

# MILESTONES

MAY 2018, ISSUE 21



Bequest of \$1 million to Alzheimer's WA



Life in an Aged Care Home



A Round to Remember

**alzheimer's**wa  
the dementia experts

# MILESTONES

MAY 2018, ISSUE 21



## CONTENTS

- |    |   |    |  |
|----|---|----|--|
| 1  | CEO's Report  | 13 | Social support groups offer more than just a day out                         |
| 2  | Alzheimer's WA successfully completes Eden Alternative® re-registration       | 14 | Financial advice and support for people living with dementia                 |
| 3  | Carers are truly inspirational people   | 16 | Adapting your home to support a person living with dementia                  |
| 4  | Life in an Aged Care Home   | 17 | Love is in the air... at Mary Chester House                                  |
| 6  | Memory Cafés encourage inclusive communities                                  | 17 | Dinner clubs at Mary Chester House   |
| 8  | Research from the United Kingdom provides hope for better dementia treatments | 18 | A Round to Remember  |
| 10 | Risk Reduction for Dementia in a Rapidly Ageing Australia                     | 19 | Resident of the Great Southern region bequests \$1 million to Alzheimer's WA |
| 11 | Alzheimer's WA Open Day at Mary Chester House                                 | 20 | Chocoholics raise over \$40,000 for Alzheimer's WA                           |
| 12 | Andy is living well with younger onset dementia                               | 21 | Dementia Friendly Communities project celebrates successful collaboration    |

**1300 66 77 88**  
**[alzheimerswa.org.au](http://alzheimerswa.org.au)**



[facebook.com/alzheimerswa](https://facebook.com/alzheimerswa)



[twitter.com/alzheimerswa](https://twitter.com/alzheimerswa)



[youtube.com/alzheimersauswa](https://youtube.com/alzheimersauswa)

### Alzheimer's WA

55 Walters Drive, Osborne Park WA 6017  
PO Box 1509 Subiaco WA 6904

**P:** 1300 66 77 88 **F:** (08) 9388 2739

### Advertising Enquiries

For advertising enquiries please email  
[moira.mckechnie@alzheimerswa.org.au](mailto:moira.mckechnie@alzheimerswa.org.au)



# CEO's Report

Recently, one of our staff received a delightful compliment that resonated with me for the rest of the day.



The compliment included five words which confirmed the work we do as an organisation is highly regarded by the community, and the path we have chosen to take with our services is indeed the right one.

Those five words were simply:

‘You lightened the load considerably.’

It is compliments like this one from a client that serve to endorse our renewed vision to support and value people on their dementia journey.

Generous donations have allowed Alzheimer's WA to do incredible things for people living with dementia in Western Australia over the last three decades.

In 2017, after receiving government funding to deliver overnight respite in the metropolitan area, it was through donations from our members and the community that allowed us to refurbish Mary Chester House and provide three bedrooms for the overnight respite service.

Following on from another very successful open day at Mary Chester House in April 2018, I am pleased to report our overnight respite service has become so popular that some weeks it is fully booked from Monday to Friday.

In January of this year I was honoured to accept a remarkable gift on behalf of Alzheimer's WA. That gift was a bequest of \$1,000,000 from the estate of the late Don Brandenburg. The bequest will allow Alzheimer's WA to dramatically increase the availability of dementia-specific services in the Great Southern region of Western Australia, now and well into the future.

When faced with uncertainty over government funding of our services, it is reassuring to be reminded of the kindness of the human spirit.

It is this kindness that we, as an organisation, seek to repay through our ongoing work with people living with dementia, their families and carers.

Please enjoy this edition of *Milestones*. I trust you find it informative and inspirational.

A handwritten signature in blue ink, which appears to read 'Rhonda Parker'.

**Rhonda Parker**  
Chief Executive Officer



## Alzheimer's WA successfully completes Eden Alternative® re-registration

The Eden Alternative® is a philosophy of person-centred care that focuses upon empowering residents, clients, staff, families, volunteers and other stakeholders to provide a better life for residents and clients.

There are ten Eden Principles associated with the Eden Alternative®. These ten principles are the foundation for fundamental culture change for individuals, communities and organisations. The aim is to shift from an institutional or medical model of care, to one that is more about the person. By embedding these principles into a day centre environment you begin to eliminate the three plagues of our elders: loneliness, helplessness and boredom.

By combating loneliness, helplessness and boredom we reduce much of the distress and anxiety experienced by residents and

clients in aged care. Alzheimer's WA's Mary Chester House and Hawthorn House, first started applying the principles of the Eden Alternative® in 2002, and applied for registration in 2008. All Eden Alternative® centres must renew their registration every two years.

Mary Chester House, Perth, and Hawthorn House, Albany have successfully re-registered in all ten Eden Alternative principles. Ella's House, Mandurah, has been successful in obtaining their first two principles.

In order to continue to be Eden Alternative® registered, staff at Mary Chester House and Hawthorn House have worked tirelessly to ensure they are actively implementing all ten Eden Principles every day.

For more information on the Eden Alternative® please visit [edeninoznz.com.au](http://edeninoznz.com.au).

# Carers are truly inspirational people



“I love to swim, it’s an escape for me. Since my husband Alan has been diagnosed with vascular dementia, life is not the same, so I can swim up and down the pool and get away from it all.”

Penny Green has been a member of the Beatty Park Masters Swimming Club for 30 years, and has competed in many open water and pool events such as the Swim Thru Rottnest, Busselton Jetty Swim, Rottnest Channel Swim and the Masters Swimming Australia National Championships.

Penny says, “I love to swim, it’s an escape for me. Since my husband Alan has been diagnosed with vascular dementia, life is not the same, so I can swim up and down the pool and get away from it all.”

In April this year, Penny swam in six events at the 2018 Masters Championships, held at HBF Stadium in Perth. She also worked as an official. 630 swimmers from all over Australia competed at the event, and Penny came away with four individual medals, and two relay medals - one of which was a gold.

At the 2017 Masters Championships on the Gold Coast, Penny won four silver medals, one bronze, and broke four state records. Penny says her husband attended both events and the members of her swimming club provided wonderful support, looking after Alan while she was competing.

Although she prefers pool events, Penny has also competed in the Swim Thru Rottnest every year for about 30 years, and last year won her age category - no easy feat when that age category is 75-79 years.

“I learnt to swim in primary school in England, and loved it from there on. We have three daughters who all swim well; our number two daughter competed in the Rottnest Channel Swim and the Port to Pub, as a solo, earlier this year,” she says.

Caring for someone with dementia can be physically and emotionally demanding. As a carer, it is just as important to look after yourself as it is the person you are caring for. Some carers feel guilty leaving the house to attend an activity they enjoy without the person they are caring for. Other people may not know how to get help to organise a break. Often, carers can become isolated from their own social networks.

Make time for the things that matter to you.

There are a number of ways you can organise to have a break so that you can have a rest, pursue an interest or hobby, or attend an appointment. Alzheimer’s WA can provide respite in the form of in-home support, through activities or outings at one of our Enabling Households, or even overnight. A break can be for as little as a couple of hours, to several days or a week, depending on your needs. You can find out more by calling 1300 66 77 88.



# Life in an Aged Care Home

## - An Insider's View

By Ron Elphick, Aged Care Home Resident

.....



I am 91 years of age and have been a resident of an aged care facility since February 2016. This followed fourteen years, with my late wife, as residents of a retirement village. In view of this experience, I believe I can claim some practical knowledge of matters relating to aged care. So I offer my thoughts in the hope they may be of some assistance to the many families with ageing loved ones.

From time to time, including very recently, there have been media reports regarding ill-treatment of residents in aged care facilities and this is something that should never be tolerated. There has also been criticism of privately owned and operated facilities for being “profit-oriented”.

The aged care facility where I am living is privately owned and at times there are some indications of cost-cutting. However, I believe that it maintains an acceptable standard and that belief has been tested. All aged care homes receiving Government subsidies have to meet quality standards. These cover management, staffing, health and personal care, resident lifestyle, catering, cleaning, continuous improvement and safety and security. These standards are monitored through accreditation assessment teams which make planned and unannounced visits. This facility was visited this month by accreditation assessors and I made a contribution to the therapy team submission with respect to the newsletter.

It is stating the obvious to say that a normal human being will pass through many phases and face many challenges during their lifetime. Phases and challenges that come to mind include education, puberty, establishing personal relationships, marriage, parenthood, developing and maintaining a career, and retirement which may eventually lead to the need for aged care and the Final Challenge. It is this final phase and challenge of which I write.

Thousands of pages have been written and millions of words have been spoken about

preparing for retirement and, if necessary, the selection of appropriate home or residential aged care. I cannot too strongly emphasise the need for careful forward planning by families in the early stage of this phase. While there has been a marked increase in Government assistance to enable ageing people to remain in their homes, in many cases full time care is essential. There is an increasing demand for aged care places and I strongly recommend families with a loved one in declining physical or mental health register their names with several facilities that are accredited and otherwise suitable. Such places often have long waiting lists and it is not illegal or immoral to apply to more than one facility.

I entered this aged care facility after three weeks in two hospitals having treatment for severe lower back pain. I had been on a waiting list for some time and my wife was already in the dementia wing in the facility. My application for the allocation of a room was supported by social workers at both hospitals and I was transferred from hospital to the facility by ambulance transport. So I was really in rehabilitation in my early days.

I was well cared for from the beginning by nurses, carers and therapists but there were some aspects of life in an aged care facility to which I had to adjust. One which I found relatively easy was the regularity of meal times including dinner at 5.00pm. The more difficult aspect was that all my medications were handled as in a hospital - in other words I lost control of them for the first time outside of a hospital environment. Initially I found this loss of independence very difficult to accept but in time I became accustomed to the situation. Later my doctor prescribed some basic medications such as Osteo Panadol and Mylanta to be “self-medicated”.

Another aspect which did not trouble me but which some residents find hard to accept, was the full reason why we are here. We know we are here because we need full time care but one lady

was horrified one day when I said that we were in “One of God’s waiting rooms.” But it is a fact that we are in the twilight of our lives and should be actively preparing ourselves and our families for our death.

Despite my age I have never seen the body of a deceased person and have always had an innate fear that I might see one. However I have no problem now with seeing people with whom I have become acquainted, or even become friends, slowly wither away. This is often manifested by rejecting food despite encouragement by the carers. That, and the effects of a severe fall was the fate of my wife last December.

Many families of aged care residents face difficult decisions regarding their loved ones “end of life” wishes. I have signed an Advance Health Directive in which I simply state that I would refuse consent for any treatment which was solely aimed at prolonging life. I have granted to my eldest daughter an Enduring Power of Guardianship whereby she has authority to make health decisions on my behalf if I am mentally or physically unable to do so. I have also given her a Power of Attorney and appointed a son to be Executor of my Will. All my immediate family are aware of these provisions. They are also aware of my intention to reject such measures as intubation or forced feeding just to keep me alive.

I strongly recommend that all aged care residents consider completing an Advance Health Directive and granting to a family member an Enduring Power of Guardianship to assist their families during what can be a very difficult time.

While they are well enough, I also strongly recommend all aged care residents take part in whatever facility activities of which they are physically and/or mentally capable. This facility has an active team of therapists who conduct activities including table games, floor games, a dance club, a knitting club, a movie club, an art class, exercises and physio, word games, quizzes and bingo. Regular and occasional entertainers provide different types of music. Two hour bus trips for various groups are arranged from time to time. Anglican, Catholic and non-denominational church services are held regularly. A Friendship Group is conducted by church-based volunteers fortnightly.

For myself, as a former public figure and historian, I like to keep up to date with the latest

news through the internet and the daily papers. More particularly I like to write, and I derive much satisfaction from providing contributions for the facility newsletter.

One area that causes problems for some residents is that of meals. I believe that management makes quite some effort to provide for the differing tastes and diets of the residents but inevitably not everyone will be satisfied all the time. Residents are given the opportunity of selecting one of two options of lunch and dinner meals on the following day’s menu. For those with gastric or other problems, residents may order other foods such as salads, sandwiches, scrambled eggs etc. There is also a choice of desserts with yoghurt and fruit always being one of those offered.

A meeting is held every second month to which residents and family members are invited and where concerns and comments may be aired. Also forms are available at the reception desk where residents may make complaints or offer suggestions at any time.

It has to be remembered that aged care facilities are not hospitals but steps are taken to manage the health care of each resident and in the case of a fall or an accident an ambulance is usually called. Most residents are referred to one of the doctors who visit regularly and an “after- hours” service is available. Nursing staff include Clinical Nurse Managers, Registered Nurses (one of whom is always on duty), Enrolled Nurses and trainee nurses. There is a trained kitchen staff and a large staff of carers who are responsible for serving meals, assisting with showering and toileting, making beds, monitoring bowel movements, replenishing water jugs and assisting residents as may be required. Aged care staff need a great deal of patience and be motivated by a deep sense of caring for others. They are entitled to our utmost respect.

In reviewing my 15 months residency of this facility, I really appreciate the care I have been given. I have learnt the need for acceptance - that things will not always be to my liking and that I am living with people of different nationalities and degrees of cognitive ability. But above all I am grateful that I am facing my Final Challenge in a clean, well equipped aged care facility.

---

Published by *The West Australian* in Money Matters and on Facebook on 12 June 2017.



## Memory Cafés encourage inclusive communities

Once a month in a select number of cafés across Perth, a very special morning tea takes place.

.....

Memory Café morning teas are for people living with dementia and their carer or a support person; an informal and social affair where people can feel welcomed and accepted, remain socially active and make new friends.

In recognising the need to encourage inclusion of people living with dementia in the local community, Alzheimer's WA has partnered with Local Governments and businesses to bring the Memory Café concept to Western Australia.

Each of the cafés involved has an inviting and friendly atmosphere, employs delightful staff and offers delicious coffee and cake!

Do you, a family member or friend live with dementia? Visit a Memory Café, enjoy a

coffee, some great conversation, and most of all, enjoy the warm acceptance.

### Memory Cafés in the metropolitan area

#### Belmont

**Where:** Tavolo Café, Reading Cinema Complex, Belmont  
**When:** First Wednesday of the month  
**Time:** 10.30am  
**Contact:** (08) 9477 7149

#### Booragoon

**Where:** Coffea Fine Espresso Garden City Shopping Centre  
**When:** Last Tuesday of the month  
**Time:** 9.00am - 10.30am  
**Contact:** (08) 9316 7903



### Fremantle

**Where:** The Kiosk  
123 Beach Street, Fremantle  
**When:** Second Wednesday of the month  
**Time:** 10.00am - 11.30am  
**Contact:** (08) 9432 9890

### Kingsley

**Where:** Waldeck's Lakeview Café  
173 Wanneroo Road, Kingsley  
**When:** Last Wednesday of the month  
**Time:** 10.00am  
**Contact:** Vicki 0409 045 373 or  
Bev 0414 370 325

### Mundaring

**Where:** The Hub of the Hills  
8 Craig Street, Mundaring  
**When:** Second Tuesday of the month  
**Time:** 9.30am - 11.00am  
**Contact:** (08) 9290 6683

### Rockingham

**Where:** The Clipper Café  
20-30 Patterson Road,  
Rockingham  
**When:** Third Monday of the month  
**Time:** 10.00am - 12.00pm  
**Contact:** (08) 9528 0333

### Roleystone

**Where:** Garden Tea Rooms &  
Cottage Nursery  
121 Croyden Road, Roleystone  
**When:** First Friday of the month  
**Time:** 10.00am - 11.00am  
**Contact:** Angi 0468 549 143

## Memory Cafés in regional areas

### Albany

**Where:** The Store Café  
55 Frederick Street, Albany  
**When:** Last Thursday of every month  
**Time:** 10.00am  
**Contact:** RSVP to Hawthorn House  
on (08) 9841 3755

### Manjimup

**Where:** Coming soon  
**Contact:** Shire of Manjimup for more  
information on (08) 9771 7777

---

Thanks to City of Belmont, City of Melville, City of Fremantle, Shire of Mundaring, City of Armadale, City of Rockingham, Shire of Manjimup and Shire of Albany as well as all the cafés involved, for their support of Memory Cafés in their areas.

## Memory Café in Rockingham open for business

---

The Drop in the Ocean Memory Café, located in Rockingham, held its first session in April 2018 with more than 60 people attending. The Memory Café was founded by a caring group of local residents who met through a course run by Alzheimer's WA.

The Drop in the Ocean Memory Café will give more access to support services for people living with dementia in the area. The Memory Café initiative is run in partnership with the City of Rockingham and Rockingham and Districts Alzheimer's WA Inc.

# Research from the United Kingdom provides hope for better dementia treatments

An article by Rhonda Parker, Alzheimer's WA CEO

---

Reports of miracle cures for dementia seem to surface often in the media. I take a cautious approach to reporting to you on so-called research breakthroughs, as many are very early in the trial process and often still pre-clinical and not yet being trialled in humans. However, there have been some recent developments that are worthy of sharing with you to keep you up to date on what is happening to find better treatments for this terrible group of conditions.

I draw your attention to three research projects that have come out of the United Kingdom in recent months. The first looks at mapping proteins present in the brain of people diagnosed with Alzheimer's disease. The second and third focus on the use of medicines, one new and one existing, that show potential in combatting neurodegenerative diseases.

Protein activity has been the subject of research into the most common cause of dementia - Alzheimer's disease - for some time. Two proteins form unusual clumps in the brains of people with Alzheimer's disease. These proteins are known as tau and beta amyloid. Tau deposits are found inside neurons, where they are thought to inhibit or kill them, whereas beta amyloid forms plaques outside brain cells.

Researchers at the University of Cambridge in the United Kingdom<sup>1</sup> have been examining tau activity in Alzheimer's disease, and have used brain imaging techniques to map the build-up of tau. Results suggest the tau may spread in a similar way to influenza: the tau starts in one place and moves across neighbouring neurons and synapses to other places in the brain. This is called 'transneuronal spread' and has been demonstrated in mice but not people.

Understanding how the tau protein spreads across neurons is a new approach to understanding Alzheimer's disease. Unlocking this secret could inform the future development of medicines that could attack the protein and stop its spread, potentially halting its progression altogether.

The second research advance to report received coverage in December 2017, when the ABC reported on a 'ground-breaking' new drug able to target a toxic protein present in the brains of people diagnosed with Huntington's disease<sup>2</sup>. Huntington's disease, a type of dementia, is a genetic and progressive neurodegenerative disease that usually surfaces between the ages of 30 - 50 years. Treatment breakthroughs in Huntington's disease may have relevance to treating other types of dementia in the future.

The Huntington's research takes a gene-altering approach and has now conducted clinical trials in humans. The new drug being trialled stops a gene producing a particular protein thought to be causing the destruction of the brain tissue. In a one-off process, researchers injected the drug into the spine of patients, which led to a reduction in the levels of the toxic protein that causes Huntington's. However, the results are still early and the drug is yet to be trialled to see if it can slow progression of Huntington's disease.

The drug has now been licenced by pharmaceutical company Roche. This research is cause for optimism given the results in clinical trials.

Meanwhile, an already existing drug originally developed to treat Type 2 diabetes has been found to significantly reverse memory loss in mice with Alzheimer's disease.



There is a known link between Type 2 diabetes and Alzheimer's disease. Type 2 diabetes is considered a risk factor for Alzheimer's disease that may cause the disease to progress more rapidly.

The drug was found to work by protecting the brain cells attacked by Alzheimer's disease in three separate ways, rather than relying on a single approach<sup>3</sup>. In the trial the drug was seen to improve levels of brain growth factor, reduce the amount of amyloid plaques in the brain and slow down the rate of nerve cell loss. Researchers are now looking to test the drug on humans.

At Alzheimer's WA, we support the pursuit of risk reduction, treatment and cure for dementia. There are currently no effective treatments for dementia, only medications focused on managing symptoms. These are limited in their effectiveness, and there has

been no new drug treatment for Alzheimer's disease for over 20 years. While the global search for answers continues we will continue to focus on supporting those living with dementia, providing best practice support, advice and education where dementia experts are required.

---

## References

1. [www.sciencemag.org/news/2018/01/alzheimer-s-protein-may-spread-infection-human-brain-scans-suggest](http://www.sciencemag.org/news/2018/01/alzheimer-s-protein-may-spread-infection-human-brain-scans-suggest)
2. [www.abc.net.au/news/2017-12-12/ground-breaking-new-drug-gives-hope-in-huntingtons-disease/9248832](http://www.abc.net.au/news/2017-12-12/ground-breaking-new-drug-gives-hope-in-huntingtons-disease/9248832)
3. [www.sciencealert.com/diabetes-drug-significantly-reversed-memory-loss-in-mice-with-alzheimer-s](http://www.sciencealert.com/diabetes-drug-significantly-reversed-memory-loss-in-mice-with-alzheimer-s)

## SAVE THE DATE



### **Walk to Remember and raise money to support and advocate for the 41,149 people living with dementia in Western Australia**

Alzheimer's WA's 2018 *Walk to Remember* consists of three events in October and November across Western Australia:

- » Mandurah: Sunday, 7 October
- » Albany: Sunday, 21 October
- » Perth: Sunday, 4 November

Full event details to be announced soon.  
[alzheimerswa.org.au](http://alzheimerswa.org.au)



# Risk Reduction for Dementia in a Rapidly Ageing Australia

As we get older we can experience changes to our brain function, such as slower processing of information and increased forgetfulness, and this is considered to be normal. However, when we think of 'increased forgetfulness' we often associate the term with Alzheimer's disease or another type of dementia. Although some people experience forgetfulness as a symptom of dementia, dementia itself is not a normal part of ageing.


The prevalence of dementia in Australia is increasing, and for many older Australians this is a growing concern. Most people can reduce their risk of developing dementia as they age, and this involves looking at lifestyle factors including: diet and exercise, whether you smoke, and how much alcohol you consume.

A recent study by the ARC Centre of Excellence in Population Ageing Research (CEPAR), in collaboration with Neuroscience Research Australia (NeuRA), highlights seven key lifestyle factors which are attributed to dementia.

Professor Kaarin Anstey, CEPAR Chief Investigator and NHMRC Principal Research Fellow at NeuRA, said the report highlights the prevalence of dementia in Australia, which doubles every five years between ages 70 and 84, and how our ageing population trends will result in greater numbers of people with dementia.

"Australia's ageing population is leading to an increasing number of Australians with the disease which will further impact individuals, society and the economy over the next decade," said Prof Anstey.

The report also found that the knowledge-base around the cause of dementia varied greatly, raising the need for in-depth dementia awareness workshops and community involvement.



Reduce **RISK**

**Simple changes you can make to reduce your risk of developing dementia include:**

- » Eating a healthy diet
- » Ensuring you get enough sleep
- » Staying socially active
- » Engaging in mentally challenging activities
- » Increasing exercise
- » Reducing alcohol consumption
- » Quitting smoking

"While some detrimental attributing factors to dementia such as smoking and alcohol consumption were known, other factors connected to cognitive health were unknown to over 95% of the sample population," Prof Anstey said.

"This highlights the need for increased local community engagement and advocacy."

Anstey has estimated that close to 50% of dementia cases can be attributed to seven key modifiable lifestyle factors; midlife hypertension, diabetes, low educational attainment, smoking, physical inactivity, mid-life obesity, and depression.

Commenting on the outcomes of the report, Professor Anstey said further investment into ageing research is needed to identify more risk factors.

"We need to develop better diagnostic tests and assessments, increase community education to ensure risk factors attributed to dementia are better managed," Prof Anstey said.

Further information on the study is available at [neura.edu.au/news/rapidly-ageing-australia/](http://neura.edu.au/news/rapidly-ageing-australia/)



# Alzheimer's WA Open Day at Mary Chester House

On a typically warm and sunny autumn day in Perth, more than 100 people gathered at Mary Chester House in Shenton Park, all connected through their journey with dementia.

Our most recent open day, held on 7 April 2018, was a day to meet others living with dementia, hear from dementia experts, explore the gardens and facilities, and enjoy a barbeque lunch.

Alzheimer's WA open days are an informal yet informative, family-friendly event where people can find out more about our services and view some of our facilities. Our friendly and highly experienced staff are always on hand to answer questions and provide guided tours on the day.

Mary Chester House is one of three Enabling Households run by Alzheimer's WA. Mary Chester House provides day and overnight respite for people living with dementia, allowing family and carers a short break while providing an enriching and enjoyable experience for the person with dementia.

The house also offers a wide range of meaningful activities, social groups and outings for people living with all types of



dementia. Social groups meet across the Perth metropolitan area, and all activities are facilitated by specialist support workers.

Alzheimer's WA Enabling Households are also located in Mandurah, Ella's House, and Albany, Hawthorn House.

Open days are held regularly throughout the year. If you would like to be contacted with the details of our next open day, email [events@alzheimerswa.org.au](mailto:events@alzheimerswa.org.au). If you would like to find out more about the services offered at Mary Chester House, Ella's House or Hawthorn House please call our Customer Support Line on 1300 66 77 88.

## SAVE THE DATE

### The 'WE' in Dementia Community Services Symposium

**Achieving wellness through  
the Domains of Wellbeing®**

**Tuesday, 16 October 2018  
Perth Convention Centre**



**Dementia Partnership Project**

**hacc**  
home and community care  
A NOT-FOR-PROFIT ORGANISATION

Be inspired by international and national speakers and leaders on a range of topics that challenge a new way forward in best practice dementia care.

**Registrations open 11 June, 2018.**

If you would like to learn more about this event, please contact us on **1300 66 77 88** or email [dpp@alzheimerswa.org.au](mailto:dpp@alzheimerswa.org.au) or visit [alzheimerswa.org.au/dpp-symposium](http://alzheimerswa.org.au/dpp-symposium)

**alzheimer's wa**  
the dementia experts

# Andy is living well with younger onset dementia



“Volunteering has really helped me as I have younger onset dementia and it gets me out of the house. It connects me to the community and I am respected by my peers and other volunteers,”

Andy Creighan (right) with friend Alfie Di Meo.

Andy Creighan has been working as a volunteer gardener with Chorus, formerly Volunteer Taskforce, since 2015 and was recently nominated by his colleagues for Volunteer of the Year 2018 - People's Choice.

The People's Choice Award celebrates an individual who is an 'unsung hero' in the community and who has enhanced the lives of others through their volunteering.

In true fashion, Andy was very humbled by his nomination and explains,

“Volunteering has really helped me as I have younger onset dementia and it gets me out of the house. It connects me to the community and I am respected by my peers and other volunteers,”

It has had a very positive impact on me, I feel happy and I like that I am giving back to the local community. I really like the jobs we do and the people I work with too.”

Andy was diagnosed with younger onset dementia in March 2016. The diagnosis was a relief for Andy who had struggled with memory problems for a number of years. Once he had his diagnosis he said he was going to “make the best of it”.

His attitude changed from a glass half-empty person to a glass nearly full.

He and his wife Jackie utilise a number of Alzheimer's WA services including the men's walking group south of the river, group exercise in the water at Melville Aquatic Centre, the south of the river friendship group, social support to attend speech therapy, and have planned respite at Mary Chester House after attending the recent Open Day in April.

Andy is busy every day and is leading a fulfilling life. He really is “living well” with younger onset dementia.

Andy currently spends two full days a week volunteering with Chorus and his work led to him being featured in Chorus's show garden at the recent Perth Garden Festival. Andy's photo and story were included on a banner in the garden. Chorus won Silver and the coveted People's Choice Award for their 'Kaleidoscope' show garden this year, designed with input from Alzheimer's WA to be a welcoming, inclusive and joyful space for people with cognitive impairment.



# Social support groups offer more than just a day out



Alzheimer's WA recognises the importance of feeling connected to your local community, particularly after a diagnosis of dementia. We offer a number of social support groups, clubs and volunteering groups throughout the metropolitan area, and in some regional areas, and can connect you to local groups with other people who are living with dementia.

Social support groups provide a friendly and engaging environment for people living with dementia to socialise, remain active in the community and build new friendships. Groups also offer family members and carers an opportunity to have time to themselves, or to meet with other carers. Alzheimer's WA works with all new members to encourage input into group activities, helping to foster a sense of belonging and ownership.

Most of our groups meet once a week for between two and four hours, and some of the groups have become so popular we have recently introduced several new options. The list below is an example of the different social support groups, clubs and volunteering programs currently running in the Perth metropolitan area.

- » Cockburn Conservation Crew
- » Northies Conservation Crew
- » Kalamunda Coffee Club
- » Ladies of Leisure
- » Walking Groups
- » Pool Walking Groups
- » Men's Shed
- » Rocky Rovers - Rockingham Group
- » Ladies and Mens Groups - specific for younger onset dementia
- » Golf Group
- » North and South specific groups

If you or a family member are interested in attending one of our groups, we encourage you to contact Alzheimer's WA to discuss the different groups available to suit your needs and interests.

Contact Alzheimer's WA on 1300 66 77 88 or email [support@alzheimerswa.org.au](mailto:support@alzheimerswa.org.au).



## Financial advice and support for people living with dementia

A diagnosis of dementia, and the subsequent search for support, can be overwhelming. Alzheimer's WA has been supporting people living with dementia in Western Australia for over 35 years.

If you or a family member have received a diagnosis of dementia, and you are unsure what to do next, call us on 1300 66 77 88 and have a chat with one of our friendly and caring team members. We are here to talk you through your options and our advice is freely available to anyone who is concerned about dementia.

### Financial planning

Dementia affects everyone differently, however over time the ability for a person with dementia to make decisions about financial matters will decline. Planning ahead means the person with dementia can take part in discussions about financial matters, and is able to legally sign documents if required.

One simple step that can be taken is to ensure all financial accounts have joint signatures.

Consideration should also be given to making an enduring power of attorney. An enduring power of attorney is a legal agreement that allows a nominated person to look after the financial affairs of another person.

Alzheimer's WA has partnered with N.C. Bruining & Associates, a group of Perth's leading and highly experienced financial planners, to provide free financial seminars designed specifically for carers and families of people living with dementia.

The two-hour seminar provides a step-by-step guide on how to manage your financial future, and covers a range of topics including tax, superannuation, insurance and pensions.

Seminars are held four to five times a year and free to people who are living with dementia, have a family member with dementia, or are caring for someone with dementia. All seminars are held at Mary Chester House in Shenton Park and bookings are essential.

**For more information or to make a booking call 1300 66 77 88 or email [events@alzheimerswa.org.au](mailto:events@alzheimerswa.org.au)**

### Accessing government funding

Most people diagnosed with dementia want to stay in their own home for as long as possible. To help people stay at home, there are many services and supports available to people living with dementia, their family and carers. Often Government funding is available to assist with the cost of support services. An assessment of eligibility is required for most programs.

The types of services available may include:

- » Respite
- » Counselling
- » Social support groups
- » Carer support groups
- » Home care: such as assistance with household chores, home maintenance, gardening, meals, transport, personal care and nursing care.

Alzheimer's WA provides a variety of respite, counselling and support group services exclusively for people living with dementia, their families and carers. Whether you have had an assessment or not, we welcome your call to find out more about how we can help you to live well with dementia.

## Government funded services for over 65's

If you or a family member have been diagnosed with dementia your first step to accessing Government funding for services is to contact My Aged Care, the Federal Government aged care portal.

When you call My Aged Care, a staff member will ask you a number of questions to better understand your care needs, or the care needs of your family member. Have your Medicare details ready before you call.

Based on your needs, you may be referred for an assessment. Assessments are provided free and usually take place in your home with a qualified assessor. It is important to know you do not need to make any decisions about your future during the assessment.

Types of assessment:

- » If you need low level support at home: you will receive a home support assessment with a Regional Assessment Service (RAS). This will determine your eligibility for the Commonwealth Home Support Programme (CHSP), sometimes referred to in Western Australia as Home and Community Care (HACC).

- » If you have more complex needs: you will require a comprehensive assessment with an Aged Care Assessment Team (ACAT). You will be assessed for a home care package to help you stay at home. There are four levels of packages available.
- » My Aged Care website: [myagedcare.gov.au](http://myagedcare.gov.au)
- » My Aged Care contact number: 1800 200 422

## Government funded services for under 65's

A diagnosis of dementia can be particularly complex for someone under the age of 65 years, as often the person is still working to support a family or pay off a mortgage. Currently there are approximately 2,500 people in Western Australia who are under the age of 65 and living with a diagnosis of dementia. This type of dementia is known as younger onset dementia.

Government funded services are available for people diagnosed with younger onset dementia through the National Disability Insurance Scheme (NDIS).

The first step to accessing the NDIS is to call the national contact centre. Alternatively, you can fill in the online form to receive more information.

- » NDIS website: [ndis.gov.au](http://ndis.gov.au)
- » NDIS contact centre: 1800 800 110
- » NDIS online contact form: [ndis.gov.au/form/contact-form](http://ndis.gov.au/form/contact-form)

The NDIS is continuing to roll out across Western Australia with the scheduled roll out due to be completed in 2020. If the NDIS is not available in your suburb and you need to access support, contact the Regional Assessment Service on 1300 785 415 to organise an assessment and access HACC services. Alzheimer's WA will continue to provide support to people under 65 through HACC as well as being able to provide support to people who have a disability support package.



# Adapting your home to support a person living with dementia

It is estimated that between 60-70% of people living with dementia live at home. Most people want to stay at home for as long as possible and making small changes can enable this to happen. A well designed environment, planned with cognitive impairment in mind, can help to maintain a person's abilities by providing essential prompts, improving accessibility and reducing risks.

People often feel happier if they can remain independent and in their own homes for as long as possible, and staying at home can help to maintain a person's quality of life. There are many simple low cost adaptations that anyone can make to their home, to support enablement of a person living with dementia. Some of these adaptations are outlined below.

## **Use of clear signage on cupboards and doors**

Clear signage using words and a picture with good contrast can help guide people to find items or spaces they use every day, especially in a newer home. This could mean labelling kitchen cupboards with items that will be found inside, such as pots and pans. Signs can also be used to help direct people to the bathroom or toilet or used as a reminder.

## **Using colour contrast**

Some people living with dementia have difficulty seeing objects, especially if the item and background colours are the same. Using contrasting colours around doorways and on door handles, light switches and crockery will help distinguish these areas or items and make them easier to find.

## **Assistive equipment**

There are many inexpensive items that can be purchased to make life easier at home. Examples include: tilt kettles; irons with 30 second shut off if left; clocks showing the time, day and date with an enlarged display; memory prompts; GPS location devices; and simple use phones.

## **Improved lighting and use of sensor lights**

People living with dementia may need brighter lighting that helps them better perceive the environment around them. Sensors can help to avoid trips at night time and assist people find

areas such as the bathroom or toilet. These can be inexpensive plug in lights or sensors fitted to main lighting.

## **Remove trip hazards or other perceived hazards**

Remove trip hazards such as rugs or cords. Keep floor colours the same or similar, to avoid the appearance of floor level changes, especially at thresholds such as in doorways.

## **Keeping everyday items in sight and in groups**

Keeping items in line of sight, and grouping everyday items together, makes them easy to find and use. By doing this, you are also providing visual cues which may help to prompt a desired outcome. In the kitchen, this could mean grouping tea bags, tea cups and kettle on the bench rather than in a cupboard, to encourage making a cup of tea. In the bathroom, this could mean placing toothpaste, toothbrush and hair brush together on the bathroom vanity top.

By placing items where they are easily seen they are more likely to be used.

## **More information**

Supporting people to remain at home through design and assistive technology will be a crucial response to Australia's ageing population into the future.

Alzheimer's WA's Dementia Enabling Environments website [enablingenvironments.com.au](http://enablingenvironments.com.au), includes a very easy to use diagram of a house to show you what changes can be made in each room of the home. You can also download information sheets for ideas on adapting your home.

Alzheimer's WA has an assistive technology demonstration room at Mary Chester House, where family members and carers of people living with dementia can learn about and view the latest technology and practical ideas to adapt a home.

The assistive technology demonstration room is located at 9 Bedbrook Place, Shenton Park and is open every day (except public holidays) from 9.00am to 4.00pm. Family and friends are always welcome to visit and learn how technology can help enable people living with dementia.

## Love is in the air... at Mary Chester House

On Wednesday, 14 February love was in the air at Mary Chester House as 60 people attended a very special Valentine's Day dinner.

Tables and decorations were set up outside and in the dining room. Guests enjoyed dinner, dessert, and dancing to the sounds of Frank and Nancy Sinatra singing 'Somethin' Stupid', The Beatles' classic 'When I'm Sixty-Four', and other well loved songs of yesteryear. The Swing Zing Dancers also offered entertainment to the delight of guests.

The importance of the night was summed up in these words from one carer:

"After my wife walked through the doors last night it was like she was nearly back to her old self.... For the first time in 3 years I was able to get my wife up to dance."

Julie Szczurowski, Coordinator at Mary Chester House, writes below of her first-hand experience with this and other dinners hosted for carers at Mary Chester House.

## Dinner clubs at Mary Chester House

Dinner clubs were first introduced at Mary Chester House in 2014. A need for carers to connect in a social atmosphere became apparent as many were saying connections with long term friends had broken down or they didn't feel comfortable going out at night anymore.

At the time we were holding a very successful carers group at the House. Many carers were still working or needed their valuable respite time to fulfil other responsibilities. By holding a night function where they could bring

their loved ones, we were able to provide an opportunity for connection with other carers in a safe, non-formal setting.

Over the years, we have had several themed dinners from Mexican, cocktail parties, barbeques and roast dinner nights.

As the dinner clubs progressed, the idea for the Valentine's Day dinner formed when it was recognised our couples were missing the opportunity to dance. A lot of our couples had first met at the Pagoda Ballroom in Como (one of the most popular places to meet future partners in Perth at that time). No Tinder back then!

On the night of the first Valentine's Day dinner, a volunteer band played and around 60 people attended. It was a delight to see couples, mothers and sons, brothers and sisters all up and dancing.

We regularly ask carers for feedback on the dinners. At the Valentine's Day dinner we handed out love hearts and asked "What does love mean to you?". The responses were quite amazing and very valuable feedback for our team to reflect on. It became apparent how special these nights are. The relationships built during the dinners certainly enables us to provide stronger support to our families.

The dinner clubs have evolved over the years and firm friendships have been formed. We were delighted on one occasion when, after setting the House up and everything looking beautiful, our carers arrived and started shuffling the tables around. Our setting of eight per table was no longer good enough as the connections had grown and everyone wanted to sit together. It was also apparent the comfort level had increased as people bought their favourite wine along to share with the group.

Volunteers, members and staff always prepare our dinners in-house. We offer a buffet-style, home cooked meal with lots of variety followed by dessert. We do ask for a \$10 donation to assist with costs and most evenings will run a raffle to help raise a little extra money.

Mary Chester House is one of three Enabling Households run by Alzheimer's WA in Western Australia.



## A Round to Remember

On Friday, 13 April 2018 a group of more than 100 enthusiastic and competitive amateur golfers descended on Araluen Golf Course for the annual Alzheimer's Charity Golf Day.

28 teams competed to be the overall winners of the shotgun start Ambrose competition. The teams enjoyed a day of good-natured fun in a picturesque setting, and all for a worthy cause.

The Alzheimer's Charity Golf Day was created by Olivia Holtmeulen, an inspirational young lady who has organised the event every year for the last four years.

Olivia and her committee created the event in recognition of her grandfather, Arney, who passed away from dementia in 2013. In the years since, the annual Alzheimer's Charity Golf Day has raised a staggering \$56,000, which has been generously donated to Alzheimer's WA.

In 2018 the golf day, affectionately nicknamed a Round to Remember, featured three novelty holes including longest drive and closest to the pin.

Once the golfing action was over the 100-strong crowd went on to enjoy a dinner and auction. Up for grabs at the auction were some highly coveted items including a cricket bat signed by the 2017 Australian team and a signed West Coast Eagles jersey.

Remarkably, the item that drew the most attention was a raffle prize of a Manchester United-branded clock, which exchanged hands several times before one dedicated fan paid \$100 to make sure it went to a good home.

Alzheimer's WA is humbled by Olivia's efforts, and grateful for the continued support of the Holtmeulen, Janssen and Chiera families. The 2018 Alzheimer's Charity Golf Day raised an amazing \$15,012.

Olivia, you are a true leader of tomorrow and we look forward to supporting you and your family at next year's event.

---

Thank you to major sponsor Reece Plumbing who have supported the Alzheimer's Charity Golf Day since its inception.







## Resident of the Great Southern region bequests \$1 million to Alzheimer's WA

Alzheimer's WA is grateful for the vision of those who leave us gifts in their Wills or make significant endowments. Bequests help improve the quality of life for people living with dementia and deliver hope that someday future generations can live without dementia.

The late Don Brandenburg, a resident of the Great Southern, bequeathed part of his estate for the wellbeing of older people in the region. Aside from donations to other local organisations, in January this year the trustees of the estate gave \$1,000,000 to Alzheimer's WA, which will allow additional dementia-specific respite facilities to be developed in Albany.

Hawthorn House, now located in Henry Street, Albany, has been providing respite and support services to people living with dementia in the Great Southern since 1993. Demand for dementia-specific services in the area is high and will continue to grow as our population ages. Bequests such as the one from the estate of the late Don Brandenburg will allow Alzheimer's WA to significantly improve the services and support available to people living with dementia in the region.

All bequests to Alzheimer's WA are preserved for special projects. We value the generosity of such gifts and respect our donors and their amazing support.

These special projects include:

- » Identifying and delivering effective new services that will help change lives
- » Increasing awareness and understanding of dementia in the community
- » Improving advocacy and empowering people living with dementia to ensure their voices are heard

One of the most powerful ways of ensuring you leave an enduring legacy is through a gift in your Will to Alzheimer's WA. Funds bequeathed to Alzheimer's WA will enhance the lives of all Western Australians living with dementia and help create a better future.

A bequest brochure can be downloaded from our website or mailed to your home. For more information please call 1300 66 77 88.

Alzheimer's WA sincerely thank the family of Don Brandenburg for this generous bequest.

## Chocoholics raise over \$40,000 for Alzheimer's WA

The annual Chocolate Block Challenge is over for another year and we are delighted to announce an incredible total of \$40,123.30 was raised for Alzheimer's WA.

155 individuals took up the challenge of going chocolate-free to raise funds for Alzheimer's WA this year and we are in awe of their will power, especially in the lead up to Easter. Only six cheats were purchased this year which leads us to believe our fundraisers have astonishing willpower!

Alzheimer's WA was honoured to be supported by five celebrities; Tim Gossage, John Burgess, Jessica Bratich Johnson, Pippa McManus and Mark Gibson. Between them, our ambassadors raised over \$4,500 towards our fundraising total. More importantly, as ambassadors for Alzheimer's WA they helped to increase awareness and reduce the stigma of dementia through sharing their involvement over the radio, in newspapers, and through social media posts.

We are extremely pleased to announce the highest fundraiser for the Chocolate Block Challenge was Perth local Matt Budge. Matt's tremendous fundraising efforts lead to his family, friends and colleagues donating a total of \$9,000 to Alzheimer's WA. We are incredibly grateful for your support.

The winner of a jumbo jar of chocolates was Felicity Martin. Congratulations Felicity!

Money raised by the Chocolate Block Challenge will be used by Alzheimer's WA to support and make a positive difference in the lives of people living with dementia in Western Australia.

If you would like to organise a fundraiser in support of Alzheimer's WA please call us on 1300 66 77 88 or email [support@alzheimerswa.org.au](mailto:support@alzheimerswa.org.au).



### Wine and Horses Charity Ride - Call for Volunteers

**13 - 14 October 2018**

Wine and Horses in Perth Hills would love to hear from anybody who is willing to donate a few hours on Saturday, 13 October to help out with this amazing event in support of Alzheimer's WA (no horse experience is necessary).

Live music, dinner and a charity auction with over a hundred items including holidays, restaurant vouchers and jewellery will be auctioned off on the night and all are encouraged to attend for a fun evening.

#### Further information

To find out more, talk to Maryanne Phillips on **0439 957 237** or email [wineandhorses@bigpond.com](mailto:wineandhorses@bigpond.com)



# Dementia Friendly Communities project celebrates successful collaboration

The Dementia Friendly Communities project has been a state-wide collaboration between Alzheimer's WA, state and local government, local businesses, service providers and community members over the last two years.

A major milestone will be celebrated in 2018 with the completion of a 12 month pilot for Australia's first ever Dementia Friendly Towns.

**'You have transported me to a whole new level of understanding. Thank you from the bottom of my heart.'**

**'One of the most inspiring and emotional sessions I've experienced.'**

Comments from community information session attendees.

## Why are Dementia Friendly Communities important?

Social stigma has a devastating impact on the lives of people with dementia. Post-diagnosis not only brings cognitive changes, but also changes how family and friends respond to the person.

The biggest challenge for the Dementia Friendly Communities project over the last two years has been to increase community awareness and understanding of dementia, in order to reduce the stigma associated with it.

By informing local communities how to support people living with dementia, the project has helped to create inclusive communities where people living with dementia, their families, friends and carers feel welcomed and supported.

## Reaching out to regional towns in Western Australia

As a direct result of the project, Alzheimer's WA has engaged with more than 1,000 people in 72 towns across the Wheatbelt, Goldfields and Great Southern regions.

Evaluations of community information sessions found 100% of attendees felt inspired to support people living with dementia in the community. Furthermore, 99% of attendees felt the sessions helped them to understand the 'stigma' of dementia and the negative impact that stigma can have. Almost all attendees felt confident to communicate with a person living with dementia as a direct result of attending a community information session.

## Dementia Friendly Towns - Manjimup and York

As part of the project, the towns of Manjimup and York participated in a 12 month pilot. Alzheimer's WA worked with the wider community in a whole of town approach to provide education, support and awareness to help address the stigma associated with dementia.

The learnings from these two towns are ongoing and will inform future Dementia Friendly Communities initiatives.

The final report on the success of the pilot project is due out at the end of the financial year, however we can reveal the following achievements:

- » Over 80% of people evaluated in a pre-survey felt that a Dementia Friendly Community will result in people living with dementia being able to 'age in place' (remain in their community) for longer.
- » Over 20 Certificates of Commitment and Achievement were awarded to businesses in York and Manjimup.
- » Public toilets in York will be upgraded to be dementia friendly.
- » Staff based at Balladong Lodge in York have reported stigma has been reduced by people knowing more about Dementia Friendly Communities.

Alzheimer's WA wishes to acknowledge the State Government of Western Australia, the Southern Inland Health Initiative and WA Country Health Service for their ongoing support and funding of the Dementia Friendly Communities project.



**Everyone living  
with dementia  
has their own  
story to tell.**



*January 20, 1962*



*Norm and Bonnie*



*Princess Cruise*



*Valentine's Day Dinner*



*Their Children*

Those living with dementia will never stand alone because of the vision and generosity of those who make donations. Please dig deep and help us make a difference to Western Australians living with dementia.

**To make your donation:**

Phone 1300 66 77 88

Visit [alzheimerswa.org.au](http://alzheimerswa.org.au)

**alzheimer'swa**  
the dementia experts