

MILESTONES

AUTUMN 2016, ISSUE 18



Reshaping Respite



Mary Chester Club

■ MILESTONES

The Alzheimer's Australia WA newsletter. Autumn 2016. Issue 18.

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Front Cover Photos

Top: Ella's House opens and changes the respite and dementia landscape for Mandurah.

Bottom from Left: Lady Cosgrove joins the respite team, members and guests at the Mary Chester Club for morning tea; Governor General Peter Cosgrove, a firm fan of AAWA Respite, visits the Mary Chester Club and chats to the guys in the Men's Shed; Deputy Premier the Hon Kim Hames MLA Minister for Health opens Ella's House with trustee Shirley Altree from the Theodore & Isabella Wearne Charitable Trust.

CEO'S COMMENTS



Alzheimer's Australia WA
CEO, Ms Rhonda Parker

Welcome to our very valued members to the first Milestones of the year. How quickly is 2016 passing us by? We are already into the second quarter of the year and here at Alzheimer's Australia WA, we have been busily preparing for the new federal reforms and introducing new services. If you do not understand the reforms, we are running Consumer Directed Care workshops with COTA and I urge you to come along.

The federal reforms are changing the way dementia services will be funded and accessed. The reforms present challenges for us, but as with every challenge presented, we are up to the task and remain committed to standing by those living with dementia. We have always met change and challenge with vigour and commitment, and we plan to do the same in 2016.

Alzheimer's Australia WA hopes the federal reforms to dementia services increases the focus on person centred care and on well-being for service providers delivering Consumer Directed Care. It remains our goal to champion this level of care as we always have in our own services.

To ensure that our staff, the industry and our consumers are in the know about the latest in dementia knowledge, information and research, we invited one of the world leaders in dementia care, Co-Founder of the De Hogeweyk Dementia Village in Amsterdam, Yvonne van Amerongen to Western Australia in March.

De Hogeweyk Village opened in 2009. It houses 160 people living with dementia in 23 homes in a specially designed, safe and enabling neighbourhood. They are free to do as they please, free of restrictions and constraints.

What makes De Hogeweyk dementia village a leader in dementia care environments is it has few boundaries. It is designed for people with dementia rather than frail aged care residents where people sometimes need to fit the environment. Yvonne and her team provide a higher quality of living for people with dementia by placing emphasis on living and wellbeing; the care vision is to deliver normal living as you would experience at home.

The village environment was designed this way to enable happiness, creativity and independence.

The residents manage their own households together with the De Hogeweyk staff. Washing and cooking is done in all of the houses and groceries are bought in the Hogeweyk supermarket by the residents. The village has streets, gardens and a park where the residents can visit anytime and the village offers a selection of facilities like a restaurant, a bar and a theatre. These facilities can be used by De Hogeweyk residents and also residents of the surrounding neighbourhoods.

At the end of last year, we took steps to ensuring those with dementia and their families in the Peel Region are able to receive high quality dementia care, services and education. The opening of our third dementia hub, Ella's House in Mandurah, highlights our philosophy that dementia is a human experience rather than just a biological condition.

The contribution of the Theodore & Isabella Wearne Charitable Trust of funds to purchase this house has changed dementia care for many generations in the Peel Region and we are grateful for such a significant endowment.

Thank you for your ongoing support, even though the midst of change. You help make all this happen.

Happy reading,

A handwritten signature in blue ink, appearing to read 'Rhonda Parker'. The signature is fluid and stylized, with a large 'R' and 'P'.

Rhonda Parker

WELL-BEING AND GENEROSITY - THE KEYS TO RESPITE



What provides the feeling of well-being and why is it needed in respite centres?

Some years back, an expert team led by the late Dr Bill Thomas, an international authority in elder care identified seven primary domains of well-being; identity, growth, autonomy, security, connectedness, meaning and joy.

These domains don't change because you have a diagnosis of dementia. The more challenges you might face, the more the elements of your well-being become essential to your happiness.

The domains start with you, your **identity**, being known, your individuality and history. They include your ability to **grow**, develop, expand and evolve. They recognise your **autonomy**, your liberty, choice and freedom. They take into account your **security**, freedom from doubt and anxiety, as well as your safety, privacy and dignity. They entail the need for **connectedness**, our sense of belonging, engagement and being involved. They highlight having **meaning** in your life, matters of significance, hope, value and purpose. Last but not least, they embrace our need for **joy**, happiness, pleasure, delight, contentment and enjoyment. I'm sure most people can see in these domains the many things that make them happy and make them who they are.

At Alzheimer's Australia WA we committed some years ago to delivering a model where every service model for every consumer embraced these domains. What we found was astounding. People were happier, more at ease, enriched and more engaged since their diagnosis. We now consider the domains in everything we do and see the resulting happiness every day.

When you visit our respite centres Mary Chester Club and Hawthorn House we ensure consumer well-being is our number one priority. In 2015, we added Ella's House in Mandurah with the same well-being philosophy.

Ella's House - Generosity Changes a Community

Late in 2015, we opened a residential dementia hub in Greenfields catering for the growing number of people in the region who have been diagnosed with dementia and continue to live in the community.

For those living with dementia, Ella's House is providing services such as home respite, individual social support, counselling, carer support groups, social support groups, day centre services and training and education to people living with dementia, their carers and families.

Ella's House was made possible because of a very generous endowment from the Theodore & Isabella Wearne Charitable Trust. Such benevolence in donations, bequests, endowments and trusts changes the lives of thousands of people in a region.

Alzheimer's Australia WA and the region are deeply indebted to this game changing generosity from the Trust that will transform dementia services to Mandurah.

In Mandurah, Ella's House will bring the peace of well-being to a great many families. Alzheimer's Australia WA could not do everything it does if it was not for the benevolence of those who want to stand beside those living with dementia.

If you are considering a will or an endowment and you want to provide for those living with dementia, give our Giving Team a call (08) 9388 2800 for a confidential chat. Together we can make a difference big or small.



Trustees Rosemary Peek, Shirley Altree and Geoff Taylor with AAWA CEO Rhonda Parker.

Ella's House will transform a community and bring the peace of well-being to a great many families.



A portrait of Theodore and Isabella Wearne welcomes you to Ella's House.



Minister for Health Hon Kim Hames MLA with Trustee Shirley Altree.

PEOPLE WITH DEMENTIA AT INCREASED RISK OF FINANCIAL ABUSE



Earlier this year, Federal Attorney General George Brandis drew attention to the growing problem of elder abuse amongst people living with dementia in Australia.

"We need to ensure that older people, especially those with cognitive impairment, are protected against all forms of elder abuse whether they are in aged care facilities or in the community," Alzheimer's Australia's National President Graeme Samuel AC said.

Elder abuse can present itself in many different forms. Professor Samuel highlighted that people with dementia are at significantly higher risk of being taken advantage of financially, termed 'financial abuse'. Due to the natural progression of dementia, there is usually a loss of ability and capacity to manage financial affairs.

The Australia Human Rights Commission defines financial abuse as "when a person you trust uses that relationship of trust to gain access to your money or property." This can include:

- Pressure to act as guarantor for a loan;
- Pressure to transfer or sell property;
- Pressure to give away money; or
- Persons authorised to manage your money not acting in your best interest, or using your money for themselves.

Unfortunately, victims of financial abuse usually know the perpetrator. In most cases, they are a family member appointed to manage the person with dementia's finances. There have also been cases where friends and neighbours have been the abusers. Although less common, it can also be perpetrated by a person who comes into contact with the person with dementia and then takes advantage of their vulnerability.

Signs that someone is being financially abused may include:

- Fear, stress and anxiety expressed by a person with dementia;
- Unfamiliar or new signatures on cheques and documents of a person with dementia;

- Significant withdrawals from accounts of a person with dementia;
- The accounts of a person with dementia suddenly moved to another financial institution;
- Significant changes to a Will of a person with dementia;
- Isolation and control of a person with dementia by carer; or
- Evidence of undue influence e.g. coercive behaviour by another person.

These 'red flag' behaviours and activities may indicate that a person with dementia is being financially abused. However, some of these behaviours are also tell-tailing signs of other forms of abuse, such as physical abuse, sexual abuse, psychological abuse and neglect. Either way, you should alert someone if you suspect elder abuse is being carried out.

The best way to safeguard yourself against financial abuse is to appoint someone to act as your attorney through a financial Power of Attorney. A Power of Attorney document gives an individual or individuals authorisation to act on your behalf when you no longer have the capacity to manage your financial affairs. The person/s you appoint as your attorney should be trustworthy, capable and financially literate. If you decide to appoint two people you should be confident that they will not be in conflict about what is in your best interests.

Alzheimer's Australia has developed a resource to help people plan ahead in case of cognitive impairment. To access go to: start2talk.org.au

Some forms of financial abuse are criminal offences and in these instances, you should contact your local police. If you have been financially abused, or you suspect someone is being financially abused, contact Advocare WA on 1800 655 566 or (08) 9479 7566.

TO DRIVE, OR NOT TO DRIVE?



In 2014, the University of Wollongong released **Dementia and driving: a decision aid to help people living with dementia decide on what to do about their driving.**

A diagnosis of dementia is usually accompanied by a variety of changes to one's lifestyle and needs. Most older adults have driven safely and remained accident-free for many years. Driving is a valued tool of independence. However, dementia can silently affect your driving skills. Our advice is don't put yourself, your loved ones or other families on the road in danger.

Licensing requirements

All drivers are required by law to tell their local licensing authority of any medical condition that might affect their ability to drive safely. Conditions such as dementia, diabetes and some heart conditions need to be disclosed.

Once notified, the licensing authority will ask the driver's doctor to make an initial assessment of the driver's medical fitness. After this, a formal driving assessment may be required. Based on the results of these assessments the licensing authority will decide if the person can continue to drive.

If a person with dementia can continue to drive they will be issued a conditional licence. Conditional licences are valid for a maximum of 12 months; after that the driver will be reassessed. Sometimes restrictions may be put in place on times of the day or speed limits.

Be wary that if you have dementia, continue to drive without notifying the correct authorities and are in a crash, you could be charged with driving offences or be sued. In addition your insurance company may not provide cover.

Eventually, most people with dementia find it unsafe to drive. Over time, the risk of becoming lost or having a car accident rises.

It is important to keep in mind that we drive for a great number of reasons and a person might be cautious discussing driving safety for fear of losing their licence.

The first thing to ask yourself is have you noticed any warning signs of unsafe driving. Have you experienced any of the following warning signs while driving? If so, this may be a sign that your driving skills may no longer be adequate.

- Find changing lanes difficult to do.
- Find roundabouts difficult to use.
- Drive very slowly.

- Confuse left and right.
- Become lost on short trips.
- Drive on the wrong side of the road.
- Notice damage to your car that you cannot explain.
- Car accidents or a near miss.
- Numerous traffic fines.

Most experts would agree that drivers with dementia are at a higher risk of getting lost or having a car accident. Some researchers have found the risk of accident to be 2.5 to 10 times higher than other people of the same age. This is a difficult topic to research and your exact risk is uncertain.

Many drivers say that being able to drive is important, especially in a state as vast as Western Australia because it gives them independence, allows them to visit family and friends, get to appointments and because they like driving.

However, you need to make the right decision based on your safety, the safety of others on the road and look at the risk of accidents, or being lost.

If you are unsure, it pays to ask others if they have seen changes in your driving ability. If you have a person in your life with dementia and you have concerns about their driving, it's definitely worth having a chat about it. Driving is important but not at the cost of risking a life.

The information from the article was provided by Dementia and driving: a decision aid (University of Wollongong 2014). To learn more go to fightdementia.org.au/about-dementia-and-memory-loss/dementia-and-driving

RESEARCH UPDATE: Curtin University of Technology has applied for funding jointly with a number of partners including AAWA for a project to understand better the impact of driving with dementia. A substantial gap remains in the evidence regarding the natural progression of the disease and its impact on driving performance. A proposed longitudinal prospective study will use an innovative combination of real time in-vehicle driver monitoring devices to objectively measure natural driving patterns and self-regulation practices. The proposed project will create a partnership between leading researchers and policy makers in order to provide an answer to this complex problem.

THE GIFT OF FINANCIAL WISDOM



Financial planning is of critical importance to families with dementia and this year Alzheimer's Australia WA added a unique programme of wisdom, direction and understanding from one of WA's most respected financial experts.

Nick Bruining contacted AAWA CEO Rhonda Parker, an old associate, and explained that he was keen to give back to the community and help those affected by dementia navigate through the tricky world of personal finance and welfare. Well-known for being Channel 7 and the West Australian's financial expert, Nick and his team at N.C. Bruining & Associates kicked off a series of seminars to help those caring for someone with dementia organise their finances.

"We have the third best disability support system in the world, but it also one of the most complicated to access," Nick said.

"It's important for families whose loved one has a diagnosis of dementia to rearrange their affairs so they can be in the best possible financial position."

Nick highlighted the importance of taking an integrated approach to get the best out of the system. The integrated approach involves:

- Working out what your expenses are and will be;
- Setting out a wish list;
- Identifying income from all sources;
- Restructuring to optimise your financial position; and
- Reducing financial risk.

The presentation covered how to maximise returns from resources and discussed the areas of tax, superannuation, the pension and Centrelink. Nick's big point was to avoid 'sharks' in the financial sector.

"So, how do we avoid sharks? We start by visiting www.moneysmart.gov.au and following the links about getting financial advice. We ask our friends and colleagues about people they have used and if they were happy. We then interview 3 or 4 prospective financial planners, telling them up-front that we are talking to a number and will be choosing between them. We're looking for people we can talk to, who don't try to blind us with jargon or impress us with what they've done. We're looking for someone we can confide in and trust. Take your time doing it, it will be worthwhile."

Nick had one last surprise in store for those attending the seminars. Along with colleagues and associates including DJ Carmichael, Nick announced he and his team would be holding one-on-one financial planning sessions for those who attended the seminars for families living with dementia free of charge in 2016.

Nick and his team will be presenting more great financial seminars in 2016. More information about the seminar dates and venue will be released soon.

DEMENTIA PARTNERSHIP PROJECT SYMPOSIUM

Alzheimer's Australia WA brings international speaker Dan Cohen to town.



As we all know, from hearing that song associated with a first love or leaving home, music is profoundly linked to personal memories. In fact, our brains are hard-wired to connect music with long-term memory.

Even for persons whom cognitive skills have been severely affected by dementia, music can tap deep emotional recall. For individuals with Alzheimer's, memory of things—names, places, facts—is compromised, but

memories from our teenage years can be well-preserved.

Favourite music or songs associated with important personal events can trigger memory of lyrics and the experience connected to the music. Beloved music often calms brain activity and enables the listener to focus on the present moment and regain a connection to others.

Visiting speaker Dan Cohen reminded us of the challenges of ending up alone and isolated in an aged care facility, often separated from the things you love and the experiences that make you happy and how music can make such a difference.

Dan's programme, *Music and Memory*, provides extensive evidence of the positive life changing effect of bringing someone's favourite music back into their lives during their care.

Music and Memory's work is rooted in extensive neuroscience research. In 2013, UK organisation Arts 4 Dementia looked at those with early onset dementia who participated in art workshops, including musical workshops. The study assessed the effectiveness of each activity in improving cognitive function and wellbeing. Results were enhanced cognitive ability, stress relief and a decrease in memory problems. Ninety-four per cent of people with dementia appeared energised, unstressed, happy and alert for at least 24 hours after a workshop, 89 percent claimed to feel more confident and 84 percent of people with dementia recognised they had learned new skills.

Music and Memory has been helping people in nursing homes and other care organisations who have a wide range of cognitive and physical challenges to find renewed meaning and connection in their lives through the gift of personalised music. The results are nothing short of amazing.

The approach is simple and effective care professionals are trained to set up personalised music playlists delivered on iPods and other digital devices, for those in their care. These musical favourites tap into deep memories not lost to dementia. It can bring participants back to life, enabling them to feel like themselves again, to converse, socialise and stay present.

According to Cohen, music means something different to everyone. Music can evoke emotion and remind people of certain memories. In fact, our brains are hard-wired to connect music with long-term memory. Personal music favourites allow a person to focus on moments and feelings, to focus on the present moment and regain a connection with others.

The benefits of personalised therapeutic music have been studied and documented in the film 'Alive Inside', which follows Dan's work and shows the experiences of people with dementia in the US for whom music has strong emotional recall.

"The benefits are huge as witnessed see in *Alive Inside*," Cohen said.

For more information go to musicandmemory.org

In 2016, Alzheimer's Australia WA hope to pilot a music and memory programme – watch this space.



TALKING WITH PEOPLE WITH DEMENTIA. LEARNING TO LEAVE YOUR TRADITIONAL COMMUNICATION BAGGAGE AT THE DOOR

In October 2015, Alzheimer's Australia WA held a series of training events that dared to step into the world of late stage dementia and hope for connection.

It's tricky territory because when we lose traditional communication methods we often withdraw and begin grieving for the person with whom we can no longer converse and recollect with.

Michael Verde, creator of the award winning *Memory Bridge* documentary, delivered for us a series of workshops proving we can leave our traditional communication beliefs behind and have meaningful relationships with those who can no longer communicate through traditional means.

Verde started a foundation called *Memory Bridge* to connect people who have Alzheimer's with family, friends and the community. He teaches professionals and families how to leave their own perceptions behind and communicate with someone with dementia.

This all started because of Michael's drive to diminish the emotional and social isolation people with dementia usually feel.

Memory Bridge is motivated by the conviction that the primary challenge for people with dementia is loneliness the feeling of no longer being meaningfully connected with others. Such a challenge, is not principally caused by the death of brain cells but by the disappearance of conversational partners. In other words, the principle source of challenges that people with irreversible dementia experience is not ultimately caused by what is in their heads but by what is in ours: namely, our collective conviction that people with dementia become increasingly incapable of participating in meaningful communication.



Memory Bridge works in the belief that while Alzheimer's disease cannot be cured, the 'dis-ease' of Alzheimer's (and other forms of dementia) namely emotional and social isolation can be healed.

In line with this vision, *Memory Bridge* teaches how to communicate with people with dementia in meaningful ways.

It explores new ways of thinking about dementia, and the development of improved communication and validation skills.

According to Verde, "Dementia often requires that we don't use words. Words cease to be the mode of transaction, so we have to communicate in ways that are usually discouraged. For example, we're so cerebrally oriented that we don't touch each other. Alzheimer's gives us a chance to remember that the only thing that fulfils us emotionally is meaningful communication."

"There are a lot of cultural assumptions around the idea of identity that make memory loss terrifying," he said, "And there's a vested interest behind the pictures of memory loss that terrify us. But it depends on whether you think your identity resides in your neurons. The dread associated with memory loss will diminish if we remember that our identities live in our relationships and not in our neurons."

For more information visit www.memorybridge.org.



MICHAEL VERDE

Founder and President of Memory Bridge: The Foundation for Alzheimer's and Cultural Memory

Memory Bridge creates programs that connect people with Alzheimer's disease and related dementias to family, friends, and other people in their local community. They also create programs that reveal to the general public the depths of memory that dementia does not erase.

In 2003, Michael founded *Memory Bridge*. To date, *Memory Bridge* has connected over 8,000 people with and without dementia to each other in one-to-one relationships.

In 2008, he produced the internationally acclaimed PBS documentary, *There is a Bridge*, that explores the power of empathetic attention to keep people with dementia emotionally connected to others.

He is currently pursuing a PhD in the area of empathetic education at Indiana University.

DE HOGEWYKE'S DEMENTIA VILLAGE

In March, Alzheimer's Australia WA invited world leader on dementia care, Co-Founder of the De Hogewyke's dementia village Yvonne van Amerongen, to Western Australia to reveal details of how she provides a higher quality of living for people with dementia.



Features of De Hogewyke Model

- A dementia care village environment.
- Emphasis on living and wellbeing: the care vision is to deliver normal living.
- 152 elderly people live in 23 homes in a specially designed safe and reliable neighbourhood.
- Creating 7 types of apartments based on 'genres'. E.g. urban, homely, cultural.
- People with dementia live together in houses with a carer.

The 'weyk' in Hogeweyk translates to a group of houses, similar to a village. The residents manage their own households together with a constant team of staff members. Washing, cooking and so on is done every day in all of the houses. Daily groceries are done in the Hogeweyk supermarket. Hogeweyk offers its inhabitants maximum privacy and autonomy.



The village has streets, squares, gardens and a park where the residents can safely roam free. Just like any other village, De Hogeweyk offers a selection of facilities,

like a restaurant, a bar and a theatre. These facilities can be used by Hogeweyk residents and residents of the surrounding neighbourhoods. Everybody is welcome to come in!

De Hogeweyk's Dementia Village has become an international phenomenon since it first appeared in the world of dementia care.

De Hogeweyk is achieving a range of ground breaking outcomes including reducing typical symptoms of advanced dementia and stabilising conditions. They are focussed on designing environments that can enable happiness, creativity and independence. Innovation in technologies and activities has been used to appeal to memories, senses and communication.

The model is being trialled with success in Australia with Synovum's community for 120 seniors planned in Queensland following a successful trial in the Wynyard Care Centre in Tasmania.

Is this the future of care?

CREATIVE ARTS THERAPY AND DEMENTIA



The creative arts is an effective way to engage people living with dementia and is now strongly supported as a way to improve wellbeing by research findings.

Research of the Alive!¹ program in 2015, a range of art activities in 2,263 workshops for an estimated 6,400 people across the UK has shown a very positive impact on well-being.

In conjunction with the West of England University, the Alive! program evaluation was undertaken by Willis Newson Consultants who found that creative activities positively impacted mental and emotional wellbeing as well as providing enjoyment, enabled social connections and gave participants opportunities to demonstrate skills, knowledge and a sense of pride and achievement.

It was also observed that residential care staff who engaged with residents during Alive! workshops were able to interact positively and meaningfully and many found ways into the worlds of residents who did not always communicate well.

The activities offered opportunities for people in care, including those at different stages of dementia, to share elements of their life history and to explore and express their personal identity, knowledge and skills through creative activity and shared interaction with others. Individuals were encouraged to express personal choices and emotional needs.

Alzheimer's Australia WA has been utilising creativity and the arts as a wellbeing strategy for our clients and club members since 2008.

After seeing the benefits of including art and creativity in the lives of those living with dementia, Alzheimer's Australia WA is now offering *Artistic Endeavours*, a brand new art studio

experience based on the highly successful *Artistic Adventures*.

This new therapeutic creative art group, run at the Mary Chester Club, offers a peaceful two-hour art session for up to eight participants who have a diagnosis of dementia. Classes include a flexible mix of art media, including paints, pastels, clay and much more and participant are supported and encouraged to express themselves in their own unique, artistic way.

Alzheimer's Australia WA's art programme offers opportunities for increased self-esteem and confidence and our staff see many positive emotional responses when those with dementia are involved in self-expression and creativity. The programme is calming, engaging and encourages fine motor skills and hand / eye coordination.

Artistic Endeavours is well suited for those who have enjoyed art in the past but are having difficulties in maintaining their art practice or for those new to art and would like to try something different.

As well as offering art therapy, we also offer music therapy for those who enjoy verbal and theatrical expression.

For more information about *Artistic Endeavours* or about art and creativity in dementia care, please call Jackie Lewis or Althea Gordon on (08) 9388 2800. Alternatively, you can email: jackie.lewis@alzheimers.org.au or althea.gordon@alzheimers.org.au

1 The Alive! Difference: An Evaluation of Alive! Workshops and Training. (2015). www.aliveactivities.org/images/library/files/Alive_evaluation_executive_summary_FINAL.pdf.

MARK & MARIE

When I first met 54-year-old Fremantle couple Mark Beggs and Marie Jones they epitomised a typical Aussie couple. Mark – a rugged, burly man who loves a good yarn and motorbikes and Marie – a friendly, bubbly woman with a quirky sense of humour and a green thumb. And together – they are something special. While talking to me about their life together, I could feel the admiration, appreciation and love they have for each other. Any obstacle that came their way, they always found a way to get through it, including Marie’s diagnosis of dementia.



as a person; it’s merely just a part of her. Marie is so passionate about educating people about dementia, raising awareness and showing people that it isn’t what they think it is.

“It sucks,” Marie says.

“People think you’re a weirdo or a whack job because you have dementia.”

Mark then proceeds to tell her she is a whacko in joking, loving way; another ‘taking the mickey’ moment from Mark. We all laugh and once again, I lose track of my questions.

Dementia has not changed the couple’s lifestyle much at all other than Mark becoming the cook. Mark still even works FIFO with an eight days on, six days off schedule. While Mark is away for work, Marie takes care of herself in their apartment with a couple of one-on-one social visits from support services. Marie wants people to know that people with dementia are still able. She acknowledges that every diagnosis is different, but people are still able to do many things in different capacities.

“You have your ups and downs, but life is generally good, especially when you have a tremendous group of friends and supporters,” Mark says.

“There’s a lot of change happening in society, younger people are getting dementia and they are frightened of it because there’s a lack of awareness and understanding.”

Marie finds this conversation tough. Mark hands her a box of tissues, which has a gingerbread house design on it. I can’t help but smile and comment on how funky her tissue box was. I bet she picked that design, it is very Marie like.

“It’s so frustrating sometimes, you know, you can’t care about what other people think about you.” She says.

“I just be happy because I don’t want to be miserable.”

“You just got to keep going, what else can you do?”

At this point, Marie gets up and walks over to the dining table and brings back over a small rubber sheep. She squeezes it and to my surprise, it squeals like a pig. She begins to laugh and squeezes it again. Soon, her sadness is forgotten.

“I bought this on a shopping trip. I knew I had to have it when I saw it,” Marie tells me. She holds onto the sheep for the remainder of our conversation.

It sounds silly, but this sheep that sounds like a pig has made me realise something (and I bet this sheep is from New Zealand, because I’ve never heard an Australian sheep make that noise). Marie has managed to find the joy in the simplest things. She doesn’t take the small things for granted and treasures every moment. Maybe life isn’t all about those big defining moments; maybe it’s also about those smaller moments where sharing laughs and smiles with the ones you care about are the best memories of them all.

by Sue-Mae Watt

Mark and Marie are both English born and both immigrated in 1965 – Mark to New Zealand and Marie to Australia. Mark moved to Australia in 1984 to start a career in the mining industry and this is where he met the love of his life Marie, an administration officer. They remind me that first impressions don’t always count. Marie recalls the first time she met Mark – she thought he was loud and extremely obnoxious.

Together they have worked on numerous mine sites – Fortnum Mine in Meekatharra, Jundee Gold Mine then to Useless Loop Mine in Shark Bay. Mark even did a couple of years in Tanzania. It’s easy to see where their love of the Australian bush developed. As well as travelling around WA, Mark and Marie also managed to take trips back to New Zealand and England to visit family and friends. They are currently in the process of having a house built in Binningup, their touch of paradise, located between Mandurah and Bunbury.

Although Marie grew up in Karrinyup, she tells me that she was very much a Scarborough girl back in her younger days and has fond memories of being down at the beach with her friends and family. Marie is the youngest of five kids. Mark cheekily reminds her that being the youngest, she was the spoilt, bratty one. Seeing them continuously make fun of each other throughout our conversation makes me laugh, but also leaves me with a tinge of sadness. Why does Marie, such a vivacious, happy-go-lucky woman with a larger than life energy, have dementia?

The first sign that something wasn’t right with Marie was five years ago when her friends noticed she was teary and started forgetting the small things like her car keys or her handbag. After a visit to a doctor, she was diagnosed with depression. It was only after Marie had a PET scan that she was diagnosed with dementia three years ago. I don’t want to talk too much about Marie’s diagnosis, because this isn’t what defines Marie

ALZHEIMER'S AUSTRALIA WA SERVICES



CARING FOR AND SUPPORTING CARERS

Our organisation was started by carers and GPs. After three decades, we are always here and well aware of the need to care for carers and provide specialist support in the area of dementia. We are specialists in the care and education for carers.

Carer Support

The Alzheimer's Australia WA Carer Support Programme provides a holistic support service to people who are caring for a loved one living with dementia in the community. The program attends to the psychological, social and emotional needs of family carers throughout their journey. We have two components to our Carer Support Programme. The first is the Carer Support and Information Programme, which runs over five-weeks. This is recommended before attending our monthly Carer Support Groups.

Carer Support Groups

Upon completion of a Carer Support and Information Programme, carers are then invited to attend a Carer Support Group. Carer Support Groups are facilitated across the metropolitan area and meet once a month. The Carer Support Groups enable carers to build a support network and link in with Alzheimer's Australia staff members who can link them with the support and services they need at different points in their journey.

To register your interest in attending these groups please, contact: csgwa@alzheimers.org.au or call (08) 9388 2800.

DAY CENTRE RESPITE

There are varying reasons our members access the day centre. One of them being a great opportunity to have a day out engaging in meaningful outing and activities in a safe and welcoming environment. It is a social opportunity for people living with dementia who may have limited social interactions out in the community.

Many of our members attend the Mary Chester Centre so their carer's are able to have some time out.

The Mary Chester Centre is unique from other services because it specifically meets the needs of people living with Alzheimer's and Dementia. Using the Eden Alternative Philosophy our clients' needs are met in a very person centred way. There are many benefits we have seen from our members being a part of the Mary Chester Centre. Comments from our members include "I feel like everyone is family here." Our members can feel like this is a second home for them, there is no set routine, they are free to participate in whatever they wish while they are here.

Our members form friendships with other members, staff and volunteers. There are many opportunities to try new things and participate in activities they may not have had the opportunity to do at home.



EARLY INTERVENTION

Most people access Early Intervention services during the process of or after receiving a diagnosis.

The programme aims to provide people with information and support to assist in adjusting to the changes and challenges they face. The early intervention program is often the first point of entry to Alzheimer's Australia WA services.

Alzheimer's Australia WA's Living with Memory Loss programme is unique in that it is delivered for the person with dementia and their carer/ support person, as opposed to services that are purely carer focussed.

At the completion of each program, all participants complete a program feedback form. Comments from 2015 have included people with Dementia who have reported "It's helped me to be more positive and live every day the best I can" Carers comments included; it "made us feel less isolated". Overall program feedback suggests the most valuable aspects of the program are; meeting others in a similar situations, reducing sense of isolation, and feelings of empowerment by the information received.

YOUNGER ONSET DEMENTIA

The WA Younger Onset Dementia (YOD) Program is extremely unique through its ability to:

- Cater to the needs of both the person with dementia AND their carer.
- Support people throughout their journey (e.g. from point of diagnosis, to living in the community, to residential care).
- Provide important capacity building services across the health and community sectors to assist providers to create and modify services to better support people living with younger onset dementia.

There are currently no other programmes that offer similar services, especially not for people under 65 living with dementia. Most services with specialist dementia knowledge and skills primarily cater for people over 65.

Based on consumer feedback and our observations the main benefits we have seen are reduced carer stress and better quality of life for both the person living with dementia and their carers. Carers often refer to us as 'part of their family' or a 'lifeline'. They appear to feel more confident to pursue their day to day roles knowing that they have someone to turn to whenever they need support.

Contact us on 93882800 to access these programmes.



Many people living with dementia are unaware of the dementia focused services that are available to them from Alzheimer's Australia WA. We have three decades of experience helping families with dementia. Give us a call if you need us.

■ **National Dementia Helpline 1800 100 500**

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

Free counselling

For people living with dementia and their friends and family call 9388 2800.

In home respite and social support

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

Carer support groups

Free meetings monthly in various locations for carers to spend time with peers and share experiences call 9388 2800.

Art therapy, choir and volunteering

Innovative programmes for meaningful engagement for those living with dementia call 9388 2800.

Day centre respite

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

Younger Onset Dementia Key Worker Programme

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

■ **Living with Memory Loss**

Email lwmlwa@alzheimers.org.au or call 9388 2800

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

■ **Education**

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

Industry and family / carer focused training courses.

■ **Carer Education Support Programme**

Call 9388 2800

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

■ **Dementia Behaviour Management Advisor Service (DBMAS)**

1800 699 799

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