

MILESTONES

SUMMER 2019, ISSUE 24



Home design to help with living well

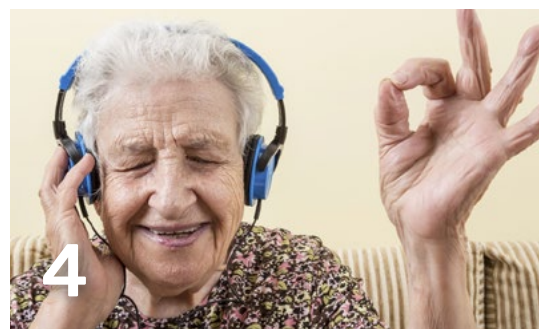


Dementia awareness month








Person-centred approach

alzheimer'swa
the dementia experts



Contents

Welcome.....	1	Help is at hand for those with a diagnosis of dementia.....	14
Home design to help with living well.....	2	Ellenbrook student volunteers in honour of grandfather with dementia	16
Music taps into memories.....	4	2019 Walk to Remember.....	18
Get moving to curb risks.....	6	Murray and Robin's story.....	19
Connecting with a person who has dementia	8	Dementia Awareness Month.....	20
Person-centred approach.....	10	Research report	21
Use it or lose it.....	12		

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Welcome



Welcome to this edition of Milestones, a bi-annual magazine for our members.

Alzheimer's WA is proud to support people living with dementia in Western Australia with a person-centred approach. Earlier this year we provided a submission to the Royal Commission into Aged Care Quality and Safety on the importance of a person-centred approach. Our submission was met with a request to view our services in action. As a result, the Chief Commissioner visited Mary Chester House the week before the Perth hearings to experience just what a person-centred approach is all about.

Our Head of Dementia Practice and Innovation, Jason Burton, was also invited to appear before the Commission to speak about how a person-centred approach can be achieved in an aged care setting. Jason's two hour testimony about the benefits of a person-centred approach was in stark contrast to the many sad and often confronting stories that have come to light during the Royal Commission. We look forward to reading the interim report when it is released.

Rhonda Parker, CEO of seven years, retired at the end of September. Rhonda headed up the organisation during a difficult period including the separation from Alzheimer's Australia. We wish Rhonda all the best in her future endeavours and thank her for the significant impact and contribution she made during her time with Alzheimer's WA.

The recruitment process for a new CEO is underway and we will report any appointment to members once a new leader for our organisation is in place.

In this edition of Milestones, we bring you a number of stories on how to live well with dementia. Read about changes you can make at home to make the environment more dementia friendly and the benefits of music for a person living with dementia.

Look for the latest research detailed in our Research Report, and be sure to read our story from Advocate Robin who talks about the value she found in attending a carer support group.

We also bring you some tips on how to reduce your risk of developing dementia through incorporating certain types of exercise into your day and through challenging your brain.

As the end of the calendar year draws near we are grateful for all the support we have been able to provide to people living with dementia and their carers in 2019, and look forward to the opportunities that 2020 will bring.

From everyone at Alzheimer's WA we wish you a very merry Christmas and a safe and happy New Year.

Warm wishes



Danielle Wrench
Chief Executive Officer (Acting)



Home design to help with living well

Elements of design can have a significant impact on how a person living with dementia experiences the environment around them.

Good design can enable or support a person's navigation or use of a space, especially if the space is unfamiliar. Who hasn't found themselves confused about which exit to take from a shopping centre or which row our car is parked in? Imagine how much more difficult it would be if you had impaired short term memory, a loss of the ability to sequence actions, or loss of colour and depth in your visual field. These are common impacts of dementia.

A well designed enabling environment can support a person living with dementia to continue to lead a full and active life by reducing the disabling impact of cognitive impairment.

On the flip side, a poorly designed environment can be confusing, disorientating and inaccessible for a person living with dementia.

There is very limited guidance on dementia specific design in the Australian Accessibility Standards or Universal Design guidelines.

This aspect of design is often neglected and overlooked by architects and urban designers when designing and creating houses, gardens, public buildings and spaces. With over 70 per cent of people with dementia continuing to live in their own home, and who want to continue engaging in the community, it is time to consider how our homes, public buildings and local community spaces could better support those with dementia.

Colour contrast, lighting, choice of wall and flooring materials, and signage can all play a significant part in how a person living with dementia experiences the environment they are in. By making even the smallest of changes you could make a big difference.

If a person is no longer able to walk you can adapt the environment to assist them to continue accessing and using it. In the same way you can use design to overcome some of the disabilities of dementia. Some of the more common difficulties a person living with dementia may have include wayfinding and orientation, spatial perception (that is identifying the 3D spaces or objects around them), sensitivity to visual and audio stimulation, and using unfamiliar objects.

The use of colour to contrast or highlight key areas or objects in the home can make it easier for a person living with dementia to navigate and identify things. Colour contrasting door handles, toilet seats and even bathroom taps can help a person to more easily identify these items. Colour contrast can also be used effectively with crockery - for example a blue plate on a white tablecloth is easier to see than a white plate on a white tablecloth.

Use of colour and strong patterns on surfaces such as flooring, fabric or wallpaper can make the environment more challenging for a person living with dementia.

People with dementia may lose their depth of vision. Highly contrasting patterns on the floor (such as a checker-board pattern or a dark floor mat on a light floor) may be perceived to be changes in floor level or 'holes' in the ground. Similarly, changes in flooring type, especially where the colour is visibly different, can create a perceived step or hole in the floor. The same principle applies to highly decorative or patterned rugs, which can also present a trip hazard.

Exposure to natural light can assist in general wellbeing and in differentiating between day and night. By opening curtains and blinds fully to maximise daylight and enhance vision, you will support wayfinding and safe walking in the home. Where natural light is not an option, consider replacing light globes with higher wattage ones or adding additional task lighting to further support good lighting levels within the home.

Use signs on doors such as the bathroom and toilet to support movement and engagement, especially if in a new home. You could also label cupboard doors and drawers with their contents using pictures and words that are easily recognisable.

Enabling dementia design need not be limited to just the home. The principles of good dementia design can also be applied to public buildings, hospitals, outdoor and garden spaces.

If you are interested in finding out how to make your home and garden a dementia enabling environment, our Dementia Enabling Environments website has information you can use within your home, as well as for private and public gardens, public buildings, hospitals and residential care homes.

The website responds to the growing recognition of the positive difference enabling environments can have for people living with dementia. It is an Australian first in that it translates enabling environments research into practice and focuses on architecture, interior design and outdoor spaces.

Use the website and its interactive illustrations as a visual guide to creating a dementia enabling environment within each room of your home. Alternatively, contact us for a wide range of practical, inexpensive and useful ideas, examples and recommendations as well as resources to make necessary changes, and to evaluate the outcomes.

By making some simple and positive changes within your home you can maximise enablement and wellbeing for a person living with dementia.

The 10 Dementia Enabling Environment Principles

- » Unobtrusively reduce risks
- » Provide human scale
- » Allow people to see and be seen
- » Reduce unhelpful stimulation
- » Optimise helpful stimulation
- » Support movement and engagement
- » Create a familiar space
- » Provide opportunities to be alone or with others
- » Provide links to the community
- » Respond to a vision for a way of life.

For more information please visit enablingenvironments.com.au



Music taps into memories

Music often accompanies defining moments in our lives. From singing the national anthem at school, to the song you walked down the aisle to, music almost always has a role to play. Music can hold cultural significance, it can elicit strong emotions and trigger long term memories. Most people will have experienced hearing a particular song and the feeling of being transported back to a forgotten time or place.

Renowned neurologist Oliver Sacks identified the important role music can play on our emotional and physical health, including lowering our heart rate and blood pressure and calming our nervous system. Singing in particular can lift mood and boost a person's self-confidence. We all use music throughout our lives for relaxation, stimulation, exercise or just for pleasure.

Listening to meaningful music engages

broad neural networks, and research has shown it to be a very useful tool for positively engaging with people living with dementia. One of the key areas of the brain effected when listening to music that triggers music evoked autobiographical memories (MEAMs) is the area just behind the forehead. This is also one of the last areas affected by Alzheimer's disease.

Listening to music with emotional significance brings back strong memories for most people. This can be used to enhance wellbeing and quality of life in all of us, but can be especially useful for people living with dementia.

There is strong research evidence promoting the use of music as a valid tool for supporting people living with dementia - whether they are still living at home or have moved to a residential care home. With up to 50 per cent

of all aged care residents diagnosed with dementia, and current care practices under the spotlight, it is a worthwhile concept to explore.

The style of music doesn't matter. It could be jazz, classical, rap or heavy metal. It simply has to mean something to the person. Music from when a person was a young adult, aged 15 to 25, seems to have the strongest MEAMs and evoke the greatest, most positive responses, though any music with a strong emotional memory attachment can be beneficial.

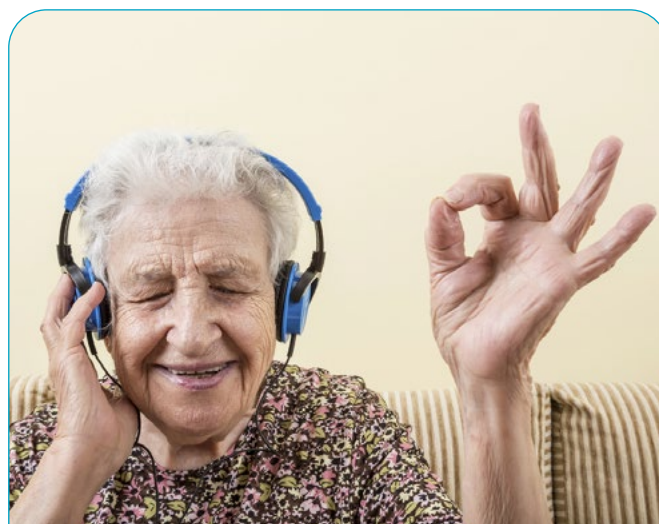
Music therapy is so effective it has even been shown to reduce pain and discomfort in some people with dementia - leading to a reduced need for some medications.

Many people living with dementia may not have the opportunity to access music that matters to them. Often we may not think about creating opportunities for the person to be able to listen to their music on a daily basis. A number of programs around the world are seeking to change this including the Music and Memory Group in the USA and the Music for Dementia 2020 group in the UK.

In a movement called 'social prescribing', supporters of the UK campaign hope to embed music into dementia care pathways and reduce the use of inappropriate chemical restraint in dementia care, instead highlighting the importance of improving wellbeing and quality of life. Useful tools and resources for creating playlists can be found on the Music for Dementia 2020 and the Playlist for Life websites.

If you are still not convinced of the benefits of music in supporting people with dementia, try searching YouTube for a clip aptly named 'Alive Inside - Henry's Story', and watch the transformation of Henry for yourself. For anyone who knows a person living with dementia, it is powerful viewing.

If you know someone with dementia, consider bringing some music back into their life. It may only feel like a small gesture, however for a person living with dementia it could help bring back some wonderful memories.



How to re-introduce music to a person with dementia

- » Start by finding music that the person enjoys and connects with, and that brings a positive response.
- » Create playlists of songs that illicit different emotions. Music can make us feel many different things and all are valid and important emotions to express.
- » Listen to music together. It could be on the radio, the television, using an old fashioned tape player, or even live music. Create a sing-a-long playlist. Why not have a dance at the same time!
- » Use an iPod or similar device that the person can access easily. Using headphones can help the person living with dementia to concentrate on the music without distraction.
- » Look out for music groups, choirs or music based activities in your area.
- » Visit the Music for Dementia 2020 website to get tips and resources: musicfordementia2020.com



Get moving to curb risks

Dementia is the second leading cause of death in Australia, according to the Australian Institute of Health and Welfare's latest report, and this makes dementia a national health priority. With no cure for dementia, and limited treatment options available, now more than ever we need to seriously consider what our risk reduction options are.

We are regularly bombarded with messages about the benefits of leading a healthy lifestyle, especially for reducing our risk of health complications later in life. How many of us actually pay attention to the warnings?

Researchers report that leading a healthy lifestyle could reduce your risk of dementia by as much as 30 per cent, and this was recently confirmed at the 2019 Alzheimer's Association International Conference, held in the United States.

Researchers advised that a combination of exercise and healthy eating could cut a person's chances of developing dementia by between 20 to 30 per cent depending on underlying factors. Their report was published last month in the Journal of the American Medical Association.

This is not the first report to herald this advice, nor will it be the last. So called 'modifiable risk factors' for dementia could hold the key to reducing the impact of the disease on current and future generations. Looking at several recent studies, the key areas to focus on are exercise and diet, as well as mental stimulation and social engagement.

Simply being told you need to exercise more for good health is probably not enough of a driver to make you actually do it. However, according to the World Health Organisation and their recently released guidelines 'Risk reduction of cognitive decline and dementia', exercise is at the top of the list of effective dementia risk reduction strategies.

Now the warmer weather has returned perhaps it is time to reconsider taking up that early morning or evening stroll.

Evidence is mounting that people who are physically active are less likely to develop cognitive decline or dementia, compared to people who are inactive. The question now is why? And exactly what type of physical activity is best?

The 'why' is twofold. Firstly, exercise maintains good blood flow to the brain and encourages new brain cell growth in the hippocampus. By increasing your brain matter you can combat age related brain shrinkage, which in turn, can help to delay the onset of dementia.

Secondly, physical exercise has a positive effect on your risk of heart disease or stroke, blood pressure, type 2 diabetes and obesity - all of which are risk factors for developing dementia.

The recommended types of activity are aerobic, strength training or a combination of both. Aerobic exercise is anything that gets you breathing harder and increases your heart rate such as brisk walking, cycling, swimming or dancing. Strength training could be using resistance bands or weights. Look at combining some moderate-intensity activities (ones that make you breath harder) with some high-intensity ones (where you can't easily talk while doing them).

For those who find it hard to fit scheduled exercise into their busy day, there is hope. Any kind of physical activity is better than doing nothing, and there are plenty of ways to incorporate incidental exercise into your everyday life.

Think about all the opportunities you have in your day, or week, to increase your exercise... take the stairs instead of the escalator, park further away from work or the shop, clean the car by hand (not in a car wash), get involved with the kids sport.

Like the government campaign said, find your 30. Exercise doesn't have to be completed in one sitting to be beneficial, so try spreading it out throughout your day.

Incidental exercise can add up quickly, particularly when you seek out opportunities for it. Of course, consult your doctor before starting any new exercise program. And most importantly, make it enjoyable so it becomes part of your lifestyle.

Look for incidental opportunities to get more exercise

- » Sit less... at work and at home
- » Take the stairs rather than the lift or escalator
- » Walk the dog around the park, rather than standing still throwing a ball
- » Get involved with your kids or grandkids sport
- » Get off the bus a stop or two earlier
- » Park further away from work
- » Walk on your lunch break
- » Wash the car, or clean the house
- » Put on some music videos and dance to your favourite tunes
- » Walk with friends, or take the kids to the park
- » Make the bed every morning
- » Get out in the garden.



Dementia Advisory Service

Personalised and practical advice to help you plan for your future and dementia specialist services and supports to suit your lifestyle.

For further information, please contact us on **1300 66 77 88** or visit **alzheimerswa.org.au**.

alzheimer'swa
the dementia experts



Connecting with a person who has dementia

Think about the number of people you talk to, you connect with, in one day. From the moment you wake up, to the time you go to bed. Most of us communicate with at least one other person every single day of our adult lives.

Now think about how you would feel if your ability to connect with others was taken away, through no fault of your own. What would it be like if you could no longer communicate with other people, and other people didn't communicate with (or even acknowledge) you. It would be a very isolating experience.

Everyone, no matter whether they have a physical or mental disability, no matter their age, race or political persuasion, is a human being. As humans, we are profoundly social and we constantly seek out opportunities to connect with others.

So what happens when you lose the ability to communicate with others, as can often happen in the late stages of dementia. Does a person's need for communication and connection disappear along with their ability to speak? Of course it doesn't. They are still a human being with a very real need to connect.

Let's take this concept one step further and relate it to a care environment. What happens to our perception of a person when they can no longer communicate, and we are required

to care for them? In a very task oriented environment where staff must attend a set number of 'beds' in a limited amount of time, it is very easy to start viewing the person you are caring for as less of a person. As an object of the task at hand.

And at the heart of this objectification, apart from a lack of time, is a lack of knowledge. How do you connect with a person who can no longer communicate themselves? There is one person who has found the answer, and his name is Michael Verde.

Michael Verde is an international dementia expert from Texas, USA and the founder of Memory Bridge. Through his work, Michael teaches others the importance of communication - and how to communicate - with people living with dementia.

Michael believes that emotional and social isolation is the greatest pain a human being can experience, and he has an extraordinary way of explaining why connections are so important.

Listening to Michael speak, it makes you wonder why this kind of information isn't mandatory training for anyone who works in aged care. Or with anyone, anywhere.

It seems so logical, so normal. Communication between people is, and should, be a normal concept. Yet for some

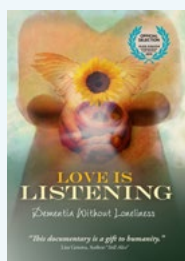


reason when we talk about communicating with a person with dementia, it becomes complicated. Difficult. Impossible even.

It turns out nothing could be further from the truth. With a little insight. Michael's work has a powerful impact on many of the people who come across it, with many remarking it is 'life changing'.

At Alzheimer's WA we often say that although a person with dementia may not remember what you said, they will remember how you make them feel. This is why it is so important to continue to communicate with people living with dementia. Even if they have lost the ability to talk, they are still a whole person with real emotions. Still just as much a person as you or I. And when you can make that connection with a person with dementia, it is something truly magical to behold.

Michael Verde was in Western Australia in August for the Australian premiere of his latest documentary "Love is Listening: Dementia without Loneliness".



The documentary offers an understanding of how to genuinely connect with a person who is living with dementia. The documentary can be purchased from memorybridge.org.



In October, International Validation Method Master Vicki de Klerk-Rubin visited Perth from The Hague, Netherlands to speak at the 2019 Alzheimer's WA Dementia Symposium. Vicki also ran a half day Validation workshop with over 100 people in Perth.

The Validation Method is a communication method that can assist carers to explore expressions of need with their loved ones, particularly in the later stages of dementia. It involves reading a person's body language and micro expressions to help carers step into the reality of the person and connect with them. By doing this, a person's need for connection and identity is validated, which in turn can help to reduce any stress, anxiety and even pain they may be feeling.

Vicki's career has seen her travel the world to deliver Validation workshops, lectures and training programs in more than 20 countries. She has also authored two books on communicating with people living with dementia.

For more information about the Validation Method please visit vfvalidation.org.

Person-centred approach

By Danielle Wrench, Acting Chief Executive Officer, Alzheimer's WA

A person-centred approach isn't something that can be bought, or created with a fancy new building. It is more than just words on the pages of a policy document. It starts with a culture of change at board and senior management level, and filters down to all staff within an organisation. The result is something you can see, and also something you can feel.

I recently visited our day centre, Mary Chester House, and that feeling was all around me. I'd like to share my experience with you.

Mary Chester House in Shenton Park is surrounded by natural bushland. The House, designed with dementia enabling design principles in mind, runs typical services such as day and overnight respite, social clubs and a Men's Shed.

The people living with dementia who attend our Houses are known as our club members. Each member has a one page information sheet displayed in plain view, stating the member's preferred name, likes and dislikes, and what occupation they once had. This gives staff, volunteers and visitors like me the opportunity to learn something meaningful about them. It reminded me that these are people who have lived full and vibrant lives, and this should be respected and acknowledged.

Each morning the staff, volunteers, and members meet to decide what activities they will do for the day. Some activities, such as outings, are planned ahead with members input. However, variety and spontaneity are encouraged.

On the day of my visit there was a partially completed jigsaw left out on a table, and a few rows of knitting - with needles still attached - sitting in a basket next to a comfy armchair. The piano was set up with the lid open and sheet music sitting ready, as if

inviting passers-by to sit down and play.

In other facilities, knitting needles might be seen as a hazard to the resident's health. An unfinished jigsaw puzzle a mess to clean up. A piano may be on view to promote reminiscence. But a sign that says 'do not touch' defeats the purpose of having the piano in the first place.

At our House, the jigsaw and knitting is an opportunity to bring about joy, for members to enjoy a favourite pastime. The open piano an opportunity to invite music, singing and a great deal of spontaneity to the House. These simple activities also provide opportunities for members to connect with others over shared interests.

Consider the alternative... being 'parked' in a chair in front of a blaring TV, and left to fend for yourself. I don't know many people who would choose that option.

When I visited, the intimate dining area held several tables and chairs, each set with real flowers in a real vase. I later learned that members took great pride in picking flowers from the garden to decorate the tables - just as they would have at home.

Members could choose where to sit to eat their meal and who they sat with, rather than being told where to sit. Cutlery was left out for those who wished to set the table, giving members the opportunity to do for someone else - rather than having tasks always done for them.

Too often, the everyday choices that we take for granted are taken away from people with dementia. This can slowly erode a person's confidence, and lead them to eventually give up trying to do anything for themselves.

The kitchen was staffed by volunteers, the door was left open, and several members were in the kitchen helping with food preparation. You may be thinking, why would you let a



person living with dementia into a kitchen with potential danger? To give that person the opportunity to engage in an activity that is normal and enjoyable. Staff and volunteers are all so intimately familiar with each member's abilities, they know just how much supervision to provide. The potential risks are far outweighed by the look of satisfaction on a person's face when they have helped to prepare lunch. And to date, we've had no burnt fingers.

Later, staff and volunteers sat and ate their meals with members - just like one big family.

The dining room led to a garden area, through doors that were unlocked and open, and members were able to move from inside to outside as they pleased. The garden was brimming with opportunities for members to be active, or to sit and relax, enjoying the sunshine and the sounds of birds from the neighbouring bushland.

A paved courtyard was set up with an ongoing communal mosaic project. A gazebo strung with fairy lights and covered with greenery invited members to sit and chat around the 10 seater table. A grassed area provided a seat for quiet contemplation, and a small cubby for toddlers from the mother's group who visit.

Around the corner I could see the Men's Shed. The sound of buzzing saws radiated from

the Shed, and the nearby garden beds were a hive of activity as new vegetable and herb seedlings were being planted by members. Further along in another undercover area a serious ping pong match was underway.

It may sound risky supporting a person with dementia (who has also worked with timber all his life) to operate a drop saw, but worth the risk if it means that person can achieve the sense of achievement that only comes from creating something useful from a piece of timber.

Throughout my visit one thing was clear. I was surrounded by smiles, laughter and life. It didn't feel like a facility. It felt like a community. It felt like home. Our House is founded on the Eden Alternative Principles™, which focus on combating the loneliness, helplessness and boredom experienced by many people in aged care. Everything that happens at our House is guided by the ten Eden principles. While the safety of all members is paramount, our aim is to provide a home-away-from-home where people with dementia are respected and supported to make their own choices, learn a new skill or two and above all form friendships with others who are on the same journey. I am so grateful we can care for our clients in this way.



Use it or lose it

Can you prevent dementia? While you can't do anything to guarantee you won't develop dementia there is a growing body of evidence that you can significantly reduce the risk of developing it.

It's previously been shown that higher levels of education early in life could help to ward off cognitive decline as we age. However, over the last few years researchers have also been looking at whether regular mental stimulation in mid and later life can provide a better defence against developing dementia.

Like physical exercise, mental exercise can help build up levels of healthy brain cells and also increase the connections between them. It's known as 'neurological plasticity' and by building it up now you could be protecting your brain later in life.

It is thought that some pathology changes related to Alzheimer's disease can start 20 years before any obvious symptoms. That means investing in your health in your 40s and 50s is critical to what will happen to you in your 70s or 80s.

Recent studies suggest by engaging in mentally stimulating activity throughout your life you can improve your brain's ability to function, therefore reducing your risk of developing dementia or helping to delay the onset of dementia as you age.

In a study published in journal *Neurology* early this year, Swedish researchers confirmed mental exercise could help as much as physical exercise to reduce a person's risk of developing dementia.

What is interesting about this study is that it started four decades ago, which is significantly longer than most other studies looking at links between mental activity and cognitive decline. It also used participants who were much younger than other studies. The study involved 800 Swedish women who were on average 47 years old, and over the course of 40 years researchers asked participants questions about the mental and physical activities they engaged in, conducted cognitive testing, and recorded any dementia diagnoses.

The results showed that the women who participated in more mental activities were able to lower their risk of developing dementia by 34 per cent, and those who participated in regular exercise lowered their risk by 57 per cent.

Researchers concluded that mental activity really is just as important as physical activity for reducing your risk of developing dementia as you age. Their findings support a number of other studies released in recent years.

Published a few years ago in the Journal of Aging and Health, the NIH ACTIVE study looked at the benefits of mental training for older adults. Results showed those who completed at least 10 sessions had improved cognitive function in the months and years that followed.

A study published around the same time in JAMA Neurology looked at people in their 70s and 80s with no cognitive impairment, and compared their education levels, whether or not they had mentally stimulating jobs and whether or not they engaged in mentally stimulating activities later in life. The results showed that although education and employment were important, engaging in mentally stimulating activity in mid and later life could delay the onset of cognitive impairment by several years.

Finally, another study of people in their 70s and 80s with no cognitive impairment asked how often they did particular activities including reading, writing, crossword puzzles, and board or card games. Over the next five years, those who engaged in the most mentally stimulating activities were

50 per cent less likely to develop any kind of cognitive impairment or dementia.

It just goes to show, if you don't want to lose it, you need to use it.

To introduce some mental exercise into your week, look for activities that involve learning something new or are reasonably complex. You could start a new hobby, like knitting or crochet, learn to play an instrument or speak a new language. Pick up a book - and if you read regularly, try a different author or genre. Join a bridge club, go to bingo or complete a crossword. Challenge your mind at the supermarket by adding up the groceries in your head as you go. Rely on your brain rather than the satellite navigation in your car, or drive a different way to work.

If self-motivation is an issue, a good way to get into a routine is to sign up for a weekly class. Better yet, join with a friend and you can motivate each other.

Like all things in life, make it interesting and enjoyable and you will be more likely to incorporate it into your everyday life. As with physical exercise, any mental exercise is better than none, so be sure to grab the puzzle pages out of your favourite newspaper or magazine, find a pen, and get stuck into your favourite brainteaser.

Top tips for exercising your brain

- » Learn a language or an instrument
- » Sign up for a regular class
- » Start a new hobby
- » Use mental math rather than your smart phone
- » Play a board game
- » Read a book
- » Drive a different route to your regular one
- » Complete a crossword or puzzle.





Help is at hand for those with a diagnosis of dementia

They say in life the first step is often the hardest. Whether it's starting a new relationship or ending one, going for your first job interview or re-entering the workforce after a long absence, taking those first few physical or metaphorical steps can be daunting. And no matter how old we get, in life there are always more 'firsts' to experience. Some are positive, and some not so.

When it comes to a diagnosis of dementia, there can be many 'firsts' that a person has to face and often these can look and feel like insurmountable hurdles.

These could be acknowledging to yourself that perhaps there might be something more going on than just occasional forgetfulness. Discussing your concerns with your partner or a loved one. Speaking with your GP. Receiving

an actual diagnosis. Deciding who to share that diagnosis with. Accepting that some early intervention or support services may be helpful. Finding the appropriate support services.... the list goes on.

A diagnosis of dementia can come as a shock even if it has been long suspected. Many people say once they receive a diagnosis they just don't know what to do next. They are unsure what that next step is.

No matter where you are on the journey, there are organisations that can help. The Dementia Advisory Service at Alzheimer's WA is one of the ways we can help a person with a diagnosis of dementia, and their carer or loved one, work out what their next steps might be.

It is a non-threatening way to start to find out a bit more, to help ease any anxiety or stress a person may be feeling about their diagnosis, or about some of the changes they may be experiencing. It is also a free service, and although some eligibility criteria apply, setting up an appointment is as simple as giving us a call.

One of our trained and experienced staff can come to your home for an hour or two, anywhere in the metropolitan area, and give you information on supports and services that may be available to you now and into the future. They are also there to answer any questions you may have.

Our staff get asked all sorts of questions, from “what does my diagnosis mean?”, to “what is this particular type of dementia?”, to “if there’s no cure, then what else can I do?”. Many people want to know what support is available, not only for the person with the diagnosis, but also for their partner and loved ones.

Although the Dementia Advisory Service is for people diagnosed over the age of 65, we have a similar service available for younger people who are diagnosed with

dementia. For people living outside of the metropolitan area, where a personal visit is not practical, we can talk through your options on the phone.

Another service we offer is the Adjusting to Change program. This program is suitable for people recently diagnosed with dementia, and their carer or support person. The program offers information and support for those living with early stage dementia and includes a series of structured information sessions held weekly, over a five week period. Courses start regularly in a variety of locations in the Perth metropolitan area.

For family members and friends, we also offer the Family and Friends course. This one day course is for people who know or care for a person with dementia. Attendees learn about dementia, how to communicate with and how to support a person with dementia. Courses are held regularly in Perth.

If you or someone you know is living with dementia, give us a call on **1300 66 77 88** and we can help you take the first step towards living well with dementia.



Family and Friends

Dementia workshops

A one day workshop exploring dementia and its impact on the person living with dementia and their family.

It is designed to give an understanding of dementia and how to communicate with and support a person living with dementia.

For further information contact us on **1300 66 77 88**, education@alzheimerswa.org.au or visit alzheimerswa.org.au.

Places are limited | Bookings are essential | Small co-contribution required

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Ellenbrook student volunteers in honour of grandfather with dementia

Fifteen year old Ellenbrook resident Brady recently spent two days volunteering at Mary Chester House in Shenton Park as part of his school's LIFE Week program, in honour of his grandfather Graham who lived with dementia for ten years. Graham passed away in 2017.

As part of the Holy Cross College LIFE Week program, students in years 10 to 12 are required to complete 50 hours of volunteer service in the community throughout the year.

The year 10 student always had a close bond with his pop, and helped nan Sandra care for her husband while he was still living at home. Sandra said Brady was her biggest support at home, always helping her out, and she was very proud when he chose to volunteer at Mary Chester House.

"I think what Brady is doing is great. He didn't hesitate to say yes when I suggested it. On his second day he just went straight up to one of the men who was sitting in a group, shook his hand, sat down and started chatting. Most other teenagers wouldn't feel comfortable doing that."

Brady said he was a bit nervous at first, but felt at ease once he saw some familiar faces at the House. On his first day they visited King's Park and then returned to the House

where they played table tennis and board games. Brady said he was glad he came to the House to volunteer.

"It's different. You get to meet new people. When you see a smiling face, it feels good."

Graham lived with dementia most of Brady's life, and Brady grew up accepting that was part of who his pop was. Brady spent a lot of time visiting Graham at Mary Chester House and enjoyed helping him to look after the birds.

"It [the dementia] became normal to Brady, which is why I think he is able to connect so well with other people with dementia. Anywhere his pop went, Brady was there. Including Mary Chester House. It was good for Brady to see him outside of the home environment," Sandra said.

Sandra said spending time with older people has helped shape her grandchildren to be the kind and caring people they are today.

"They always loved coming to visit their pop, especially when he was at Mary Chester."

Brady said he plans to attend TAFE when he leaves school, to study electrical work "or something hands on".

Diagnosed at an early age

Sandra and Graham met when she was just 16, and he was 18. The childhood sweethearts were married four years later.

Graham was diagnosed with early onset dementia at the age of 61. Prior to that, he was a fireman for over 30 years.

Sandra said they carried on for the first couple of years after Graham's diagnosis, but then she realised they needed more support. Graham attended Mary Chester House two days a week for almost six years. Having been a fireman for most of his career, he was always fit and healthy, and he enjoyed getting out and about.

"Having somewhere to come like Mary Chester House was really important for Graham. It provided more than home care can. It provided him with mateship. He enjoyed

any interaction with 'the boys' at Mary Chester, and especially any outings. Mary Chester House is a life saver for people living with dementia."

Around the same time Graham started attending Mary Chester House, Sandra joined a support group with eleven other wives caring for their husbands with dementia at home. Over ten years later they continue to support each other and the bonds of their friendship, formed over their husband's shared diagnoses, remain strong.

"We still meet up for lunch. One of the ladies still has her husband living at home. Unfortunately, the others have now either passed away or are living in aged care. It's important to have that support when your partner has dementia."



Brady with his grandmother Sandra at Mary Chester House.



A younger Brady (right) with grandfather Graham and brother Judd looking after the birds at Mary Chester House in 2013.

2019 Walk to Remember

The Walk to Remember is our biggest series of community events and this year over 800 participants and 100 volunteers took part. We held three Walks over three weeks, starting with Mandurah on 20 October, Albany on 27 October and Perth on 3 November.

This year we moved the Mandurah Walk to a new location, starting and ending at the Old Mandurah Bridge. Based on advice from locals we pushed the Albany Walk back to later in October and hoped for warmer weather than the previous year, and our hopes were rewarded with a glorious Spring day. We were especially touched by all the personal messages and photos left on our Memory Wall at all three events.

We are so grateful to Advocates Keith Bleach, Barry Rodwell and Davena Toth who shared their journey with dementia on the day. Also to the Rodwell, Alaraibi and Wallace families for agreeing to be interviewed for local papers.

We were thrilled to host the SES Canine and Mounted Units for the first time in Perth, whose dogs, horses and firetruck were a huge hit with young and old alike. The Holden Car Club brought down number of models on the day and proved to be a real crowd pleaser.

Special mention must be given to major sponsor HHG Legal Group, as well as Aussie Natural Spring Water for providing bottled water for all our walkers and DJCA who donated a stunning yellow gold diamond and sapphire necklace for the raffle at the Perth Walk. We are grateful also to the City of Mandurah, City of Albany and Town of Cambridge for their support.

The 2019 Walk to Remember raised more than \$54,000 which will allow Alzheimer's WA to continue providing dementia-specific care and support to people living with dementia in Western Australia.

Thank you to all our members, volunteers, participants, fundraisers and sponsors for all your support. Without you we would be unable to run events like these. We look forward to seeing everyone at next year's Walks!

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Research report

Australian treatment for dogs may help humans with dementia

Research into dementia in dogs may lead to treatments for people living with the condition, experts say. The trial, which began in 2014, involves implanting stem cells from the dogs' skin into their hippocampus. Within a short space of time, the dogs appeared to regain some of their normal cognitive abilities and showed a reduction in anxious or confused behaviours, such as pacing or forgetting where to go to the toilet. The researchers believe the treatment could also work in people, because of the similarities between human and canine brains.

New dementia guidelines for GPs in Australia

The Lancet Commission on Dementia Prevention, Intervention, and Care has found that around 15 per cent of dementia cases globally could be prevented by making straightforward GP-recommended changes, such as reducing blood pressure or increasing physical activity. With this in mind, new guidelines have been issued for Australian GPs that will hopefully help reduce dementia rates nationally.

Eye tests to detect dementia

An eye test, capable of identifying people with high levels of amyloid beta, has been developed by researchers from the Centre for Eye Research Australia and University of Melbourne. The eye scan uses hyperspectral imaging to shine a rainbow-coloured light into the eye, and identifies changes in the retina which can predict the likelihood of developing Alzheimer's disease later in life.

Another eye test, this one to detect the risk of developing a form of Mild Cognitive Impairment (MCI - which may lead to Alzheimer's disease) is the focus of a new study conducted by researchers in the United Kingdom. The test tracks eye movements.

People with Alzheimer's often show signs of eye movement impairment, the inability to direct their gaze in the appropriate direction when movement is detected, even before other cognitive symptoms appear. Analysis of the test results showed it was possible to distinguish between types of MCI, and that the participants with aMCI - amnesiac mild cognitive impairment - had scores closely resembling those with full-blown Alzheimer's.

In home treatment trial

An in home treatment device for Alzheimer's disease is being trialled by NeuroEM Therapeutics in the United States with interesting results. The device, named TEMT (Transcranial Electromagnetic Treatment) uses electromagnetic waves to break up accumulations of amyloid-beta and tau proteins. After two months using TEMT at home, participants showed no negative effects on behaviour or physiology and, importantly, showed improvements in cognitive performance, seemingly reversing memory loss and restoring it to a level experienced a year earlier. Benefits were also experienced even after the treatment ceased. All participants were offered, and accepted, an extension of the trial, which will be ongoing.



Dementia Awareness Month

Dementia Awareness Month, held during September, is an opportunity to engage the wider community about dementia and the challenges it presents, and this year we asked all Western Australians to reach out to people with dementia in their community to let them know they are not alone.

As part of Dementia Awareness Month our amazing Dementia Advocates Angi and Michael, Tom, and Murray and Robin agreed to share their inspiring stories on our website, on social media and in newspaper articles.

We created a range of new information sheets, booklets and posters which were posted out to interested community groups. Health services and libraries across the State created displays promoting Dementia Awareness Month with these resources.

We launched a new fundraising campaign, *Game On!*, which encouraged individuals and businesses to host a games night or games day in their own homes or offices and fundraise for Alzheimer's WA. Alzheimer's WA staff were very supportive and some held their own *Game On!* events. The nature of *Game On!* meant we were able to raise awareness of dementia in areas of the community we would not normally reach.

Prominent accountancy firm PwC hosted a cocktail party for Alzheimer's WA in honour of World Alzheimer's Day. An auction and raffle of amazing donated items including a ruby and diamond ring from DJCA, a Wildcats signed jersey and a night at Crown Towers raised over \$11,000 for Alzheimer's WA from over 160 attendees.

We drove the very recognisable Alzheimer's WA van to the city the day before World Alzheimer's Day, parked it in Murray St Mall and set up an awareness stand for the day. This year we once again handed out bright orange gerberas and brochures. The day we chose to have our awareness stand coincided with the Greta Thunberg climate rally in the city, so we can confidently estimate over 10,000 people walked past our stand.

Alzheimer's WA also undertook a comprehensive advertising campaign during September, including radio and newspaper advertising. In addition, we contributed several articles in The West Australian and Have a Go News.

The Advocate stories and resources mentioned in this article are available to view and download from alzheimerswa.org.au/dementia-awareness-month.



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Adjusting to Change

A program for people living with early stage dementia

Receive information, education and support to give you the skills and knowledge to help you on your dementia journey.

Please contact us on **1300 66 77 88** for more information and eligibility criteria.

support@alzheimerswa.org.au | alzheimerswa.org.au

Murray and Robin's story



Murray was 76 years old when he realised that he needed to see his GP about problems he was having with finding the right words to say and remembering details of past events. He was referred to a Memory Clinic and assessed by a psychologist then seen by a gerontologist. More than two years later that he received a diagnosis of mild Alzheimer's disease.

I had noticed changes in his memory and ability to find the right words five years before but, looking back, I realised that problems had started even earlier than that. He was always a teller of jokes and tales (both tall and true) but he had gradually stopped telling new jokes, although he still repeated old favourites.

It was difficult for some friends and colleagues when the man they knew was less able to take part in conversations so making new friends was not easy. We had to resign from our lawn bowls club. Murray gave up playing pennants and we played only social

bowls, but a few players were very impatient and critical although some were most understanding and helpful.

Family and old friends were very concerned and very caring, but I knew I needed to connect with a support group. I needed to be able to discuss problems with others who would understand. I needed to air the occasional grumble when things weren't going well and to voice some frustrations managing everyday situations.

The Alzheimer's WA Carers Support Group provided the support I needed. At meetings we carers shared experiences about what had worked for one couple or ideas about what we could do. This gave us an insight into what might happen later on, so it helped us to anticipate problems and work out possible solutions. Sometimes we were able to suggest alternative ways of managing troubling behaviour. Our facilitator gave us information about where to seek professional help. Even if there were no solutions, there was always understanding information about problems and difficulties.

Through that group I heard of another social group for couples which met one evening each week to share a simple two course meal. This was followed by activities that everyone could join in. We played games such as dominoes or mini golf or listened to live music performed for our small group.

It was wonderful to be able to meet new people and make new friends in an atmosphere of acceptance and understanding where nobody asked, "What's wrong with him?" or belittled his efforts. Instead they encouraged his efforts and cheered his successes. We looked forward to our weekly nights out and to the company.

- Robin



Dementia specialist

Home care packages

Alzheimer's WA is a home care package provider, delivering 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 will work with you and support 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.

Get help today

Visit our website for more information at alzheimer'swa.org.au/home-care or call us on **1300 66 77 88**.

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