

MILESTONES

DECEMBER 2018, ISSUE 22



Walk to Remember



Wine and Horses



Ageing in place safely

alzheimer'swa
the dementia experts



18








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CEO's Report



Part of the commitment Alzheimer's WA has to its 3,000-plus members is to keep you informed of the challenges we face and of our achievements and direction as an organisation. Our members are a vital part of our team, and I hope that by providing you with these updates we are able to support your sense of ownership in the work we do.

More importantly, I hope these 'report cards' affirm your commitment to our mandate and mission. The organisation belongs to you, the members. The Board and the staff are to carry out a program of works it believes best delivers on the mission of the organisation and the priorities of its members.

Of course, we can't do everything, but we should be prioritising correctly and investing resources into the areas where we can have the most impact. For Alzheimer's WA, we believe that if we are to drive change and improve the support for those on the dementia journey, we should be at the leading edge of change. We should also be providing the very best quality in any and all of our services.

The end of the calendar year provides an opportunity to reflect on what has been achieved over the year. The aged and disability reforms continue to present challenges to us as an organisation. More importantly, the reforms are presenting significant challenges to clients and consumers as they seek to navigate a very complex, changing system. We spend a significant amount of time raising the issues being faced by individuals and families so that the reform delivers better support. We are still a long way from this goal.

This edition of *Milestones* brings you a number of stories of individuals and couples living with dementia and examines the issues those experiences highlight. We have also reported on the amazing support we receive from many, a research roundup and some of the new activities we are delivering that you may not know about.

There are many issues that will demand priority attention in the coming year. Funding to effectively support carers, dealing with the wait list for home care packages (which is now at an unacceptable level), driving change in dementia practice away from a task-focussed, medicalised response to one that understands the impact of the dementia on the individual's wellbeing, and supporting those with dementia to continue to engage in the community are just a few of the issues we will focus attention on in 2019.

For all of us at Alzheimer's WA, we get out of bed in the morning to make a difference in the lives of those on the dementia journey. We are grateful to know we are not alone in this. We are well supported by our clients and their families, who often provide us with generous feedback about the value of the work we do. We are also grateful to know there are thousands of others who join with us as members, confirming that they share our mandate and mission, and are our fellow travellers. In difficult times, this company makes a difference. It makes tough times less lonely.

I'm grateful for your membership and your support of what we do and how we do it. Thank you.

The team at Alzheimer's WA will meet the new year fresh with determination to ensure challenges become opportunities, and that we will grow our impact in 2019.

Wishing you all a wonderful Christmas and festive season. Take time to make happy memories.

Warm wishes

Rhonda Parker
Chief Executive Officer

Alzheimer's WA dementia houses

- 'care at its best'

The care and support given at our three dementia houses has won praise from near and far away.

Dr Allen Power told an international conference that a visit to Western Australia and any of Alzheimer's WA's dementia houses would allow visitors to see "some of the best dementia care environments in the world."

After a visit to Hawthorn House in Albany, the Federal Minister for Senior Australians and Aged Care, the Hon Ken Wyatt AM MP, commented on his Twitter page that "this is cottage care at its best."

Alzheimer's WA is different in its approach to dementia care. We never 'elder sit'. We believe each care opportunity should be therapeutic and result in improved wellbeing for the client during and after their time with us. Staff are trained and supported to understand how to do this.

The most important feedback for us is from our clients - people who belong to the 'family' or the 'household'.

Families consistently and gratefully tell us how our care supports the feeling of wellbeing for their loved one.

Here are just a few stories of how good care really matters to those living with dementia.

Our dementia-specialist houses in Perth, Albany and Mandurah provide an evidence based environment that seek to maximise wellbeing in the person with dementia. Offering a wide range of meaningful activities based on the person's strengths, identity and interests, the houses provide meaningful engagement, stimulation and friendship in specially designed dementia enabling environments.

Mary Chester House in Shenton Park, and Hawthorn House, Albany are open Monday to Saturday 10.00am - 3.00pm for centre-based respite. Overnight respite is now available at both houses.

Ella's House, Mandurah is open Monday to Friday 10.00am - 3.00pm for centre-based respite.

In home overnight respite is available in some areas. Alzheimer's WA also offer a variety of community based social support groups for people living with dementia.

“I am so grateful for the continued support, care and compassion provided by the amazing staff at Mary Chester House and thank you for always being there. As you know, being a full-time carer is a very tough, tiring and sometimes heartbreaking job, and I couldn't do this without knowing help is always at hand. I look forward to Barry being part of the Mary Chester family for many years to come.”

Rae-Ellen and Barry

“Mary Chester House is a revelation in respite care. Your understanding and devotion to the care of dementia sufferers is unique in WA. I would not hesitate to recommend Mary Chester House to anyone seeking excellent care and understanding on all levels.”

Jill and Tony



Andrew Hastie MP visiting Ella's House.

Update from Ella's House

Andrew Hastie MP visited Ella's House on Monday, 1 October to discuss possible expansion plans for the Men's Shed, taking time to talk about dementia care with Team Leader, Sally De Marni and Head of Dementia Practice and Innovation, Jason Burton. Andrew shared a video of his visit on his Facebook page posting: "The skilled craftsmen of Ella's House Men's Shed do some fantastic work out of their modest workshop using recycled pallets and other materials."

Update from Hawthorn House

At the Hawthorn House Open Day on Saturday, 28 September guest speaker Dr Craig Sinclair from the Faculty of Health and Medical Sciences UWA, spoke about Advance Care Directives. Over 70 people attended and enjoyed scones, jam and cream made by local volunteers. Several local service providers had information stands for interested attendees.

On Saturday, 30 June Rhonda Parker, CEO, welcomed the Hon Ken Wyatt AM MP, Federal Minister for Senior Australians and Aged Care and Mr Rick Wilson MP, Member for O'Connor to Hawthorn House. Ken and Rick both had a round of indoor golf with the Saturday club members and a tour of Hawthorn House, the surrounding gardens, Harold's Shed and the famous chook house.

Update from Mary Chester House

Mary Chester House held an Open Day and Fete on Saturday, 15 September to raise awareness of services provided and to encourage people to have a look at the house. 60 people attended to find out more about the services that can support them, have a game of golf, grab a sausage sizzle, and check out the potted plants, soaps, jams and Men's Shed items available for sale.

A morning tea was also held for 24 carers on Thursday, 18 October. Portraits of carers with their loved ones were on display thanks to the generosity of Rockingham Photography Club who organised the photo shoot at no charge to members. The morning tea was supported by Lotterywest and Carers WA.

"Really beneficial, lovely morning tea and lovely to meet fellow carers. I no longer feel alone."

"Thank you for today, it gave an opportunity to meet a fellow carer. We found that our beautiful wives had some similar habits and needs. We were able to compare things and I hope support each other."

Everybody has a story to tell...

Donations are the reason we are able to continue providing the specialist support, advocacy and care that Western Australians living with dementia need every day.

Our commitment is to provide support that embraces wellbeing. We want to do it well, or not at all. We are also different in that we are committed to advocate for those on the dementia journey, to be their voice if they need us to, and to join with their voices to innovate and deliver new responses. All of this requires funding. Donations enable us to continue to deliver services that are at the leading edge of dementia care and support. We can't thank our donors enough.

To show you the true value of each and every donation, this year we shared the stories of five families living right here in Western Australia who have benefitted from past donations, as part of our 2018 Christmas Appeal. Read their stories below.



Clare and Patrick

Clare, Patrick and their three sons have been on a seven-year journey following Clare's diagnosis of dementia in her early 50's.

"At first I thought it was depression and blamed

myself because I wasn't paying her enough attention," said Patrick.

Although Clare was an accomplished cook, her cooking abilities were gradually deteriorating, but she refused to see a doctor.

"This went on for about three or four years with me still thinking it was my fault. She gradually experienced trouble in communicating and would 'shut down' for prolonged spells. During such spells, I could not get her to eat. There was one occasion

when she completely forgot where she had parked the car.

"We finally got to see the specialist and she was diagnosed with Younger Onset Dementia.

"It was a melancholic relief as I knew in my heart there was something wrong. She was still so young, so it never really occurred to me that it could be Alzheimer's disease.

"My advice to anyone who has noticed changes in their partner is to seek medical advice with them as soon as you can, as it's so important not to mistake dementia for depression."

Support for carers on the dementia journey is essential. Funding changes mean that our Carer Support Groups will soon end, so we are working to create new programs that will support carers.

Thanks to donations, Patrick was able to access dementia-specific support groups, giving him an opportunity to meet other carers who understand what he and Clare are going through.

Laurie and Derene

Laurie and Derene live in Manjimup and are grateful for the changes brought about by the Dementia Friendly Communities project in their town. Laurie was diagnosed with Frontotemporal dementia five years ago and says the program has given him a new lease on life.

"People are coming to me, giving me support that I didn't know was there before. It's a disease that you've got and you just become a recluse, but not anymore."

Laurie has been invited to join the volunteering program at the local community centre.



“Volunteering has helped Laurie to feel like he’s worthwhile,” said Laurie’s wife, Derene.

Moving back to Perth had been a consideration after Laurie’s diagnosis but now Derene says Manjimup is where they will stay.

“I’m being well supported now. I can’t believe the difference that small changes have made for Laurie’s independence. I know this is where Laurie gets the best care and support and I think the future looks really good. The program is going to help a lot of other families as well.”

Thanks to donations, Laurie no longer spends his days at home. He is able to volunteer within his community, giving him a sense of pride and purpose.

Rae-Ellen and Barry



Rae-Ellen recently travelled overseas for the first time without husband Barry, who has dementia. This was Barry’s first time in long term respite care.

“I knew that I had made the right decision to place Barry at Mary Chester House as he always seemed settled and happy during our conversations when I was away. I was able to relax and enjoy my holiday, knowing that Barry was in familiar surroundings with familiar people.

“During his stay our daughter Caitlin mentioned that on every visit Barry was happy, affectionate and a lot more alert and able to initiate and carry on conversation in context. When compared to his usual state, the improvement was incredible.

“I am so grateful for the continued support, care and compassion provided by the amazing staff at Mary Chester House. As you know, being a full-time carer is a very tough, tiring and sometimes heartbreaking job. I couldn’t do this without knowing help is always at hand. I look forward to Barry being

part of the Mary Chester family for many years to come.”

Funding from donations was used to refurbish Mary Chester House to create the bedrooms and facilities for overnight respite.

Thanks to donations, Rae-Ellen was supported to relax and take a well-deserved break from her caring role, knowing Barry was receiving the best possible care.

Jackie and Andy / Marie and Alfie

Andy Creighan and Alfie Di Meo were both diagnosed with Younger Onset Dementia in 2016. A chance meeting at a support group led to the two men becoming firm friends, providing support to one another through their shared diagnosis.

“Andy and Alfie met 21 months ago at the men’s walking group run by Alzheimer’s WA. They have become best buddies and their lives are constantly intertwined. Having dementia is a very socially isolating experience for the person who has it and also for the loved ones caring for them.

“Andy and Alfie’s friendship has grown strong and we now meet once a week to share a meal, have a few laughs and a couple of drinks. Alfie recently told his specialist that he has a friend - Andy - and that they fill in each other’s gaps. The specialist was very impressed with their connection.

“To find a friend who totally understands what you are going through is exceptional and these two men have found that.”

Funding from supporters enables Alzheimer’s WA to pilot new support group models. Without donations, Andy and Alfie’s walking group may never have existed.

Thanks to donations, Andy and Alfie have formed a lifelong friendship and continue to volunteer in the community as an inseparable team.



A carer's life can be a lonely one

Let me ask you two questions. What happens after we retire and the social interaction of our working life ends? What plans have you made to remain socially connected and engaged?

Research establishes that being socially connected is vital for physical and emotional wellbeing. Australians may be more connected than ever before through social media, but according to Relationships Australia we are in the midst of a “loneliness crisis”.

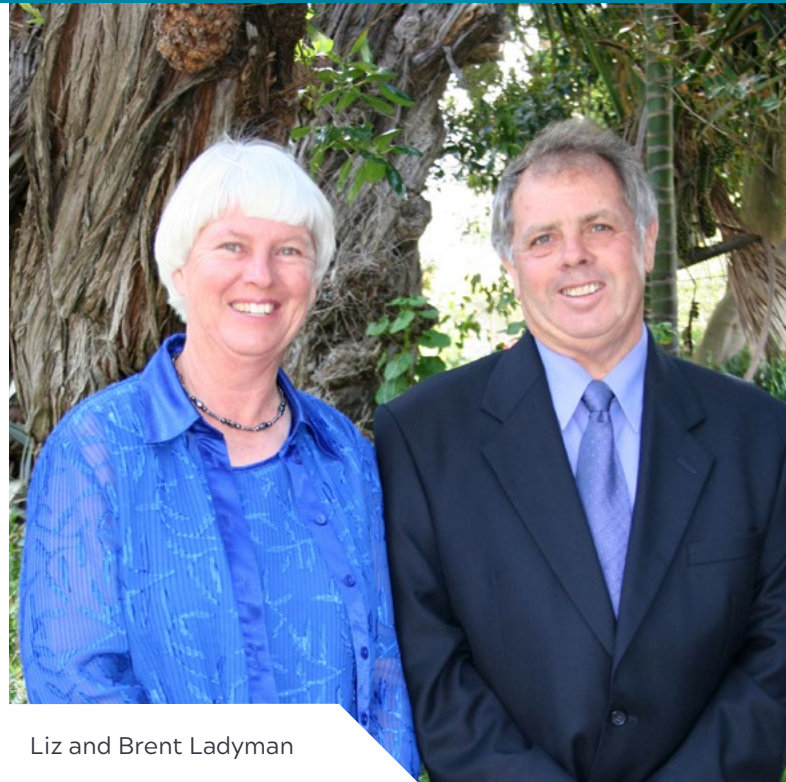
Feelings of loneliness can affect anyone at any time, whether you are a successful businessperson or recently retired, a working or stay-at-home mum or somewhere in between. Most of us will have, at some stage in our lives, experienced feeling lonely and alone despite being in a room full of people.

A recent OmniPoll survey revealed most Australians have half the amount of close friends they did just ten years ago, and some would argue the rise in popularity of social media has contributed to this.

Men are more at risk of social isolation than women, with 40 per cent having “low levels of connection” and 15 per cent found to have no close friends outside of their long-term relationship.

Imagine then, how easy it is for someone to become completely socially isolated through divorce, disease or death taking away their significant other. For Katanning farmer Brent Ladyman, it is Alzheimer's disease that has taken away the companionship of his business partner and wife, Elizabeth.

Brent is a local identity and a bit of a larrikin. The volunteer fire fighter and former breakfast radio presenter talks down his achievements in typical Aussie bloke style.



Liz and Brent Ladyman

Yet when asked what it has been like living alone on the farm where he and Liz raised their children, he is quiet for a moment.

“The loneliness is terrible,” he said, “It’s made worse by still living on the farm.”

Brent grew up on the family farm, 25kms from town, learning the tools of the trade from his parents. The third generation farmer has spent most of his working life looking after the cropping, leaving the sheep enterprise to Liz - who Brent says had a keen eye for stock, something he never inherited. They met through Rural Youth and married in the 1970's.

Liz also kept the farm diary, and it is entries in this diary that showed the subtle signs of changes occurring in her brain that were otherwise fairly undetectable.

Brent said, “Looking back now, I can pick out little things from as early as 2010. It was when her writing really deteriorated in 2012 that I took copies of the diary to a specialist. She was diagnosed with Alzheimer's.”

Even after her diagnosis, Brent says they were both in denial for some time, recalling how Liz would shrug off memory lapses as “no big deal”.

Brent made the decision to lease the farm in 2013, allowing him more time to look after Liz whose eyesight and speech were starting to be affected by the condition. Caring for a person with dementia can be a difficult and lonely time for carers as they struggle with the demands of looking after a loved one.

Brent is very grateful for the support of local health care professionals, one of whom would provide respite by visiting Liz at the farm.

“It helped a lot,” he said,

“The support worker from Alzheimer’s WA would drive out to the farm and take Liz into town for a coffee,

“I would spend that time doing something I enjoy like restoring old cars.”

Farmers are a practical bunch. In true form Brent says the decision to give up caring for his wife was not hard. Liz’s eyesight and speech continued to deteriorate and Brent realised she needed someone who could look after her 24 hours a day.

“You do the best you can, but I couldn’t keep her safe anymore,” he said.

Liz is now in full time care.

Brent has always been engaged in his community - only recently stepping down as



Brent and Liz Ladyman outside their Katanning shop

president of the local Rotary Club. The local community now provides the friendship and connection necessary to overcome the loneliness associated with living alone in a house which was once so full of life.

“And I have a few mates who drop in for a beer every now and then,” he said.

Give some thought to how connected you are and plan to try new things and make new friends to remain socially and emotionally connected.

Reduce your risk of becoming socially isolated:

- » Become a volunteer
- » Know your neighbours
- » Try an exercise class or group
- » Start a hobby
- » Get a pet



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.

Adjusting to Change

A program for people living
with early stage dementia

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

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Next of kin should be informed when dementia is diagnosed - Pippa McManus

One in seven people in Australia are affected by dementia - either themselves, or through a parent or a friend.

Despite this startlingly high statistic, many people do not think it will happen to them. You certainly would not think this insidious disease could manifest itself in both of your parents. Unfortunately, it can. And for Pippa McManus, the only child of Bill and Sonia McManus, this has been her reality for the last 25 years.

Pippa's journey with dementia began when her father Bill was diagnosed with Alzheimer's disease in 1994. Pippa had just started high school. She said it was confusing and heartbreaking to watch her beautiful, charming, smart and hilarious dad just slip away.

Even with an official diagnosis of Alzheimer's, people around Pippa - including her mum - were reluctant to acknowledge the disease or the changes that were occurring in her beloved father.

Bill passed away in 2001 and it was around ten years later that Pippa started to notice changes in her mum, Sonia.

Pippa said, "She actually left to live in the south of France, for a while.

"Before that she was very sociable, but started to cut her friends off - we think she must have known something was going on.

"We noticed some mood changes and organisational issues. She had a reputation as a wonderful entertainer and would host morning teas where she would bake for groups of ladies, but all that stopped.

"When I tried to bring it up with friends, I was told I was 'seeing it [dementia] everywhere'."

Pippa says getting her mum to acknowledge there was a problem was an agonising process. With no siblings to call on for support, it was up to Pippa to convince her mum to visit the family doctor.

Sonia was adamant there was nothing wrong, yet her memory loss was becoming so significant it was putting an incredible amount of strain on the relationship.

Pippa said, "I ended up giving her an ultimatum... go to the doctor with me or you will no longer see me for Monday night dinners, movies or coffee dates.

"And she did. We visited her doctor together. I was asked to wait outside. She came out and said 'he thinks I'm very fit' and that was it."

As it turns out, that wasn't it. Pippa's mum had been given a diagnosis of dementia, but it took 12 months and a near breakdown before Pippa was informed by her GP.

"I went to the same doctor for a referral to a psychologist because I thought I was going crazy. Mum's behaviour was getting stranger and her memory was getting worse.

"That's when I found out she had dementia.

"I had assumed at the appointment a year earlier I would have been informed, being next of kin, or that I would have received a call to discuss it. I wondered if I should have followed up instead.

"If your loved one is given a diagnosis of dementia the next of kin should be informed," she said.

Once Sonia's diagnosis was out in the open, Pippa was able to organise support for her mum, and for herself. Sonia, Pippa, and Pippa's husband attended the Alzheimer's WA Adjusting to Change program, and Pippa says it was the best thing they ever did.

Pippa said, "I still use the skills I learnt on those Thursday meet-ups two years later.

"Alzheimer's WA are helping mum live a full and happy life while offering incredible support to me as her carer. I am so grateful everyday for the support I have received."

Pippa is now an ambassador for Alzheimer's WA.



Dementia Awareness Month

Dementia Awareness Month is in September each year and includes World Alzheimer's Day on 21 September. Dementia Awareness Month is an opportunity to engage the wider community about dementia and the challenges it presents.

This year our theme was *Together we can ensure no one faces dementia alone* which highlights the need for all Western Australians to reach out to people with dementia in their community to let them know they are not alone.

Alzheimer's WA undertook a comprehensive advertising campaign during September that included radio advertising and newspaper advertising. In addition, Alzheimer's WA contributed articles in both the Dementia Awareness Month and World Alzheimer's Day liftouts in *The West Australian*, and an article in the Australian Medical Association's *Medicus* journal.



Awareness stand in the Murray Street Mall, Perth CBD on World Alzheimer's Day.

During the month of September Alzheimer's WA hosted Open Days at Mary Chester House and Hawthorn House, and handed out bright orange gerberas and provided information at an awareness stand in the Murray Street Mall in Perth CBD. Staff volunteered their time to hand out the flowers, which had a small message attached:

We forget a thousand things every day, but some memories we treasure forever.

Think of a happy memory when you tie this ribbon around your index finger, one that makes you smile. Every time you see or touch that ribbon for the rest of the day, you'll think of that memory, and hopefully, you'll smile. Because memories truly are our most valuable possessions.



5th Annual Dementia Partnership Project Symposium

Alzheimer's WA held the 5th annual Dementia Partnership Project Symposium, *The 'WE' in Dementia: Achieving wellness through the domains of wellbeing*, on Tuesday, 16 October 2018 at the Perth Convention and Exhibition Centre.

The Symposium brings together community care service providers to participate in a dynamic event of sharing ideas and opportunities to enhance the lives of people living with dementia, and supports providers to implement a person-centred approach in their work.

Over 200 people attended the event, with representation from more than 50 organisations including community care providers Brightwater, Silver Chain, Avivo and Bethanie.

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

Keynote speakers included Dr Helena Popovic, medical specialist and best-selling author, and Helen Sanderson, CEO of Helen

Sanderson Associates. Dr Helena Popovic lives with her father who has dementia and much of her work involves looking at ways to boost brain function through diet, exercise and mental wellbeing. Helen Sanderson is a UK leader in person-centred practice and spoke about the importance of person-centred teams to deliver person-centred care.

Other presenters included Dr Bob Zeigler, Ambassador with COTA for the Living Longer, Living Stronger exercise program, and Meredith Blake, UWA, researcher in supported decision making. Amy Bouckley, Alzheimer's WA Advocate and secondary care giver, spoke bravely of the role of primary and secondary carers and the importance of support for all carers.

Alzheimer's WA Advocate Tom Harmon, who lives with Parkinson's disease and Lewy Body dementia, took the stage to share his journey with both diseases. Tom shared how he reacted to each diagnosis (which were one year apart), and how he was determined to learn as much as he could about both diseases.



Dr Helena Popovic



Dr Bob Zeigler



Helen Sanderson

Tom also shared what he does to keep his mind and body active including: using a diary to help him remember daily activities, practicing writing, keeping his mind active and stimulated, attending the local Memory Café and meeting new people, and using specific exercises for people living with Parkinson's and for those living with dementia. Tom's presentation was an inspiration and we are grateful for his continued support of Alzheimer's WA.

For more information

Videos of presentations delivered at the Symposium are available to view at dementiapartnership.com.au/dementia-training-videos.

More information on the Dementia Partnership Project, including the Dementia Change Champions program, can be found at dementiapartnership.com.au.

The Dementia Partnership Project is an initiative between the WA State Government and Alzheimer's WA.

2018 Dementia Change Champion of the Year

Congratulations to Jeannie Connell from Silver Chain Group on winning the 2018 Dementia Change Champion of the Year Award. Jeannie developed activity backpacks for support workers that include resources such as craft materials, iPads and iPods. Well done Jeannie!

Congratulations to our two other nominees - Laura Coleman from Avivo: live life and Wendy Bennet from Advocare.

The Dementia Change Champion program is for community organisations to develop staff in the specialised field of dementia care, with a focus on person-centred care. The program consists of accredited specialist dementia training and access to Alzheimer's WA's extensive resources, to provide staff with the knowledge and skills to support and enhance dementia approaches in their workplace.

The Dementia Change Champion Award recognises Dementia Change Champions



Alzheimer's WA CEO, Rhonda Parker with 2018 Dementia Change Champion of the Year winner Jeannie Connell.

who have made a significant contribution to the workplace through dementia education and training, or resource development and distribution. Champions are nominated by their supervisor and all applications are reviewed by a panel of Advocates.

Telling people about your dementia diagnosis

A diagnosis of dementia is often confronting. Sadly, the first emotional response is usually one of shame. The stigma of dementia means that shame can complicate how individuals respond to their diagnosis.

The stigma associated with dementia can have an incredibly negative impact on the way a person diagnosed with the disease views themselves, and the way others see them. So much so, around 25% of people living with dementia will hide their diagnosis from family and friends. In Western Australia alone, this equates to around 10,000 people currently living with a diagnosis of dementia who have not let anyone know about it.

Clients will say to us 'I haven't spoken to all of my family about it' or 'it is difficult to talk to them about it'. It is important to remember there is no right or wrong way of sharing your diagnosis.

A common misconception is that dementia is a normal part of ageing. This is like saying a diagnosis of cancer is a normal part of ageing. It is simply not true.

We often hear people with dementia will stop going out or attending social events, fearful of how others may perceive them. Over time they may slowly withdraw from family and friends. Yet this is a time when social connections are vital to maintaining the wellbeing of a person with dementia.

According to Dr Sean Maher, Honourary Medical Director for Alzheimer's WA, a diagnosis of dementia is usually not a surprise to a person's close friends and family. It can actually be a relief.

Some people worry an official diagnosis means their life is over. Life changes, but it does not end. The earlier the diagnosis, the more chance a person has of slowing the progression of the disease through the use of risk reduction strategies and trying available medical treatments.

It may help to re-assure your family and friends that people who have a diagnosis of dementia can still live well. There are many specialised services and supports available for people who are living with dementia.

How do you actually tell your family and friends about your diagnosis?

- » **Do I need to tell everyone or anyone?** Some people choose to share the diagnosis with their close family and that is all. Others share with their whole network of family and friends.
- » **How and when should I discuss it?** Some people choose to chat to all of their family together. This allows questions and feelings to be explored. Others choose to speak to people individually about the diagnosis.
- » **How will people respond to me?** People will respond in different ways, such as being supportive, upset, dismissive or in denial. Give them some time to process it.
- » **Explain what has changed for you and, importantly, what hasn't.** Let people know the affect the diagnosis is having on you. For example: word finding difficulties, short term memory loss. This gives people more understanding about what dementia really is and may help reduce the stigma.
- » **Share how you feel about the diagnosis.** Let your family and friends know how you feel about the diagnosis. Some people feel devastated, others feel relieved. This can help others process their own feelings.
- » **Explain how others can help.** Often people with dementia want to be treated the same. Let people know if this is how you feel. Ask others to be patient and understanding as you adjust to life with dementia.
- » **Share our 5 Tips to Connect with family and friends.** These tips were developed for Alzheimer's WA by people living with dementia in Western Australia. Visit alzheimerswa.org.au/5tips.



GPS devices for people living with dementia

There's been a lot of discussion recently, both in the media and the community, about the challenges of people living with dementia walking and becoming lost, as well as the use of GPS devices.

Many people like to take a walk, go to the shops or exercise a pet. This doesn't change when a person is diagnosed with dementia. However, due to the impact of cognitive impairment a person with dementia may become disorientated, forget the way home or try to head to a location other than was first intended.

For many people with dementia the freedom, autonomy and choice of taking a walk is an important right that maintains their emotional wellbeing. There are a number of assistive technology devices available to help minimise the risk of becoming lost for people living with dementia.

If the person usually takes their mobile phone with them, this list of phone-locating apps can make it easier to locate them, should they become lost.

Find a Samsung phone:
findmymobile.samsung.com/

Find an Apple phone:
support.apple.com/en-au/HT201472

Find my friends:

itunes.apple.com/au/app/find-my-friends/id466122094?mt=8

Free mobile tracker:

mobile-tracker-free.com/

Helpful equipment

Be sure to involve the person with dementia in any decisions to implement assistive technology. A GPS device is no use if the person does not want to wear it.

There are a range of technology solutions that can prove very useful if someone is lost. These include GPS location devices, tags that can be attached to handbags or wallets that will alert you if the person has left a certain area, door alerts that will wake you if the person leaves the house during the night, and apps on phones that can help find the phone. A range of this type of equipment can be found on the assistive technology page on our website.

Alzheimer's WA has an assistive technology demonstration room with all the latest technology ideas and information located at Mary Chester House, Shenton Park. The display room is open from 9.00am - 4.00pm on weekdays.

With the number of people with dementia increasing, we at Alzheimer's WA will continue to pursue solutions that support wellbeing but minimise the risk and distress of a person with dementia becoming lost while walking.

Research report

Jason Burton, Head of Dementia Practice and Innovation

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The last 12 months have seen mixed outcomes regarding research in dementia. While there have been positive study findings there have also been a number of early stage successful trials cancelled as they moved into later phase trials because they showed no beneficial outcomes. A late stage trial of a drug called “Lanabecestat” was halted after results indicated that there was no improvements for early Alzheimer’s disease or mild dementia. This follows the cancellation of research into a drug called “Verubecestat”, again after no positive clinical outcomes were identified in trials.

Both of these trials and a number of others are using drugs called beta secretase cleaving enzyme (BACE) inhibitors. These are being researched as they may be able to target high levels of beta amyloid build up which is thought to be one of the biggest contributors to the development of Alzheimer’s disease. While most trials to date have focused on clearing beta amyloid from the brain after a person has been diagnosed with Alzheimer’s disease, and when marked cognitive impairment is being experienced, there seems a growing recognition that efforts may be best focused on targeting the amyloid build up well before brain cell damage is at a significant level.

The Verubecestat trial has now switched its focus to premorbid (pre symptom) Alzheimer’s disease to ascertain if early usage may prevent unusual amyloid build up and reduce the risk of developing Alzheimer’s dementia.

This refocus of research is also leading to a change in language with the term “Alzheimer’s disease” increasingly being used to describe the pre symptom stages

of pathology change in the brain. The term “Alzheimer’s dementia” is now being used to describe the stage where symptoms of cognitive impairment are apparent and impacting on a person’s abilities and daily activities.

The ability to now accurately measure abnormal amyloid build up prior to obvious cognitive impairment is a considerable breakthrough in looking at risk reduction strategies and identifying people who may be at greater risk of developing Alzheimer’s disease. This early detection of amyloid changes, possibly 10-15 years prior to cognitive impairment being evident, is offering new avenues to find interventions that may prove beneficial in reducing the number of people who develop Alzheimer’s disease in the future.

One trial recently reported at the 2018 Alzheimer’s Disease International Conference offers some hope of a breakthrough. “BAN2401” is a BACE drug designed to target amyloid build up and remove excess build up. A trial of 856 patients with early Alzheimer’s disease reported that after 18 months, those receiving the highest dose had an 81 per cent reduction in amyloid build up as measured by positron emission tomography (PET) scans and a 30 per cent reduction in clinical indicators of early Alzheimer’s dementia. Side effects of the drug did include 10 per cent of patients suffering from inflammation in brain cells. It is expected that the early success of this drug will lead to a multi-national study in 2019.

The other big research news to come out of this conference was from a study looking at the effect that high blood pressure has on

the risk of developing dementia. The Systolic Blood Pressure Intervention Trial (SPRINT) study showed clear risk reduction success in managing hypertension. The lowering of the systolic blood pressure reading to under 120 led to a 19 per cent lower rate of new cases of mild cognitive impairment (MCI) and a 15 per cent reduction in MCI and dementia combined. This is a significant reduction in a high risk population group. With a growing understanding that dementia is likely to be triggered by a number of factors combining, it is likely we will see an increasing research focus on understanding what these risk factors are, how they combine to lead to the triggering of dementia and what we can do to intervene early to reduce this risk.

Studies into possible trigger factors such as: testosterone, stress hormones, genetic factors, lifestyle and impact of modern living, concussion and other brain trauma in younger life, as well as continued research on the role of amyloid and tau are all underway. Over the coming years this research will paint a much clearer picture of why some people develop the different types of dementia. This new strategy gives us hope for early interventions to reduce the prevalence of dementia in the future.

While a great deal of research is focused on Alzheimer's disease, other types of dementia are also being researched. This year saw a breakthrough in our understanding of Lewy Body dementia with a Japanese study

identifying two different types of Lewy Body dementia through lumbar punctures. This greater understanding may lead to more individual treatments in the future.

Although many people were disappointed to hear one of the big pharmaceutical companies, Pfizer, was withdrawing funding for Alzheimer's research this year, the news was counter-balanced by Bill Gates announcing a personal investment of \$100 million towards research into innovative solutions in diagnosing and treating Alzheimer's disease.

With growing global collaboration, technological advancement allowing us to understand dementia pathology in ways never understood before, matched with unprecedented investment in dementia research, the hope for breakthrough treatments, risk reduction and one day a cure remains very positive.

Earlier this year Alzheimer's WA received a generous bequest of \$1 million from the estate of the late Dorothy Joy Jones. The bequest will be used to fund a research strategy for Alzheimer's WA for the years ahead. This strategy will focus into best practice in dementia care as well as partnerships with other research projects and institutions.



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Living at home with dementia

Home sweet home. T.S. Eliot wrote ‘home is where one starts from’. With age, we also know that home is where we want to end. Interestingly, more Western Australians die at home than in any other state.

Ageing in place means being able to live at home as long as you are able. It means staying connected to your local community, to what is familiar and what you cherish. It may also mean accessing aged care services within your home instead of moving to an aged care facility.

Around 70% of people living with dementia live at home, and supporting people to remain at home through clever design and assistive technology will be a crucial response to our ageing population. Dementia can affect your ability to complete everyday tasks or make it hard to distinguish between items of a similar colour. There are many simple tips and cost effective items available to assist with this.

Think about lighting, colour contrasts (people with dementia may lose their depth of vision or recognition of colour), items that automatically detect a fall or contain a panic button to alert family members if you need assistance, pendants, watches and phones that can be worn or carried discreetly and usually include GPS tracking.

It is possible to introduce safety measures into your home while maintaining your dignity and the homeliness you’ve come to love and feel comfortable within. Visit the Independent Living Centre WA or Alzheimer’s WA’s resource centre in Shenton Park for advice and assistance for dementia-specific challenges.

If you are living with dementia these tips may help:

- » Change as little as possible. Familiarity is important for a person with dementia.
- » Improve general lighting. Install night lights with sensors.
- » Use contrasting colours to help with visual identification.
- » Label cupboards and drawers with photos of the items kept inside.
- » Make life easier with inexpensive equipment such as tilt kettles, irons with 30 second shut off if left on, calendar clocks with enlarged display.
- » Maintain your independence and stay safe. Consider ID bracelets, GPS enabled devices or personal alarms.

Working with the Bidyadanga community to improve dementia care

In remote Indigenous communities access to aged care services, in particular dementia-specific support, is limited or even non-existent. There is a pressing need for improved services, greater awareness and understanding of dementia among Indigenous Australians.

Data suggests dementia prevalence in Indigenous communities is three to five times higher than the rest of the population, diagnosis is common in people as young as 45 and understanding of dementia is poor. Some Indigenous languages do not have a word for dementia.

Faye Dean is a Karajarri Elder from the Aboriginal community of Bidyadanga, 170kms south of Broome. She is also a support worker at the local community care centre.

Faye explained how the locals see dementia in an ABC interview earlier this year, “They don’t really understand what dementia is. They can’t see the illness, so they don’t think it’s there.”

For residents of Bidyadanga, and other remote Indigenous communities, accessing services often means travelling long distances and extended stays separated from family and country. Family separation and removal from country and culture can have a detrimental impact on wellbeing.

“It is hard when the old people have to go away into care, there is the language barrier. If you are in Perth it is all non-Indigenous, so they have got no one to talk to, they are lonely and scared,” said Faye.



Bidyadanga Aboriginal Community

In 2016 Alzheimer’s WA partnered with Bidyadanga Community Council and Kimberley Aged Care Services to pilot a program to build capacity within the Bidyadanga community and local care providers to care for elders with dementia in the community for as long as possible.

The community leaders, staff and Kimberley Aged Care clients embraced learnings from the program and implemented sustainable strategies. The collaboration has seen the community grow in confidence and knowledge, utilising the individually developed tools aimed at supporting elderly clients and those living with dementia to stay connected to country.

The pilot project in Bidyadanga finished in July 2018 with positive outcomes for the community. Following on from the success of the program a partnership was formed with Warnum Community in East Kimberley to expand the program into their community.

Faye Dean was recently a finalist in the WA Seniors Awards.

2018 Walk to Remember

Our biggest fundraising event, the Walk to Remember, is over for another year. In 2018 we held not one but three Walks over six weeks.

The weather was picture perfect on Sunday, 7 October in Mandurah and Sunday, 4 November in Perth for our annual Walk to Remember events.

However, locals did warn us not to host an outdoor event in Albany in October and they were right! It was overcast, windy and very chilly but that didn't dampen the spirits of the walkers. Perhaps next year, we will heed their advice and aim for a November date in Albany.

All three days went off without a hitch and we have been overwhelmed with positive feedback from the over 900 participants who said all three Walks were a lovely family friendly morning out, with an incredibly welcoming and inclusive atmosphere.

We are very proud to announce that more than \$71,500 was raised for this year's Walks. This is an incredible sum, and will allow us to continue providing much needed dementia-specific care and support to people living with dementia and those who care for them in Western Australia.

Successfully hosting three Walks in one year is a significant undertaking and could not have been achieved without the support of our members, volunteers, and all the amazing participants and fundraisers.

As with any successful fundraising event there are many people who deserve to be thanked for their involvement.

This year, we were delighted for Ros Thomas and Pippa McManus to come on board as ambassadors for the Walk to Remember events. Ros and Pippa helped to raise awareness of the Walks and of dementia through their social media pages.



Dementia Advocates Ken Eaton, Barbara Ward and Jeanette Whittington each spoke at one of the Walks, sharing their personal experience of caring for a person living with dementia. Thank you to each of these people for being brave enough to tell their story in front of a crowd of hundreds.

Thanks to Walk participants who shared their photos and heartfelt messages on our Memory Wall, and to the families of those living with dementia who agreed to be interviewed for articles in *The West Australian* and local community newspapers:

- » The Fernihough family (featured right)
- » Patrick and Clare Koo: Patrick participated in all three Walks!
- » Barry and Sheila Rodwell
- » Bev and Brian Godfrey
- » Susanne and Stewart Godden
- » The Wallinger family

Thanks to major sponsors HHG Legal Group and Aussie Natural Spring Water. Lastly, thank you to each and every person who volunteered their time to ensure the Walks were a spectacular success. Without you, we would be unable to run events like these. We now turn our thoughts to planning for the 2019 Walk to Remember events and hope to see you there.

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Volunteer champion inspires family to walk for Alzheimer's WA

A large gathering of family and friends of well-known Salvation Army volunteer Phyl Fernihough took part in this year's Perth Walk to Remember to honour their champion who gave so much to the community before being diagnosed with Alzheimer's disease in 2014.

Husband and Salvation Army member Alf Fernihough said family and friends walked with Phyl around Perry Lakes on November 4 to raise funds and awareness for Alzheimer's WA.

"Phyl has always helped others, so now everyone wanted to help her," said Alf.

"For eight years Phyl and I led of team of 200 volunteers providing thousands of hot meals and refreshments to police and emergency service workers during major crime incidents such as murder investigations, bushfires and missing persons.

"She made sure no one ever went hungry and no matter how tired she was she always had a smile and an encouraging word."

Phyl and Alf's son Ross agrees.

"All her life Mum has helped other people which is why I think so many people joined Mum and the family on the Walk," Ross said.

"Before the diagnosis Mum was very social, very generous with her time and never had a bad word to say about anyone.



Alf and Phyl Fernihough and family.

"Unfortunately Mum's health has recently deteriorated and you feel very helpless, so we thought if there's something we can do to help we'll do it - which is why we all took part in this year's Walk to Remember."

Daughter's Robyn and Fran attended a four-week training course with Alzheimer's WA not long after Phyl's diagnosis.

Robyn said it was important for her and her sister to be informed in order to support their Mum and Dad.

"Because Mum was newly diagnosed we need to get as much information as possible," she said.

"We can't change the outcome for Mum, but we hoped that by taking part in the Walk to Remember we could change the outcome for someone else."

Wine and Horses team raise almost \$30,000 for Alzheimer's WA

Maryanne Phillips and the amazing team from Wine and Horses in Perth Hills organise an outstanding event every October to raise funds for Alzheimer's WA and this year was no exception.

Now in its fifth year, the event involves a team of approximately 70 riders riding the Kep Trail and CY O'Connor Pipeline to Northam return over two days. This year the event was held over the weekend of 13-14 October.

Organiser Maryanne said the event was hard work but very rewarding, "The ride requires a lot of training for both the horses and the riders - both need to be fit. It's always a highlight watching the riders achieving their personal goals."

More than 100 dedicated people volunteered to help out over the weekend, despite the initial weather forecast for thunder and lightning. Maryanne said most of the volunteers know at least one person with dementia and the ride will continue for as long as possible in honour of those living with dementia.



"This year we did two new things which were a huge success - the first was a memory wall for riders and volunteers and the second was people could come on stage and give a two minute account of how they've been touched by dementia. Both were very personal and brought a lot of emotion to the event," she said.

The annual auction and dinner, held at the Avon Valley Equestrian Centre Northam, saw over 100 donated items auctioned. A raffle offered an amazing first prize of a holiday in Broome.

The 2018 event has raised close to \$30,000, bringing the total amount raised for Alzheimer's WA to more than \$130,000 in five years.

Keep an eye out on the Wine and Horses Perth Hills Facebook page for details of next year's ride. New riders and volunteers are always welcome.

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Dementia Friendly Towns come to Margaret River and Toodyay

A very special project will shortly commence in the towns of Margaret River and Toodyay.

The Dementia Friendly Communities project, an initiative of Alzheimer's WA, empowers rural communities to support people living with dementia to live as well as possible for as long as possible.

Why create dementia friendly towns?

A dementia diagnosis is often accompanied by stigma, isolation and discrimination which impacts on a person's continued engagement in the community. There are currently 41,000 people living with dementia in Western Australia. Of this number, around 70% live in their homes.

The project helps to build awareness and understanding, reduce stigma and develop a community that enables and supports people living with dementia.

The project has proven successful in the towns of Manjimup and York, which were the pilot sites last year. Read about local York couple Laurie and Jane's journey below, or Laurie and Derene from Manjimup by visiting alzheimerswa.org.au/videos.

The project is supported by the Western Australian State Government through the WA Country Health Service.

Jane and Laurie Parkin

Jane was in the prime of her early childhood teaching career when she was forced to retire due to symptoms caused by early onset Alzheimer's disease. At an age when many working men and women are enjoying the peak of their careers, at 62 Jane was suddenly unemployed.

The hardest part, according to Jane, was the sudden and overwhelming lack of regular connection with others. Compounding this was her concern about how she would be treated by others in the close-knit regional town she and husband Laurie call home. So, she stopped going out.

Jane went from spending her days teaching boisterous four-year-olds to being isolated at home. Alone. All day. Wondering what to do with herself.

The Dementia Friendly Communities project in York gave Jane a newfound confidence that she would be accepted by her local community. York Shire, Balladong Lodge and other businesses took part in training to understand more about dementia and how people living with dementia still have much to offer to their local community. As a result,



Jane was offered the opportunity to call for Balladong Lodge's weekly bingo night. The couple also joined a local boot scooting class which they thoroughly enjoyed.

Both Laurie and Jane are very appreciative of the positive changes in their town as a result of the project.

"I'm trying to push myself to go into the main area of town, so that I'm not here all the time wondering what I'm going to do with myself," said Jane.

"This program has been tremendous, it got us involved in the community, something we would not have done. It has got Jane out of the house and has brought us closer together which is great," said Laurie.



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has a story to tell...*

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