LIVING AND LEARNING

DEMENTIA EDUCATION IS THE PATH TO EMPOWERMENT
At the Alzheimer’s Australia NSW annual general meeting on 26 November, we announced our four new directors, including a new chairman. We are very fortunate that Malcolm Shyvens, Eileen Hoggatt and Dr Jennifer Alexander have joined the board.

We welcome them as directors and thank them for their interest and commitment. Our incoming chairman is Paul Robertson AM, who will take over the reins in February 2016. Paul brings a wealth of experience and talent to his role as director and chair, and I am very pleased that he has agreed to take up the position.

As we welcome our new directors, we also say thank you and goodbye to our departing directors who have made such a magnificent contribution to the governance and direction of the organisation over many years. Outgoing directors include Barry Groundwater, Nick O’Neill, Essa Witt, The Hon. Professor Peter Baume AC and myself.

Recently, Alzheimer’s Australia has been successful in lobbying the Federal Government for ongoing funding to continue the Younger Onset Dementia Key Worker program. This innovative service was under threat and its continuation is welcome news across all Alzheimer’s Australia state and territory organisations, where some 40 staff are engaged in its operation.

Since 1 July 2015, Alzheimer’s Australia NSW has been the sole operator of the National Dementia Helpline. The consolidation of this service into a single national operation has resulted in an improved service, staffed by knowledgeable and professional helpline advisors. Also, new technology systems were introduced to help improve the consumer experience and an extensive training program was undertaken for new staff. Importantly, the number of calls to the helpline has exceeded expectations. It was pleasing to see the team handle the large spike in calls resulting from increased media activity and Alzheimer’s Awareness Month.

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Reflecting on my term as your chairman, the growth of services and geographic coverage have been significant achievements over the past three years. As a result, we are helping more people living with dementia than ever before. This growth would not have been possible without the contribution of dedicated and talented staff led by a strong senior management team, with John Watkins at the helm as CEO. I leave my role as chairman humbled by the wonderful people I have met and excited by the opportunities available to Alzheimer’s Australia NSW in the future.

Jerry Ellis AO
Chair, Alzheimer’s Australia NSW

The research aims to assist retirement village operators with incorporating dementia-friendly design and principles, thus ensuring they are providing people living with dementia optimum support. Recommendations include education for staff and residents to become more dementia aware, and co-locating villages and residential aged-care facilities for a smoother transition if the need arises.

The research also identified an opportunity for retirement village operators to make villages healthy ageing places, thus helping to reduce the incidence of dementia by promoting social interaction and brain-healthy lifestyles, as well as preserving the independence of residents.

This is the final edition of In Touch for 2015, and I would like to take this opportunity to thank everybody who has been involved with and supported Alzheimer’s Australia NSW this year. I wish you all a safe and happy holiday season and a successful 2016.

The Hon. John Watkins AM
CEO, Alzheimer’s Australia NSW

As I write this column, we are celebrating the success of Dementia Awareness Month 2015. Throughout September, I was delighted to have had the opportunity to attend many of the events and initiatives hosted across New South Wales. It was inspiring to see so many members of the public from all walks of life engaging with and supporting the idea of creating a dementia-friendly nation. I am confident that our Dementia Awareness Month activities have contributed to educating Australians about the importance of creating communities in which people living with dementia are supported to live a high quality of life with meaning, purpose and value.

Since our previous edition, Alzheimer’s Australia NSW released new research relating to dementia in retirement villages, marking the first time this topic has been looked at in-depth.

The research found greater clarity is needed around the difference between a retirement village and a residential aged-care facility, as there was confusion about the different levels of support each offered. Additionally, the research identified disparities in the design, management, operation and business models of retirement villages, resulting in varying levels of support.

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Gill Aylng, the head of Global Action Against Dementia with the United Kingdom’s Health Department, spoke about the role nations can play in raising awareness about dementia. She toured the country and urged governments to develop national strategies to tackle the growing dementia challenge. Many more people in the UK now receive an accurate dementia diagnosis than ever before, Gill says. She credited the success of programs such as the National Dementia Strategy for achieving this.

“We already have more than 105 communities across England that have signed up to work towards becoming dementia-friendly,” Gill says.

Alzheimer’s Australia has a holistic plan to tackle dementia focused on raising awareness about risk factors; the importance of dementia-friendly communities; the need for more education for healthcare professionals; better support networks for carers and families; and greater investment in dementia research.

Action is needed on dementia now, says Alzheimer’s Australia CEO, The Hon. John Watkins AM. “Dementia is already the second leading cause of death for Australians,” John says. “By the 2060s, spending on dementia is set to outstrip that of any other health condition in the country. We need to act and we need to act now. The UK experience has shown us this type of program is possible, and it has already brought about huge benefits to communities across that country.”

Thanks to all the dementia advocates who shared the one thing that would help make their community more dementia-friendly for our #1StartsWithYou social media campaign as part of Dementia Awareness Month. There were some great suggestions shared on Dementia Daily, featuring everything from age-appropriate respite care right through to the need for informed communities. You can catch up on those stories here: www.dementiadays.org.au/conversations/it-starts-with-you/

Congratulations to Michelle de Mari, Alzheimer’s Australia NSW’s librarian, whose poster From Collection to Connection was awarded best poster at the recent Dementia Collaborative Research Centre’s National Dementia Research and Knowledge Translation Forum. Prizes included a subscription to the Australian Journal of Dementia Care and a copy of Live and Laugh with Dementia by Associate Professor Lee-Fay Low. Both of these items are also headed to Alzheimer’s Australia NSW’s Port Macquarie library branch.

Alzheimer’s Australia NSW is, in collaboration with local Illawarra dementia services, held a forum for carers, people with a diagnosis of dementia and the community on 24 September in Wollongong. The forum discussions focused on the diverse experiences and understandings of dementia within culturally diverse and Indigenous communities. Two hundred people attended from Wollongong and the surrounding area – some from as far away as Nowra.

Several speakers took the stage to highlight some triumphs in dementia education and awareness programs, as well as to discuss new research and initiatives. The themes of inclusion and diversity carried through all topics, and speakers asked attendees to keep in mind the unique challenges faced by people from culturally, ethnically and linguistically diverse backgrounds associated with finding and receiving care.

The program comprised five Yarn Ups in the Bega Valley and Eurobodalla shires during November 2015. The dementia rate is three times higher for Aboriginals and Torres Strait Islanders compared to the general population. It is hoped that the Yarn Ups will increase understanding of dementia and dementia risk reduction strategies, and empower community members to seek help if symptoms arise.

Aunty Doris Moore (right) chats with dementia advisor Gaye Finch.

Alzheimer’s Australia NSW partnered with Katung Aboriginal Medical Service to provide Aboriginal Elders with culturally sensitive information on dementia risk reduction.

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A DEMENTIA DIAGNOSIS EXTENDS BEYOND JUST THE INDIVIDUAL – FAMILY, LOVED ONES, AND PROFESSIONAL AND COMMUNITY SERVICES ALL INTERLINK TO PROVIDE SUPPORT, WHEN THESE GROUPS ARE EMPOWERED THROUGH EDUCATION, THERE ARE BETTER OUTCOMES FOR ALL INVOLVED.

LIVING AND LEARNING

Living with dementia, or caring for someone with dementia, can be an overwhelming or isolating experience. But with support and strategies in place, people affected by a diagnosis can continue to lead very full and meaningful lives.

Everyone that a person with dementia comes into contact with has the capacity to make a difference in that person’s life. Gaining a greater understanding of dementia, and being able to recognise and anticipate a person’s needs to ensure they are supported, is the primary aim of these programs.

Alzheimer’s Australia NSW provides a range of education programs about dementia and its impact on a person, family and friends; the organisation also supports learning and development for services across NSW.

The programs include courses and workshops for families and volunteer care providers of people with dementia. Tailor-made programs can be designed to meet specific learning and professional development needs. These include health and allied care staff, residential care staff, community care workers and volunteers across all sectors.

“Good education is a major component to enhancing the quality of life of people living with dementia,” says Danielle White, Alzheimer’s Australia NSW Manager, Education and Sector Development.

“Our programs consider the breadth of relationships: the person with the diagnosis, their family and social network, and the professional and community services, which all interlink in the support of a person.”

Alzheimer’s Australia NSW aims to give the best possible care and support for that person,” says Alzheimer’s Australia NSW Dementia Care Advisor, Genelle Sharrock.

Most important takeaway:
“Greater understanding of the experience of people with dementia, to recognise their needs and be better able to anticipate and respond to those needs. That ensures the person is valued, retains dignity and control.” says Judi Weaver, Senior Dementia Care Advisor.

What it is:
“People with dementia interact with a spectrum of health professionals and care providers. We aim for everyone to have the knowledge, skills and confidence to give the best possible care and support for that person,” says Alzheimer’s Australia NSW Project Officer Genelle Sharrock.

Why it’s important:
“People with a diagnosis of dementia come into contact with has the capacity to make a difference in that person’s life. Gaining a greater understanding of dementia, and being able to recognise and anticipate a person’s needs to ensure they are supported, is the primary aim of these programs.”

Why it’s important:
“Greater understanding of the experience of people with dementia, to recognise their needs and be better able to anticipate and respond to those needs. That ensures the person is valued, retains dignity and control.”

Most important takeaway:
“People can still experience happiness and a meaningful life by living well.”

PROFESSIONAL WORKING IN AGED CARE

What it is:
“Evaluation of the program completed by people living with dementia have demonstrated increased feelings of understanding, connection, inclusion and empowerment,” says Alzheimer’s Australia NSW Group Work Facilitator Sonja O’Sullivan. “Comments have included a renewed sense of hope to live positively alongside a diagnosis of dementia.”

Most important takeaway:
“Those with a diagnosis of dementia take away that they have a voice, that they are not alone and that dementia is not all-encompassing.” Sonja says.

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PERSON LIVING WITH MEMORY LOSS

What it is:
“Broadening community awareness and education also goes a long way towards supporting a person with dementia,” she says. “Education for all is key to helping a person walk forward and thrive. It helps people living with dementia make plans for the future, families and friends to support the changes as they come along, the community to maintain connectedness for the person and family, and the service sector to preserve the essence and sense of self, dignity and purpose.”

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Information and advice on education options is available through the National Dementia Helpline, 1800 100 500 or at the Alzheimer’s Australia NSW website www.fightdementia.org.au/nsw
IN TOUCH SUMMER 2015

COVER FEATURE

3 FAMILY/ UNPAID CARE PROVIDERS OF A PERSON LIVING WITH DEMENTIA

What it is: Information, advice and practical strategies for living with dementia. Includes how to maintain good communication, support the person’s independence and maintain wellbeing in a caring role.

What is offered in this space: A range of short to comprehensive courses, workshops, evening seminars and webinars. Education for families is free. Key themes include: understanding dementia and its impact; effective communication; planning ahead; coping with grief; making the most of services and support; and transitioning into care.

Why it’s important: “It’s really great for primary care partners and families to connect with each other and be able to share their experiences. They can often feel very isolated and overwhelmed,” says Pam Davis, Alzheimer’s Australia NSW Educator. “It can help put things into perspective when they learn that they are not alone and that others are experiencing similar issues.”

Most important learning that carers can take from the sessions: “Learning effective communication is incredibly valuable,” Pam says. “Good communication is incredibly valuable,” Pam says. “Communication is central to keeping the person with dementia connected and enables them to remain part of the ‘social club’ of life.”

BROADENING COMMUNITY AWARENESS AND EDUCATION GOES A LONG WAY TOWARDS SUPPORTING A PERSON WITH DEMENTIA... IT’S PART OF WHAT ENABLES PEOPLE.

4 COMMUNITY EDUCATION

What it is: Programs aimed at increasing awareness of dementia, its prevalence, signs and symptoms, and risk reduction. Community education benefits people with concerns about themselves, family, friends and the community.

What is offered in this space: Healthy Brain Ageing and Your Brain Matters are programs aimed at reducing the stigma associated with dementia and dispelling myths. We also have a Memory Van, which is a mobile information service that visits regions throughout NSW 5 presenting sessions about dementia and ways to maintain brain health.

Why it’s important: “Being out in the community is often the first encounter for people who want information about dementia and a ‘better understanding,’” says Paddy Parnell, Alzheimer’s Australia NSW Brain Health Awareness Officer.

Most important takeaway: “There is more to dementia than just memory loss. It’s not just ‘an old people’s disease’, and there are steps you can take to try to prevent it,” says Paddy.

5 CALD COMMUNITY EDUCATION

What it is: Dementia education for people from non-English speaking backgrounds, known as culturally and linguistically diverse communities (CALD).

What is offered in this space: Staying Connected is a program designed to transcend the English language by using visual elements to educate people about dementia. Alzheimer’s Australia NSW has also produced a series of short films in multiple languages called ‘It’s Not a Disgrace... It’s Dementia’ that are available on DVD and YouTube.

Why it’s important: “Community awareness is critical to understanding that dementia has a medical basis. People from some communities attribute superstitions or religious connotations that are negative, so the person doesn’t get optimum care,” says Michelle Bruce-Basic, Alzheimer’s Australia NSW CALD Liaison Officer. “It just becomes a huge barrier to getting a diagnosis. It’s something we try to overcome.”

Most important takeaway: “The message ‘there is no shame in having dementia’ is absolutely crucial. To walk away with a sense of how we depend on one another and not just having a healthy brain, that when somebody develops dementia they don’t have healthy brain function. If it’s not behaving correctly, go to a doctor,” Michelle says.

CASE STUDY 1

CAROL FALCONER

For residents and staff at St Hedwig Village in Blacktown, a dementia education program has made the aged-care facility a happier, more relaxed and empathetic environment.

Staff from the facility, which provides dementia and palliative care for more than 130 residents, met with Alzheimer’s Australia NSW educators in April 2014 to discuss types of dementia education available.

A survey of staff and families of residents was conducted, and a report was provided setting out recommendations.

“We wanted to ensure our staff had the necessary skills to best care for people living with dementia and Alzheimer’s Australia NSW explained the various types of training that could be offered,” says Carol Falconer, Educator and Workplace Health and Safety Coordinator at St Hedwig Village.

“We realised all of our staff have some interaction with people living with dementia,” Carol says.

“Whether they are cleaners, nurses or other workers.”

Some of the subsequent education sessions – such as Effective Communication and Meaningful Engagement modules – were arranged for staff who wanted additional training.

“The Alzheimer’s Australia educators were brilliant. They imparted knowledge, listened to what our staff had to say and tailored sessions around that,” Carol says.

“The sessions really put us in the residents’ shoes. The training gave everyone a much greater insight into what it’s like to have dementia – it made them more tolerant, patient and more empathetic.”

CASE STUDY 2

ALAN GRAVOLIN

When Alan Gravolin started experiencing difficulties caring for his wife, who had been living with dementia for 20 years, the call he made to the National Dementia Helpline “was one of the most significant things we have done that has helped us,” he says.

“At that time I was struggling,” Alan admits. Lyn, 75, a former primary school teacher, began to experience dementia symptoms in her mid-50s.

In 2009, Alan decided he needed options for additional support.

“I rang the helpline and they put me in contact with aged-care people in our local area and also got me involved with the Living with Memory Loss program,” he says. Alan, 75, is a former aged-care administrator.

“I was invited to join a younger onset dementia support group and I was given the name and contact details for the dementia support person in my local area. She organised some day care for Lyn, one-on-one social support in which she did activities that she enjoyed, as well as short-term respite.”

Through the program, Alan says he learned the need to take care of himself so that he could continue his role as carer.

“We’ve all got different stories, each one of us has a different situation, but the common task is dealing with some form of dementia. I would suggest that anyone who wants to find out about their options should ring the helpline.”

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

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E: helpline.nat@alzheimers.org.au

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GIVING EXPERT CARE

PROFESSOR HENRY BRODATY AO AND PROFESSOR AMANDER SACHDEV AM, CO-DIRECTORS, CENTRE FOR HEALTHY BRAIN AGEING (CHBA)

Education is important for dementia, and I don’t just mean that more education builds a stronger brain. What I mean is education enables those around the person with dementia to be better at helping their loved one and themselves.

Family members already know the person affected better than anyone else. Now their responsibility is to learn about Alzheimer’s disease or whatever form of dementia they are facing. What can the person with dementia do or not do at different stages of their progress? What are the legal and financial implications? Knowledge creates a better quality of life for the affected person and family carers. The Alzheimer’s Australia Living with Memory Loss is an excellent start.

Education is also crucial for professional carers. Nurses, personal care assistants and patients themselves need to be aware of the special needs of people with dementia provide better care for residents in homes or patients in hospital.

The community needs education, too. People fear dementia, and associated with fear is stigma. All Australians should be aware that dementia is a word, not a sentence. People with dementia can – and want to – lead fulfilling lives for many years, and communities can become dementia-friendly. After all, most of us will be touched by dementia directly or through a loved one.

Find out more about CHBA at www.chba.unsw.edu.au.

Professor Brodaty is an honorary medical advisor to Alzheimer’s Australia NSW and Professor Sachdev is an honorary medical advisor to Alzheimer’s Australia.
Global pharmaceutical companies have been investing billions of dollars into experimental therapies targeting amyloid plaques and tau tangles, two of the prime suspects that damage and kill brain cells. The plaques are deposits of a protein fragment called amyloid-beta that build up and damage the brain’s nerve cells, while tangles are twisted fibres of another protein called tau that build up inside the brain’s cells. Although a lot is known about these plaques and tangles, researchers are still trying to fully understand their cause and how to remove them from the brain.

One of these pharmaceutical companies, Eli Lilly, has been trialling Solanezumab, an antibody therapy designed to target amyloid plaques and remove their toxic function. In the latest analysis of a clinical trial involving thousands of people, the results suggest the therapy might be effective in removing amyloid plaques, as well as slowing clinical impairment in people within the early stages of Alzheimer’s disease. Once again, the researchers want to replicate these promising early results in larger trials.

**UNFORTUNATELY, NO, WE AREN’T QUITE THERE YET, BUT CLINICAL RESULTS ARE MOVING IN THE RIGHT DIRECTION.**

Last year, the World Dementia Council set a goal of finding a disease-modifying therapy for Alzheimer’s by 2025. Unfortunately, no, we aren’t quite there yet, but clinical results are moving in the right direction.

The Australian National University’s Alzheimer’s Disease Risk Index (ANU-ADRI) is a series of questions designed to evaluate a person’s risk of dementia based on their lifestyle. However, it was unknown whether participants were motivated to take action based on the results of the test. Dr Maree Farrow from the Wicking Dementia Research and Education Centre received funding from the Dementia Collaborative Research Centre for Early Diagnosis and Prevention to undertake this evaluation. She presented the survey results at the ninth annual Dementia Research and Knowledge Translation Forum in Sydney in September.

“At our evaluation of 184 Australian adults who completed the ANU-ADRI online assessment, we found that a large majority of users did, in fact, intend to take some action to change their lifestyle,” Dr Farrow says.

The survey results found that users were most likely to change their lifestyle, “Just as importantly, users also found the ANU-ADRI recommendations easy to understand, helpful and motivating.”

**THERE’S AN APP FOR THAT**

**DEMENTIA CARERS AND HEALTH PROFESSIONALS BECOME TECH SAVVY**

A new dementia care app was launched at the ninth annual Dementia Research and Knowledge Translation Forum in September in Sydney. Kim Burns, the Project Coordinator, said carers and family members want to have information and advice at their fingertips in language that is clear and easy to understand.

“The app was developed after extensive consultation with experienced caregivers and expert clinicians,” Kim says. “It covers an array of potential behavioral scenarios that might arise in dementia and strategies to manage these.”

More than 90 per cent of people with dementia display some form of behavioral or psychological symptoms during the course of their condition. The app’s content is based on information produced by the Dementia Collaborative Research Centre for Assessment and Better Care (DCRC ABC).

Professor Henry Brodaty, Project Leader and Director of the DCRC ABC, UNSW, cautioned that carers should always seek guidance from a professional for concerning behaviour. At the forum, Kim also presented results from an evaluation study that looked at clinicians’ use of an app to support health professionals managing behavioural and psychological dementia symptoms.

More than 20,000 participants have already completed the test.
PREPARATION IS KEY

RETIREMENT VILLAGES BETTER EQUIPPED TO DEAL WITH THE GROWING ISSUE OF DEMENTIA AFTER NEW RESEARCH

The growing popularity of retirement villages coupled with an increase in dementia cases has led to new research to help village operators become more dementia-friendly.

“The research found that there needs to be more clarity about the difference between retirement villages and aged-care facilities. It also found there are opportunities for operators to make villages “healthy ageing places”, which could reduce the incidence of dementia by promoting social interaction and healthy lifestyles,” Alzheimer’s Australia CEO The Hon. John Watkins AM said that with more than 2200 retirement villages in Australia, it’s an issue that needs to be addressed.

“In 2014, approximately 184,000 Australians were living in retirement villages, and this rate is projected to increase to 7.5 per cent in 2025,” John says.

“There is currently an estimated 342,800 Australians living with dementia – 112,000 of these live in NSW – and that is expected to soar to almost 900,000 by 2050. Dementia is an issue that is only going to become more prevalent generally, in our community, and in retirement villages as well,” he says.

This is the first time dementia in retirement villages has been looked at in-depth, and the research found vast variation in the design, management, operation and business models of retirement villages – and thus variation in the types of support and services offered.

The research was co-funded by the IRT Foundation and the Property Council of Australia. IRT Group Chief Executive Nieves Murray said the research would ultimately help people age well in their own homes for as long as possible.

“As a lifestyle and care provider, we know we are doing our best when we can tailor support and services to the individual, and encourage independence,” Murray says. “It’s not always easy, of course, and some facilities are better placed to support residents with dementia than others. That’s why this research is so important – it provides an evidence base to inform the support and services that we provide.”

Mary Wood, Executive Director of Retirement Living at the Property Council of Australia, says retirement villages are a great setting to “age in place,” which leads to reduced hospital stays, improved mental wellbeing and delayed entry into aged care.

“Village managers and staff have significant contact with their residents, and many are well-placed to give guidance to the resident and their family about support options,” Wood says. “Retirement villages are ready to take the next step in providing support for people with dementia.”

Recommendations from the paper Dementia in Retirement Villages include:

• State and Territory Governments should ensure greater clarity and transparency for consumers;
• Information from sources such as MyAgedCare website that clearly delineate the differences between residential aged care and retirement villages;
• Government pilot funding for grants to retirement villages to incorporate dementia-friendly or universal housing designs;
• Government dedicated funding for dementia education programs; and
• Retirement village industry peak bodies to encourage operators to develop housing that achieves the highest level universal housing designs.

A copy of the paper can be found on Alzheimer’s Australia NSW’s website.

LITTLE EFFORTS GO A LONG WAY

KIDS COMPLETE TRIATHLON FOR ALZHEIMER’S AUSTRALIA NSW

A group of children from the northern beaches took it upon themselves to organise and compete in a special fundraising triathlon for Alzheimer’s Australia NSW. The young group was led by brother and sister team Isla and Fin Hendry, whose grandfather Bill was diagnosed with the condition 10 years ago at the age of 57. They were joined in their endeavours by neighbours Amelie and Tahli Snape.

The triathlon comprised a 50-metre swim, five-km bike ride and two-km run. The children raised $310 in sponsorship money from knocking on doors locally. According to them, although the event was hard work, it was worth every moment because, in their own words, “Doing a triathlon is much, much easier than living with Alzheimer’s disease.”

DON’T FEEL PATHETIC, ESPECIALLY IF YOU HAVE ALZHEIMER’S DISEASE

“I’m not amazing. I think kids can deal with it – it’s not amazingness, it’s kindness,” he says.

Grace, 13, says she also hopes to educate other children about what it is like having a loved one with dementia by participating in the video series.

“I think it is really important for people to know about dementia, because it has been hard for me and I wanted to help,” she says. “I really liked talking about it because we don’t often speak about grandma. It was good to speak to an outsider who won’t judge us. If you speak to a friend about it, they might think it is weird.”

The videos are part of a dementia education program developed by Dr Baker and a team of teachers, people with dementia, children and academics. It features the videos along with seven short modules covering topics including what causes dementia, how it feels to have dementia, how to keep the brain healthy and what happens in an aged-care facility.

The modules are told through the story of Ollie, Ruby and their Pops. Each one is accompanied by a class activity, such as an interactive brain, role-playing game or drawing exercise.

Q&A

Q: My mother recently moved into full-time residential care. When we visit, she is quiet and seems disinterested in things. What can I try to better engage her with? There are lots of things you can do to make the most of your visits. Bring a magazine or newspaper, and read interesting articles aloud to your mother or do the crossword together. Consider helping her write a letter to friends or other family members. This will also help maintain links to important people in her life.

Q: A friend told me exercising my brain could reduce my risk of dementia. Is this true? Numerous studies have shown that engaging in mentally-stimulating activities throughout life is associated with better cognitive function, reduced cognitive decline and a reduced risk of developing dementia or a memory issue.

Mental activities are of most benefit when they involve learning new things and are reasonably complex. Some activities that involve exercise for the brain include reading, taking a course, learning a language, playing an instrument, and doing crossword puzzles or other puzzles.

National Dementia Helpline: 1800 100 500

DOING A TRIATHLON IS MUCH, MUCH EASIER THAN LIVING WITH ALZHEIMER’S DISEASE.

From left: Zack Garnham, Tahli Snape, Katie Brittain, Fin Hendry, Amelie Snape, Isla Hendry, Hannah Garnham and Georgia Snape.
A NEED FOR NURSES

A NSW GOVERNMENT INQUIRY INTO REGISTERED NURSES IN RESIDENTIAL AGED CARE SHOWS THAT EXPECTATIONS ARE NOT IN LINE WITH REALITY.

The need for registered nurses in nursing homes and other aged-care facilities was the subject of a recent NSW Government inquiry. The focus of the inquiry was on residents who require a high level of residential care, the impact of Commonwealth Government changes to aged-care policy, the need for regulation and minimum standards, and the adequacy of patient-to-nurse ratios.

The Commonwealth-Aged Care Act 2014 does not mandate that aged-care facilities with high-care residents have a registered nurse on duty at all times. Rather, Division 64-1 (b) of the Aged Care Act 2014 requires that aged-care facilities ensure that there are at least one registered nurse on duty at all times and that registered nurses be allowed to complete their own shift without being required to cover for other staff. This means that residents may not receive the care they need.

The inquiry found that residents of aged-care facilities are not always receiving the care they need.

A LIFE, CHANGED

TREVOR CROSBY WAS DIAGNOSED WITH DEMENTIA AT AGE 65. HE SAYS THE DIAGNOSIS CHANGED HIS LIFE, BUT HE’S USING HIS REMAINING TIME TO RAISE AWARENESS ABOUT THE DISEASE

It was just 10 months ago that I received the news that would change my life forever – I was 65, and I was diagnosed with dementia. I got choked-up, I cried ... it felt like all my defences had been smashed. I felt helpless and pathetic.

“I’m going to die,” I said. I had never even thought about that before.

Although I felt a little stronger when my diagnosis of Lewy Body Dementia was confirmed a few months later, it still gave me an almighty knock.

Having Jill, my wife, beside me and the support of Alzheimer’s Australia NSW has been selected for a highly commended NSW Carers Award. Kevin cares for his wife, Maree, who was diagnosed with younger onset Alzheimer’s disease in 2007.

Kevin is part of Alzheimer’s Australia NSW’s Southern NSW Community Advisory Group and is an active Dementia Advocate, sharing his story in the media, as well as participating in service development and representing consumers at conferences and other events. Dementia Advocates Helen James and Barry Freeman were also recognised with a Local Carers Award.
ALZHEIMER’S AUSTRALIA
NSW COURSES

THE ALZHEIMER’S AUSTRALIA PROGRAM OFFERS COURSES FOR CARE WORKERS, FAMILY CARERS AND VOLUNTEERS

CARE WORKER COURSES – FEES APPLY
A Positive Approach to Understanding Dementia, Effective Communication and Behaviour Changes
North Ryde 25 February 2016
Meaningful Engagement in Activities
North Ryde 22 March 2016

FAMILY CARER INFORMATION
Three-Day Carer Course
North Ryde 10, 17, 24 March 2016
Four-Evening Carer Course
North Ryde 10, 17, 24, 31 May 2016
Family and Friends
North Ryde 17 February 2016, 19 April 2016

VOLUNTEER COURSES
Interacting with a Person with Dementia
North Ryde 4 May 2016

For more information, or to register, please contact:
T: (02) 8875 4660
E: nswoducation@alzheimers.org.au

EDUCATION

DEMENTIA ADVOCATE DAY
Back row, left to right: Trevor Crosby, David Doig, Anne Kern, Imelda Gilmore, Shaun Lannon and Sean Fielder. Front row, left to right: Mike Bryan, Linda Bryan, Melissa McManus, Helen James and Paul Williams.

Last August, we held the inaugural Dementia Advocates Introduction Day for 14 new Dementia Advocates. The day provided an opportunity for advocates to hear from Alzheimer’s Australia NSW CEO John Watkins about their integral role in the organisation, and how important it is for us to provide a platform for their voice to be heard, both internally and externally in the community.

Department general managers explained how consumer engagement fits into the work they do in service development, research and fundraising. During the second half of the day, a trainer from Health Consumers NSW gave a very valuable presentation about consumer representation and acknowledged the increasing importance of consumer engagement in the health sector.

Lastly, Sarah Price gave a presentation on sharing your story in the media. Thanks to everyone who attended. We hope to do more of these events next year.

CAFÉ CONNECT
Raymond Terrace (Cups n Sausers
Cafe 5/43 William St, Raymond Terrace)
10 – 11.30am (Second Friday each month) 8 January, 12 February, 11 March
Miriam Low (02) 4962 7000

Newcastle (Birdy’s 169 Maitland
Road, Tighes Hill)
10 – 11.30am
(Third Thursday each month)
15 December, 19 January, 16 February, 15 March
Stuart Torrance (02) 4962 7000

Maitland (East’s Leisure &
Golf Club, Tenambit St, East Maitland)
11am – 12.30pm
(Third Thursday each month)
12 January, 21 January, 18 February, 17 March
Stuart Torrance (02) 4962 7000

Toronto (Toronto Workers
Club, 9 James St, Toronto)
10 – 11.30am
(Thursday each month)
12 December, 21 January, 18 February, 17 March
Stuart Torrance (02) 4962 7000

Warwick Bay (Warner’s Bay, 320 Hillsborough Rd,
Warner’s Bay)
10.00 – 11.30am
(First Wednesday each month)
(No group January)
2 December, 3 February, 2 March
Miriam Low (02) 4962 7000

Coffs Harbour
(No group)

Newcastle (Yatte Yattah nursery)
10 – 12pm
16 December, 20 January, 17 February, 23 March
Sandra Kay (02) 8875 4694

Fairly Meadow
(29 Nicolson Street)
10 – 12pm
17 December, 21 January, 18 February
Jane Bushell (02) 4849 5651

Carers Cafe Connect (For Carers Only)
Hamilton (Hunter Dementia and Memory Resource Centre)
10 – 11.30am (Second Thursday each month)
10 December, 14 January, 11 February, 10 March
Jane Bushell (02) 4849 5651

Younger Onset Dementia Cafe Connect (Under 65)
Gundagai (A & B Cafe)
10 – 12pm
19 January

Younger Onset Dementia Support Groups (Under 65)
Coogee (Cups n Saucers
Coogee O’Meara)
10 – 12pm
10 December, 14 January

Dementia and Younger Onset Dementia Support Groups (Under 65)
Sydney Harbour (The Nelson Resort)
10.30am – 12pm (No group)
18 March

Murrumbateman Inn
Christmas Lunch/Final get together for the year
11.30am – 1.30pm
16 November
Libby Smith (02) 6241 0881

Boorowa (Superb Bakery)
10am – 12pm
2 February
Libby Smith (02) 6241 0881

Harden (Jackson's Bakery)
10am – 12pm
3 February, 2 March
Libby Smith (02) 6241 0881

Newcastle (Newcastle
Cruising Yacht Club
Wickham)
10 – 7.30pm
(No Cafe January)
2 December, 3 February, 2 March
Clare Coyle or Deb Veness (02) 4962 7000

Merimbula (Dolphin Room,
Club Sapphire)
10am – 12pm
9 February, 8 March
Barbara Williams (02) 6492 6158

Bega (Thornleigh
On Newtown)
10 – 11.30pm 2 December,
3 February, 2 March
Barbara Williams (02) 6492 6158

Cooma (Werri-Nirra Centre)
10.30am – 12.30pm
19 January, 23 February, 22 March

Bredbo (Snowy Mountains
Gourmet Food)
10am – 12pm 9 February
Jindabyne (Rydges Horizons)
10am – 12pm 2 March
Verity Jackson (02) 6462 3981

Batemans Bay (Batemans Bay
Community Centre)
10.30am – 12pm
3 February, 2 March
Gaye Finch (02) 4474 3843

Cruikshank and District
10.30am – 12pm 19 January,
23 February, 22 March

Port Macquarie
28 January, 25 February, 24 March
Kath Storey (02) 6584 7444

Port Macquarie Dinner Group
8 December, 9 February
Kath Storey (02) 6584 7444

Laurieton Beef Week
22 January, 26 February
Kath Storey (02) 6584 7444

Laurieton Lunch Group
11 December, 12 February
Kath Storey (02) 6584 7444

COMMUNITY EVENTS

OPPORTUNITIES FOR PEOPLE WITH DEMENTIA,
THEIR CARERS AND FAMILIES TO SOCIALISE.
BUILD SUPPORT NETWORKS AND LEARN.

THEIR CARERS AND FAMILIES TO SOCIALISE,
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BUILD SUPPORT NETWORKS AND LEARN.

COMMUNITY EVENTS

Opportunities for people with dementia, their carers and families to socialise, build support networks and learn.

They acknowledge the increasing importance of consumer representation and valued presentation about Younger Onset Dementia.

Consumers NSW gave a very valuable presentation about the day, a trainer from Health Consumers NSW gave a very valuable presentation about consumer representation and acknowledged the increasing importance of consumer engagement in the health sector.

Lastly, Sarah Price gave a presentation on sharing your story in the media. Thanks to everyone who attended. We hope to do more of these events next year.
**FUNDRAISING**

**IT TAKES A VILLAGE**

**LIKE MANY, THE NAVARRA FAMILY HAS BEEN TOUCHED BY DEMENTIA. THEY WENT ALL OUT TO RAISE FUNDS FOR ALZHEIMER’S AUSTRALIA NSW. PLUS, LEARN ABOUT COMMUNITY FUNDRAISING OPPORTUNITIES WITH ‘BE THE ONE’.

When you sign up, our community fundraising executive will send you your very own fundraising pack that you can personalise to suit any event or activity. You don’t even have to have a specific idea in mind to start off with, as there are plenty of ideas and tips in our A-Z of Fundraising Ideas, from auctions and bake sales, to Zumbathons. Although you can organise and run your own event, you will not be alone – our staff on the fundraising team are just an email or a phone call away, and they are always happy to hear from you.

Alzheimer’s Australia NSW is appreciative of the time, energy, talent and resources that are generously donated by fundraisers each year. These fundraising and awareness-raising champions help us to spread the message about how we can work together in our communities to support people living with dementia. They also support investment in research strategies to deliver better treatments and preventative measures for the future.

For more information, please contact Emma Jackson-South on: E: emma.jackson-south@alzheimers.org.au T: (02) 8875 4625 M: 0413 178 158

**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; and
- Volunteer.

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

**BEQUESTS**

Leave a gift in your will

To meet the growing demands for our services, please consider supporting us by leaving a gift in your will. Helping us in this very special way will allow us to continue to provide the vital support, education services and social research to help people with dementia, their carers, families and communities.

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 4629

E: karen.carran@alzheimers.org.au

**IN MEMORIAM**

**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**

Rose Adamson

Annie Angely

Vicki Ahtanasatos

**B**

Bevan Henry Badger

Sylvia Evelyn Baldwin

Haris Bals

Geoffrey Barber

Mary Therese Barry

Sandy Benson

Linda Bertoldo

Robert Boffs

Jim Boultatsakos

Jean Bow

Stanley William Bowden

Frank Brescoa

Lou Burford

Heather Patricia Burns

**C**

Barbara Jane Campbell

Myra Loraine Cherry

Clementina Chiolfao

Panayiotis Christou

Franzo Cipollone

Evantha Citsas-Ioanides

Isobel Margaret Clarke

Joan Clarke

Patrick Michael Clifford

Elaine Coleman

Verna Collison

Giuseppe Commissio

Con Cotsios

Philip Mark Cutler

**D**

Charlotte Daly

Fausto De Santi

Iima Joan Duggan

**E**

Ivy Eades

Pamela Mary Eades

Douglas Edgar

Jean Engeltr

Norma Evans

**F**

Marie Ella Fitzgerald

**G**

Valerie Helena “Peg” Garrock

Norman Stanley Gibbeson

Ernest Glover

**H**

Isabella Harding

John Haritos

Grace Harris

Marilyn Harvey

Roy Edward Heath

Ronald Hickey

Betty Hyam

**I**

Antonio Giuseppe Iorfino

**J**

Stella Jones

**K**

Marios Kalapon

Wilma Ann Kane

Irene Kolivos

Anica Konda

**L**

Nicolaos Laggas

Pattie Lawless

Peggy Jean Leeds

Margaret Lyons

**M**

Robert Michael Marshall

Peg Martin

Caterina Musso

**N**

Agnes Nagle

Susan Nakhoul

Elaine Neville

William John Maxwell Nissen

**O**

Anthony O’Dea

**P**

Vasilios Pandelios

Leo Papast

Cynthia Parke

Antonino Pizzolo

Ronald Joseph Prudames

David John Pulford

**S**

Armando Scacciootti

Vincenzo Signorelli

Peter Smedley

Anton Stariha

Giuseppina Suppa

Doreen Lillian Swane

**T**

Valerie Tennant

Eliza Ellen Timms

Michael Tooke

Betty Triantafyllou

Angela Tripodi

**V**

Sidney Valentine

John Voudounis

**W**

Judith Clyda Watkins

Nica Webster

John Joseph Whelan

Mary White

Warren Wynn

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**

**Live and Laugh with Dementia: The essential guide to maximising quality of life**

This is an easy to read book that highlights the importance for all of us to keep our brains healthy as we age through mental and physical activities. It outlines the ways the brain functions and shows how dementia might affect these abilities. The author provides really practical strategies and tips on topics such as: whether it is okay to lie to a person with dementia; how to present activities; how to communicate more effectively; and how to maintain friendships and connections, and get family and friends to become more involved.

The book is interspersed with some really useful case studies that offer examples of interactions between a person with dementia and their carer. The great thing about this book is that it is not only based on research and science, but also on the author’s years of experience working with people with dementia and their carers.

**Dementia Beyond Disease: Enhancing wellbeing**

Focusing on seven essential domains of wellbeing, G. Allen Power, M.D., a board-certified geriatrician, challenges readers to evaluate their attitudes, expectations and approaches to dementia, and to embrace new ways of thinking that will lead to better solutions to problems encountered in all types of care settings. Learn how to overturn the prevailing disease-based care practices by emphasising wellbeing and the many ways to enhance it in people with dementia. Readers can also see how current care practices chronically erode individual wellbeing, and then discover more dignified and strengths-based alternatives that build it up.

Inspiring and highly readable, this book confronts widely accepted dementia care practices and presents approaches that promise a new vision for achieving the best possible outcomes for every person touched by this debilitating disease. From the internationally acclaimed author of the groundbreaking and award-winning book *Dementia Beyond Drugs*, comes another eye-opening exploration of how to improve the lives of people with dementia and those who care for them.

**I’m Still Here**

John Zeisel recognises the place for joy in living with Alzheimer’s disease. He explores non-pharmacological approaches to the treatment of this condition. This ‘treatment’ is concerned with how we can access the senses, structure the environment and adapt relationships to promote quality of life.

Zeisel is a pioneer in the use of the arts and creating appropriate living environments to enhance independence and wellbeing for people with dementia. His book leaves us with a feeling of enthusiasm for dementia care and a recognition that despite disabling conditions, we are all still human and have the capacity to experience pleasure, respect and empowerment.

**The Dementia Care Workbook**

This workbook builds on the person-centred approach to dementia care. It gives students, practitioners and carers a new way of looking at dementia and the people who live with it. The workbook is full of exercises and activities to try, all designed to help the reader to engage and connect with a person with dementia, thus empowering both them, and their families and carers. Key topics explored in the workbook include: understanding how it feels to live with dementia; recognising the issues and feelings involved for family carers or healthcare professionals when caring for individuals with dementia; and questioning one’s own care approach and attitude, to encourage more compassionate, person-centred care.

Throughout the workbook, vignettes featuring two fictional characters living with dementia provide examples of good and realistic practices. These encourage the reader to examine his or her own practice and explore ways in which care can be enhanced.

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