed with Alzheimer’s disease and she is living interstate. I am really worried about her and what I should do. Can you give me any advice?

A diagnosis of dementia does not automatically mean that a person is incapable of caring for themselves. Helping someone to stay in the familiar surroundings of their own home for as long as possible is the ultimate goal. To be able to support your mum and help her to be independent, it would be helpful to access our help sheets here: www.fightdementia.org.au

To talk about your feelings and how dementia affects you, call our National Dementia Helpline on 1800 100 500.
CHANGES TO COMPLAINTS MANAGEMENT

ALZHEIMER’S AUSTRALIA AND OTHER ORGANISATIONS HAVE SUCCESSFULLY LOBBED FOR CHANGES TO HOW COMPLAINTS ABOUT AGED-CARE SERVICES ARE HANDLED.

From 1 January 2016 the Aged Care Commissioner, Rae Lamb, will be directly responsible for managing complaints about the care and services provided to people receiving Australian Government subsidised aged care in their homes and in aged-care facilities. The official title is the Aged Care Complaints Commissioner.

Alzheimer’s Australia NSW is encouraged by this development, as it separates complaints receiving, handling and resolution from the Department of Health, which funds the services, and from the Australian Aged Care Quality Agency, which monitors service delivery standards. This change was lobbied for by a range of organisations for many years.

The Aged Care Commissioner states, “It means people can have confidence in the independence of the complaints process because decisions will be made by me and on my behalf as an independent statutory office holder who is outside the department.”

For more information about the changes visit: www.agedcarecommissioner.gov.au or call 1800 500 294 (free call).

NSW TRUSTEE AND GUARDIAN

The NSW Trustee and Guardian performs a variety of services including drafting of wills, power of attorney and enduring guardianship, estate administration, trust management, and private or direct financial management. Like many government agencies, it seeks to improve the sustainability and efficiency of its operations by capitalising on web-based platforms, shared services arrangements and clients able to make contact with teams of staff in client services teams.

Beginning in early 2016, changes to the services will include:

- Access to trustee and guardian services through Services NSW locations;
- Access to a team of staff rather than reliance on one person to handle your situation, which can be an issue if it is not available when you need them;
- Increased use of online services to save time and reduce turnaround times;
- Greater autonomy for clients requiring financial management; and
- A new proposed fee structure that is simpler and more transparent.

If you are a client of the NSW Trustee and Guardian, you are encouraged to provide it with feedback, particularly if you notice changes in the quality, responsiveness, level of service and outcomes you have been getting.

Feedback can be directed to 2017andBeyond@tag.nsw.gov.au

WALKING THE WALK AND TALKING THE TALK

ALICIA AND HER HUSBAND, DAVID, HAD A BUSY LIFE AS PARENTS AND BUSINESS OWNERS. BUT AFTER DAVID WAS DIAGNOSED WITH ALZHEIMER’S, ALICIA DECIDED TO BECOME A DEMENTIA ADVOCATE AS WELL.

David and I have been married for almost 46 years. We have four sons and were successful businesspeople within the Parkes and Forbes communities. We had busy lives and were always highly motivated people. I would describe David as a free spirit – he’d get an idea and then just go out and do it.

In his late 50s, David started having difficulty processing conversations, and he would just get up from the dinner table and start doing the dishes. We realised that for him, that was his way to stay in control of the situation.

I visit him every day. Most of the time he doesn’t know who I am. In May last year, his two brothers came to see him and his face lit up like a neon sign. He didn’t know their names but he knew they belonged to him.

We know we’re not the only family affected, and the reason I became a Dementia Advocate was to try and help people have a better understanding of the effects of dementia. It’s important for people who have walked the walk to tell their story and let others know what may be ahead. There’s lots of information available, but it’s a big learning curve for anyone. For me, it would have been helpful if I’d known some of the things I know now, so I try to help pass that on to others who are going through similar experiences in any way I can.

I was always an easygoing, laid-back person, but he does have some behavioural issues. There were incidents where David hit staff. It wasn’t malicious, but when you’ve always been independent and now you have two people helping you shower, it can be very confronting.

I was diagnosed with Alzheimer’s nine years ago. It was very difficult for my family to deal with my Dad’s personal changes; we were facing the unknown. I became a Dementia Advocate so that I could share my family’s journey, help others, and raise awareness of this disease and how it affects so many people and their families.

What is one thing that is important for all carers to hear? You are not alone. Being a carer can become overwhelming: you feel exhausted, frustrated, and at times you feel absolutely helpless. But please know these feelings are normal. The day-to-day caring of a person with dementia can be draining not only mentally, but also physically. Please take care of yourself so that you can take care of your loved one.

If you would like to be a Dementia Advocate please contact Jo-Ann Brown or visit the Fight Dementia website. T: (02) 8875 4636 | E: jo-ann.brown@alzheimers.org.au W: nsw.fightdementia.org.au/nsw/support-us/dementia-advocates-program

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icare about your story with others who are helping them and you are letting them know that they are not alone on this journey.

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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.
Mt Kilimanjaro, located in Tanzania, is the highest peak in Africa and the freestanding mountain in the world at 5895 metres. To climb Mt Kilimanjaro is a great challenge, but entirely feasible for the hill-walker. Alzheimer’s Australia NSW has teamed up with highly respected tour operator Adventure Alternative, who have put together a seven-day itinerary that offers the opportunity to experience five different habitats from bottom to top. The ascent, accompanied by experienced guides and two members of the Alzheimer’s Australia NSW fundraising team, will be undeniably unique. In a matter of days, climbers move from the equator to what feels like the Arctic, through grasslands, tropical rainforest, alpine meadows, moorlands and desert uplands, and finally to snow and ice. Climbing Mt Kilimanjaro with Alzheimer’s Australia NSW will not only be an experience and an achievement that participants can be immensely proud of, but also an opportunity to make a real difference. The trip stands out from many due to the fact that participants will be exclusively climbing for Alzheimer’s Australia NSW, meaning everyone in the group will be fighting for the same cause.

“Taking on the challenge of climbing Mt Kilimanjaro is a great way to tick something off your bucket list and also do something great for charity,” says Alzheimer's Australia NSW CEO The Hon. John Watkins AM

For more information or to book your place, please contact Community Fundraising Executive Emma Jackson-South: 02 8875 4625 or emma.jackson-south@alzheimers.org.au

JOIN THE FIGHT
Do you want to be part of the fight against dementia? Here are a few of the ways you can get involved:
- Register for Memory Walk & Jog
- Hold a fundraising event of your own;
- Become a regular giver as a Dementia Fighter;
- Donate through your workplace; or
- Volunteer.

To learn more, contact Alzheimer’s Australia NSW Fundraising. T: 1300 636 679 E: nsw.fundraising@alzheimers.org.au

A
Patricia Aitchison
Patricia
B
Eve Beckingsale
Eve
C
William ‘Bill’ Joseph Callanan
William
D
John Davis
John
E
Charles Edward Ellis
Charles
F
June Elaine Faulder
June
G
Rosa Gagliano
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John Milton Hanns
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Anna Kapoukranidis
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Andre Lapacek
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Salvatore Macaluso
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Brian Ohlmus
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Constantina Papadimatos
Constantina
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Remigio Petrocco
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Giovanni Rascigno
Giovanni
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Alice Simmons
Alice
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Margaret Helen Thomas
Margaret
V
Lambert Vandenburg
Lambert
W
Mavis Mary Waterson
Mavis
Y
Derrick Younger
Derrick
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
Mindfulness for Carers: How to manage the demands of caregiving while finding a place for yourself
Dr Cheryl Rezek shows how simple mindfulness techniques can help caregivers manage the stress, anxiety, depression and burnout that too often accompany the care of people with special needs. The enjoyable mindfulness exercises will help caregivers regain control and maintain a positive outlook.

10 Helpful Hints for Dementia Design at Home
This book builds on the person-centred approach to dementia care and gives practitioners and carers a new way of looking at the disease. The workbook is full of exercises and activities to try, all designed to help the reader engage and connect with a person with dementia. Key topics explored in the workbook include: understanding how it feels to live with dementia; recognising the issues and feelings involved; and questioning one’s own approach to care to encourage compassionate, person-centred care. Throughout the workbook are helpful vignettes featuring two fictional characters living with dementia who provide examples of good and realistic practices.

FILMS
Glen Campbell: I’ll be me
In 2011, musician Glen Campbell set out on a tour across America. He thought it would last five weeks; instead, it went for 151 spectacular sold-out shows over a year and a half. What made this tour extraordinary was that he was just diagnosed with Alzheimer’s disease. Glen was told to hang up his guitar. Instead, he and his wife went public with his diagnosis and announced they would set out on a ‘Goodbye Tour’. The film documents this journey as he and his family try to navigate the unpredictable nature of Glen’s progressing disease using love, laughter and music as medicine. Special appearances from Bruce Springsteen, The Edge, Paul McCartney, Blake Shelton, Keith Urban, Brad Paisley, Steve Martin and Chad Smith, among many others.

The Sandwich Generation
In this emotionally charged account of family caregiving, filmmaker Julie Winokur and her husband, photojournalist Ed Kashi, show their personal lives with unflinching candour. Julie and Ed uprooted their two children and their business to move 4828km to care for Ed’s father, Herbie, 83, who has dementia. Julie and Ed face difficult choices and overwhelming responsibilities as they charge head-on through their ‘sandwich years’. It’s a story of love, family and the sacrifices of those who are caught in the middle.

LOANING ITEMS
These items and more are available to members of Alzheimer’s Australia NSW, and can be found at local resources centres and offices. Resources can also be posted to you if you are unable to get to a library site. Find a list of offices and resources centres on the Alzheimer’s Australia NSW website, and contact the library to borrow items.

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

DEMENTIA CARING
Specialist Home Care

Why clients choose our Specialist Services
✓ We Provide Relief from the strains of caring for a loved one
✓ DIY Home Care Kits supporting you in your own home
✓ Specialised Dementia Advice delaying the need to move into a nursing home

SPECIALISED HELP FOR YOUR FAMILY

EARLY STAGE CARE
- Support in caring and delaying onset of dementia.
- General support at home
- Mind exercises and games

MIDDLE STAGE CARE
- Home organisation
- Dressing, bathing, cooking, feeding
- Helping with complex care needs

LATE STAGE CARE
- Around the clock 24 / 7 specialised care
- Professional respite services and advice

www.dementiaacaring.com.au Call 1300 100 788 Heart, Mind & Health Solutions

IN TOUCH AUTUMN 2016