A good death is our right - consumers tell MPs

Federation Square public lecture
14 September

Don't miss earlybird rate for National Dementia Conference
Welcome to the spring edition of Memory Matters. We are now more than two thirds of the way through the year, and what an exciting year it has been.

Twice yearly, I present to Members of Parliament during our Parliamentary Friends of Dementia meeting, held at the Parliament of Victoria. Our first meeting for the year was held in June. The subject was a submission that we made to a Parliamentary discussion paper on Voluntary Assisted Dying. We made the submission on behalf of consumers. You may read more about the June meeting on page five.

Our second meeting of the year was held on 10 August. It focused on people living with younger onset dementia, their carers and the National Disability Insurance Scheme. These meetings are an important avenue for us to articulate the views of people living with dementia, their families and carers.

As September approaches, Dementia Awareness Month is almost upon us. Every year, it is a delight to see members of our team, volunteers, people living with dementia, their families and carers, and members of the general public help us raise awareness about dementia. I’m looking forward to seeing many of you at our events across Victoria. This year we are continuing last year’s theme, ‘You are not alone’ - a sentiment that acknowledges dementia as a condition that impacts everyone in some way.

During the month, Professor Steven Sabat will deliver a series of public lectures about dementia. Prof Sabat is Professor Emeritus of Psychology at Georgetown University, USA. More information about the Melbourne lecture is on page three.

Dementia Awareness Month will see a host of informative and exciting events take place across the state. We aim to generate widespread awareness of dementia, to create an increased understanding of the condition and to elevate the conversation about dementia to the broader community. More than 70 per cent of Australians admit they know very little about dementia. That’s why initiatives such as Dementia Awareness Month are so important.

The next step towards unification will be a Special Meeting for members on Wednesday 30 August inviting financial members to vote. Similar meetings will occur over the next few weeks around Australia. The aim of unification is to improve the overall effectiveness and agility to better position us to meet the needs of people with dementia, their families and carers.

A unified organisation will continue to deliver the range of services and functions currently provided by the state and territory organisations. Members will have received an invitation to the meeting in the mail.

Finally, I would like to take this opportunity to thank and acknowledge staff who are celebrating five years of service with Alzheimer’s Australia Vic. They are Vincent Poisson, Program Manager, Rural Services; Narelle Cullen, Administration Officer; and Karen Gray, Program Manager, Rural Services. Congratulations to you all and thank you for your dedication and the contribution that you have made.

Leanne Wenig
Acting CEO

Cover Jane Sandow, cares for her husband who is living with dementia. She spoke about their experience at the recent Parliamentary Friends of Dementia meeting. See ‘A good death is our right – consumers call for Voluntary Assisted Dying access’, page five.

Photo Arsineh Houspian
Dementia Awareness Month 2017

As Dementia Awareness Month 2017 is almost upon us, we are excited to share details of the calendar of events planned across Victoria this September.

The theme this year is ‘You are not alone’, a continuation of the theme from 2016, which focuses on dementia as a condition that impacts everyone. Consequently, our events and awareness-raising activities are aimed at a broad and diverse audience.

People living with dementia, their families, personal and professional carers, and members of the public are all invited to get involved with Dementia Awareness Month in whatever way they can. You can attend an event or raise awareness amongst your own communities and networks by sharing Alzheimer’s Australia Vic content on social media. All involvement is welcomed and encouraged. Let’s do this together!

This year there will be events in Mildura, Horsham, Bendigo, Geelong, Shepparton and Warrnambool to name just a few regional locations. There will also be events in metropolitan Melbourne, including a public lecture entitled Forget Memory Loss - What About the Person? presented by international expert and author Professor Steven Sabat of Georgetown University, USA. This event will take place on Thursday 14 September at ZINC in Federation Square.

You will find the Victorian Dementia Awareness Month calendar of events in the middle of this publication and we would be delighted if you would help spread the word by removing it and putting it on display in your home, workplace or any other location where you think people might be interested.

Follow Alzheimer’s Australia Vic on Twitter, Facebook, LinkedIn and Instagram, or search #dementia2017 for the latest updates.

Sign up for our monthly electronic newsletter at bit.ly/vicenewssub

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International experts set to ‘be the change’ at national dementia conference

Naomi Feil, a social worker, developed Validation in the 1960s and 1970s as she was dissatisfied with traditional methods of support for people living with dementia. Validation emphasises empathy and listening.

‘When you can step into someone else’s shoes and see through their eyes, they can understand why the person behaves as they do,’ Ms Feil said.

Ms Feil is one of the impressive line-up of international and local speakers at the forthcoming 17th Alzheimer’s Australia Biennial National Dementia Conference in Melbourne. She will present a day-long pre-conference workshop on Validation and a keynote address and workshop during the conference.

Other international speakers joining Ms Feil are Dr Cameron Camp, Montessori in dementia care expert, Prof Dawn Brooker, Director of the University of Worcester’s Association for Dementia Studies, and Prof Linda Clare who leads the Centre for Research in Ageing and Cognitive Health at the University of Exeter.

Also on the line-up will be Kate Swaffer, the 2017 South Australian of the Year, and an activist and author. Kate is living with dementia. She will be joined by consumer advocate and former top scientist Christine Bryden. Christine was just 46 when diagnosed with dementia in 1995. Dr Alan Duffy, astrophysicist, media personality and Research Fellow at Swinburne University, will be master of ceremonies.

During the conference, delegates will be encouraged to ‘be the change’ that improves quality of life and support for people living with dementia, their families and carers.

Leanne Wenig, Acting CEO Alzheimer’s Australia Vic and conference host, said that in a time of unprecedented change in dementia and aged care, the conference will provide a unique opportunity for people from across the world to come together and share their insights and experiences.

‘We are looking forward to welcoming speakers and delegates from the aged and health care sectors; clinical and social researchers; those working with new technologies; architects; designers; people living with dementia; carers and community leaders. The goal of our exciting program of practical and interactive sessions is to encourage attendees to consider how they can “be the change” in their own spheres of influence,’ Ms Wenig said.

The conference will take place in Melbourne between 17 and 20 October 2017 at the Melbourne Convention and Exhibition Centre. Early bird registrations close on 31 August 2017 and further information can be found at dementia2017.org

Enquiries can be emailed to info@dementia2017.org or call 03 9682 0500. All are welcome to join the online conversation using #BeTheChange2017

Assistance is available for people living with dementia, their families and carers, to help with travel, registration and accommodation. For more information, see page 15, ‘Funding to attend the national dementia conference still available.’
A good death is our right – consumers call for Voluntary Assisted Dying access

June’s Parliamentary Friends of Dementia event focused on an Alzheimer’s Australia Vic submission to a discussion paper on Voluntary Assisted Dying.

MPs including co-convenors Gabrielle Williams MP, Parliamentary Secretary for Health, Parliamentary Secretary for Carers and Volunteers; and Emma Kealy MP, Shadow Minister for Senior Victorians and Shadow Minister for Mental Health; gathered to hear consumers talk about the importance of people living with dementia not being excluded from having the right to choose a dignified death if voluntary assisted dying is legislated in Victoria.

Leanne Wenig, Acting CEO Alzheimer’s Australia Vic said if this legislation was passed, excluding people living with dementia from being able to seek physician-assisted death would deny them the right to make their own choices.

‘Many people living with dementia have the capacity to make competent, informed and considered decisions about aspects of their life. Consumers have told us they would like to see eligibility defined in a way that does not discriminate against people with incurable, degenerative illnesses,’ Ms Wenig said.

Jane Sando, whose husband, Rob Trinca, is living with dementia, was among the carers who spoke.

‘We do know that people dying of end stage dementia very often suffer greatly,’ Ms Sando said. ‘Much of the fear associated with dementia is the fear of a lack of control over suffering. We strongly urge for the assisted dying laws to be inclusive of people with dementia. This means giving people like Rob a chance to influence end of life in advance, when there is still cognitive capacity to do so.’

In the submission to the Parliamentary Committee developing the discussion paper on Voluntary Assisted Dying, Victorian consumers expressed the view that people with degenerative disorders should have the right to make an enduring request in an advance care plan.

‘Consumers believe that family members should be included in the assisted dying decision-making with the person’s consent and with proper protections for the person with a diagnosis of dementia. It should not be assumed that all people with a diagnosis of dementia are unable to make important decisions about their life.

‘Our organisation is neither for nor against assisted dying. We do advocate, however, that all individuals should have a choice. With appropriately trained doctors a person with dementia’s rights in relation to the proposed Voluntary Assisted Dying legislation can and should be upheld,’ Ms Wenig said.

Final Parliamentary report

Since the meeting, the final report of the Ministerial Advisory Panel on Voluntary Assisted Dying, released on 21 July, has recommended that a person must have decision-making capacity throughout the voluntary assisted dying process. The report can be accessed at bitly.com/advisoryrep.

Alzheimer’s Australia Vic submitted A good death is my right to the Parliamentary Committee preparing the Voluntary Assisted Dying discussion paper on 10 April 2017. It can be read in full at vic.fightdementia.org.au/vic/publications/submissions.
Volunteer and police veteran recognised in Queen’s Birthday Honours List

Alzheimer’s Australia Vic volunteer Ray Morgan OAM has been recognised with an Order of Australia Medal in the Queen’s Birthday 2017 Honours List, which recognises a diverse range of contributions and service across all fields.

Mr Morgan, a former Victoria Police Superintendent, was diagnosed with younger onset dementia four years ago. He lives at Hastings on the Mornington Peninsula and, since his diagnosis, has willingly shared his experience of living with dementia in the hope that he can help others and raise community awareness about the condition.

As a volunteer consumer advocate with Alzheimer’s Australia Vic, Mr Morgan has spoken about his disease in a variety of forums, assisted with making documentaries and makes a regular contribution to Victoria Police’s Community Encounters Program for new recruits. The program, run at the Victoria Police Academy, brings together recruits and community volunteers from diverse backgrounds to discuss their safety and security needs.

Mr Morgan paid tribute to the people who have supported him since he was diagnosed.

‘It’s the Australian way,’ Mr Morgan said. ‘Australia is very much a country of mates. We look after each other. Since I was diagnosed, I have found the support that I have received has been amazing. In this country, we are smart enough to realise that if we keep people in the community, and keep them engaging with the world, then that will keep them going.’

Maggie Beer enjoys The Virtual Forest™

The delightful Maggie Beer AM joined Alzheimer’s Australia Vic during a recent demonstration in Adelaide of its The Virtual Forest™ technology.

By projecting interactive landscapes onto a big screen, the technology can take a person with dementia into a virtual environment where they can experience awe, giggles and amazement. With movements detected by Microsoft Kinect technology, the person can easily instigate changes in the scenery such as butterflies fluttering through flowers, a row boat floating around a pond or a family of ducks splashing about in the water.

The technology was developed by Alzheimer’s Australia Vic and incorporated feedback from residents and staff of major sponsor Lifeview Residential Care.

The Virtual Forest™ is available for purchase and use in aged care homes, hospitals and healthcare centres. For hardware, software specifications and pricing packages visit vic.fightdementia.org.au/the-virtual-forest or call the National Dementia Helpline on 1800 100 500.

New dementia learning website launched

The Learning & Development team at Alzheimer’s Australia Vic recently launched its new online Dementia Learning Hub, to provide a single point of access for all things relating to dementia education.

Dr David Sykes, General Manager Learning & Development Alzheimer’s Australia Vic, said, ‘We understand that each organisation and individual has different needs when it comes to dementia education in these ever-changing times, and invite you to explore our diverse offerings, all of which are now accessible via this one central site.’

By signing up for an annual professional development subscription at a fee of just $60, users can access unlimited online courses, videos, library resources and podcasts.

For more information, or to view the site for yourself, visit dementialearning.org.au
Consumers tell their stories on ABC’s Four Corners

Three families – one in Geelong and two in Melbourne – recently shared their stories of living with dementia with an audience of half a million Australians.

The ABC’s Four Corners program, Forget Me Not, aired on Monday 10 July. It featured Mandy and Garry Lovell, Heather and Brian Fischer, and Suzie O’Sullivan.

The program gave a consumer perspective, focusing on Garry’s experience living with younger onset dementia, Suzie’s experiences living with frontotemporal dementia, and Brian’s experiences living with Alzheimer’s disease.

The reporter’s aim was not to present the program from her point of view, but to allow the participants to speak for themselves.

Mandy Lovell spoke about caring for her husband, Garry, 54, who has been living with younger onset Alzheimer’s disease for about seven years. His mother and other close family members also had the rare form of the disease, which is passed down through families. He now lives in residential care. Garry was diagnosed when he was 48, having undergone a gene test in 2001, which indicated that he was likely to develop the disease.

‘It is really quite tiring and exhausting, and it is very, very difficult to watch the process of this disease’ said wife Mandy, 45.

It took 11 years for Brian Fischer, 79, to be diagnosed. He said that he did not believe the diagnosis, thinking dementia only happened to ‘old’ people.

Brian’s wife, Heather, said the diagnosis came as a relief.

‘We came out of there feeling a million dollars, which was really quite silly, but it was like we can do something now,’ she said.

Suzie O’ Sullivan, 58, from Geelong, was diagnosed with frontotemporal dementia in June last year.

‘About three years ago, I started to notice little things,’ she says. ‘Language - just occasionally, you know, words weren’t there. At work, my job as a receptionist, I had trouble with new technology.

‘I went to a GP and the first time it was very much pointed out to me “Oh that is all just symptoms of menopause.” It was getting on towards two years.

‘Finally, I was given a referral to the Cognitive Dementia and Memory Service but I call it the memory clinic at Barwon Health here in Geelong.’

Frontotemporal dementia affects language and behaviour. Suzie said that she wondered if she would have received a diagnosis if she had not been referred to the memory clinic.

‘I guess when you do get diagnosed it’s a shock, but you also then have to think well, it is a positive,’ she said. ‘If I’m going to have it, I know what it is and I’ll deal with it my way.’

Alzheimer’s Australia Vic would like to thank the participants and its staff members for participating in the program.
NEWS IN BRIEF

Seniors with dementia at greater risk of financial abuse

On World Elder Abuse Awareness Day in June, Alzheimer’s Australia Vic added its voice to those from across the globe in drawing attention to the incidence of financial abuse amongst older people, particularly those with dementia.

Older people living with dementia are increasingly vulnerable to financial abuse and exploitation as dementia progresses, due to the gradual loss of their ability and capacity to manage their financial affairs.

Leanne Wenig, Alzheimer’s Australia Vic Acting CEO, said World Elder Abuse Awareness Day was a timely opportunity to remind the public that financial abuse of people with dementia can occur, with victims often knowing their perpetrator.

‘There are many signs and behaviours to look out for that could indicate someone with dementia is being financially abused, most notably fear, stress and anxiety,’ Ms Wenig said.

‘People should also be alert to other forms of abuse, such as physical, sexual and psychological abuse and neglect, which can occur alongside financial abuse.’

The Alzheimer’s Australia resource Preventing Financial Abuse of People with Dementia provides information on the red flags of financial abuse, how you can protect yourself or the person you care for from being financially abused, and who to contact if you or a loved one have been a victim of it.

The resource can be accessed at bit.ly/AANSWelderabuse

Epworth HealthCare seeks volunteers for insomnia research

The Epworth HealthCare Clinical Trials Department is coordinating a research study with adults aged between 50 and 90, with the aim of improving insomnia in people with mild to moderate Alzheimer’s disease.

If you are interested in participating and would like more information about this clinical research study, please contact Julie Cook at julie.cook@epworth.org.au or 03 9805 4295.

Focus group participants wanted at Deakin University

Deakin University is seeking people living with mild dementia who are older than 60 and able to speak and read English, and people who provide unpaid care to a family member or a friend who is living with dementia.

Participants will take part in a focus group. The aim is to discuss the appropriateness of questionnaires that are used to assess the quality of life in individuals living with dementia. The focus group will last 60 to 90 minutes.

Participation in this study is voluntary and responses will be kept confidential. All participants will be compensated for their time and travel.

The focus groups will be held in locations around Melbourne and Geelong on various dates. For further information, phone Lidia Engel or Jessica Bucholc on 03 9246 8573 or email dementia@deakin.edu.au
Enabling EDIE™ showcased to family carers

The Carers Big Day Out, hosted by Melton City Council, gave carers an opportunity to come together and enjoy a day of fun and relaxation with workshops including woodwork, flower arranging, massage, cookery and laughing yoga.

The Enabling EDIE™ technology offered attendees the chance to walk in the shoes of a person with dementia and provided insight into their day-to-day lived experience. The aim of Enabling EDIE™ is to improve empathy for and communication with the person living with dementia.

If you or someone you know is caring for someone living with dementia and would like to experience Enabling EDIE™, contact the National Dementia Helpline on 1800 100 500 for more information.

NAIDOC Week celebration

Each July, NAIDOC Week celebrates Aboriginal and Torres Strait Islander history, culture and achievements, and recognises the contributions of Indigenous Australians to our country. A recent celebration took place at Wathaurong Aboriginal Co-operative in Geelong, and was attended by Alzheimer’s Australia Vic staff members Karen Gray, Program Manager Rural Services, and Nola Wood, Counsellor.

Members of the local community braved the cold and wet conditions to hear a welcome to country given by Aunty Judy Dalton. The celebration included a smoking ceremony, the raising of the flags, and a performance by three musicians playing didgeridoos. Guests then moved to the shelter of a marquee for the presentation of the NAIDOC Week awards to community and staff.

Did you know Alzheimer’s Australia Vic has a variety of dementia-related resources specifically developed for Aboriginal and Torres Strait Islander people? You can view them at bit.ly/vicATSIresources

Understanding Dementia – free online course

The Wicking Dementia Research and Education Centre at the University of Tasmania offers a free online, nine-week course, the Understanding Dementia MOOC (massive open online course).

More than 90,000 participants have done the course. It is suitable for everyone - whether you know and care for someone who is living with dementia; whether you are living with dementia; or perhaps you work in health or aged care. The course has no exams or assignments and there is a certificate of completion available.

Enrol at mooc.utas.edu.au/landing/alzheimers

The course opens on 25 July and enrolments will be accepted until 18 August 2017.
Forget memory loss - what about the person?

International speaker Prof Steven Sabat USA

ZINC at Federation Square off Princes Walk
9:00am Registration | 9:30-11:30am Lecture

People living with dementia are actively breaking down stereotypes while being supported and empowered to take control of their lives. Prof Steven Sabat says that people with dementia can, in fact, make new memories and they therefore should not be thought of as having ‘memory loss’.

BOOKINGS ESSENTIAL by 7 September

Register at publiclecture2017.eventbrite.com.au
FREE for members | $15 for non-members includes BONUS one year membership
For more information call 9816 5784 email dementiaawareness.vic@alzheimers.org.au

September 21

DANDENONG
The South East Culturally and Linguistically Diverse Network meeting
9:30am - 11:30am
DHS Centrelink, 27 Robinson Road

RICHMOND
Thinko! Trivia Night
6:00pm for 6:30pm trivia start
The Eureka Hotel, 1 Church Street

GEELONG
Dementia and your community
1:00pm - 2:00pm Oration
2:00pm - 3:30pm Information and activities
Geelong West Town Hall, 192 Princes Street


eventbrite.com.au

## September 21

**MILDURA**
Dash for dementia Community fun run
8:00am - 11:00am $7
Calling all super heroes! Join in the fun to raise awareness and support Alzheimer’s Australia Vic. Event organised by a community fundraiser. For registration and prices: trybooking.com/296630 or dash4dementia@gmail.com

**MORWELL**
Through their own eyes Photographic exhibition. Images of treasured items taken by people with early dementia. Open to the public For more information 9816 5784
9:00am - 5:00pm daily Latrobe Community Health Service Foyer, 81-87 Buckley Street

**HORSHAM**
Dementia. You are not alone
1:30pm - 5:00pm Expo 3:00pm - 4:00pm Lecture
9:00am - 5:00pm Daily Expo Latrobe Community Health Service Foyer, 1 Church Street
Register online: horsham2017.eventbrite.com.au
For more information 9816 5784

**NEWTOWN**
Driving and dementia
1:30pm - 3:30pm Alzheimer’s Australia Vic 318 Pakington Street
A free session that will help family and friends support a person living with dementia to balance their independence and safety, while allowing them to stay active, mobile and socially connected.

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**Sunday 3**

Father’s Day

**(Mon-Fri 4-8**

**Wednesday 6**

**Thursday 14**

**Thursday 21**

**BENDIGO**
A dementia-friendly morning tea
2:00pm - 3:00pm
A heart-warming event at Bendigo Library for people living with dementia, their families and carers to enjoy morning tea and write letters of love together. For more information 5449 2700 or email dementiaawareness.vic@alzheimers.org.au

155 Oak Street

**NEWTOWN**
Driving and dementia
1:30pm - 2:30pm
A free session that will help family and friends support a person living with dementia to balance their independence and safety, while allowing them to stay active, mobile and socially connected.

**WARRNAMBOOL**
Making Memories variety concert
11:00am - 1:30pm
Expo style event. Find out more about dementia and the community care services to better support people living with dementia and their families. Open to the public
Club Mulwala, Function Room, 2 Pertobe Road

**PARKVILLE**
Learning Technology Showcase
12:30pm - 3:30pm
Come and explore the ways in which we are using Information and activities at the Perc Walkley Dementia Learning Centre. Find out what’s available in your area. More information 9816 5784 or email showcasemonday.eventbrite.com.au

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**CALLING ALL SUPER HEROES!**
Join in the fun to raise awareness and support Alzheimer’s Australia Vic. For more information call 9816 5784 email dementiaawareness.vic@alzheimers.org.au

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#dementia2017

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Alzheimer’s Australia Vic is a supporting partner of these activities presented by external organisations. The National Dementia Helpline and Dementia Awareness Month are funded by the Australian Government
### Calendar of Events

**Thursday 7**
- **NUNAWADING**
  - 10:00am - 12:00pm
  - Whitehorse Civic Centre (Willis Room), 397 Whitehorse Road
  - Worried about your memory?
    - Information for the community on factors impacting on memory including dementia. Includes tips on how to look after your brain.
    - For more information call 9816 5784

**Friday 8**
- **BENDIGO**
  - 11:00am - 1:00pm
  - Bendigo Library, 251 Hargreaves Street
  - Letters of love and dementia
    - A heart-warming event at Bendigo Library for people living with dementia, their families and carers to enjoy morning tea and write letters of love together.
    - For bookings call 5449 2700 or register in person at the library

**Mon-Fri 11-15**
- **WONTHAGGI**
  - 9:00am - 5:00pm daily
  - Latrobe Community Health Service, 88-88 Graham Street
  - Through their own eyes
    - Photographic exhibition. Images of treasured items taken by people with early dementia.
    - Open to the public
    - For more information 9816 5784

**Wednesday 13**
- **MULWALA**
  - 10:00am - 12:00pm
  - Club Mulwala, 271 Melbourne Street
  - Making Memories variety concert
    - Everyone loves a variety concert, so come along. With something for everyone, especially the young at heart!
    - For more information call 9816 5784

**Thursday 14**
- **MERBEIN**
  - 12:30pm - 3:30pm
  - Merbein Library, Main Avenue
  - Worried about your memory?
    - Information for the community on factors impacting on memory including dementia. Includes tips on how to look after your brain.
    - Afternoon tea provided.
    - For more information call 9816 5784

**Monday 25**
- **PARKVILLE**
  - 1:30pm arrival
  - 2:00pm - 3:00pm
  - Alzheimer’s Australia Vic 155 Oak Street
  - Learning technology showcase
    - at the Perc Walkley Dementia Learning Centre
    - Come and explore the ways in which we are using technology to engage with carers and people living with dementia. Afternoon tea provided.
    - Register online: [showcasemonday.eventbrite.com.au](http://showcasemonday.eventbrite.com.au)

**Wednesday 27**
- **SHEPPARTON**
  - 10:00am - 12:30pm
  - The Vault, Laneway off Maude Street
  - A dementia-friendly morning tea
    - An opportunity to engage with those living with dementia as well as their carers over morning tea. A chance to discuss how the City of Greater Shepparton can become a more dementia-friendly community.
    - For bookings call 9816 5708 or email dementiaawareness.vic@alzheimers.org.au

**Thursday 28**
- **PARKVILLE**
  - 9:30am arrival
  - 10:00am - 11:00am
  - Alzheimer’s Australia Vic 155 Oak Street
  - Learning Technology Showcase
    - at the Perc Walkley Dementia Learning Centre
    - Come and explore the ways in which we are using technology to engage with carers and people living with dementia. Morning tea provided.
    - Register online: [showcasethursday.eventbrite.com.au](http://showcasethursday.eventbrite.com.au)

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**GO TO FIGHTDEMENTIA.ORG.AU/VIC FOR MORE ON DEMENTIA AWARENESS MONTH**

**You are not alone**
For information, support and advice
**CALL 1800 100 500**

**FREE EVENT unless marked: $**

Alzheimer’s Australia Vic is a supporting partner of these activities presented by external organisations

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Follow #dementia2017 | Call 9816 5784
Email dementiaawareness.vic@alzheimers.org.au

The National Dementia Helpline and Dementia Awareness Month are funded by the Australian Government
Experiencing changes with memory loss and dementia can mean changes in the activities you take part in. If you have trouble remembering or expressing yourself, your confidence may be down a little. You may feel embarrassed about memory loss or not being able to do things as well as you used to.

However, keeping involved and active in the things you enjoy is extremely important. Rather than giving up activities that are becoming difficult, it may be possible to modify the activity. For example, one man was having trouble keeping his golf score. He felt embarrassed and thought about stopping altogether, but decided instead to modify things by asking his partner to keep the score on his behalf. This change meant he was able to keep on playing the game he loved.

Breaking an activity down into smaller parts may also help. Even if you can’t manage all the steps, you may be able to take part in some of them. For example, if you are having trouble preparing a meal, rather than completely stopping, you may be able to do some parts of it, such as peeling the vegetables, setting the table or helping to serve.

It often helps to talk to others about how you are feeling. Sometimes a family member or friend may be able to offer support with an activity, perhaps by helping to get you started so that you can continue on your own. Or they may be able to help you throughout, so that you both enjoy the activity together.

Some people with dementia find that being among large groups of people can be overwhelming. Too much noise or activity can create anxiety or confusion. It may be that you aim to be with one or two other people to continue gaining pleasure from social gatherings, rather than being with a large group of people.

To find out about services in your area, call the National Dementia Helpline 1800 100 500.
Geelong tango dancers

Following on from a successful pilot last year, Pam and Richard Jarvis, instructors, have developed a new course to teach tango to people with a diagnosis of dementia and their spouse or main caregiver.

This program runs over six weeks offering the opportunity to learn Argentinean tango supported by Richard and Pam and their tango volunteers. The hour of instruction is followed by a shared morning tea. The session provides physical and mental exercise as well as social interaction. Research has shown tango to be a particularly useful dance for improving balance and engaging the brain.

Nola Wood, Counsellor from Alzheimer’s Australia Vic in Geelong, who attends each of the weekly sessions, said it is a great opportunity for couples to come together in a shared activity that provides benefits to all participants.

‘Pam and Richard are able to tailor the program to meet the needs of all participants and the music is fabulous. It is wonderful to see how people progress across the weeks and the shared morning tea is a great way to finish off the session,’ Ms Wood said.

Living with Dementia at Ballarat

For six weeks during May and June, a Living with Dementia group met at Alzheimer’s Australia Vic’s Ballarat office. The group comprised seven people with early stage dementia, each accompanied by their support person.

Living with Dementia offers the opportunity for discussion in small, supportive peer groups made up of people in similar circumstances. Topics covered include dementia symptoms and diagnosis, adapting to the changes brought about by dementia, research and medications, practical strategies, relationships and communication, planning for the future and support services.

The program included the opportunity to ask Associate Professor Mark Yates of Ballarat Health Services questions about the clinical aspects of dementia. The group also heard from local service providers about dementia-related support available in the Ballarat area.

The Caring Role in Camperdown

Ten carers from the Barwon South West region commenced a four-week course, the Caring Role, in February at Camperdown.

The course, run by Alzheimer’s Australia Vic, includes information about dementia and the associated changes, while also incorporating discussion on the loss and grief associated with becoming a carer. Creating an environment to facilitate the caring role and available support for carers were also covered.

Feedback was overwhelmingly positive, with carers affirming the support gained from facilitators and other members of the group came at just the right time for them and their loved ones. The sessions were so popular that there is now a waiting list for the next course at Camperdown.

For more information, contact Jason Kelly, Counsellor Alzheimer’s Australia Vic on 03 5562 1666 or jason.kelly@alzheimers.org.au.
A few years ago, scientists from the Queensland Brain Institute, based at the University of Queensland, developed a scanning ultrasound approach that could restore memories in mice and even reverse the symptoms of Alzheimer’s disease.

At the time, the news was very preliminary having only been proven in mice.

The research has now moved to a second stage and, while still only working with animal models, the news is promising. Published in the journal Brain, the researchers found that combining the ultrasound therapy with an antibody treatment was even more effective at removing the toxic proteins which clump around the brain, and reduce Alzheimer’s disease symptoms.

Professor Jürgen Gotz, Director of the Queensland Brain Institute’s Clem Jones Centre for Ageing and Dementia Research, said this combination treatment increased uptake of the therapeutic antibody into the brain and its individual neurons, and could be used to make treatments for brain diseases more cost-effective.

However, it is still some time away from human trials, but the researchers are excited because delivering drugs to the brain can be difficult due to the blood–brain barrier, which exists to prevent toxins from entering the bloodstream. The good news is that the ultrasound approach can temporarily open the barrier, increasing the uptake of drug treatments and restoring memory functions.

The researchers want to undertake future studies to determine whether continued treatment can clear Tau proteins completely from the brains of mice and prevent memory impairment in mice with Alzheimer’s disease.

It is still hoped this research and technique could be applied to human treatments, but this is still some time away from becoming reality.

Queensland Uni further develops ultrasound technology

Childhood stress linked to dementia rates in Aboriginal Australians

Aboriginal and Torres Strait Islander people have some of the poorest health outcomes of indigenous populations globally, with higher rates of injury, mental health conditions, chronic disease and dementia.

A new Australian study, published in the American Journal of Geriatric Psychiatry, has found that high levels of childhood stress may be linked to the higher rates of dementia found amongst indigenous Australians.

The research team, led by Dr Kylie Radford of Neuroscience Research Australia in Sydney, recruited 336 indigenous Australians from NSW between 60 and 92 to complete the Childhood Trauma Questionnaire (CTQ). The questionnaire captured a range of childhood experiences using a ‘point based’ scale.

The researchers found participants who had high childhood stress scores were more likely to have gone through depression, anxiety and suicide attempts, with many having received a diagnosis of dementia, more specifically Alzheimer’s disease.

The results indicate that childhood stress amongst indigenous Australians appears to have a significant impact on emotional health and increased rates of dementia in later life.

The research team is now aiming to undertake further studies to explore why this might be the case.
Funding to attend the national dementia conference still available

People living with dementia and carers that are interested in attending the 17th Alzheimer’s Australia Biennial National Dementia Conference are invited to apply for financial assistance through the Consumer Participation Fund.

Funding is still available for people wishing to attend as general participants or for community groups. Assistance for registration fees, travel and accommodation is available.

To apply visit dementia2017.org/consumer-participation-fund

Pre-conference workshops to offer families practical skills

A series of pre-conference workshops have been announced that will offer people living with dementia, their families and friends practical skills in navigating aged care and empathetic listening.

The 17th Alzheimer’s Australia Biennial National Dementia Conference is due to take place in Melbourne this October.

In 2016 Alzheimer’s Australia Vic consulted with people living with dementia and carers about what they would like to gain from this national event. The ability to gain new skills and knowledge that will help them in their day-to-day lives came back as one of their main needs.

Debra Nicholls is the Senior Educator and Advocate for Elder Rights Advocacy. Elder Rights Advocacy provides independent support and advice to people receiving home-based and residential aged care services in Victoria. Debra will be presenting a half-day workshop on how to raise concerns whilst maintaining a good relationship with your aged care provider. People attending this workshop will learn about consumer rights in aged care, how to document your concerns, how to raise your concerns in a way that gets a positive outcome, as well as learn where to go to get further support.

Naomi Feil is the pioneer of the globally recognised ‘Validation’. The validation approach uses empathy and listening to create a deeper understanding of the person with dementia. Naomi will be running a full-day workshop for people wishing to learn how to apply Validation at their work or at home.

Pre-conference workshops will be held on Tuesday 17 October at the Melbourne Convention and Exhibition Centre. Workshop tickets are discounted for people living with dementia and carers. People not attending the conference are still welcome to attend these workshops.

For more information and to buy tickets please visit dementia2017/workshops

Augmented reality project gets the go-ahead

Alzheimer’s Australia Vic has taken another step into the high-tech world with a project to use augmented reality to improve the lives of people living with dementia, their carers and families.

Alzheimer’s Australia Vic received Federal Government Dementia Aged Care Services funding for a two-year project to develop ‘augmented reality technology for people living with dementia’. The application was submitted in partnership with Alzheimer’s Australia National Office and Swinburne University, who will undertake the evaluation of the development.

Alzheimer’s Australia Vic, already a world leader in the development of virtual reality with our Virtual Dementia Experience™ and Enabling EDIE technology, began the augmented reality project in June and it will end in June 2019. The outcome will be to develop an application or solution using augmented reality technology and smart devices, which may include wearable or carry-able devices, to assist people living with dementia with daily living challenges.

Virtual reality is achieved by using technology in combination with hardware, such as wearable devices to create a ‘virtual’ computer generated environment. For example the Virtual Dementia Experience™ simulates the experience of a person living with dementia.

Augmented reality uses technology to heighten or enhance a person’s experience of the real world. The senses most often used with the technology are hearing and sight.

‘Augmented reality applications have the potential to assist a person living with dementia to navigate their environment. They also have the potential to be used to provide the person with memory prompts,’ Ann Reilly, Acting General Manager Client Services, said.

The applications may be used on smart devices, such as smartphones, smart speakers and tablets. They may also be incorporated into wearables, for example smart watches, or smart glasses.
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**Suzanne McMeikin**
suzanne.mcmeikin@alzheimers.org.au
03 9816 5791

**Marie Norman**
marie.norman@alzheimers.org.au
03 9816 5716
Our library is at 100 Riversdale Road, Hawthorn and a smaller branch collection is also available at 155 Oak Street, Parkville
Open Monday to Friday 9:00am - 5:00pm
Call 03 9815 7800 or email vic.library@alzheimers.org.au

LIBRARY
OUR SEASON PICKS

Relationships and dementia

‘Our intimate and family relationships are complex. Living with dementia increases this complexity, so relationships need to be reframed and constantly renegotiated as the dementia progresses.’
(Relationships and dementia, Alzheimer’s Australia NSW 2017)

Following is a variety of library resources that illustrate the complexity of these relationships.

Loving Someone Who has Dementia: How to Find Hope While Coping with Stress and Grief
Pauline Boss (2011)
This book is intended for partners, family members, friends, neighbours and caregivers of a person living with dementia. The author discusses the meaning of relationships and offers approaches in a conversational style, suggesting ways to embrace rather than resist the ambiguity of a relationship with someone who has dementia.

Bettyville: A Memoir
George Hodgman (2015)
A witty, tender memoir of a son’s journey home to care for his irascible mother – a tale of secrets, silences, and enduring love. When George Hodgman leaves Manhattan for his hometown of Paris, Missouri, he finds himself – an unlikely caretaker and near-lethal cook – in a head-on collision with his aging mother, Betty, a woman of wit and will.

The Things We Keep
Sally Hepworth (2016)
Anna Forster, in the early stages of Alzheimer’s disease at only 38, knows that her family is doing what they believe to be best when they take her to Rosalind House, an assisted living facility. She also knows there’s just one other resident her age, Luke. What she does not expect is the love that blossoms between her and Luke even as she resists her new life at Rosalind House.

Alzheimer’s: A Love Story
Vivienne Ulman (2009)
The author records with tender lyricism and searing honesty the progress of her mother’s Alzheimer’s disease, her own grief and the way in which her parents’ enduring love for each other sustains them.

Green Vanilla Tea
Marie Williams (2013)
In a compelling story that spans both joy and sadness, Marie Williams writes about the bonds in her family, her sons’ love for their father, the spirit that sustains them all during the most testing of experiences and about the struggle they faced in dealing with the inexplicable.

Goodbye, Vitamin
Rachel Khong (2017)
Ruth is 30 and her life is falling apart: she and her fiancé are moving house, but he’s moving out to live with another woman; her career is going nowhere; and then she learns that her father, a history professor beloved by his students, has Alzheimer’s. Goodbye, Vitamin is the wry, beautifully observed story of a woman at a crossroads, as Ruth and her friends attempt to shore up her father’s career; she and her mother obsess over the ambiguous health benefits – in the absence of a cure – of dried jellyfish supplements and vitamin pills; and they all try to forge a new relationship with the brilliant, childlike, irascible man her father has become.

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FUNDRAISING IN THE COMMUNITY

Aged-care duo swap suits for boots in Kokoda Trek

Two intrepid aged care executives will swap their suits for boots at the end of Dementia Awareness Month to raise funds for Alzheimer’s Australia.

Lifeview Residential Care’s Chief Financial Officer, James van Beek, and Manager – Person Directed Care, Sarah Pettenon, will take on the gruelling Kokoda Track in the aid of Alzheimer’s research and support. Alzheimer’s Australia’s Trek to Remember follows the success of treks in Nepal, Vietnam and Tanzania.

The trek will take place from Sunday 24 September until Tuesday 3 October.

Sarah says she is undertaking the trek because she sees the impact dementia has on individuals and their carers on a daily basis. James says he wants to pay his respects to the Australian soldiers who fought in the Kokoda battle of World War Two.

They are both training extensively to prepare themselves for the trek. In addition, the pair, along with Lifeview residents, staff and families, is pursuing a range of fundraising activities to underpin their efforts – including the raffling of a trailer full of household goods worth in the vicinity of $3,000. All funds raised by James and Sarah will go to Alzheimer’s Australia.

THINKO! IT’S GAME ON FOR DEMENTIA

Join Alzheimer’s Australia Vic on the 21 September at the Eureka Hotel, Richmond, for the worlds-biggest fundraising trivia night!

Thinko! is fun and exercises six key areas of your brain. Best of all, you’ll be raising funds for people impacted by dementia

Get your mates together and test your mental prowess on World Alzheimer’s Day. Games, prizes and celebrity appearances are on offer!

Tickets are $30 each or $250 for a table of 10.

Visit thinkotriviamelbourne.eventbrite.com.au to buy your tickets now!
Caring for someone you love

Ken Holland is a wonderful man whose story, caring for a very dear friend, Jennie (Jen) Tyrrell, represents more than 196,491 carers in Australia who each have their own story to tell about caring for someone they love.

‘We were both married,’ Ken said. ‘Jen’s husband was a good friend and as couples we were also good friends. We used to go out and away on holidays together. A number of years ago, my wife and Jen’s husband died within a few weeks of each other. I helped Jen out at the time. We became very good friends and were so lucky to have each other. When I had my hip replacement, I stayed with Jen and she looked after me. To have a friend to help was so important for me. I really wanted to marry her, such was our love for each other. However, she did not want to marry again.

‘In 2012, Jen and I were at a seminar at Caulfield Hospital and the health professional running the seminar mentioned that he had noticed that there may be something wrong with Jen. She was diagnosed with Alzheimer’s disease and could no longer drive.

This small investment in me being trained by Alzheimer’s Australia Vic as a carer had wonderful outcomes for both Jen and me.

‘I telephoned Alzheimer’s Australia Vic, as I wanted to make a donation and I was seeking advice on carer-training sessions. Judy Claringbold in Education Services (now Learning and Development), was most helpful. I attended these lectures for about one year.

This small investment in me being trained by Alzheimer’s Australia Vic as a carer had wonderful outcomes for both Jen and me, as I had been prepared on every level for each stage of Alzheimer’s disease.

‘I looked after Jen daily for five years until she moved to full care accommodation.

‘Jen passed away in January 2016 at 92. Approximately 80 of her friends attended the memorial service and Alzheimer’s Australia Vic provided In Memoriam envelopes on request for donations. It was a fitting farewell for a wonderful woman.

‘I am now 96 years old and taking one day at a time.’

It was such an honour to meet Ken recently.

Alzheimer’s Australia Vic is most grateful that he gave permission for his story to be told in his own words. Thank you, Ken.

Jo Fairbairn Bequest Officer Alzheimer’s Australia Vic.

Above Jennie Tyrell and Ken Holland

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By leaving a gift in your Will you can make a difference.

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☐ I would like to find out more about making a bequest to Alzheimer’s Australia Vic
☐ I have already included a gift to Alzheimer’s Australia Vic in my Will
☐ Please contact me about organising my own fundraising event
☐ I would like more information about becoming a member

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