

MILESTONES

WINTER 2015. ISSUE 17



Enhancing Well-Being:
Bridging the Gap between
Philosophy and Reality

G. Allen Power, MD, FACP
Rochester, New York, USA
17 April 2015



Still Alice
Producer
Opens
World Forum



**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

Milestones

The Alzheimer's Australia WA newsletter. Winter 2015. Issue 17.

On the cover: **top left:** Elizabeth Gelfand Stearns – Still Alice producer, **top right:** Edie Mayhew and Anne Tudor who shared their experience of Edie's journey, **bottom:** Dr Al Power talks about enhancing well being.

CEO's Message 3

Services 15

Research

ASPREE World-first Aspirin Study 14

ADI2015 conference 4–8

Reducing the use of antipsychotic medications in people 9

Opportunity for consumers to have their say on medication management 16

Dementia-friendly Information

Events calendar 16

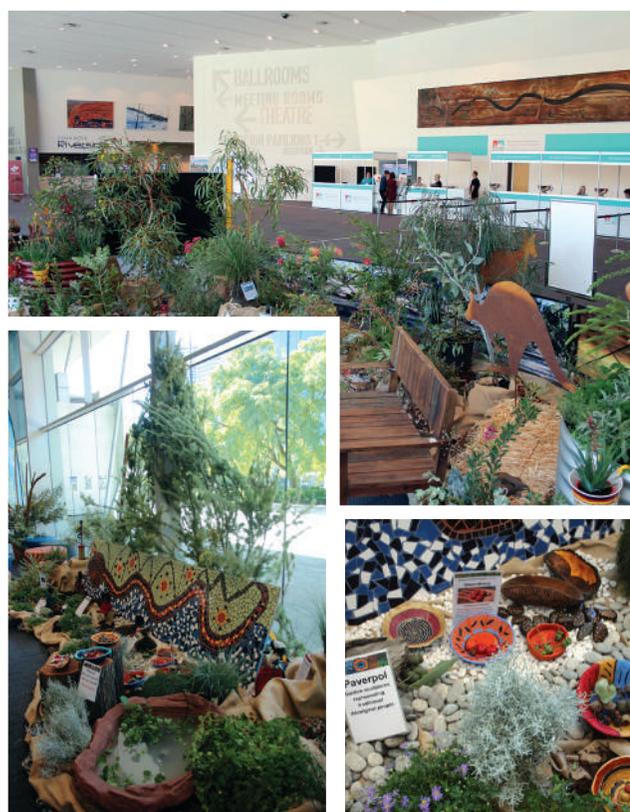
From motorbikes to river cruisers 10–11

Language use 13

What happens to your donations? 12

Bush sensory garden

Designing outdoor environments for people with dementia



Alzheimer's Australia WA with help from a group called Moorditj Mia (Good Home), many of whom were Nyoongar, created an amazing indoor bush sensory garden which brought the conference alive.

Are you interested in becoming a dementia champion for your organisation

Why not complete the Certificate IV in Dementia Practice (10341NAT)?

The next intake for the above course commences on 1 September 2015. This qualification is applicable to experienced care workers, allied health workers, nurses and other health professionals who would like to enhance their career opportunities in supporting people with dementia. This qualification can be a pathway for those wishing to pursue leadership roles and be innovative in their workplace.

The Certificate IV in Dementia Practice consists of 14 units which cover a breadth of knowledge and skills to support quality care and service provision for people living with dementia. The cost of undertaking this qualification is \$2,500 with payment options available.

For further enquiries regarding the Certificate IV in Dementia Practice, contact Alzheimer's Australia WA on 9388 2800 or email: sheila.haywood@alzheimers.org.au.

CEO's message



Alzheimer's Australia WA
CEO, Ms Rhonda Parker

Welcome to this winter edition of Milestones. We delayed this edition so we could bring you the highlights of the Alzheimer's Disease International 2015 conference in Perth. We are still a little breathless from such a big event hosting 1100 delegates from 49 countries.

Care, cure and the dementia experience were the conference themes. These themes were comprehensively and expertly covered by many wonderful speakers. New thinking, great commitment and deep honesty dominated the presentations.

We believe the conference made a real contribution in shifting how dementia is viewed and understood. The conference has the potential to have a lasting, positive impact on changing the way dementia is viewed across the world at all levels from government to aged care. We will continue to contribute to this evolution in the months and years to come.

The impact was also felt internationally on a social media scale. We reached almost 318,000 accounts generating over 3.9 million Twitter impressions. That means the conference has appeared in posts nearly four million times across the world! Clearly dementia is a global hot button.

People living with dementia provided some of the most poignant moments and statements in the event. A major highlight was Edie Mayhew and Anne Tudor who shared their experience of Edie's journey from pre-diagnosis through to diagnosis with younger onset dementia.

Helga Rohra, also a dementia advocate who is living well with younger onset dementia, gave a fabulous heartfelt presentation saying: "I am still valuable, I am me! – I don't want to be a victim of dementia I want to be the VICTOR!"

"Each of you are enablers to make us live well with dementia – include us as much as possible," was her request to decision makers.

Dr Allen Power, Associate Professor of Medicine from the University of Rochester in the USA, spoke about enhancing the wellbeing of people with dementia by focusing on wellness, avoiding

using stigma and fear to advance the cause, and creating a shift from being not just 'dementia-friendly' but 'dementia inclusive' and quoted colleague Dr Richard Taylor who has said:

"I believe as people progress with dementia, their humanity increases."

Dr Power finished by saying, "we can start working on wellbeing now."

He later commented to me that he thought the conference had created a turning point in the global conversation about dementia, that we had succeeded in putting the person and not the disease first, and from now on the personhood of people living with dementia could be foremost in the conversation in a way it hadn't been before. I could not have asked for a better outcome from the conference.

I appreciated Al's comments, they meant a lot. Of course, sustaining this change will be the next big task, but the conference will have achieved its goals if what Al commented was in fact what other attendees also experienced.

The conference opened so many new doors and so many eyes. We are hopeful that delegates working in the areas such as treatment and care will go back to their workplaces with an absolute focus on the words of Harry Johns, (President and CEO Alzheimer's Association) "tomorrow a cure, today care."

I would like to thank our brilliant local organising committee, the AAWA team and volunteers, and all of the inspiring and committed people living with dementia who attended for all pulling on their oars to row this event to the great success it was.

I commend this conference edition of Milestones to you. Happy reading.

Rhonda Parker
Chief Executive Officer

CONFERENCE REPORT

Keeping an 'eye' on dementia research at the ADI2015 conference

New developments in eye imaging technology used to detect dementias were outlined by American and Australian dementia researchers at the Alzheimer's Disease International (ADI2015) conference in Perth. Some trials suggest eye imaging may detect Alzheimer's disease and other dementias 10-20 years before symptoms appear.

Retinal specialist and Assistant Professor of Ophthalmology at Duke University Medical Center, Dr Eleonora Lad, stressed the importance of early detection and highlighted there are few reliable methods to detect the early signs of dementia.

"It is becoming more evident that if we can treat dementia early, before symptoms occur and too much damage is caused, the progress of the condition can be stalled.

"Because the retina is an extension of the brain, retinal changes may mirror the changes that occur in the brain with dementia. It has long been recognised that people with early-stage Alzheimer's disease experience abnormalities in vision, perception of colour, motion, and peripheral vision," Dr Lad said.

In collaboration with her colleagues, Dr Lad developed novel image-analysis software that is able to make correlations between eye layer thickness and other structural changes, and the likelihood of a person to develop Alzheimer's disease.

"The resolution of our eye imaging technology is 100 times that of a brain MRI scan, improving our ability to detect early changes caused by dementia. It can be performed more frequently and at a small fraction of the cost of a brain MRI scan, which can be in the thousands of dollars.

"While our software is still a few years from becoming

routinely available in a clinical setting, it has already been used in a number of large-scale clinical trials. It is possible that in the future an image could be analysed on the spot and any suspicious images would be referred to that person's GP for further consultation," Dr Lad said.

Australian researcher, Dr Mojtaba Golzan from the School of Advanced Medicine at Macquarie University is also undertaking similar experimental research, which was also presented at the conference.

"Our preliminary research suggests changes in small blood vessels in the eye may correspond to similar changes to blood vessels in the brain, which are known to play a role in the development of Alzheimer's disease. Our research may lead to a relatively low-cost and non-invasive approach to enable early detection of Alzheimer's disease," Dr Golzan said.

Alzheimer's Australia WA, CEO Rhonda Parker said what was being presented at the conference was research that may help in less invasive, earlier detection of Alzheimer's disease in the future.

"It is becoming quite evident that the way we detect and diagnose Alzheimer's disease and other types of dementia could be much simpler and quicker in as little as 10 years' time. This would be a good development for the hundreds of thousands of Australians with dementia and their carers."

CONFERENCE REPORT



Serge Gauthier

One of the keynote speakers of the conference was Canadian world authority on dementia Professor Serge Gauthier (McGill University) who explained at length the latest in treatments and diagnosis.

He covered the experimental treatment called Aducanumab trialled in people with early stages of Alzheimer's disease and the FINGER trial. Below are extracts about both from Ian McDonald and can also be found at: dementiaresearchfoundation.org.au

The Aducanumab Study

The experimental Alzheimer's disease treatment called Aducanumab trialled in people with early stages of Alzheimer's disease has shown to reduce amyloid plaque levels, and in turn slow down their cognitive decline.

These interim results were recently presented by Pharmaceutical Company Biogen Idec at the 12th International Conference on Alzheimer's and Parkinson's Diseases and Related Neurological Disorders. This Phase 1b clinical trial included 166 people with the early stages of Alzheimer's disease.

What is a Phase 1b study? They are intended to demonstrate 'proof of concept' and confirm a hypothesis, while also evaluating the safety, tolerability, and efficacy of the experimental treatment. If the results are promising, the researchers will then move into larger trials and longer term trials, known as Phase 2 and 3.

The participants in the study were randomly split into five dosage groups and given their treatment over 54 weeks. The results showed that those people who received higher doses of the treatment observed a reduction of amyloid plaques over the course of the 54 week period, and also performed better on two different cognitive tests (Mini Mental State Examination and Clinical Dementia Rating scales). Those who received low treatment doses or placebo control did not show any reduction in amyloid plaques or improvement in cognition.

Roger Nitsch, co-founder and President of Neurimmune and one of the companies involved in financing this clinical trial was very welcoming of these results saying:

"The dose and time dependent reductions on brain amyloid levels in addition to the slowed cognitive decline and an acceptable safety profile are encouraging results for Aducanumab. We are looking forward to the planned Phase 3 clinical trials."

About the Aducanumab vaccination: It is an experimental passive vaccination that involves the injection of antibodies which target and remove amyloid beta plaques. Amyloid plaques are suggested to play a role in the neurodegenerative process in Alzheimer's disease.



KEY TALKING POINTS ABOUT THIS TRIAL

- This is a Phase 1 clinical trial only- this treatment is not available outside of research.
- This trial was undertaken in people with early stages of Alzheimer's disease and the results in people with later stages of Alzheimer's disease or other types of dementia are unknown.

The FINGER study

Dementia risk reduction strategies prove beneficial for enhancing memory performance in older people.

Researchers have shown that older adults who follow a healthy eating plan and undertake regular exercise and brain-training activities have enhanced memory performance over those who don't.

The 'FINGER' study, from Finland, is the first large, long-term, and methodologically robust trial showing that multiple approaches can improve or maintain cognitive functioning and reduce the risk of cognitive decline among older individuals.

The results were published in The Lancet Neurology Journal and found that those who were in the intervention group who received comprehensive brain health advice had improved or maintained cognitive function over time (anywhere from 25-150% better than the control group who were given only basic health advice).

CONFERENCE REPORT



Still Alice movie heavyweight speaks at world dementia forum

Former Universal Studios Senior Vice President and Still Alice producer Elizabeth Gelfand Stearns was an inspiring opening speaker at the Alzheimer's Disease International conference.

Gelfand Stearns passionately spoke about how inspired she was after listening to author Lisa Genova read a moving passage from *Still Alice* at an Alzheimer's Association advocacy event. By then, the book had caught fire within the Alzheimer's community and had hit the New York Times bestseller list despite being initially rejected by 35 publishers.

Together with her producing and advocacy partner, Maria Shriver, Gelfand Stearns helped shepherd the book to its big-screen debut, collecting various co-producing partners.

Julie-Anne Moore signed on to play the titular character and convinced fellow cast members to sign up for well below their typical star-status fees, including Alec Baldwin as Alice's husband and Kristen Stewart as the eventual caregiving daughter, Lydia.

"We now want to use the movie to help move the cause forward, like *Philadelphia* did for HIV and *A Beautiful Mind* did for schizophrenia," Gelfand Stearns said.

In her 16 years at Universal Studios she was named by *Newsweek* and *Advertising Age* as a member of 'The

Marketing 100' – the Top Marketers of the Year- for her work developing the Jurassic Park franchise.

Gelfand Stearns left her Universal Studios post in 2004 to manage The Judy Fund, a fund that Elizabeth and her family created in honour to her mother Judy, who was diagnosed with Alzheimer's at age 62, and her maternal grandmother.

As Chair of The Judy Fund, Gelfand Stearns works to ignite public awareness and engagement in the battle against Alzheimer's disease.

To date, The Judy Fund has raised and granted close to \$5 million dollars to support Alzheimer's research and public policy.

The Judy Fund joined the Zenith Society, the highest level of giving at the Alzheimer's Association Worldwide. It invests in research from beta-amyloid trials to patient care and in the Association Ambassador Programme, helping support the creation of a network of 511 advocates to lobby legislators.

Gelfand Stearns was appointed to the National Board of Directors of the Alzheimer's Association in 2011.

CONFERENCE REPORT



Investment in dementia risk reduction a must

The Federal and State Governments, businesses and the community can all help curb the soaring number of people expected to be diagnosed with dementia over the next decade, but not without new and significant investment.

A paper, released at the Alzheimer's Disease International Conference, has estimated that a 20 per cent reduction in cases of Alzheimer's disease could save as much as \$570 million by 2020 and up to \$8.3 billion by 2050, and has called for a continuation of funding and increased investment in the Your Brain Matters risk reduction programme.

“Dementia is now the second leading cause of death in Australia¹,”

Alzheimer's Australia WA CEO Rhonda Parker said.

“We estimate that the direct and indirect costs of dementia could be as high as \$73 billion by 2050. It is vital that Governments do something to reduce this future financial, not to mention social and emotional, impact on Australian society.”

According to research published last year, approximately one third of Alzheimer's disease cases worldwide are potentially attributable to seven key risk factors.

The biggest contributor of these by far is physical inactivity, followed by high blood pressure in mid-life.

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

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

As the McKinsey Global Institute found in its analysis of more than 70 programmes around the world designed to reduce obesity, the cost savings and higher productivity outweigh the financial investment.”

Alzheimer's Australia's risk reduction programme *Your Brain Matters* was the world's first publicly funded dementia risk reduction programme.

The *Your Brain Matters* programme had already proven to have some success in changing public perceptions of



dementia risk reduction and in programme participants' intent to change behaviour to lead a healthier life, despite the modest amount of funding out.

However, the programme has been refunded in the 2015 budget.

“The Australian Government was a world leader in funding this programme and we would ask for them to continue to show good leadership and good sense by refunding the programme,” Rhonda Parker said.

“We know that not all cases of dementia can be prevented through risk reduction, but reducing those that we can will be enormously beneficial.”

The discussion paper, *Reducing the Prevalence of Alzheimer's disease: Modifiable Risk Factors or Social Determinants of Health*, makes several recommendations, including that the:

- Australian government reinvests in the Your Brain Matters dementia risk reduction programme;
- Australian government identifies opportunities to incorporate brain health messaging in other preventative health campaigns around smoking, obesity and diabetes;
- Australian and State Governments assess *Closing the Gap* health policies to ensure they also address the need to reduce dementia risk;
- Australian and State Governments implement incentives for healthier dietary choices including taxes on foods known to increase the dementia burden; and
- Australian Government prioritise research funding through the National Health and Medical Research Council into how to encourage the population to embrace dementia reduction behaviour, in particular for populations of social and health disadvantage.

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

¹ Australian Bureau of Statistics (2015) Causes of Death, Australia, 2013: Cat no. 3303.0

Comments from Perth 2015



What the consumers said

- "Too many excellent presentations to mention! All consumer talks (Edie and Anne, Kate, Maxine Thompson, Helga) were very powerful. The last session (on YOD) presenters were excellent ... The consumer retreat was wonderful."
- "The connection to numerous websites for ongoing support is invaluable. The sessions are enthralling and it's difficult to decide what NOT to go to! Well done ADI and all involved."
- "Excellent organisation of programme. Well balanced, themes idea worked well."
- "(Good) To be able to 'see' the world through my husband's eyes, at this time."
- "The consumer room has provided a lovely place to regather thoughts and rest."
- "The talk given by Edie Mayhew and Anne Tudor was amazing."
- "It has provided me with a more educated view on future ways to help."
- "Feel comfortable and happy. Listening to people with dementia who can relate with the right words of how I feel but can't express."
- "Meeting so many friendly people from far and wide. The speakers I heard were very informative and enjoyable. Lots of valuable information."

What the experts said

- "A great welcome from our Australian hosts! The human content (talks from persons with dementia, exchanges with caregivers) out performed the scientific content. I hope that my plenary talk on new diagnostic approaches and therapies, both pharmacologic and non-pharmacologic life-style changes, gave some hope to persons at risk." Serge Gauthier, C.M., MD, FRCPC, ADI MSAP Chair
- "Dementia is a societal problem and we need to provide care today while we look for the cure tomorrow," Mark Wortmann, Executive Director, Alzheimer's Disease International.
- "The conference has created a turning point in the global conversation about dementia," Dr Allen Power, MD, clinical associate professor of medicine at the University of Rochester, USA.
- With over 1,000 delegates from 49 countries, the conference provided an excellent opportunity to showcase research, care and risk reduction strategies that are advancing the lives of people living with dementia and their families and carers." Carol Bennett, National CEO, Alzheimer's Australia.
- "It is our role to synthesise global evidence for policymakers and the public in a way that is both digestible and evidence based," Professor Martin Prince. Centre for Global Mental Health, Kings College, UK.
- "It is becoming more evident that if we can treat dementia early, before symptoms occur and too much damage is caused, the progress of the condition can be stalled." Dr Eleonora Lad, Retinal specialist and Assistant Professor of Ophthalmology at Duke University.



Reducing the use of antipsychotic medications in people with dementia: a new approach

A new, free resource to help doctors decrease the over-prescription of antipsychotic medication in people with behavioural and psychological symptoms of dementia has been released.



LEFT TO RIGHT:

Paul McMahon CEO Southern Cross Care NSW & ACT

Dr. Julian Pierre GP working in aged care who features in the video

Katherine Burchfield Director Integrated Care, NSW Department of Health

Associate Professor Henry Brodaty AO Co-Director Centre for Healthy Brain Ageing UNSW and Director Dementia Collaborative Research Centre

The Hon. John Watkins CEO Alzheimer's Australia NSW

Timothy Perry Consultant Pharmacist who appears in the video

The short film, *Antipsychotics & Dementia: Managing Medications*, has been developed in response to recent research which has found that antipsychotic medication, which can have serious side-effects, is used too frequently to manage behavioural and psychological symptoms of dementia.

Available on Alzheimer's Australia's Detect Early website, the resource has been developed by our federation partners Alzheimer's Australia NSW, in conjunction with Southern Cross Care (NSW & ACT) and the Dementia Collaborative Research Centre. It has also been supported by the AMA (NSW).

Alzheimer's Australia NSW Medical Advisor Professor Henry Brodaty, who appears in the short film, said that there are often a range of non-pharmacological interventions that can and should be considered first when managing behavioural and psychological symptoms of dementia, such as pain therapy and person-centred activity, before prescribing antipsychotic medication.

"In some cases, the use of antipsychotic medication is appropriate," said Professor Brodaty, who is also the Director of the Dementia Collaborative Research Centre.

"However, we know that in many cases, there are other, much more appropriate treatments that should be looked at first.

"For example, providing pain relief, tailoring personal care practices to the individual's preferences, treating an underlying urinary infection, correcting problems with vision or hearing, playing favourite music or working with the family to engage the person in more meaningful and stimulating activities.

An Alzheimer's Australia report, released in March this year, found that about half of people in aged care facilities and up to 80 per cent of those with dementia are receiving psychotropic medications. However, it also found that international data suggests that only 20 per cent of people with dementia who are receiving antipsychotic medication get any clinical benefits from it.

The report, *The Use of Restraints and Psychotropic*

Medications in People with Dementia, also found that these medications can have a range of serious side-effects, including increased risk of stroke, increased risk of mortality, a greater chance of falls, and increased confusion.

Southern Cross Care (NSW & ACT) Chief Executive Paul McMahon said the organisation had identified the need to better manage behaviours of people with dementia without the reliance on anti-psychotic medication.

"We also realised the need to educate our staff and health professionals, such as GPs, on eliminating high dependency on medication and improving outcomes for our residents with dementia."

Alzheimer's Australia NSW CEO The Hon. John Watkins said the short film was a positive step in supporting GPs, pharmacists and other healthcare professionals working with people with dementia in care homes and in the community in how best to deal with behavioural and psychological symptoms of dementia.

"This really emphasises the importance of a partnership approach between the family of the person living with dementia, their treating doctor, their pharmacist and the care staff," Mr Watkins said.

"It provides the evidence-base for the review and de-prescribing of antipsychotic medications.

"The first line approach should always be to look and see if there are non-pharmacological approaches that may work better."

Margaret Wood, daughter of a resident at Southern Cross Care (NSW & ACT), spoke of her experience of visiting her mother who has dementia.

"Mum was put on a drug which made her very sleepy and her speech garbled," Mrs Wood said.

"She was also depressed and talked about wanting to die. When mum was taken off the medication, she began to improve. Her speech got better, and she was eating. She recognises us most of the time and she is bright and cheerful. It is so nice to visit her now."

From motorbikes to river cruisers

A glance at Keith's favourite memories

In research with those of you living with dementia we often find people telling us that they feel stigmatised and even discrimination from greater society. This is the first in a series of articles celebrating the lives of those living with dementia and reminding everyone to see the whole rounded, complete person and not just the diagnosis they have of dementia. Keith is one of our members living with dementia, and a frequent contributor to many of our activities. We asked him to tell us about his memories growing up in Perth.

On childhood...

Once upon a time, beach towns across WA were littered with family shacks. In such a holiday home, Keith started his memories. During the holidays, as the town population swells by 500%, the Glance family are one of many who take the 127km drive to Lancelin. He describes sunny days knocking around with his brothers and his sister living a sandy footed life during many family holidays in their shack built by his dad Jeff. The family regularly visited Lancelin throughout his young life. Keith's father proved his skills as a carpenter, making a boat for his family which made for many further adventures.

The fondest Lancelin adventure memory came when he was a little older. On his 250 Yamaha, Keith blazed the trails that surround the tiny holiday town. The area is still a favourite for off roaders. You can always get a smile as he tells you about the trails he rode and the mischief he got up to. But he chooses to forget the time spent fixing the motorbike after the sand from the trails filled the running gear!



A teenage Keith.



The Glances in Lancelin in a boat built by dad.

On sport...

Few people know about Keith's time as a promising young tennis player. He was a student at Marshall's Tennis Academy, established in 1958 by Wimbledon player Arthur Marshall in East Fremantle. It was involved in every aspect of tennis from state teams, developing elite coaches, producing state champions and running tennis tournaments. Arthur Marshall learnt his trade with players Rob Laver, Lew Hoed, Ken Rosewall. Keith didn't end up with a tennis career but he still likes to relive success on the court including hitting up with tennis legend Yvonne Goolagong. When asked if he ever thought he might be a pro tennis player he just laughs and shakes his head.

On work...

His first career after school was as a plumber. Keith does not speak much about his time in plumbing. However, weekends working landscaping with his brother are special memories of his working life. It may well have been the cause of the green thumb he puts to good use today. With soaring interest rates and low wages, working weekends were a fact of life. Keith and his brother Steve toiled and had many a good laugh landscaping under the blazing WA sun and pouring rain.

Plumbing gave way to something better. Keith jumped at his chance for a career with Telstra. By the 90s he was a linesman which led to more than two proud decades



Ever the rev head Keith tries out a jet ski.

with the Telco. Keep in mind, this was barely the dawn of mobile phones and internet connections. As technology grew meteorically, Keith climbed the management ladder to the role of Field Supervisor. He ended up working all over the state from Port Hedland to Albany. The company rapidly changed its business model, outsourcing more and more of its core services. "There was so much pressure on contractors and staff," he recalls. "It became a tough place to work. I often needed to do unpaid work on a Saturday and Sunday just to keep up."



Keith and Wendy Glance.

On love...

Keith speaks with a smile about his greatest romance. One fine evening 16 years ago in a small hotel called The Orient, Keith's luck took a giant turn for the better. A chance argument between a couple he did not know was the catalyst for the start of a wonderful relationship. For the first time in a long time Wendy had left the kids with a babysitter for a rare night out with a couple of friends. Their subsequent argument that night lead to them walking out leaving Wendy alone. Not willing to forgoe a rare free evening, Wendy decided to finish her wine and watch the band. Enter Keith, and there began a chat that became a conversation that lasted for the evening, then into the morning and has really never ended for 16 years. Keith and Wendy are an inseparable couple who married four years ago and built their perfect home.

On travel...

Together they have seen much in their travels together. Locally they have snorkelled the Great Barrier Reef and had a creepy walk around Tasmania's Port Arthur. They have also spent a month touring Europe and wandered in Kota Kinabalu, Singapore and Bali.

Later this year, Keith and Wendy along with Keith's 85 year old mum and his sister Deb are off for the trip of a lifetime. They are headed to Amsterdam to take a river cruise through the European rivers through places like Budapest, Cologne, Bratislava and Vienna. It seems a fair return for all their years of hard work, but Keith said they are lucky to be able to go.

On fitness...

Keith never let his diagnosis stand in the way of his ever present fitness routine. This couple are the first people I have heard of to have yoga injuries (Wendy had knee surgery and Keith said his arm nearly fell off!). Keith is still fond of eight kilometre walks down his beloved river and he regularly heads to Renouf fitness where he does circuit training ("I didn't want to do all the macho stuff") with an otherwise all female group who lend a helping hand if he can't quite recall a particular exercise activity.

On volunteering...

A great love these days is the hours he volunteers with the Volunteer Task Force (VTF) as a gardener helping maintain the gardens of people who might not be able to maintain their own. Alzheimer's Australia WA worked with VTF to help Keith in his plan to give back to those who need help. The green thumb he developed from all that landscape gardening came in very useful. I like to make my contribution to the community," he said. He doesn't mind the cuppa and the chat with his clients either!

And on life...

Keith's 'glass is half full' view of the world is ever present. "Having the diagnosis has opened up new avenues and meant I have met people I would not have met," he said.

If you ask Keith what he loves in the world beside his family and staying fit he laughs says – "Well, I'd love a cure."

Together we can save a million “I Love You’s”

What happens to your donations?

It has been one year since the opening of Hawthorn House in Albany. During this time, it has been providing the region with the finest dementia respite facility in Australia.

The generosity of the people from the region has sparked an extraordinary year of generosity towards people living with dementia in Western Australia.

Hawthorn House was an incredible project funded by *Royalties For Regions* and *Lotterywest*, but also made possible by the spirit and altruism of the people from the region who provided the energy, hours and often the tools to bring the house to fruition.

The paint was barely dry on the house when the charitable kindness of *The Theodore and Isabella Wearne Trust* meant we were able to commence a similar project in Mandurah. The property situated in *Candelo Loop* with its huge garden and its leafy outlook will shortly provide the same amazing service to the Peel region as our Albany clients receives.

As I have said before, such altruism is a game changer in dementia and in the last year we have celebrated arguably the most altruistic year we have ever seen.

In June 2014, the tax year appeal saw our members dig deeper than they have ever donated before. This resulted in a considerable ability for *Alzheimer’s Australia WA* to ensure we were equipped to provide the best ever *Dementia Awareness Month* and to launch the *Memory Walk* in a new location to new people with a guaranteed bigger, brighter future. We consider these events sacrosanct, especially as we are so often told that people with dementia frequently experience stigma and misunderstanding. The more often we can tell the right story and build awareness, the more we can change views forever.

We also experienced great generosity in bequests. These are the amounts that people chose to leave in their wills to those living with dementia.

There has been so much interest in bequests that we will be shortly launching a more formal bequest programme as it is one of the most powerful ways of leaving an enduring legacy.

Funds are used to make sure those living with dementia never stand alone in the time it takes to find a cure. Bequestors have asked if they can choose the future of their funds, which is why we have now formalised a programme and allowed people to make their own choices for their bequest.

If there is no specific requirement, these gifts will help improve the quality of life for people living with dementia and deliver hope that someday future generations can live without it.

The last, but still very important area of generosity we have seen grow, has been the huge number of people who has participated in events and raised funds for dementia.

People have raised funds in all of these events:

- Karma Resorts Rottnest Channel Swim
- HBF Run for a Reason
- WA Today Swan River Run
- Chevron City to Surf for Activ Perth
- The Swisse Color Run Perth

There were 70 runners in the recent 2015 HBF Run For A Reason raising funds for people with living with dementia.

To give you an idea of the impact this can have, a four man team called *There’s Only One Sardini* completed the 2015 Karma Resorts Rottnest Channel Swim and raised more than \$6,000. Our event fund raisers are a very important part of ensuring those living with dementia are a priority.

We thank everyone for their kindness and generosity and hope that you can continue to support us in the future.

If you have any questions about bequests or any other donations or events, please have a chat with our giving team on 9388 2800.



Hawthorn House, Alzheimer’s Australia WA’s world class facility in Albany completed in 2014



Language Use

People living with dementia have recently played a major role in helping develop guidelines for language use in the area of dementia. These guidelines are always open to change and comment.

In recent years, AAWA has promoted the consistent use of appropriate, inclusive and non-stigmatising language. Words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community. Talking about dementia in a negative manner or using incorrect terminology or inaccurate facts can reinforce stereotypes and further exacerbate the myths and misinformation about dementia. The words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression. A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person with dementia experiencing stigma or discrimination. Appropriate language should always be

- Accurate
- Respectful
- Inclusive
- Empowering
- Non-stigmatising

Respectful language recognises that dementia is not the defining aspect in the life of someone with a diagnosis and does not reflect their capacity or level of understanding. It is important to respect others' preferences about words used about them, regardless of whether the person being talked about is present or not.

Everyone with dementia is unique, as there are many different types of dementia and symptoms may present differently in different people. It is important to know the facts about dementia. For example, dementia is not a normal part of ageing, nor is memory loss the only symptom. Dementia can affect language, planning, problem solving, behaviour, mood and sensory perception.

You can find more information about dementia at www.fightdementia.org.au.

Don't be afraid to ask

Individuals and families will express their experiences of dementia in ways that has meaning and significance to them. Not everyone will wish to have their experiences with dementia described in the same way. Where possible, ask that person directly. We can respect the dignity of each individual by respecting that person's wishes regarding use or non-use of certain terms relating to dementia.

Empowering language

It is important to use language that focuses on the abilities (not challenges) of people with dementia to help people stay positively and meaningfully engaged, and retain feelings of self-worth.

Cultural awareness

Using the term 'dementia' and related words in English may not always be appropriate when talking to people from culturally and linguistically diverse communities or in translation as it may be seen as offensive or disrespectful. Although the understanding of dementia is growing in the Anglo Australian community, there is still a lack of awareness of dementia in many diverse communities. In some cases, dementia may be regarded as a mental illness or as something that simply happens when people get old. Words and phrases that are appropriate in one community may be offensive or of no meaning in another community. It is important to be aware of the cultural background of the person, family or community so you can use the most appropriate language.

There is a lot more information at: wa.fightdementia.org.au in a number of languages.

The exact link for the English version is: wa.fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone01-Communication_english.pdf.

ASPREE

World-first Aspirin Study

Thousands of older people enrolled in a large international study are undergoing regular thinking and memory exercises to help determine if aspirin can affect the development of dementia and maintain quality of life.



The ASPirin in Reducing Events in the Elderly (ASPREE) trial is investigating whether low-dose aspirin intake prevents or delays the onset of cardiovascular disease (heart attack and stroke), dementia, depression and some types of cancer in healthy older people.

The \$50 million trial is also testing the effect of aspirin on age-related macular degeneration, age-related hearing loss, osteoarthritis, severe infection, osteoporosis and changes in small blood vessels in the brain.

As aspirin is also known to have side effects, such as bleeding, which may counteract potential benefits, ASPREE researchers will, for the first time, weigh the overall benefits against the risks

Led by the Monash University School of Public Health and Preventive Medicine and Berman Center for Outcomes and Clinical Research in the USA, ASPREE has enrolled 19,000 healthy participants into the trial.

In Australia, ASPREE is primarily conducted through general practices in the south-eastern states and territory.

More than 16,700 Australian participants, between 70-98 years of age, have been randomly allocated to take daily 100mg aspirin or a matching placebo tablet. Participants undergo annual clinical evaluation, cognitive exercises, measures of physical strength and questions on functional independence, depression and quality of life until late 2017.

If the benefits of aspirin are proven to outweigh the risks, thousands of healthy older people around the world can be safely advised to take the drug; if aspirin is proven not to be of benefit, many will be saved from taking an unnecessary medication.

Results are expected in 2018.

The ASPREE study is funded by the US National Institute of Aging, a branch of the National Institutes of Health.

It is recommended to always consult your GP before self-prescribing daily low dose aspirin.

To stay up to date on the progress of the trial, visit www.aspree.org. Twitter address @aspree_auE.

Services

Many people living with dementia are still unaware of the services that are available to them from Alzheimer's Australia WA. Please have a look through the services below and give us a call if you need us.



■ National Dementia Helpline 1800 100 500

Free service for those who require support anywhere in Western Australia.

■ Free counselling

For people living with dementia and their friends and family.

■ In home respite and social support

In home support or community activities with a number of clubs. Perth and regional services available.

■ Carer support groups

Free meetings monthly in various locations for carers to spend time with peers and share experiences.

■ Art therapy, choir and volunteering

Innovative programmes for meaningful engagement for those living with dementia. The Art Therapy programme includes 'Artistic Adventures' which is designed for couples and is based at the Art Gallery of WA.

■ Day centre respite

Care centres for people with dementia in Perth, Albany and Mandurah.

■ Younger Onset Dementia Key Worker Programme

Support for people under the age of 65 including links to services.

■ Living with Memory Loss

Email lwmlwa@alzheimers.org.au or call 9288 2800

Free programme supporting both the person with a diagnosis of dementia and those in the process of receiving a diagnosis, and their support person, helping navigate practical and emotional support matters.

■ Education

Register online fightdementia.org.au/wa or call 9388 2800

Industry and family / carer focused training courses.

■ Carer Education Support Programme

Call 9388 2800

Psycho-educational support service to family members providing care for someone with a diagnosis of dementia, and still living in the community.

■ Dementia Behaviour Management Advisor Service (DBMAS)

1800 699 799

Support and advice for staff/carers and family where the behaviour of the person with dementia is impacting on their care.

Calendar of events

Opening 29 June	Great Men by Great Boys Fremantle City Library	Exhibition
18-19 June	Tides of Change Symposium	DBMAS Residential Age Care Industry Training
26 July	WA Today Swan River Run	
30 August	Chevron City to Surf for Activ	
20 September	Albany Memory Walk & Jog	
September	Dementia Awareness Month	Range of public and media events to raise awareness of dementia
18 October	Perth Memory Walk & Jog	
27th October	DPP Symposium	Dementia Partnership Project Industry Training
1 November	The Color Run Perth	



Olivia and Grandad Arney

Olivia's story warmed our hearts about the special relationships within families and how an older family member can shape and nurture a young person's life and help them form special memories.

Ten-year-old Olivia remembers her grey-haired, olive-skinned, bespectacled granddad, who always had a huge smile. Arney is remembered proudly by his family as an upstanding patriarch who loved going fishing with his mate at Rottnest Island and listening to music. They especially remember and cherish the loving role he played as grandfather to his 13 grandchildren.

Arney was diagnosed with dementia shortly after his retirement. Olivia misses her Grandad in lots of ways. She misses his sense of humour and fun most of all.

After her Grandad passed, Olivia told her Dad, "I want to do something to help." Olivia and her family participated in Alzheimer's Australia WA 2012 and 2014 Memory Walks in honour of her Grandad. This wasn't enough for Olivia.

After the Memory Walk last year, Olivia boldly decided to

Amazing Olivia!

As part of our 2015 tax appeal, we shared a little girl's story about her journey with her much-loved granddad Arney, who was diagnosed with dementia in 2008, and of her determination to help Alzheimer's Australia WA help other families like hers.

host a charity golf day in Arney's memory. Olivia said, "I will give all the money raised to Alzheimer's Australia WA so that they can help other people like Grandad."

Olivia's golf day was on May 22 with much help from Dad Geoff, the rest of her family and her dad's great mates.

It was an amazing day raising more than \$11,000 for people living with dementia with an unforgettable speech and poem from tournament chairperson, Olivia.

Everyone at Alzheimer's Australia WA sends their sincerest thanks to an amazing young woman who made a huge difference to people living with dementia.

Well done Olivia. And thank you.

Olivia and her family have made their stand for people living with dementia and you can too. Don't forget us during our tax deductible mid year appeal. You can donate at https://wa.fightdementia.org.au/admin/content/donate_entities/add/wa or send your donation to PO Box 1509, SUBIACO WA 6904.