

# MILESTONES

AUTUMN 2019, ISSUE 23



Care conversation crucial



Memory Cafés








Driving and dementia

**alzheimer's**wa  
the dementia experts



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# CEO's report



Thank you for your membership.

Our members are our bedrock. We know it is your personal experience on the dementia journey that is the reason behind why you support the important work that we do.

The start of 2019 has been busy and productive. I am excited to announce that we now offer the only dementia-specialist home care packages in Western Australia.

This has been a long time in the planning but now means we can provide specialist support to our clients longer in their home and their community. Please read more about our home care package offering on page 4.

As you are no doubt aware the Royal Commission into Aged Care Quality and Safety is currently examining the aged care system and will make recommendations for improvement.

There have been many harrowing stories in the media that highlight the impact that a lack of quality care can have on a person, and the challenges and difficulties that people with dementia face in accessing the support they need.

We believe that dementia-specialist training and person-centred care can make a significant difference to the lived experience of dementia. We will continue to make submissions to the Royal Commission to advocate on behalf of people living with dementia.

This edition of *Milestones* brings you a number of stories to help you to plan for the future for yourself or a loved one. Check out the story on how assistive technology can assist you to stay at home longer. One of our advocates, Tom, also shares his tips on driving after a diagnosis of dementia and how to have the conversation about when to stop driving.

You can also read about our partnership with the towns of Toodyay and Margaret River to make them Dementia Friendly Communities.

Finally, our Walk to Remember events are on again in October and November this year. We hope to see you there.

Warm wishes

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

**Rhonda Parker**  
Chief Executive Officer

# Memory Cafés provide support networks

Would it surprise you to learn that only 30 percent of people diagnosed with dementia live in residential care facilities? The vast majority live in the community, like you or I, often in their own homes. With growing numbers of people living with dementia in the community, continuing to access the local shops and services, it is vital for these spaces to be welcoming and accessible.

People with dementia tell me they want to continue to participate in everyday life but require support and understanding from the rest of us to do so. It is imperative that opportunities exist for people living with dementia to have continued engagement in the local community in ordinary, everyday activities, and that they feel safe, comfortable and confident participating in those activities.

The introduction of a unique concept only three years ago in Western Australia has started to see a groundswell of interest from local community members, business owners and local government authorities. Called a “Memory Café”, the concept is a simple way for local communities to provide a welcoming and accessible space for people living with dementia.

There are now nine Memory Cafés operating in Perth, and three in regional Western Australia, and Alzheimer’s WA is in discussions to help facilitate the opening of several more.

Memory Cafés show how the simple, everyday pleasures of engaging with the community mean so much for all of us, and how simple it is to extend that opportunity to those living with dementia.

A group of people who regularly meet at a Memory Café in the northern suburbs have taken the concept of a supportive community one step further for people

diagnosed with younger onset dementia - dementia diagnosed before the age of 65.

There are approximately 26,400 people living with younger onset dementia in Australia and that figure is set to increase to 42,252 by 2056. In Western Australia, it is estimated that five percent of the population live with the disease.

Thirty couples, ranging in age from 50-65, are now part of the Younger Onset Dementia (YOD) Support and Social Network based in Perth. Vicki Barry, a founding member of the group and carer to her husband who was diagnosed with younger onset dementia a number of years ago, said they started the group in 2017 as a way of providing support to other families who were going through similar experiences.

“The YOD Support and Social Network is really a community of care and support for carers and their loved ones living with younger onset dementia.

“The issues we face with younger onset dementia are very different to people diagnosed with dementia after the age of 65. The impact is enormous. We are mostly still trying to work and raise families.”

Vicki said people come from all over Perth and even regional areas to take part in regular activities organised by the group.

“The Memory Café at Waldecks in Kingsley is one of the many social activities we enjoy each month.”

Some members arrive early for an hour long walk around the local lake before sitting down for a well-deserved cuppa. The group also arrange monthly outings, such as bowling, the movies, picnics and pub lunches, as well as day trips to Mandurah, Toodyay and York. A two night trip to Rottne is planned for later this month.



The YOD Support and Social Network enjoying a day out in Mandurah.

“We have developed a strong bond and provide a lot of support to each other. We have a lot of experience and skills and the best understanding of what we are going through,” Vicky said.

Initiatives such as Memory Cafés help to reduce the stigma attached to dementia. Instead, they develop a community that enables and supports people living with dementia to remain socially and physically active rather than be confined within the four walls of their home.

If you, a family member or friend live with dementia, visit a Memory Café and enjoy a coffee and some great conversation. If you can not find one in your local area, contact Alzheimer’s WA and we can give you some tips for how you can start your own and make a difference in your local community.

### Memory Cafés in the metropolitan area

- » Belmont: Tavolo Café
- » Booragoon: Coffea Fine Espresso, Garden City Shopping Centre
- » Fremantle: Bistro 21
- » Innaloo: The Coffee Club
- » Kelmscott: Avocados Café
- » Kingsley: Waldeck’s Lakeview Café (younger onset dementia only)
- » Mandurah: Memory Café @ Lakelands Library
- » Mundaring: The Hub of the Hills
- » Rockingham: The Clipper Café

### Memory Cafés in regional areas

- » Albany: The Store Café
- » Toodyay: The Cola Café and Museum
- » York: Granny’s Home Kitchen

Find more information about Memory Cafés at [alzheimerswa.org.au/memory-cafes](http://alzheimerswa.org.au/memory-cafes).



# Thinking about Home Care Package providers? Alzheimer's WA can help.

**Alzheimer's WA is the only dementia specialist home care package provider in Western Australia.**

Our philosophy of care embraces a person-centred approach that respects the individuality and the experience of those living with dementia.

We aim to help you to remain living at home for as long as possible.

If you are living with dementia, Alzheimer's WA can provide you with a range of services to assist you on your dementia journey.

Our dementia specialist care managers will work with you to develop a care plan for services that suit your goals, needs and lifestyle.

As the dementia experts, Alzheimer's WA uses evidence-based therapeutic care to provide meaningful activities based on your individual strengths and interests with the aim of building and supporting your wellbeing.

Our services include:

## **Support in your home**

- » Individual support and personal care
- » Therapy and health services
- » Nursing care
- » In-home respite

## **Support in the community**

- » Social support groups
- » Dementia specialist households
- » Short stay and overnight respite

## **Reasons to choose Alzheimer's WA**

- » Dementia specialists: providing support for people living with dementia is core to who we are and what we do.
- » Consistent team of staff: so you can develop relationships with your care staff and they can get to know your preferences and routines.
- » Individual plans to meet your individual needs
- » Dedicated care manager: one person for you to contact and work with for any changes you require to your services
- » We listen. Our approach in everything we do is guided by people, like you, who are living with dementia.

Information on Alzheimer's WA Home Care Packages can be found at [alzheimerswa.org.au/home-care-packages](http://alzheimerswa.org.au/home-care-packages) or by calling **1300 66 77 88**.



# What's happening



## Workshops

### Financial and Legal Seminars

Alzheimer's WA has partnered with industry experts to deliver free financial and legal seminars for families living with dementia. Check our website for dates and locations as they are added throughout the year.

### Family and Friends Course (one day)

One day course for people who know or care for a person with dementia. Learn about dementia, how to communicate with and support a person with dementia.

- » 19 June: Mandurah
- » 15 August: Perth
- » 16 September: Perth

### Adjusting to Change Program (five weeks)

Suitable for people recently diagnosed with dementia, and their carer or support person.

- » July: Shenton Park and Kenwick
- » August: Rockingham
- » September: Melville
- » October: Shenton Park and Bassendean

More information can be found at [alzheimerswa.org.au/events](http://alzheimerswa.org.au/events) or by calling **1300 66 77 88**.

## Accredited Training

Alzheimer's WA is a registered training organisation providing dementia-specific training and education to health care professionals. Our range of courses have an applied focus on skills development and reflective practice, enabling course participants to transform their own practice and enhance the quality of life of people living with dementia under their care.

More information can be found at [alzheimerswa.org.au/accredited-training](http://alzheimerswa.org.au/accredited-training) or by calling **1300 66 77 88**.

## Dementia Change Champions™

Dementia Change Champions™ is a capacity-building program that supports organisations to develop and maintain a skilled workforce to better support the needs of people living with dementia.

Participants in the program will have access to nationally accredited training, ongoing mentoring and support, access to Alzheimer's WA's extensive resources, and networking opportunities.

More information can be found at [alzheimerswa.org.au/dementia-champions-program](http://alzheimerswa.org.au/dementia-champions-program) or by calling **1300 66 77 88**.



## Equipped to care for you

As we age we may find that things are no longer as easy to do as they used to be. Sometimes it may seem impossible, or be so risky that we stop doing them. But did you know there are many adaptations and technologies now available to help enable you to keep doing the things that matter the most?

Most changes or equipment will cost very little, and could help delay the need to move into a residential aged care facility for months or even years.

Advances in assistive technology have resulted in some amazingly simple, yet effective, products available for use in the home market. These products can be surprisingly useful as we age.

### Support a person living at home

Supporting a family member who is living alone, especially if they are living with dementia, can be particularly stressful. An example of assistive technology that can help in this situation is a system that uses a series of sensors placed around the home, including

on doors, to monitor the movement of a person throughout the day and night.

Data from the sensors is fed back to you and alerts such as 'not up and about', or 'door left open' can be set. The result is you and other family members can monitor what is happening with your loved one without actually having to be present, and you can have peace of mind that everything is ok.

Initially piloted with social service authorities in the UK, now over 80% of UK local authorities use this technology for assessment and care planning. The system has supported many people to stay living at home longer, saving hundreds of thousands of dollars in inappropriate long term care admissions.

### Useful equipment

While not all equipment is as sophisticated as a sensor system, there are many useful assistive technology products available locally - some from your local department store, others from specialised suppliers.



One particularly common issue as we age is our short term memory may not be as good as it used to be. Devices such as medication prompters, diaries and appointment prompters on your phone and even apps that can help you find your car in the car park can all be useful aids to memory.

Other devices around the home can reduce the risk of forgetting. These include irons that sense when you are not using it and turn off after a short period, cook top alerts that sound an alarm if you have left the stove on and flood detectors to warn you if your bath is overflowing.

Motion activated night lights are a great idea if you have difficulty finding the toilet or bathroom at night, or may be at risk of falling if the hallway is dark.

## GPS devices helpful

Although some may curse the advent of smart phones and our ever-increasing reliance on them, mobile phones can be very useful in finding missing items, or even missing people.

Small Bluetooth tags can be attached to easily or regularly misplaced items such as a handbag, keys, wallet or phone. Once attached to the item, an app downloaded to a smart phone can help you to quickly locate a misplaced item.

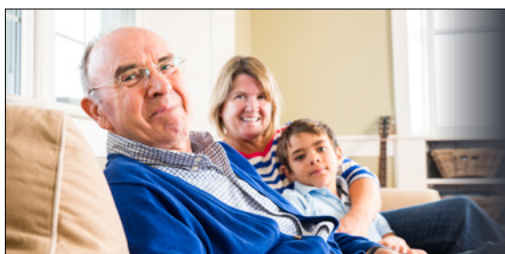
If you usually take your mobile phone with you when out, phone locating apps can make it easier to locate you, should you become disoriented or lost.

Difficulty in wayfinding and orientation is not uncommon for people living with dementia. To enable you to continue to enjoy going for a walk, doing the shopping or taking the dog out, a range of Bluetooth and GPS enabled devices such as watches and pendants are also available.

These GPS products and apps can provide peace of mind while helping to maintain independence, in addition to providing potentially lifesaving information to authorities in the event you do go missing. Although the cost of some of these devices is still quite high, they may prove to be priceless in the event you become lost.

For anyone wishing to stay in their home as they age, the assistance provided by some of these products could be just what you need to continue living independently.

Alzheimer's WA has a dementia-specialist assistive technology display area at its Shenton Park library or visit the Independent Living Centre for more information on assistive technology solutions.



## Adjusting to Change

A program for people living  
with early stage dementia

Receiving a diagnosis of dementia can be an overwhelming experience. Alzheimer's WA's Adjusting to Change program is designed for people who have recently been diagnosed with dementia, as well as their primary carer.

The program offers information and support for those living with early stage dementia.

For information on eligibility and accessing this program, please visit [alzheimerswa.org.au/adjusting-to-change](http://alzheimerswa.org.au/adjusting-to-change) or call us on **1300 66 77 88**.

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## Driving after a diagnosis of dementia

A diagnosis of dementia does not mean you must stop driving straight away, however because the condition involves a gradual decline in cognitive and physical ability, you will need to stop driving at some point.

Alzheimer's WA Advocate Tom Harmon was diagnosed with Parkinson's disease in 2014 and with Lewy body dementia a year later. Despite his diagnoses, he still drives around his local area to go out and to meet up with friends, as well as using public transport extensively for longer journeys.

Tom's family are very supportive of his desire to remain as independent as possible and say that being open and honest with each other is the key to keeping Tom on the road and safe, while addressing any concerns they may have.

Tom, his wife Annette and daughter Nakita came together at a family meeting to talk about Tom's driving, and to work out the best way to support Tom to continue to drive for as long as possible.

In a recent conversation with Alzheimer's WA Tom said, "Yes, I still drive. It gives me some independence."

"Because of the cognitive issues, it was best that I get an automatic, in a smaller car that's easy to drive,

"I stay in areas I feel safe, and only drive during the day," Tom said.

Tom acknowledges that one day he will need to give up driving, but for now he will stay behind the wheel until he, his family and his doctor all agree it is time to give up the keys.

### Tom's tips to keep safe while driving

If you are diagnosed with dementia there are a number of things you can consider to help keep you safe on the road.

- » Swap to a small car that parks easily
- » Don't drive self-locking cars - or if you do have one, disable the setting
- » Know exactly where you need to go and don't deviate from the route
- » Use a GPS device such as Google Maps in the car, especially if you're going somewhere unfamiliar
- » Download a 'find my car' app on your smartphone in case you lose your car
- » When possible, try not to drive alone. Having someone in the car can be helpful
- » Avoid driving at night
- » Avoid busy roads, freeways and busy intersections.



## Tom's tips for talking to your loved ones about driving

If you are a carer or family member, and have concerns about a person's ability to drive, speak to them or their doctor as soon as possible. Here are some tips to get the conversation started:

- » Start the conversation when everyone is calm, rather than during or following a driving incident
- » Have short and frequent conversations rather than one long discussion

- » Acknowledge that giving up driving is hard to do but everyone has to stop driving at some point
- » Focus on the financial benefits of selling the car/saving on petrol and upkeep
- » Be respectful of how the person with dementia will be feeling.

## Contact the Department of Transport

All drivers are required by law to notify the Department of Transport of any medical condition that may affect their ability to drive safely. A diagnosis of dementia is a mandatory reporting condition. As such, be sure to report your diagnosis to the Department of Transport.

## More information

Find more information on dementia and driving and watch Tom's video at [alzheimerswa.org.au/driving](http://alzheimerswa.org.au/driving).



## Dementia Enabling Environments

The Dementia Enabling Environments Virtual Information Centre provides practical tips, guides and resources to help make the places where we live more dementia enabling.

Visit [enablingenvironments.com.au](http://enablingenvironments.com.au)



alzheimer'swa  
**Dementia**  
Enabling Environments™



# Early intervention important for the management of dementia



Les was diagnosed with Alzheimer's disease last year.

Like so many before him, Les said he was initially in denial about his Alzheimer's diagnosis, but as time went on, things began to get serious.

"I was in a state of denial and certainly wasn't about to accept the opinion of these specialists," said Les.

"But I began to have serious problems with keeping scores at two of my favourite pastimes - bowls and golf.

"I was marking (scoring) a game of bowls, when I was asked by one of the players what the score was. I looked at the card and could not make head nor tail of it.

"I was totally humiliated and was in tears over my unwanted experience."

Les said there were a few similar experiences while trying to score at golf.

Receiving a diagnosis of dementia is not something people plan for and as Les experienced, it can be overwhelming. But, it is important to know there is support available.

Accessing support as early as possible can help improve symptoms and slow down progression of the disease. It can also help the person and their family accept the diagnosis and prepare for the journey ahead.

## Adjusting to Change program

Alzheimer's WA offers an early intervention program called Adjusting to Change. The program offers information and support for those living with early stage dementia and their carers, and includes a series of structured information sessions held weekly, over a five-week period.

When Les and his wife Kaye heard about the Adjusting to Change program, they decided to give it a go. Kaye said they were so grateful to the wonderful staff from Alzheimer's WA who guided them through the five-week course.

"The support from our sessions helped us to have a better understanding of Alzheimer's disease," said Kaye.

"The practical support, discussions and avenues for assistance were extremely helpful and informative.

"I now know some of what my very dear Mother suffered."

Les agreed.

"I cannot thank them enough for their efforts," he said.

"Let's hope the day of cure is somewhere in the wings. It is certainly frightening to learn how many people and families are affected by this disease."

If you, a family member or a friend have recently been diagnosed with dementia, contact Alzheimer's WA and find out what support is available and where to begin.

To find out more about the Adjusting to Change program, call us on **1300 66 77 88**, email [support@alzheimerswa.org.au](mailto:support@alzheimerswa.org.au) or visit [alzheimerswa.org.au](http://alzheimerswa.org.au).

# Towns embrace Dementia Friendly Communities initiative

**The Cola Café and Museum in Toodyay, and Margaret River Organic Garden, have thrown their support behind both town's Dementia Friendly Communities initiatives.**

## Cola Café and Museum, Toodyay

A new Memory Café has launched at Toodyay's well-known Cola Café and Museum.

The Memory Café opening comes just six months since the launch of the Dementia Friendly Communities project in the town.

The Memory Café was started by Alzheimer's WA Advocate Angi McCluskey and is supported by the WA Country Health Service and the Toodyay Shire.

Alzheimer's WA CEO, Rhonda Parker said she was thrilled the Cola Café and Museum had chosen to become WA's next Memory Café, and that all people living with dementia deserved to visit community spaces where they felt comfortable and welcomed.

"A Memory Café is simply an informal meeting place, such as a café, for like-minded individuals going through a similar experience.

"It provides an opportunity for people living with dementia to socialise, feel welcomed in a safe and inclusive environment, and make new friends - a simple pleasure we all enjoy and take for granted."

The Cola Café and Museum is located at 128 Stirling Terrace, Toodyay. The Memory Café will run on the second Tuesday of each month at 10.00am.

## Margaret River Organic Garden

Next time you are in the Margaret River region, pay a visit to the Margaret River Organic Garden.

The Margaret River Organic Garden has joined the Dementia Friendly Communities project and is encouraging people living with dementia and their carers to become actively involved with the garden by volunteering.

Margaret River Organic Garden Secretary Sharyn Carroll said the 30-year-old unique garden was a place of tranquility and connectivity that supported people living with dementia to remain active in the community.

"People with dementia deserve to participate in everyday life, which is why the Organic Garden embraced the Dementia Friendly Communities initiative," Sharyn said.

"We want the community to know that the Organic Garden is a very welcoming environment for people living with dementia and their carers."

Rhonda Parker said Alzheimer's WA was delighted Margaret River Organic Garden had embraced the initiative that empowers communities with the knowledge on how best to support and involve people living with dementia.

"We know in life small things make the world of difference and the volunteers at the Organic Garden are living proof of that."

## SAVE THE DATE



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

- » **Mandurah:** Sunday, 20 October
- » **Albany:** Sunday, 27 October
- » **Perth:** Sunday, 3 November

[walktoremember.com.au](http://walktoremember.com.au)

alzheimer's wa  
**WALK**  
to remember



## Care conversation crucial

**The release of the State Government's discussion paper on end of life matters in March of this year creates an important opportunity for all of us to consider how well we have planned for this aspect of our later years. Nothing is surer than death or taxes.**

The government discussion paper in particular canvasses issues regarding medical treatment and care issues and the difficult conversation regarding voluntary assisted dying. There is sure to be varied opinions regarding these things. However, the range of health, treatment and care matters that we all need to consider is far broader than the matter of voluntary assisted dying.

What we do know is that, according to Advance Care Planning Australia, around four in ten Australians are not able to make their own end-of-life medical decisions. This group has to rely on medical professionals and family members to make those decisions for them. Why? While some of these situations are unavoidable, others could have been avoided if individuals had planned ahead.

### Expect the best, plan for the worst

If you were in a catastrophic accident tomorrow and left in a coma, do you have any legally binding instructions regarding your preferences for treatment and care? Have you ever talked to a family member about what you would want in such a situation?

This is not something anyone wants to think about, but life is unpredictable. What we don't want is a treatment regime that is not what we wished for, or to place undue stress on loved ones who are unaware of our preferences.

Data indicates that it is actually more likely that when we do die, it will not be the result of a sudden and catastrophic event. However, it is important to start planning before the need is urgent, particularly if you already have a diagnosed chronic illness or a family history of illness.





## Treat a diagnosis as a wake up call

In fact, a diagnosis of chronic illness or cognitive impairment (such as dementia) should be a catalyst to start planning if you haven't already. Consider it a wake up call and, along with seizing the opportunity to live your best life while you still can and tick some items off your bucket list, get serious about what kind of support and care you would want (and wouldn't want) in the future.

Record your wishes while you are still able to communicate them. In the case of cognitive impairment and dementia, the issue of legal capacity becomes an important consideration. A person living with dementia will likely lose the legal capacity to make or record important life decisions as the disease process progresses. This can occur before other impacts, and while there is still the capacity to enjoy life. The dementia journey is different for each individual, and it is hard to predict when capacity will be lost. It is important to finalise the conversations and decisions before this loss of capacity occurs.

## Planning is good for your wellbeing

Research has shown that families of people who have engaged in advance care planning have less anxiety and stress when asked to make important healthcare decisions for other people. Think about the important people in your life... your spouse, children, siblings, parents. How would you feel having to make such important decisions on their behalf? An Advance Health Directive, an Advance Care Plan, appointing a Guardian or at the very least an ongoing discussion with family members can take some of the stress and anxiety away during difficult times.

Every Australian adult should think about advance care planning. If death and taxes are certainties in life then we need to talk about and plan for both.

How do you start advance care planning? It starts with a conversation, and Advance Care Planning Australia has some great conversation starters at [advancecareplanning.org.au](http://advancecareplanning.org.au).

Get talking, and find out about the wishes of your loved one. If you have questions around treatments, discuss it with your GP. You can also call Advance Care Planning Australia for advice on 1300 208 582.

It is better to have started the conversation, than to never discuss it at all.

## SAVE THE DATE



### The 'We' in Dementia - Innovation in Dementia Practice Symposium

**The Power and Positivity of Connection**

**Thursday, 3 October 2019  
Perth Convention Centre**

Hear from some of the world's leading thought and practice leaders in dementia care as well as perspectives from the lived experience of dementia.

For more information, contact us on **1300 66 77 88**, email [dpp@alzheimerswa.org.au](mailto:dpp@alzheimerswa.org.au) or visit [alzheimerswa.org.au/dpp-symposium](http://alzheimerswa.org.au/dpp-symposium)



**Dementia Partnership Project**

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# Knowledge is power: busting dementia myths



There is still so much social stigma around dementia and most of it can be attributed to lack of understanding and awareness of the disease. Here's a list of common dementia myths.

## **Dementia is a mental illness**

No, it is not. Dementia is a broad term for the symptoms caused by a group of diseases that impair brain function. Dementia is a progressive neurological condition and there is no cure.

## **Dementia and Alzheimer's disease are the same thing**

Not quite. Alzheimer's disease is one of around 100 different causes of dementia. Alzheimer's disease is the most common cause of dementia diagnosed in Australia (around 70%). The other most common causes of dementia in Australia are vascular dementia, frontotemporal dementia and dementia with Lewy bodies.

## **It's normal, it happens with age**

The risk of developing dementia does increase as we get older, however dementia is not a normal part of ageing. Memory loss is a common symptom of dementia but it is not the only one. Other symptoms may include confusion and disorientation, changes in mood and behaviour, loss of language and ability to speak, and in some people impairment of hearing and sight.

Around one in 10 people will develop dementia over the age of 65. This increases to one in three over the age of 85.

## **Dementia is an older person's disease**

Although more common in people over 65, dementia can occur in people as young as 30. When diagnosed before the age of 65 the condition is referred to as younger onset dementia. There are over 2,500 people in Western Australia diagnosed with younger onset dementia.

## **It's genetic - if mum or dad had it then I will get it too**

Genetic factors can play a role, but less so than previously thought. The presence of the APO-e4 gene may increase a person's risk of developing dementia, but the amount of people who carry this gene and then go on to develop dementia is largely unknown.

## **There is no point talking to a person with dementia - they won't remember**

A person with dementia may not remember what you have said but they will always remember how you made them feel. It is never a waste of time to spend time with a person with dementia, however it is important to modify your communication to ensure you make it as effective as possible.



### **A person with dementia won't be aware of what is happening around them**

Some people assume that if a person living with dementia is unable to communicate, they are not aware of anything happening around them. The part of the brain responsible for communication is separate to the part responsible for awareness. This means a person with dementia who is unable to communicate may still be very aware of what is going on in the environment around them.

### **There is no life after a diagnosis of dementia**

Although a diagnosis of dementia is not something people plan for, it is often met with relief by the person experiencing symptoms, and by their family members. A diagnosis also means a person can access the support they need to live well and start planning for their new circumstances.

## **Benefits of support**

Accessing support as early as possible can have many benefits including being able to talk to someone about your diagnosis. Our trained consultants can visit you in the privacy of your own home, discuss your recent diagnosis of dementia and answer any questions you have around living with dementia in the early stages.

Other benefits of accessing support include meeting people who are in a similar situation as you, and being able to share your experiences. Clients often tell us after taking part in one of our early intervention programs they feel more accepting of the future, that they no longer feel 'down', and that it is wonderful to connect with other people.

**There is life after a diagnosis of dementia, and you can live it well. Find out more about the support available by calling **1300 66 77 88** or visiting [alzheimerswa.org.au](http://alzheimerswa.org.au).**



# Research report

## StepUp for Dementia Research

Alzheimer's WA is pleased to be partnering with the University of Sydney in developing a new way for people to get involved in dementia research. The StepUp program will allow people living with dementia, carers, family and the general public to register their interest in volunteering for research projects in dementia treatment and care. Researchers undertaking studies will also be able to register their projects for people to see and volunteer in. This Australian first project aims to link researchers with study volunteers in order to increase the effectiveness and outcomes of dementia research. If you would like to view more information please visit the StepUp for Dementia Research website [stepupfordementiaresearch.org.au](http://stepupfordementiaresearch.org.au).

## New form of dementia found

Researchers in the U.S. have newly-described a form of dementia that closely resembles Alzheimer's and may affect a quarter of people aged 85 and older. The disease, named LATE (limbic-predominant age-related TDP-43 encephalopathy), is caused by an accumulation of the TDP-43 protein in the brain, as opposed to the characteristic tau and amyloid proteins in Alzheimer's. Both diseases affect cognition and memory, and shrinkage in the hippocampus, but LATE appears to result in a slower decline. Previously, the disease was under-recognised and misdiagnosed; distinguishing LATE from Alzheimer's will help narrow the target for researchers developing treatments for both diseases.

## \$10 million for Dementia Centre in Perth

The Federal Government has invested \$10 million in a new research centre at Curtin University that will help improve the lives of people living with, or at risk of, dementia. The new Dementia Centre of Excellence will study the preventative, primary and chronic disease management needs of people living with dementia, as well as their mental health. With additional contributions from Curtin

University itself, targeted workforce training programs for staff working in the community, hospitals and aged care facilities will also be part of the Centre's focus.

## World Alzheimer Report 2019 - survey open now

Be part of the world's largest survey on people's attitudes around dementia. The survey, commissioned by Alzheimer's Disease International, is anonymous, accessible and available both online and offline in multiple languages. The survey will only take around 10 minutes of your time but completing it will benefit people with dementia all over the world. The survey closes on Friday, 14 June 2019 and can be accessed at [alz.co.uk/research/world-report-2019](http://alz.co.uk/research/world-report-2019).

## Current clinical trials

There is a new clinical trial starting in Perth, looking at whether a drug designed to reduce cortisol in the body can have a preventative effect on reducing the risk of developing Alzheimer's disease. The trial is for healthy people aged 50-75 with no sign of cognitive difficulties. It is not a treatment for people already diagnosed with any form of dementia. To find out more visit [linear.org.au/trials/le180803\\_alzheimers\\_study](http://linear.org.au/trials/le180803_alzheimers_study).

For anyone interested in what clinical research trials are currently underway in Western Australia, please visit the Australian Alzheimer's Research Foundation website [alzheimers.com.au/our-work/current-clinical-trials](http://alzheimers.com.au/our-work/current-clinical-trials).

## Further reading

For an in depth read on global dementia research, download the World Alzheimer Report 2018 [alz.co.uk/research/world-report-2018](http://alz.co.uk/research/world-report-2018).

Access Alzheimer's WA monthly research reports at [alzheimerswa.org.au/about-dementia/research](http://alzheimerswa.org.au/about-dementia/research).

## Willetton teen gives up chocolate for grandparents with dementia

Few of us would know a teenager as dedicated to his beloved grandparents as Willetton teen Aaron.

Aaron first signed up for the Alzheimer's WA Chocolate Block Challenge in 2017, at the age of 16. As a self-confessed chocoholic, he made the decision to give up chocolate for a month in honour of his two grandparents who are living with dementia, and to raise funds for Alzheimer's WA.

"A few years ago my Poppa was diagnosed with Alzheimer's disease, and unfortunately he is deteriorating," said Aaron.

"He has had such a big influence on my life.

"Last year, my Nanna was diagnosed with dementia. This is two out of three grandparents with this disease and I don't want to see future generations go through what I have," he said.



This year Aaron turned 18 during the Chocolate Block Challenge and had to celebrate without chocolate, no mean feat for the choc-obsessed teen.

"But I still want to help raise money for such a deserving cause," he said.

Alzheimer's WA is grateful to all our community fundraisers who, like Aaron, give so much of their time and energy to raise funds for people living with dementia in Western Australia. Thank you Aaron, we are certain you have made your grandparents and your local community very proud.



**Every 6 minutes,  
another person is diagnosed  
with dementia in Australia**

With your help, we can give a longer, happier life to the next person diagnosed with dementia and keep them with their loved ones longer.

**Donate now:** Phone **1300 66 77 88** or visit [alzheimerswa.org.au/tax-appeal](https://alzheimerswa.org.au/tax-appeal)

**alzheimer'swa**  
the dementia experts





# Pathway to care

## Dementia specialist home care services

Alzheimer's WA provides dementia specialist home care services, tailored to meet your individual needs.

Whether you need help around the home, or out in the community, Alzheimer's WA works with you and supports you to live well with dementia.

We can also arrange for your carer to have a break for a few hours, overnight or longer if required.

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### Get help today

Visit our website for more information at [alzheimerswa.org.au/home-care](https://alzheimerswa.org.au/home-care) or call us on **1300 66 77 88**.

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the dementia experts