# MILESTONES



TAKE ON ALZHEIMER'S GIVE TO AUSTRALIA

## 10 FACTS ABOUT DEMENTIA:

- Alzheimer's Disease and dementia is the second leading cause of death in Western Australia.
- 2. Dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the fourth leading cause of disability burden overall.
- 3. There are over 321,600 Australians living with dementia.
- One person every six minutes is diagnosed with dementia in Australia.
- 5. On average symptoms of dementia are noticed by families three years before a firm diagnosis is made.
- 6. Researchers now believe Alzheimer's plaques exist for some 15 years before symptoms manifest.
- 7. There are more than 100 causes of dementia Alzheimer's Disease is the most common.
- 8. An estimated 1.2 million Australians are caring for someone with dementia.
- There are approximately 24,400 people in Australia with Younger Onset Dementia (a diagnosis of dementia under the age of 65; including people as young as 30).
- 10. Dementia is a progressive degenerative disease. The progression for one person compared to another can differ greatly.

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# DEMENTIA HELPLINE 1800 100 500

## CHAIRMAN'S MESSAGE



Since I last wrote, the dementia challenge we are facing was further highlighted with the latest ABS statistics showing that Alzheimer's Disease and dementia is now the second leading cause of death in WA.

Nationally, Alzheimer's Disease and dementia remain the third leading cause of death in Australia. This new positioning sees Alzheimer's Disease and dementia second only to heart disease. As we see survival rates for heart disease improve, the diagnosis of dementia increase, and with the ageing population, dementia will continue to dominate these ABS reports

With figures like those from the ABS, the need for Alzheimer's Australia WA (AAWA) to be a dynamic, efficient and compassionate organisation is all the more important. *Milestones* is designed to keep you informed of the latest activity throughout AAWA and to outline how the board, staff and volunteers are working to deliver support and education to those living or caring for someone with memory loss in Western Australia (WA).

There are many aspects of dementia that make it a difficult disease to deal with. AAWA is focused on delivering better support to families living with dementia and we couldn't do this without the support of our members, staff, our volunteers and funders. As an important part of AAWA, we would like to thank you for all your support. It is because of you and others like you that we are able to support the 29,600 people living with dementia in WA.

Carrie Majari

Craig Masarei Chairman

## CEO'S MESSAGE



Friends of mine sometimes ask why I'm 'still involved with older people'. I think the assumption is that working with older people couldn't possibly be interesting. That assumption, when applied to dementia, couldn't be further from the truth.

Dementia and brain function is finally being recognised by governments, leaders, philanthropists and scientists as one of the greatest challenges of our times. For example, in recent months, US President Barack Obama has announced the US\$100 million BRAIN Initiative and compared its challenge to that of President Kennedy's announcement in 1961 to send a man to the moon. Just prior to that other major announcements such as the €1 billion European Human Brain Project and Bill Gates' Microsoft partner Paul Allen's US\$300 million spend on brain-mapping research also put the topic of dementia brain research in the forefront.

Here in Australia, the Federal Government last year announced that dementia would be listed as a National Health Priority Area. And in the last few months, the Australian Bureau of Statistics released data that showed that dementia is now the second leading cause of death in WA.

Could there possibly be a more important, compelling and challenging area of human endeavour than to work supporting those living with dementia, and improving our understanding of the cause, the cure and the care of this often overlooked disease? We at AAWA think not. We recognise that the task before us is immense – but we also know that it is worthwhile. The challenge drives our commitment and professionalism. It drives our level of industry.

I trust you will enjoy this edition of *Milestones*. It has been prepared to inform you of recent activity at AAWA and provides you with an update on the scope and nature of the work we do. Take special note of our Eden Alternative re-registration story, as well as our year-long program of public lectures.

In closing I wish to thank those who support us financially. While much of our income comes from governments, we could not 'go the extra mile' of leadership if it wasn't for the wonderful individuals and organisations who help to fund our endeavours. Thank you for making a difference.

Finally, thank you to every person who reads this for your continued interest in our work.

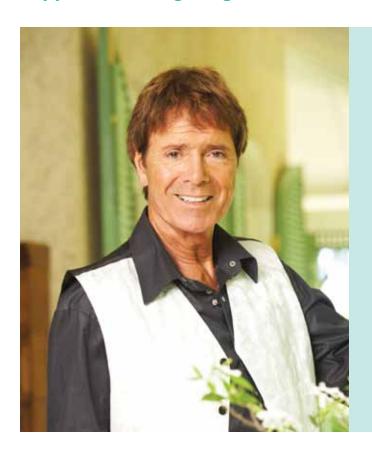
Happy reading.

Rhonda Parker Chief Executive Officer

### **LEADING THE WAY IN WA**

#### **CHAMPIONS OF OUR CAUSE IN WA**

Alzheimer's Australia WA is delighted to introduce some new faces that have each agreed to be a dementia champion for AAWA and provide support in the fight against dementia across our State.



#### SIR CLIFF RICHARD Kt. OBE

Sir Cliff became an Alzheimer's Australia WA (AAWA) dementia champion after his recent visit to Perth in February, even providing memorabilia for auctioning and prizes to help raise funds. Sir Cliff is no stranger to Alzheimer's Disease, having witnessed his mother's battle with Alzheimer's for ten years. "Dementia is such a scourge. It destroys relationships, ruins lives and is no respecter of persons. I'm really glad to champion those who are affected", he said.

Sadly, Sir Cliff's mother lost her battle with Alzheimer's in 2007, at the age of 87. During his visit to Perth Sir Cliff also 'donated' a memory about his late mother. "While I was performing "Heathcliff" I grew a beard for the part. During this time, my sister Joan and I took my mum out to lunch. I arrived and she had no idea who I was until I lifted my napkin and covered my beard. She looked at me surprised and asked me 'How did you do that?' You look just like 'that Cliff Richard'", Sir Cliff recalls.

Sir Cliff already supports campaigns to raise funds and awareness of dementia in the UK so we are grateful and proud to welcome him as one of our dementia champions in Western Australia.

#### **AKRAM AZIMI**

In addition to being Young Australian of the Year 2013, Akram Azimi is a dedicated mentor to young Indigenous people. In 2011 he co-founded a student-run initiative 'I am the other' to raise awareness about Indigenous issues in universities.

Like so many good things in my life, I have become a Dementia Champion for Alzheimer's Australia WA because of my mum who is a dementia-specialist nurse. Growing up, I vividly remember her returning home after nightshifts at the hospital. She would join us for breakfast and reflect upon her experiences. Therefore, from an early age I was gently exposed to the medical and the profound social and familiar consequences of dementia. Through my mum, I have come to understand that this is affects us all in some way. Thus, I am using my time as Young Australian of the Year, wherever appropriate, to raise awareness about this critical issue.

Akram Azimi Young Australian of the Year 2013

#### **JOSH CATALANO**

Josh first gained popularity in WA when he appeared on Channel 10's hit cooking show MasterChef in 2009. He currently works in his family business Catalano's Seafood's, an award winning seafood retailer.

I decided to help Alzheimer's WA because my Nonna is suffering from dementia and I just wanted to help. I know the battle I have with myself in the ways I deal with her condition and just thought if I get my story out there and I can help one person it would make it all worthwhile. I am just a normal person doing what they can to help another person through the tough times - this doesn't make you a champion, this makes you human. The real champions are the carers who spend every day with the people suffering from this disease. The small part that I play is all about being part of the community and I think everyone should do more of this. It truly makes you feel alive.



#### STEFANIA MUSCARA & DANIELA PIRONE

Former My Kitchen Rules contestants

Stefania and Daniela came third on the popular reality cooking show My Kitchen Rules in 2011. Stefania tells the story of her mother's experience with dementia.

This life is very unpredictable, things happen and we don't understand and sometimes we don't know how to handle or how to be in some situations.

Alzheimer's Australia WA means a lot to me and my family as we feel there is someone who understands us and is a tremendous support for my mum and the carers. A few years ago my mum was diagnosed with Alzheimer's Disease. We didn't know much about it so after some research we realised it was going to affect all of the family more than even my mum herself.

So my family and I are learning how to adjust around my mum, how to talk to her, how to hold her hand and take her out, how to be again with someone that for so long has done all of this for us. That's why it's so hard for the family of those inflicted by this terrible disease. Slowly you can see them disappearing into a world that we no longer can reach and be part of.



#### **DEBORAH KENNEDY**



Former ABCTV newsreader, Perth

Former ABC Television newsreader Deborah Kennedy is a familiar face in Western Australia. Deborah has been a journalist since 1985 and is one of only a handful in Western Australia who has had a high profile career across all three media forums - print, radio and television.

I've become a "Dementia Champion" simply to help continue to raise awareness of all forms of dementia.

The pressure on families suddenly confronted with having to care for someone with dementia is enormous and, with statistics suggesting that dementia will become more prevalent in our community, it's essential that funding for research and the care of carers be prioritised.

Nursing home carers are amongst the lowest paid workers in the country yet the work they do, under challenging circumstances, is so valuable.

The role of in-home carers, and the toll such a task takes on a person, often goes unrecognised.

Let's hope that with continued awareness and increased funding for dementia research and care, that this illness and the challenges it presents can be better managed and treated in the future.

### WHAT WE'VE BEEN UP TO

## YOUNGER ONSET DEMENTIA

As of March 2013 Alzheimer's Australia WA began the recruitment process for four Younger Onset Dementia (YOD) Key Workers (as part of the new national program) who will provide individualised support and improve the quality of life for people with younger onset dementia. This program is being funded by the Australian Department of Health and Ageing under the Living Longer. Living Better aged care reform package.



Currently, across Australia there are 24,400 people living with YOD. The challenges are very different for a person with YOD than that of a person with dementia. They may have younger families, are responsible for paying a mortgage and in fulltime employment when they are first diagnosed.

To highlight the needs of YOD people, Alzheimer's Australia Victoria hosted a National Summit in Melbourne during March entitled 'Younger Onset Dementia: A New Horizon' to identify priorities to improve care and support for individuals with younger onset dementia.

The Summit's Keynote speaker Christian Bakker MSc from the Florence Centre for Specialised Care in Younger Onset Dementia in the Netherlands also visited WA, where he spoke about the move towards an integrated approach in service provisions for YOD.

A report summarising the actions and priorities of the summit can be found at www.fightdementia.org.au/younger-onset-dementia-a-new-horizon.

The YOD Key Worker program aims to build capacity in existing services to ensure that the needs of people with Younger Onset Dementia are being met in the local community, and improve coordination of services across agencies. We look forward to the selected WA staff joining our team.

#### **HOME AND COMMUNITY CARE AUDIT**

This year AAWA participated in two Quality Review audits through Home and Community Care (HAAC). HAAC fund many of the services we offer in AAWA including respite services, counselling, carer support groups and some education programs too. Audits occur every three years but this was the first audit under the new national Community Care Common Standards which is a more rigourous process. We are pleased to announce that we met all 18 outcomes in both the Perth and Mandurah audit. The Quality Reviewers were very positive about the services we offer. We also received great feedback from the carers involved on both days.

# DEVELOPING THE NEXT GENERATION OF HEALTH PROFESSIONALS

Alzheimer's Australia WA in collaboration with Health Workforce Australia have developed and implemented a 3 year Student Clinical Placement Program to promote the interest and quality of life of people living with dementia in WA. By providing WA's aged and health care students with information, support and opportunities for clinical placements in our evidence-based care and support programs, AAWA aims to have more qualified health professionals with a greater understanding of the needs of people living with dementia. These clinical learning opportunities create student placement programs that foster holistic. inter-disciplinary approaches to service within the organisations philosophy of person-centred care.

The project has seen improved student facilities at AAWA's offices including the development of a student learning area at the Mary Chester Centre, the inclusion of a student area in the new Hawthorn House building in Albany, the refurbishment of the AAWA memory van for health promotion activities and the development of webinar facilities for student supervision and distance learning.

AAWA is grateful for the support of Health Workforce Australia (a Commonwealth Government initiative).





An Australian Government Initiative

## THE EDEN ALTERNATIVE

AAWA is proud that we have the only two fully Eden Alternative registered community centres in the southern hemisphere thanks to the successful re-registration of both centres.

Since March 2008, both Hawthorn House – our Albany respite centre – and the Mary Chester Centre in Shenton Park have been registered with the Eden in OZ NZ principles. Hawthorn House is a first for Australasia to be registered with all ten principles, and MCC had been registered with five.

In April, both services applied for re-registration, with MCC applying for the remaining five principles. Both care environments impressed again, with Hawthorn House gaining re-registration for all ten principles and MCC gaining re-registration for five and securing the outstanding five to gain full Eden Alternative registration.

What this means for our clients is a holistic and relationship-based service that, among other things, provides purpose and companionship. Relationships are fostered in our centres, a sense of community is built and people have the opportunity to engage in occupations that are meaningful to them.



Variety and spontaneity is welcomed at the centres and decision making is left up to the club members wherever possible. The staff and volunteers are also respected to make decisions about the day-to-day running of the clubs.



## HAWTHORN HOUSE TO HAWTHORN HOMESTEAD

In February, AAWA held a ground breaking ceremony to officially mark the construction of our new home in the Great Southern.

The ceremony launched the building proceedings for our new Hawthorn House. For over 10 years Hawthorn House, situated in Seymour Street, has been a place of respite in Albany for people with dementia and their families. The new premises will be built on Henry Street amongst the pristine bushland which will be cared for by the Hawthorn House community.

Attending the launch was AAWA CEO Rhonda Parker, who welcomed Hon Colin Holt MLC, local elder Lester Coyne, representatives of funders, and donors to our new Albany home. Ms Parker noted particularly the support of the Western Australian Government for funding a large portion of the project through the Royalties for Regions program.

Being able to build this establishment enables us to provide a permanent home for dementia-care services in the Great Southern, ensuring continued service provision in this rapidly growing area of need. Hawthorn House is more than a best practice model of care – it is a meaningful, real community.

#### ADAPTING YOUR HOME

The Adapting Your Home free workshops commenced this year and are being well received by family, carers and friends.

The workshop has practical ideas, advice and tips to enhance the abilities of the person living with dementia. Ideas are explored on creating a sensory garden and how to spend meaningful time with the person around the home environment. Visual cues and prompts in your home are important to maintain and support the independence and well being of the person with dementia.

Participants gain understanding about how colour contrast and good lighting can optimise a person's vision, and what patterns and floor coverings to avoid. Each participant receives a full colour book with lots of practical and helpful tips, including a sensory planting guide and a room by room home safety check list.

For further details please contact Sheila Lapping on (08) 9388 2800

Or alternatively visit the DEEP website www.enablingenvironments.com.au





#### **CERT IV GRADUATION**

Alzheimer's Australia WA held its inaugural graduation night for the Cert IV In Dementia Practice in February which saw fourteen graduates conferred, with two recipients achieving their Statements of Attainment.

This unique course was developed by AAWA and is the only Cert IV qualification available under the VET system in Australia specifically for dementia care.

The course offers in depth training and education for people with experience in dementia care, providing participants with the ability to integrate current evidence-based knowledge and applies enhanced skills for effective dementia care. It is also seen as a pathway for those wishing to pursue leadership roles and be innovative and creative in their workplace.

The course is open to those working with people with dementia in various settings, including residential, community, acute and respite care. The course has been delivered in WA and Victoria and AAWA is currently working to extend its delivery in partnership with other Alzheimer's Australia organisations.

If you wish to know more about this qualification please contact: sheila.haywood@alzheimers.org.au

## ITA BUTTROSE AO, OBE AUSTRALIAN OF THE YEAR

Ita Buttrose, Alzheimer's Australia National President, was named Australian of the Year for her work in the media and as a champion of medical causes.



The year got off to a great start with the news that Alzheimer's Australia's National President was named the 2013 Australian of the Year. Ita Buttrose was honoured in recognition of her groundbreaking media career and the commitment she has made to championing medical education and health care.

Ita is the first female to be named Australian of the Year since Dr Fiona Wood was honoured in 2005, and joins the ranks of Dr Wood, plastic surgeon, 'spray-on skin' pioneer and one of the main figures in disaster management following the 2002 Bali bombings: Australian test cricket captains Allan Border, Steve Waugh and Mark Taylor; Australia's first Indigenous senator Neville Bonner; ophthalmologist and humanitarian Professor Fred Hollows; scientist and author Professor Tim Flannery; and winners of the Nobel Prize for Medicine, Professor Peter Doherty and Sir John Eccles.

In Alzheimer's Australia WA (AAWA) the news was met with great pride Ms Rhonda Parker, CEO, said receiving this accolade was a well-deserved honour for Ita

"We at AAWA are incredibly pleased and proud that Ita has received this honour," Rhonda said. "She has had an illustrious media career throughout the years, and has made use of her high profile position to champion improvements in the health and charity sector for those who don't have a voice to do so."

"Ita has had a long-standing involvement with us at Alzheimer's Australia and has helped us achieve so much since taking on the role of President."

"Ita has continued to draw public attention to the fight against dementia and the need for increased medical research and improvements in care and support for those living with memory loss. Her dedication to the cause has been inspirational," Ms Parker added.

Ita's dedication and commitment in leading Alzheimer's Australia's Fight Dementia Campaign contributed to the April 2012 announcement of the 'Living Longer. Living Better' aged care reform package put forward by Prime Minister Julia Gillard and Minister of Mental Health and Ageing Mark Butler, and to dementia being named a National Health Priority Area.

"Ita is an incredible woman with a big heart for the community. On behalf of AAWA, our members, and those affected by dementia and their families, I would like to congratulate Ita and thank her for her contribution to the cause and her commitment to our organisation."

"I have no doubt that we will continue to see much more from Ita, and we are proud to have her as the President of Alzheimer's Australia."



Ita Buttrose, Alzheimer's Australia President, with her 2013 Australian of the Year Award.

#### **DID YOU KNOW?**

AAWA have numerous support and educational resources, including:

- Carer Support Programs
- Library Resource Centre
- Dementia Hepline
- Workshops

- Public Lecture Series
- ArtTherapy Program
- Memory Van

#### **CARER SUPPORT GROUPS**

The Carer Support Team at AAWA facilitates numerous dementia-specific support groups for family carers. Currently, 23 Carer Support Groups operate throughout the Perth Metropolitan area and in various regional centres across WA. This wide array of groups from Connolly in the North, Mandurah in the South, and as far afield as Esperance and Albany ensures carers can provide valuable support to people all across WA. The aim of the Carer Support Program is to bring together a community of carers with a shared understanding of what it means to care for someone with dementia.

Each group meets monthly, for a two hour session, co-ordinated by trained group facilitators including Alzheimer's Australia WA staff and dedicated volunteers. Call our carer support team on 1800 100 500 for further information.



#### **VALENTINE'S DAY**

On Valentine's Day AAWA took to the streets of Perth to encourage the public to 'donate a memory'. This call to action was in aid of dementia research and for all those living with memory loss. Members of the public were encouraged to share their memory or message of love and hang it on our memory tree. Hundreds of memories were shared on the day and we thank everyone who showed their support on the day.

The love spread throughout AAWA with our Kalgoorlie branch collaborating with the Eastern Goldfields Community Centre who have been a consistent and supportive partner of the Goldfields Mobile Dementia Regional Team over many years.

Our Goldsfield team held a Valentine's Day Café of Love which was a celebration of love anthems form the 40's, 50's and 60's. Guests were encouraged to entertain by singing along to Slim Dusty, Lulu, Perry Como and many more.

The invitation to celebrate Valentine's was extended to the wider community too. Groups from local residential care facilities came along to dance and sing with us. All in all over 60 party goers from carers to care recipients celebrated with the Goldfields Mobile Dementia Team ensuring we were all feeling the love on Valentine's Day.



## THANK YOU TO OUR SUPPORTERS

#### THERE'S SO MUCH TO DO...

#### AND WE COULDN'T DO IT WITHOUT YOU



The Sir Cliff Richard Movement of Australia fan club (SCRMA) coordinated their Rock 'n' Roll fundraising dance night with Sir Cliff Richard's 'Reelin' and A-Rockin' Australian Tour.

Held the night before Sir Cliff Richard's Sandalford concert, at the Austria Club of WA, the dance night was a huge success with over 250 people reelin' and a-rockin' to live music by the Shad Lads and Heart & Soul.

SCRMA is the official, not-for-profit fan club for Australian fans and provides a formal line of communication for The Cliff Richard Organisation to members.

Led by dedicated President Lesley Reti the fan club raised an amazing \$20,000 for AAWA.

The significant funds raised were achieved not only through the dance night, but also by fan club members selling signed memorabilia at concerts. An eBay auction of Sir Cliff's signed shoes, a raffle for a meet and greet with Cliff and numerous garage sales, also

contributed to funds. The most momentous fundraiser was a raffle to meet and greet Sir Cliff before his Perth concert, which was a dream come true for the two lucky winners.

As a result of Lesley's hard work, AAWA CEO Rhonda Parker was given the opportunity to be presented with a cheque by Sir Cliff Richard himself.

A big "Thank You" to everyone who contributed and supported this effort to raise funds for AAWA.

#### **GALA CHARITY BALL**

CONGRATULATIONS to the Morley Family Practice on their Gala Charity Ball held at the Laguna Vento Social Club on the 16th March in celebration of their 20th year. They raised an incredible \$15,000 in support of AAWA. A big thank you to Dr Vevil & Mrs Miriam De Kauwe and to everyone who contributed to make the night such a huge success.







#### **BRING IT TO THE TABLE WA**

Alzheimer's Australia WA (AAWA) held a successful media launch for Bring it to the Table at the beginning of June where 10 VIP guests enjoyed a seafood feast created by former MasterChef contestant Josh Catalano. Under the watchful eye of Josh, 96FM's Blackers, Carmen & Fitzi and Channel Ten's news reporter Caty Price cooked up some culinary delights enjoyed by all, including special guest Jessica Bratich, West Coast Eagles player Andrew Embley and celebrity butcher Vince Garreffa. As there is no such thing as a free lunch, the VIP's were encouraged to donate what they thought the meal was worth. Special thanks to Sophie in Taste Budds Cooking Studio for hosting the event.

The AAWA exciting culinary fundraising event Bring it to the Table will run throughout June and July and aims to bring the fight against dementia to the tables of all West Australian's. This social fundraiser is a fantastic way to encourage the conversation about dementia with friends and family in a relaxed setting; over a cuppa or around the dinner table.

Funds raised locally through this event will go into funding essential dementia care services delivered to the thousands of West Australian families living with memory loss.

We have already received a great response, with hosts holding a wide range of events from high teas, Bollywood nights, pot luck & pool and long table lunches.

You can host a work breakfast or indoor picnic, the possibilities are endless. Get creative and have guests donate to eat your culinary creations, host a retro game night, movie matinee, sports afternoon or have a cook off.

WA's highest fundraising host has the chance to win a fully catered dinner for eight, cooked in their own home by MasterChef contestant Josh Catalano. Our Top 10 fundraisers will receive a copy of Saporito! My Kitchen Rules, Daniela and Stefania cook book and all hosts who raise over \$150 will receive an exclusive *Bring it to the Table* Shopping Bag.





AAWA CEO Ms Rhonda Parker pictured with Josh Catalano and the 96FM breakfast team.

You can get involved by simply logging onto **www.bringittothetable.com.au**, to register your event, set your fundraising target and download the host pack. The pack includes a host hints and tips sheet with ideas for events, invitations, promotional posters and fact sheets.

#### RUN FOR ALZHEIMER'S AUSTRALIA WA

The inaugural Suncorp Bank Freo Fun Run was held on Sunday 11th November 2012. A congratulation to Izzy Philip who raised a phenomenal \$4,590. At only 16 years old Izzy was Suncorp Bank Freo fun runs highest individual fundraiser.

The fun run will be held in November/December this year, and we encourage you to get involved and run against dementia.

Like us on Facebook for updates on events and to check out who is supporting AAWA.



## CHAOS AND CONTAINMENT

Artist *Free Will* explored the mindbrain paradox in her 'Chaos and Containment' exhibition as part of the Perth Fringe World festival during February. In the Peoples' Choice poll run by the West Australian online 'Chaos and Containment' topped the Visual Arts category with 41% of the vote. 5% of painting sales were donated to AAWA. Thank you 'Free Will' for your generous donation.



### **DRIVING AND DEMENTIA**



#### AAWA HON. MEDICAL DIRECTOR DR SEAN MAHER

The issue of driving for a person with dementia can be very contentious and cause enormous anxiety and stress for relatives. However, some open discussion and forward planning to agree when it's time to "hang up the keys" will prevent this in most instances.

Driving is a complex skill but one that is well rehearsed. Thus, many people with early or mild dementia may be capable of driving safely. Driving requires fast reactions, intact attention, concentration, judgement, spatial awareness and memory. Unfortunately, all of these skills tend to decline as dementia progresses. Additionally, ageing may bring other problems that affect driving such as poor vision, neurological problems like Parkinson's Disease or arthritis that limits movements of the neck or limbs. It is a legal requirement for individuals to report any medical condition that they have which may impair driving skills to the Department of Transport (DoT). Failure to report can result in loss of third party and private vehicle insurance in the event of an accident. People aged 80 and over must have a medical certificate completed each year to state that they are medically fit to drive.

As dementia progresses, it is inevitable that driving will become unsafe. Every person will be different in terms of the degree of impairment of different skills and when safe driving may be compromised. A person who has significant problems with spatial skills or judgement will be much less safe than someone who only has some problems with short-term memory.

Routine psychology tests do not reliably predict who will have problems with driving in people with mild dementia. People who perform poorly on these tests, however, are generally unsafe to

drive. For example, someone who cannot draw a clock-face tends to perform poorly on driving tests; but being able to draw one is no guarantee of being safe.

The best test of driving skills is made by an occupational therapist who specialises in driver assessment. This involves an initial screen for physical and cognitive impairments including vision, perceptual skills, reaction times, strength and coordination. An on-the-road test is then performed which gives the best prediction of future driving performance. A report is written which might recommend that the person is relatively safe; or needs some further training; or may need some modifications to their car; or that they may no longer drive safely and that stopping driving would be the safest option. Referrals to a driving OT must be made by a health professional.

Knowing when driving may be unsafe can be difficult but being a passenger is often quite revealing. Seeing poor judgement in lane changing, stopping distance, speeding, recognising road signs and confusing brake and accelerator pedals are warnings that driving is now unsafe. Other indicators are new dents and scrapes on the car, getting lost, short trips taking far longer than they should and minor accidents or traffic infringements.

Many people with dementia recognise that their skills are not what they were and begin to restrict their driving by avoiding challenging conditions, like city or freeway traffic, nights or rain. These people are generally content to give up driving. Often this occurs when they are faced with having to undertake a mandatory on-the-road test, which occurs at age 85 and then yearly thereafter. Many choose not to do the test and relinquish their licence.

Unfortunately, not everyone gives up gracefully! Some people with dementia lack the insight that their driving has become unsafe and do not accept or do not remember that they have problems. Many will say, "I have driven safely all my life. I've never had an accident or a fine!" Discussions about giving up driving may become quickly heated and the threat to independence and perceived loss of dignity outweigh any rational notions about personal or public safety.

A calm and sensitive negotiation together with other family members acknowledging the feelings of the person, pledges of support with offers of regular transport, knowledge of community transport options including taxi vouchers and volunteers, can sometimes result in agreement to stop driving.

Planning in advance for the time when driving is impaired in a similar way to completing an enduring power of attorney should be undertaken for everyone with a new diagnosis of dementia. The person with dementia signs a statement acknowledging that they have dementia and that they understand that they will need to stop driving at some point. They choose several people whom they trust to give them the advice when it's time to stop driving. Many examples can be found on the internet. These have no legal weight but can be helpful in persuading someone who lacks insight that they once agreed with this notion.

What to do about someone who insists on driving who may not be safe? A referral to a driving OT will result in the best assessment of driving skills. If the person refuses, a doctor may write to the DoT noting that the person has dementia and that driving skills may be impaired. They can recommend that the person have an on-the-road test and that their licence be removed if they fail. A request to attend for a driving test usually follows within a short time! The DoT will then determine whether the person is safe to drive.

Some people will continue to drive despite losing their licence. Disabling their car, or removing keys may be needed. Relatives may be stressed by the need to keep their relative safe whilst wanting to avoid conflict.

For many, giving up driving is done phlegmatically, but with some regret. For others, it can be an emotionally charged and difficult episode. Education and future planning in the early stages may avoid this.

#### **KEY POINTS:**

Individuals must report any condition that may impair driving to the Department of Transport, including dementia.

A general practitioner or specialist can assist in assessing fitness to drive, but referral to a driver OccupationalTherapist may be needed.

Unsafe drivers may need to be reported to the Department of Transport, if they won't agree to give up driving.

Advance planning in the early stages may avoid a prolonged battle over stopping driving.

#### FRIENDS IN HARMONY

Our AAWA Choir resumed this year with six new members, one of whom plays the piano.....what a coup! For those unfamiliar with our "Friends in Harmony" choir they are celebrating their 5th year of singing together, enjoying each other's company (and afternoon tea). They meet every Thursday afternoon for 2 hours at the AAWA Shenton Park venue. Their repertoire includes a wide range of popular songs, incorporating light classics, show tunes, fun songs and some with a meaning.

The choir has performed at numerous key events such as our Annual Tea Dances in the Government House Ballroom, joined a 200 voice massed choir in Winthrop Hall at UWA, twice in the Perth Town Hall and entertained guests from the balcony at Shenton Park during our 30th anniversary celebrations last year, as well as on many other occassions.

The only pre-requisite is a love of singing and having fun. Being a choir member is a most beneficial, marvellous and effective way of doing something together. We encourage people with dementia who are living in the community, along with their family/carer to join us. If you know of someone who would like to join us, please call the office and leave a message for our Choir leader Dot. We look forward to meeting you.



#### MARY CHESTER CLUB 19TH ANNUAL TEA DANCE

Government House Ballroom has once again been booked for this year's 19th Annual Mary Chester Tea Dance. This social event will take place on Tuesday 6th August 2013 at 11.30am – 2.30pm. Invitations will be mailed out the second week in Julyearly booking is suggested as places are limited. We are delighted to say that His Excellency Mr Malcolm

McCusker AC CVO QC, Governor of Western Australia, and Mrs McCusker will be in attendance again this year. Woodside Petroleum staff members have once again committed their support of this event and we are most appreciative of their support.

## DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICES

The Dementia Behaviour Management Advisory Services (DBMAS) is funded by the Australian Federal Government.

The focus of the DBMAS program is to support the carers of people living with dementia when their behaviour is impacting on their care. In WA, we are the only organisation to provide this program.

DBMAS is a state-wide service with a team of health professionals including Registered Nurses, Mental Health Nurses and Occupational Therapists who assist carers by completing assessments, short term case management and providing education. Following the *Living Longer. Living Better* announcement earlier this year funding was increased for DBMAS to expand services into the acute and primary health care sectors.

The aim of this program will be to assist care workers and health professionals in these settings to better support people living with dementia. This will assist people to continue to be cared for in the community, help ensure that the length of hospital stays are reduced and that there are opportunities for people to return to and remain in their own homes.

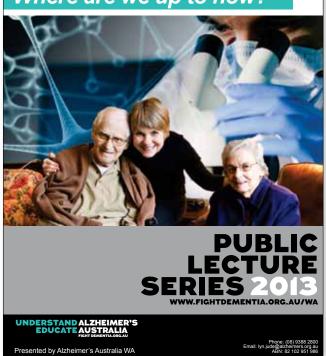
It is anticipated that the expansion of DBMAS will ultimately improve the quality of life of the person with dementia and reduce carer burden and the overall costs of care.



### **UPCOMING EVENTS**

## DEMENTIA Care & Cure

Where are we up to now?



## THE CARE & THE CURE - WHERE ARE WE UP TO NOW? PUBLIC LECTURE SERIES 2013

AAWA has created the public lecture series – The Care & The Cure – Where are we up to now? which runs throughout 2013. The public lecture series aims to increase the conversation about dementia by bringing the most current information and debate to the community. Leading international and national researchers and practitioners, and Alzheimer's Australia National President and Australian of the Year 2013 Ita Buttrose will be delving into topics such as the assessment and treatment of dementia, dementia care, and the importance of risk reduction. All lectures will be held at The University Club, UWA. Crawley, WA.

#### Still to come:

Professor Julian Hughes	4 July
Dr Cameron Camp	3 September
Associate Professor Sue Kurrle	19 September
Ms Ita Buttrose AO, OBE	5 November

**To register:** Call Lyn Jude on 93882800, email lyn.jude@alzheimers.org.au or visit www.fightdementia.org.au/wa Admission is free for AAWA members, \$15 for non-members.

#### THE AAWA MEMORY VAN

The AAWA memory van has been refurbished and is about to hit the road! The refurbishment has been generously funded by Health Workforce Australia, an Australian Government initiative. The memory van attends community events throughout WA providing information about brain health and memory loss. If you would like the memory van to visit your event call Heather on 93882800.



#### LOVE, LOSS AND LAUGHTER

#### seeing dementia differently

AAWA will be bringing international art exhibition Love, Loss and Laughter to WA this August. The exhibition illustrates the stories of those who are living with dementia through images, conveying the essential humanity of people with dementia. Photographer and sociologist Cathy Greenblat offers a new vision of dementia and care, challenging the view that people with age-related cognitive challenges are "lost", "empty shells", or "no longer here". The exhibit is a collaborative endeavour with Alzheimer's Disease International.

TALKING ABOUT ALZHEIMER'S ACROSS AUSTRALIA

#### LOVE, LOSS AND LAUGHTER

seeing dementia differently

#### **Cathy Greenblat**

International photographic exhibition visiting Perth from 8 - 27 August at Vincent library, Loftus Street, Leederville, 6007

exhibition.fightdementia.org.au



## **YOU CAN MAKE A DIFFERENCE**

Donate, bequeath a gift in your will or fundraise through activities. No matter how you do it, supporting AAWA will help thousands of people.

#### **BECOME A** COMMUNITY **FUNDRAISER**

Organise your own fundraising event or take on a personal challenge to raise vital funds. Hold a quiz night, host a dinner or take part in a fun run. You can even set up vou own online fundraising page. Just ask one of our friendly fundraising team and find out how by calling (08) 9388 2800.

#### **SHARE YOUR STORY**

You can share your story - be it funny, sad, empowering or inspirational - and help raise awareness of dementia in the community.

#### **BEQUEST**

#### Make a bequest and support the future.

Leaving a gift in your will to Alzheimer's Australia WA will help make a meaningful, positive and lasting difference to the lives of people with dementia, their family and carers. Beguests enable us to transform the lives of people with dementia. They ensure ongoing financial support of our programs and help us to continue to provide services and education for people with dementia, their families and carers.

#### **IN LIEU OF GIFTS**

Birthdays! Weddings! Anniversaries! Celebrate your special occasion and encourage your guests to make a donation to Alzheimer's Australia WA.

#### **GET INVOLVED**

Join in the fun and take part in one of our planned annual events held through out the year. You could even donate your time and volunteer to help out on the day or in the lead up to the event.

To find out more on how you can make a difference visit us at www.fightdementia.org.au/wa or call (08) 9388 2800.

#### IN MEMORIAM

A donation made in memory of a loved one is a unique and poignant way to pay tribute to them. In memoriam envelopes can be made available for family and friends to make a donation.

#### FIND OUT HOW TO MAKE DONATIONS OR TO SPEAK TO ONE OF **OUR FRIENDLY FUNDRAISING TEAM**

Phone 9388 2800 or email wa.event@alzheimers.org.au

#### **CULTURALLY AND** LINGUISTICALLY **DIVERSE** COMMUNITIES



**Western Australia is one of the most** ethnically diverse of all the Australian states - with people from over 200 different countries living, working and/ or studying here, and approximately 170 different languages being spoken.

In order to identify ways in which our organisation can best meet the needs of people with dementia from Culturally and Linguistically Diverse Communities (CaLD) backgrounds, we now have a Project Officer, Multicultural Communities - Linda Grenade. This role is one of a number of Service Access Liaison Officer (SALO) positions that have been established around Australia with the aim of improving access to services for specific needs groups and is funded via the Federal Government's National Dementia Support Program. SALO project staff are also based in our Albany and Kalgoorlie offices where the primary focus is people with dementia from Aboriginal and Torres Strait Islander backgrounds.

A key achievement since Linda started the role in September 2012 has been the development of a formal partnership agreement with Chung Wah Community and Aged Care. This agreement outlines ways in which the two organisations will work together to identify staff and volunteer training needs, and to raise knowledge and understanding of dementia within the broader Chinese, Vietnamese and other Asian communities.

Linda is also working closely with the Italian community via the Italo-Australian Welfare and Cultural Centre, with a program of community awareness raising presentations now in place. Discussions are also underway to establish a 'new look' dementia support group for Italian carers.

#### **ALZHEIMER'S AUSTRALIA WA LTD**

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Since 1982, Alzheimer's Australia WA has been working to improve the lives of people with dementia and their families. Today, we are the peak dementia organisation providing leadership in care, advocacy and education to people living with dementia and the health and aged care industry.

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#### Disclaimer

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