New data reveals dementia prevalence set to soar

An Afternoon Tea to Remember with Ita Buttrose AO OBE

New online dementia support resources
Welcome to the autumn edition of Memory Matters, the first edition of 2016.

We recently commissioned new research projecting dementia prevalence in Victoria, now and in the future. This data assists Alzheimer’s Australia Vic, Victorian Government departments, Victorian health regions, local governments, researchers and politicians in their decision making and strategic planning.

The research estimates 97,000 people are currently living with dementia across the state. This figure is expected to rise to 386,000 by 2050 - a growth rate of almost 300 per cent.

Every Victorian will be impacted by dementia at some stage during their lifetime, either through receiving a diagnosis themselves, or through caring for or knowing somebody living with the disease. Despite this, there is still a widespread lack of awareness and understanding amongst the community about dementia.

Research tells us that over 70 per cent of Australians admit to knowing very little about dementia. Almost half of the population do not realise that dementia is fatal and is the second leading cause of death in Australia after heart disease. A quarter of us also believe it is a normal part of ageing.

For this reason, we are calling on the State Government and the corporate community to join forces and support investment in a sustained public awareness and education campaign to prepare Victoria for the projected increase in dementia prevalence. You can read more about the latest research and what we are calling for on pages four and five of this edition.

This new data reinforces the need to tackle dementia together, as a nation, as a state and as a community. That is why it has been particularly heartening over the past few months to see so many members of the community turn out to support Alzheimer’s Australia Vic at events such as our Memory Walk & Jog.

So far, we have hosted these fun-filled events at Geelong, Bendigo and the Mornington Peninsula. It’s been wonderful to see people of all ages, backgrounds and abilities come together to raise awareness about dementia and contribute vital funds to support the work of Alzheimer’s Australia Vic.

You can read more about previous and future Memory Walk & Jog events on pages six and seven of this edition. We still have events coming up in Melbourne and Albury/Wodonga, so if you haven’t registered yet, I urge you to do so. It really is a great family day out for all involved!

Finally, I would like to take this opportunity to acknowledge the work of Mary-Lou Doswell, Facilitator - Cert IV in Dementia Practice and Robyn Teed, Locum Facilitator. Both Mary-Lou and Robyn have given five years of service to Alzheimer’s Australia Vic. Their contribution is very much valued and I thank them both for their commitment to our organisation, and the difference they have made to the lives of people living with dementia, their families and carers.

I hope you enjoy reading this edition of Memory Matters.

Maree McCabe
CEO
There’s still time to get involved with our Memory Walk & Jog

With the next Memory Walk & Jog just around the corner there is still plenty of time to register yourself or a team. Alzheimer’s Australia Vic Ambassador, Amy Jackson from Melbourne City will join participants in memory of her grandmother at the Doncaster event on 17 April.

You’ll be participating alongside hundreds of others, many of whom will be running or walking in memory of someone special, or in honour of a person close to them living with dementia. The events are vibrant, energised and emotional gatherings with music, face-painting and warm-up Zumba classes and dance routines.

We extend our thanks to the thousands who have participated in the Geelong, Bendigo and Point Nepean events, raising much needed funds to support our services. Turn to pages six and seven to see some great photos that will give you a taste of what to expect by getting involved.

The earlier your register, the more time you will have to inspire friends and family for those all-important donations.

To find out more, visit bit.ly/vicmwaj or call 03 9816 5746.

Alzheimer’s Australia Vic would like to thank major supporter OPAL Aged Care for making these events possible.
Major awareness campaign needed as new research reveals almost 100,000 Victorians living with dementia, the biggest yet least understood condition

Alzheimer’s Australia Vic is calling on the State Government and the corporate community to join forces and support investment in a sustained public awareness and education campaign to prepare Victoria for the alarming dementia increase projected in new prevalence data.

The new research, commissioned by Alzheimer’s Australia Vic, estimates there are currently 97,000 people living with dementia in Victoria. This figure is expected to rise to 386,000 by 2050 - an increase of almost 300 per cent.\(^1\)

Maree McCabe, CEO Alzheimer’s Australia Vic said, “Over 70 per cent of Australians admit that they know very little about the disease. Almost half of the population do not realise that dementia is fatal and is currently the second leading cause of death in Australia after heart disease.

A quarter of us also believe that dementia is just a normal part of ageing.\(^2\) This lack of awareness and understanding of one the world’s most prevalent health conditions must change.”

Ms McCabe said there needs to be a massive shift in understanding to ensure all Victorians are better equipped to recognise the early signs of dementia, know where to seek information and support, and maintain the best quality of life possible.

The 2016 dementia prevalence research and Alzheimer’s Australia Vic’s 2016-2017 Budget Submission can be found at fightdementia.org.au/vic

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1 Alzheimer’s Australia Vic commissioned Prevalence Data research by NATSEM, University of Canberra February 2016

2 Alzheimer’s Australia commissioned research by Ipsos Australia 2012

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The 2016 top 10 State Electoral Districts for prevalence are:

<table>
<thead>
<tr>
<th>District</th>
<th>Prevalence</th>
</tr>
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<tbody>
<tr>
<td>Bendigo East</td>
<td>1,854</td>
</tr>
<tr>
<td>Nepean</td>
<td>1,782</td>
</tr>
<tr>
<td>Shepparton</td>
<td>1,738</td>
</tr>
<tr>
<td>Box Hill</td>
<td>1,541</td>
</tr>
<tr>
<td>Mornington</td>
<td>1,535</td>
</tr>
<tr>
<td>Bulleen</td>
<td>1,529</td>
</tr>
<tr>
<td>Pascoe Vale</td>
<td>1,517</td>
</tr>
<tr>
<td>Clarinda</td>
<td>1,460</td>
</tr>
<tr>
<td>Kew</td>
<td>1,447</td>
</tr>
<tr>
<td>Ripon</td>
<td>1,431</td>
</tr>
<tr>
<td>Melton</td>
<td>10,753</td>
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<tr>
<td>Cranbourne</td>
<td>8,945</td>
</tr>
<tr>
<td>Yan Yean</td>
<td>8,657</td>
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<tr>
<td>Euroa</td>
<td>7,689</td>
</tr>
<tr>
<td>Monbulk</td>
<td>7,279</td>
</tr>
<tr>
<td>Tarneit</td>
<td>7,272</td>
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<tr>
<td>Macedon</td>
<td>7,240</td>
</tr>
<tr>
<td>Werribee</td>
<td>6,834</td>
</tr>
<tr>
<td>Yuroke</td>
<td>6,343</td>
</tr>
<tr>
<td>Narre Warren Sth</td>
<td>6,172</td>
</tr>
</tbody>
</table>

“Tens of thousands of people living with dementia live at home, often supported by family for five to 10 years or more before a higher level of care is needed,” Ms McCabe said. “Victorians, as a community, need to know how they too can best support people living with dementia – their neighbours, their regular customers or even the person sitting next to them on the bus.”

Ms McCabe said an increased awareness about dementia will result in reduced stigma and social isolation, and will get people talking about the disease and seeking help earlier.

“With better community support people with dementia will feel included and retain their independence longer. They and their carers will be better supported and overall have an improved quality of life,” Ms McCabe said.

According to the new data, no area in Victoria is spared. Within Melbourne, areas from Pascoe Vale to Box Hill, Kew and Bulleen show some of the highest figures.

In regional Victoria, Bendigo East, Nepean, Shepparton and Ripon rank in the top ten State Electoral Districts (SEDs) for dementia prevalence in 2016.

Elevating the level of knowledge in all areas of government, the health and aged care sectors and the wider community will play an essential role in meeting the future needs of Victorians.

“The epidemic increases are revealed when the 2050 top 10 State Electoral Districts are reviewed:”

"We need our Victorian leaders to make a political commitment to drive the change needed to make a difference to the lives of all Victorians living with dementia, their families and carers,” Ms McCabe said.

The 2016 dementia prevalence research and Alzheimer’s Australia Vic’s 2016-2017 Budget Submission can be found at fightdementia.org.au/vic
The growth corridors form a major part of this picture, with the top 10 percentage increases from 2016 to 2050:

<table>
<thead>
<tr>
<th>Location</th>
<th>Percentage Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melton</td>
<td>1,202.7</td>
</tr>
<tr>
<td>Yuroke</td>
<td>1,179.3</td>
</tr>
<tr>
<td>Yan Yean</td>
<td>1,062.4</td>
</tr>
<tr>
<td>Tarneit</td>
<td>1013.4</td>
</tr>
<tr>
<td>Werribee</td>
<td>952.2</td>
</tr>
<tr>
<td>Cranbourne</td>
<td>934.4</td>
</tr>
<tr>
<td>Monbulk</td>
<td>908.9</td>
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<tr>
<td>Sydenham</td>
<td>679.7</td>
</tr>
<tr>
<td>Macedon</td>
<td>657.1</td>
</tr>
<tr>
<td>Rowville</td>
<td>611.1</td>
</tr>
</tbody>
</table>

A number of people living with dementia and carers shared their story through the media as part of this campaign. We thank them for adding their voice to this advocacy activity and acknowledge the critical part they played in raising awareness about dementia across Victoria.

If you would like to share your story in a future campaign, please email newsvic@alzheimers.org.au
Thousands turn out across Victoria to support Memory Walk & Jog events

Hawthorn FC player and Alzheimer’s Australia Ambassador Sam Mitchell has a very personal reason for supporting Alzheimer’s Australia Vic’s Memory Walk & Jog events.

“My mother-in-law passed away about two-and-a-half years ago, and I saw first-hand how much of a difficult disease dementia can be. Being able to help in any way I can after that experience is what I want to be here for,” said Mr Mitchell, who turned out alongside hundreds of others at a recent event held on the Mornington Peninsula.

Thousands of people of all ages, abilities and fitness levels have enjoyed the numerous Alzheimer’s Australia Vic Memory Walk & Jog events across Victoria over the past few months.

Through events held at Geelong, Bendigo and the Mornington Peninsula, members of the community have been encouraged to get involved and raise funds via their own networks to help enable Alzheimer’s Australia Vic to continue providing much-needed support services, education and social research.

Sam Mitchell’s story is by no mean unique, with many attendees participating in memory or in honour of a loved one impacted by the disease. Melbourne City’s Amy Jackson - another of Alzheimer’s Australia Vic’s fabulous ambassadors - ran in memory of her grandmother. Mornington Peninsula local Sandra Erickson rallied a team of family and friends comprising 16 adults and seven children to participate in honour of her husband Richard, who is living with frontotemporal dementia.

Ms Erickson said, “Alzheimer’s Australia Vic has been a lifeline for us since Richard’s diagnosis, and this seemed like a great opportunity to give back. We want to help ensure other families can benefit from the same level of support we have received.

“It was a great event, held in a great location. There was a lovely feel to the day, with lots of activities including face painting for the kids. There was an overwhelmingly positive vibe, and we all had such a great time that we are seriously considering getting involved in a future Memory Walk & Jog event.

“The other really positive outcome for me personally was that, by using Facebook and email to help raise money, I got to touch base with people I haven’t spoken to in a long time. I received lots of really lovely, supportive messages. So the whole experience was incredibly positive!”

For their efforts, Sandra and her team raised an incredible $3,000.

Each event comprised runs and walks varying lengths, so there really was something for everyone. And don’t worry ... the fun’s not over yet. Alzheimer’s Australia Vic still has Memory Walk & Jog events planned at Ruffey Lake Park in Doncaster on Sunday 17 April, and Sumson Gardens, Wodonga on Sunday 22 May. To find out more or to register, visit bit.ly/vicmwaj or call 03 9816 5746.

And as if these photos weren’t enough to whet your appetite and inspire you to get involved, head online and view our fabulous Memory Walk & Jog video at http://bit.ly/vicMWJvideo

Alzheimer’s Australia Vic would like to thank major supporter OPAL Aged Care for making these events possible.
Above Happy participants at the Mornington Peninsula Memory Walk & Jog.

Below Back row (L -R): Chelsea, Jayne, John, Bron, Sandra, Shane (holding Teddy), Marc, Ian, Bec, Tony, Jan and Trisha
Front row(L-R): Lenny (in pram), Michelle, Glen, Hugh & Marley (in double pram), Tobi, Sibella, Tayah, and Mia.
People with dementia join forces to Engage, Enable and Empower people living with a diagnosis

Maureen, Gwladys, Peter, Iolanda, George, Huong, Rose, Jim, Geoff, Athena, Peter, Colin, Maxine and Trish have joined forces to share their experiences of living with dementia through a website and booklet specifically developed by people living with dementia, for people living with dementia.

The result is Engage, Enable, Empower, which was officially launched at the Victorian Parliamentary Friends of Dementia event in November.

“This small group of people living with dementia, by calling on Alzheimer's Australia Vic to create this resource, will encourage many others, for years to come, to make the most of living with dementia,” Maree McCabe CEO Alzheimer’s Australia Vic said.

Engage, Enable, Empower shares the stories of all fourteen participants, while communicating important information about maintaining your mind, body, overall health. It also focuses on the importance of seeking support from family, friends, community and through Alzheimer’s Australia Vic.

“We congratulate Victoria’s peak body for dementia, Alzheimer’s Australia Vic, on their leadership in developing this new national resource that will make a difference to the lives of the 81,000 Victorians living with dementia, their families and carers. We encourage all our parliamentary colleagues and the community to visit the website,” said Victorian Parliamentary Friends of Dementia Co-convenors Gabrielle Williams MP, Parliamentary Secretary for Carers and Volunteers and Emma Kealy MP, Member for Lowan, in a joint statement.

See this great tool for yourself, by visiting Engage, Enable, Empower at livingwellwithdementia.org.au

Help is at hand for people living with dementia and their carers

Knowing where to go for help has been made a whole lot easier for people living with dementia and their carers, thanks to helpwithdementia.org.au - a new online service developed by Alzheimer’s Australia Vic.

The website was unveiled in December at a special launch event, attended by Alzheimer's Australia Vic Ambassador Terence Donovan, who is currently portraying Doug Willis on Neighbours - a character living with Alzheimer’s disease.

helpwithdementia.org.au enhances existing Alzheimer’s Australia Vic services, enabling access to 24-hour information and resources; counselling via email or video conference; a forum enabling participation in an online peer support community; and 16 videos with experts and carers sharing their experiences.

Delia Bradshaw, a family carer, said she was delighted to be involved and to support the development of the service.

“Having this information at hand when my husband Bill was diagnosed six years ago would have helped enormously in our understanding about the disease and what support was available,” Ms Bradshaw said.

“The support we received from Alzheimer’s Australia Vic changed our lives for the better. Now this support is available online, any time, I know that many more people will feel supported and know that they are not alone,” Ms Bradshaw said.

Alzheimer’s Australia Vic developed the resource to enable easier access for people seeking information and support, acknowledging the time challenges people living with dementia and their carers often face juggling work, home, family, appointments and other commitments.

The website includes a number of videos experts through which family carers help others to learn more about dementia, offer tips on more effective communication, discuss changes in behaviour and offer useful information on residential care.

Delia Bradshaw giving a carer’s perspective at the launch of Alzheimer’s Australia Vic’s Online Dementia Support service.
Forthcoming regional events in Geelong

Over the coming months, Alzheimer’s Australia Vic is preparing to host three free community events in Newtown, Geelong.

Effective communication will take place on Wednesday 9 March at 1:00pm. The session is aimed at family carers who may need some help in understanding and managing the changes in communication caused by dementia. Participants will learn about supportive communication strategies, as well as reality orientation, reminiscence and validation.

Coping with changes in behaviour is scheduled for Tuesday 12 April at 1:00pm and is intended for family carers who could benefit from support and strategies to help cope with the potential behavioural changes in a person living with dementia. Attendees will learn how changes in the brain impact on a person’s behaviour, what triggers certain behaviours, a problem-solving approach, available support services, and will be given an insight into behaviours such as sundowning, hoarding and agitation.

Considering Residential Care will take place on Wednesday 4 May at 1:00pm. This session is for family members or friends who are caring for someone with dementia, and are at the point of considering their residential care options. Attendees will discuss the associated legal and emotional issues, reasons for deciding on residential care, barriers to making the decision and what to look for in a good residential care facility. They will also learn about the system, including the different types of care available and associated costs.

All sessions will take place at 1/318 Pakington Street, Newtown. To book your spot call Narelle Cullen on 03 5229 6979 or email geelongadmin@alzheimers.org.au

Virtual Dementia Experience™ recognised with prestigious Victorian Public Healthcare Award

Alzheimer’s Australia Vic’s world-first Virtual Dementia Experience™ has been recognised for exceptional leadership and excellence in providing public health services to and for the Victorian community.

At a gala ceremony, the Virtual Dementia Experience™ was awarded first place for “Excellence in person, family and community-centred care” at the Victorian Public Healthcare Awards, presented by Premier Daniel Andrews and Minister for Health Jill Hennessy.

Launched in October 2013, the Virtual Dementia Experience™ is an immersive, interactive virtual reality experience that invades the senses and takes people into the world of a person living with dementia, simulating thoughts, fears and challenges. It has been experienced by more than 2,000 people including professional and family carers, healthcare professionals, high profile business and community leaders and Victorian and Federal politicians.

The ground-breaking simulation technology was created after extensive consultation with carers, people with dementia and Alzheimer’s Australia Vic educators. The Virtual Dementia Experience™ has previously been awarded the 2014 Victorian and National iAwards in Education, the 2014 APICTA Award in Education and in July 2015 won the Microsoft Imagine Cup 2015 World Citizenship Award.

For more information on the Virtual Dementia Experience™ and how you could experience it for yourself, visit http://bit.ly/vicvde

Volunteer celebration

It’s no exaggeration to say that Alzheimer’s Australia Vic simply could not do what it does without the support of its fabulous volunteers (pictured below).

In recognition of these loyal, dedicated and talented people, a celebratory morning tea held at Hawthorn in December provided the perfect opportunity for Alzheimer’s Australia Vic to thank and acknowledge its volunteers for their contribution throughout 2015.

If you or somebody you know would be interested in volunteering for Alzheimer’s Australia Vic, find out more by visiting bit.ly/vicvolunteerivd
**Dementia learning delivered at your workplace**

Many organisations and health care professionals would love to increase the quality of dementia care practice amongst their teams, but are often unable to commit to the time involved with off-site learning.

Did you know you can now achieve your dementia learning objectives by taking advantage of Alzheimer’s Australia Vic’s education programs, conveniently delivered at your workplace?

The extensive range of educational programs offered is designed to ensure learning extends well beyond the workshop and results in practice improvement.

Discuss your own unique requirements with the team to determine the most appropriate program that best meets the needs of your staff. Experienced facilitators will then build the skills and knowledge of your team, inspiring them to provide best practice dementia support.

Email vic.education@alzheimers.org.au to start the conversation, and discuss how Alzheimer’s Australia Vic can support your learning needs.

**ExxonMobil experience**

The Virtual Dementia Experience™ proved to be a fascinating eye-opener for a group of ExxonMobil Australia employees, including Lead Country Manager and Chairman Richard Owen who attended with his wife Jenny, on 2 February 2016.

Welcomed by Alzheimer’s Australia Vic CEO, Maree McCabe, the team took the opportunity to learn more about dementia through both the Virtual Dementia Experience™ and the expertise of Alzheimer’s Australia Vic’s Learning and Development team.

The event was also a chance to recognise ExxonMobil’s ongoing support for Alzheimer’s Australia Vic, with $161,000 donated between 2010 and 2015, when they supported an awareness-raising campaign in Seniors Week. We look forward to this partnership continuing into the future.

**Multicultural Memory Lane Cafés come to Geelong**

Alzheimer’s Australia Vic is delighted to have received funding from the Victorian Department of Health and Human Services to host Memory Lane Cafés for all multicultural groups in the Geelong area.

In partnership with Multicultural Aged Care Services, the inaugural Multicultural Memory Lane Café was held in December for people experiencing memory loss, their family members and carers.

The cafés provide an opportunity for people with dementia and their family members to enjoy time together with refreshments and entertainment, in the company of people in a similar situation to themselves. Alzheimer’s Australia Vic counselling staff and trained volunteers also attend.

**Participants wanted for Alzheimer’s disease (Pre) Clinical Study**

If you are healthy and between the ages of 65 and 85, you could be eligible to participate in a new trial called The A4 Study, which is being conducted by The Florey Institute of Neuroscience and Mental Health, aims to prevent memory loss caused by Alzheimer’s disease.

The Anti-Amyloid Treatment in Asymptomatic Alzheimer’s study (The A4 Study) is a pre-clinical trial to test a new drug on older individuals who may be at risk of suffering memory loss as a result of Alzheimer’s disease.

A screening process will be carried out to identify suitable participants. This will involve examining a variety of factors relevant to the trial, such as memory measures, health assessment and brain scanning. The team behind the trial is particularly interested in screening people who are in the 70 to 75-year age group, who have a normal memory, but who are worried about either getting dementia or who might have a family history of Alzheimer’s disease.

For more information, visit florey.edu.au or call 1800 443 253.
In memory of Professor Graham Burrows AO

It was with great sadness that Alzheimer’s Australia Vic learned of the death of Professor Graham Burrows AO, in January 2016.

Graham made an extraordinary contribution to the wellbeing of people living with dementia, their families and carers, and to the evolution and ongoing success of Alzheimer’s Australia Vic itself.

Graham’s contribution started with the integral role he played in the establishment of Alzheimer’s Australia Vic in 1983. At the time, Graham headed up the Victorian Association of Mental Health, and it was his influence that saw that organisation agreed to meet the initial expenses involved in establishing Alzheimer’s Australia Vic.

Elected to the Board of Alzheimer’s Australia Vic into the role of Vice-President in October 1993, Graham proceeded to contribute 16 years of continuous service to the governance of the organisation.

During Graham’s tenure, Alzheimer’s Australia Vic went through a number of significant changes. To start with, the organisation grew rapidly and Graham played an instrumental role in the vision and drive that helped convince the Board to purchase Alzheimer’s Australia Vic’s Riversdale Road site in Hawthorn in 1994.

Graham proceeded to chair the Hawthorn Buildings Re-development Project, which oversaw the extensive renovation and expansion of the three Hawthorn buildings in 2001 and 2002.

Graham was elected President of Alzheimer’s Australia Vic in September 2001.

By 2004, Alzheimer’s Australia Vic had become recognised as a peak body serving all of Victoria. Following significant lobbying, the Prime Minister announced the Coalition Government’s commitment to making dementia a national health priority and committed $200 million over four years to support this. This recognition of dementia as an important issue heralded a new era for dementia research and care services.

These are just some of the significant milestones in the history of Alzheimer’s Australia Vic that eventuated during the time of Graham’s leadership.

Graham retired from the Board in February 2009. He was made an Honorary Member of Alzheimer’s Australia Vic later that year, in recognition of his tireless work in seeking to improve the lives of people impacted by dementia.

The organisation will be forever grateful to Graham for his generous personal contribution to the vision and mission of Alzheimer’s Australia Vic.

Vale Prof Graham Burrows AO

Timely diagnosis of dementia - can we do better?

On average, symptoms of dementia are noticed by families three years before a diagnosis is made. Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process; however, timely diagnosis has many benefits.

It can allow the person with dementia to make choices about their future while they are still able; to plan finances, powers of attorney and care in advance; to access medications that may relieve symptoms; and to receive support from community services to enable them to continue living in their community for as long as possible.

As part of a national project to promote the timely diagnosis of dementia in general practice, Alzheimer’s Australia Vic undertook a literature review and training needs analysis to inform the design and development of dementia practice guidelines, a face-to-face training workshop and online education program targeting practice change.

Scoping activities highlighted the vital role that nurses have in influencing change within general practice, as well as confirming the effectiveness of collaborative interdisciplinary approaches in dementia care management.

Focus groups with nurses, carers and former carers were held to comprehensively explore the areas of interest. The results of this research reinforced the key findings of the literature review, namely that there is willingness from nurses in general practice to play a greater role in identifying, assessing and providing ongoing care and support to patients living with dementia and cognitive impairment.

The role of the general practice nurse is rapidly developing to include greater responsibility and autonomy in working collaboratively to support their GPs in decision making and ongoing support for patients.

In collaboration with the Australian Practice Nurse Association, Alzheimer’s Australia Vic has developed practice guidelines entitled Four Steps to Building Dementia Practice in Primary Care, which provide tangible and easy-to-use resources that are helpful for practice nurses in improving dementia practice. These steps can be viewed by visiting http://bit.ly/vicDementiaPracticeGuidelines

This work will continue throughout 2016, with a view to building a dementia practice online learning series to improve knowledge, skills and confidence in dementia care, and provide the tools and resources for nurses to work collaboratively in supporting a timely diagnosis of dementia.

Make sure you keep an eye on future Memory Matters editions for further updates on this project.
Alzheimer’s Australia Vic has a host of resources translated into approximately 40 different languages. These resources include an extensive series of Help Sheets that provide advice, common sense approaches and practical strategies on the issues most commonly associated with dementia.

Other translated resources include:

- It’s not a disgrace … it’s dementia - a series of short films in different languages that aims to raise awareness, reduce stigma and dispel the myths about dementia.
- Worried About Your Memory - a booklet including details on the signs and symptoms of dementia, when you should be concerned, how you may be able to reduce your risk of dementia and where to seek help.

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- Worried About Your Memory - a booklet including details on the signs and symptoms of dementia, when you should be concerned, how you may be able to reduce your risk of dementia and where to seek help.

Eighty-six year-old Murrumbeena man Clyde Woods is sole carer to his wife Dawn, 88, who is living with Alzheimer’s disease. Here, Clyde shares his experiences as a family carer.

“It started with little things. Dawn would occasionally forget old friend’s names. She might forget a word, crosswords weren’t always completed, car keys were lost. Nothing big, nothing worrying. We would laugh and just tell ourselves we were getting old.

“However, there came a time when Dawn stopped doing crosswords altogether. Shopping trips became less frequent. Meals she cooked weren’t always up to her usual high standards. And her driving skills seriously deteriorated, to the point where her license had to be cancelled. It was an insidious thing. I couldn’t pick the day, week or month that things got worse.

“We could no longer laugh, or put it down to old age. So we went to see our GP. He did some simple memory tests and suggested it might be the beginning of dementia. He referred us to a specialist.

“We talked about it and tried to decide what to do if the GP was right. Firstly, we changed our wills. We had both been nominated as executors, which had to change. Then we made sure our power of attorney papers were up-to-date.

“Next, we sought information on dementia. We went to Alzheimer’s Australia Vic and got handouts, books (The 36-Hour Day is our dementia bible!), DVDs and advice. We looked online for information. We learned about the different stages of dementia, the behavioural problems that can occur and what we might expect if the diagnosis was correct. Indeed, Alzheimer’s disease was confirmed.

“The dementia moved along at a snail’s pace. Days, weeks, months and years passed with Dawn’s cognitive abilities steadily deteriorating. I kept a diary, so I could look back and see the first time Dawn was incontinent, when she could no longer follow a plot on TV or read a book, or hold a conversation, or had to be fed, showered or dressed.

“So how do I cope? I get two hours a week respite to do my shopping and pay my bills. This is my choice. I could get more respite, but Dawn panics if I so much as leave the room, so I don’t like to leave her for too long.

“I can mostly cope with the practical things, such as Dawn’s physical needs, but sometimes it’s behavioural problems that cause the most strain. From after tea until often the early hours of the morning, Dawn begins to chant ‘please help me’, ‘take me home’ or ‘where is Mum?’ It’s the dreaded sundowner syndrome and it’s very real.

“How do I handle it? I have learned not to argue or contradict her ideas but, where possible, to divert her attention. For instance, I might pretend to call for a taxi or drive her around for a while if she asks to ‘take me home’.

“Being a carer is truly rewarding when the ‘real’ Dawn emerges, but it can be frustrating when she doesn’t. I’ve certainly learned a few lessons long the way. For instance, try not to get emotionally distressed - adopt a professional attitude, as tears will only upset them and you. I use the philosophy Patience, Attitude and Tolerance. I don’t always succeed, but I try.”

If you have a question email it to newsvic@alzheimers.org.au

How can I access information about dementia in different languages?

Alzheimer’s Australia Vic has a host of resources translated into approximately 40 different languages.

To access any of these resources, simply visit bit.ly/viclanguages, click on the language appropriate to you, and browse the translated resources available.

For further guidance, call the National Dementia Helpline on 1800 100 500. If you require the assistance of an interpreter, you can contact the National Dementia Helpline through the Translating and Interpreting Service on 131 450.

To keep informed, why not sign-up to our bi-annual Diversity Matters newsletter? Email claire.emmanuel@alzheimers.org.au
REGIONAL ROUND UP

Alzheimer’s Australia Vic’s regional offices and staff are located in Albury, Bairnsdale, Ballarat, Bendigo, Cowes, Drouin, Geelong, Mildura, Shepparton and Warrnambool. Our staff within these regional areas welcome your contact on 1800 100 500.

The Alzheimer’s Australia Vic Geelong team worked in collaboration with Barwon Health, to facilitate a Life Book Group. Attendees with a diagnosis of dementia were assisted in developing pictorial snap shots of their lives, including treasured photographs of first cars, first jobs, weddings, children and grandchildren. The group, which ran each Friday afternoon for four weeks towards the end of 2015, was attended by five husband and wife couples, and one mother and daughter. The books will now be used by family members and care staff to aid reminiscence with the person living with dementia. It is intended for the Life Book Group will run again in 2016.

In February, Alzheimer’s Australia Vic’s Geelong team hosted a session entitled Introduction to dementia services - A good place to start. People living with dementia, their families and carers were given a basic introduction to the types of dementia and various symptoms, information about the value of early assessment and how to initiate the diagnostic process, basic strategies on coping with change and details of support services available.

Alzheimer’s Australia Vic’s Mildura and Bairnsdale offices both moved location in late 2015. The Bairnsdale team can now be found at 68 Macleod Street, while the organisation’s Mildura team is now based at Satori Health & Wellbeing, 186 Thirteenth Street. For more information on the dementia-related services available in each of these areas, contact Bertilla Campbell, Dementia Consultant - Mildura on 03 5021 2044 or Diane Scott, Counsellor - Bairnsdale on 03 5152 0515. The same range of services will remain available from these new locations.

Family members and friends caring for a person living with dementia attended a recent session focused on residential care, hosted at Bendigo HealthCarer’s Support Office. Attendees discussed the difficulties associated with considering residential care, including the barriers to making the decision, and the emotional issues involved. Discussion also focused around the family’s new role, and how loved ones can continue to provide care once the person with dementia has entered a facility. A range of information about how the residential care system works was also provided.

Family carers of people living with dementia attended a recent event held in Wangaratta entitled How dementia-friendly is your home? Participants learned about the principles of creating a dementia-friendly environment in the home, as well as being given an understanding of how a person with dementia perceives and experiences their surroundings. Practical and inexpensive ideas of how to make life at home easier for a person living with dementia were also provided.

MEMBERSHIP

It’s a good time to start thinking about renewing your Alzheimer’s Australia Vic membership.

You can do so at bit.ly/vicmembers or contact Rebecca McCormick on 03 9816 5783 or rebecca.mccormick@alzheimers.org.au

These puzzles are provided for entertainment purposes only. To keep your brain healthy, it’s important to engage in mentally stimulating activities, be physically and socially active, eat a healthy diet and look after your heart by getting regular health checks.

9 into 6

Place the 9 letters below the box into the 3x3 grid to make six valid five letter words. This puzzle is aimed at working areas of language, learning, reasoning, and problem solving to help exercise your cognitive abilities.

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Sudoko

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Solutions on page 19

Sign up for our free monthly brain exercise e-magazine
RESEARCH FOCUS

The Alzheimer’s Australia Dementia Research Foundation – Victoria was established in 2012 to distribute funds generously donated by Victorians for the purpose of dementia research. The funds are used to provide research grants to Australian-based dementia researchers.

Investment in research is vital to finding improved treatments for dementia and ensuring people living with the disease have the best quality of life possible. Some of the leading dementia researchers in the world are working right here in Australia, and the Foundation is dedicated to supporting them.

The Foundation awards dementia research grants annually, with the latest recipients being announced in October last year.

Does Social Competence Impact Quality of Life for People with a Diagnosis of Dementia?
Michelle Kelly, University of New South Wales

Impairments in social cognition are some of the most debilitating consequences of dementia. Social cognition refers to our ability to understand and respond to social cues, such as facial expressions and subtle vocal and language changes that suggest someone is meaning something other than what they are saying. Failure to interpret these cues correctly can have a detrimental impact on relationships with caregivers and can reduce the person’s overall quality of life. While research into social cognition in dementia is expanding rapidly, researchers the role of impairments in social cognition on quality of life has not yet been explored.

This project will utilise a new screening tool of social cognition (currently being piloted amongst a group of people with dementia) to determine the role that impairments in social cognition play when it comes to quality of life. The project will also examine the influence of social cognition impairments with regards to other health and wellbeing outcomes, including quality of caregiver relationship and carer burden. Outcomes of this project may provide an evidence base to develop intervention strategies aimed at improving the quality of life of people diagnosed with dementia.

The researchers propose that many characteristic of dementia, such as apathy and social withdrawal, can be explained by the presence of anhedonia, yet this area has been widely neglected in dementia research. Using a novel experimental task, researchers will measure the individual’s experience of pleasure while viewing pieces of art and listening to musical excerpts. Self-reporting and caregiver questionnaires will establish how the experience of pleasure changes from pre to post-symptom onset.

Finally, the team will determine the neural substrates of anhedonia using advanced neuroimaging analyses. The approach will result in vital information regarding the subjective experience of the dementia patient in their everyday life, while determining the effectiveness of music and art to improve patient wellbeing. This will lead to the development of targeted guidelines to enrich the everyday life of the individual living with dementia.

The neural correlates of memory improvement following transcranial direct current stimulation combined with cognitive training
Donel Martin, University of New South Wales

Currently, there is no effective intervention available for people at risk of developing dementia. The development of an effective intervention is therefore a national priority. In 2013, the researchers commenced a world-first randomised control trial to investigate the effectiveness of a novel intervention for improving memory in people at increased risk for dementia - mild brain stimulation combined with cognitive training.

Preliminary results indicated this combination is 2-fold more effective than cognitive training alone for improving memory in people diagnosed with amnestic mild cognitive impairment (aMCI). This trial is due for completion in early 2016. Researchers plan to use functional magnetic resonance imaging the first-time, to investigate the neural mechanisms for memory improvement following mild brain stimulation combined with cognitive training.

Twelve participants diagnosed with aMCI will complete a memory task before and after completing 15 sessions of mild brain stimulation combined with cognitive training. Analyses will examine neural changes and potential associations with objectively assessed memory improvement following the intervention. Results will directly inform which aspects of this promising new intervention should be modified to further enhance treatment effectiveness.

'Beauty and the Brain' - A novel approach to anhedonia in dementia
Muireann Irish, University of New South Wales

Research aimed at understanding the subjective experience of an individual with dementia is lacking, yet studies of this nature are pivotal to improving patient wellbeing. This study aims to determine the extent to which an inability to experience pleasure - otherwise known as ‘anhedonia’ - is present in younger onset dementia.
CONSUMER FOCUS

Greater say in end of life care for people with dementia

Late last year, the Victorian Department of Health and Human Services issued the discussion paper Greater Say for Victorians: Improving end of life care. It coincided with a Parliamentary review and enquiry into how Victoria’s health system delivers end of life care, and where it can improve.

Alzheimer’s Australia Vic had the opportunity to put forward a response on behalf of people with dementia and their carers based on consumer feedback provided over the years.

Alzheimer’s Australia Vic’s submission identified the following priority areas:

• Palliative care services need to improve communication and community awareness so that people can make an informed choice.
• Advance care planning and substitute decision makers should be discussed when a serious illness is diagnosed, and health professionals should help people plan for the future.
• Health care providers and social services must work together so people can access the services and assistance they need.
• If a person with dementia no longer has capacity to make medical decisions, carers should be included in all care planning, not just in acute or end stage discussions.
• The workforce needs to be trained in the unique needs of people with dementia, understand the stigma and sensitivities that surround a diagnosis and be comfortable having difficult conversations with patients and their families.
• People with dementia need access to proper pain management, must not receive inappropriate or unwanted medical procedures and should be able to receive comfortable care in a setting of their choice.

If you would like to read more about the experiences of people impacted by dementia in the area of end of life care, read Alzheimer’s Australia’s 2014 report End of Life Care for People with Dementia, at bit.ly/viceolc

While the Department is no longer taking contributions, you can read what the community had to say, and vote on the ideas you support by visiting betterendoflife.vic.gov.au

Join Alzheimer’s Australia Vic’s consumer advocates network

In 2016, Alzheimer’s Australia Vic will be opening up opportunities for more consumers to contribute towards positive change.

If you are interested in dementia care, research, improving health services, the aged care sector or sharing your personal story, we invite you to join our new consumer network.

You will receive invitations to a range of interesting, diverse activities. No prior experience in consumer advocacy is required - just a passion for raising awareness about dementia.

For more information contact Alzheimer’s Australia Vic’s Consumer Engagement Officer. You will find contact details at the bottom of this page.

Share your story: Family and carer input into medical decisions

In the coming months, Alzheimer’s Australia Vic will be hosting a consumer forum to explore how families and carers have been, and could be, included in medical decisions for people with moderate to advanced stage dementia, living in residential aged care facilities. If you have a personal story you would like to share, positive or negative, Alzheimer’s Australia Vic is taking expressions of interest now.

Your stories and ideas will be used to develop a report to be published later this year. All stories will be de-identified. One-on-one interviews can be arranged for people with transport issues or privacy concerns.

Contact the Consumer Engagement Officer to learn more.

Consumer Advisory Committee vacancies

Alzheimer’s Australia Vic is currently seeking applications from people interested in joining its Victorian Consumer Advisory Committee (current members pictured above).

The Victorian Consumer Advisory Committee is made up of consumer representatives from across the State. Through meetings and advocacy, the committee provides a unique insight into life with dementia.

Applications from people of all ages, representing all stages and types of dementia will be considered, including people living with dementia, people from rural and regional areas, from diverse backgrounds and current and former carers.

Contact the Consumer Engagement Officer, or visit vic.fightdementia.org.au to download a nomination form.

Celina Day, Consumer Engagement Officer celina.day@alzheimers.org.au | 03 9816 5720
REHTHE001A Develop and deliver Montessori based activities as part of a cognitive rehabilitative therapy model

On completion, this two-day unit will equip participants with the required knowledge and skills to provide rehabilitative therapies for people living with dementia.

This nationally recognised training provides participants with the opportunity to gain a statement of attainment for the successful completion of this unit of competence.

Cost: $405 Members | $450 Non-member
Dates: Wednesday 27th & Thursday 28th April
Location: Parkville

Dementia – breaking down the myths

Join us to find out what dementia is and what it is not. This seminar will explain, in simple terms, what dementia is including main causes, especially Alzheimer’s disease, key signs and symptoms and risk factors.

It will also explain why changes to behaviour occur. Common myths and misconceptions about dementia will be addressed as well as concerns you might have.

In addition, the seminar will explain the importance of seeking a diagnosis if noticing changes and how you can access further information as well as appropriate support and services if and when needed.

Package & Save

Doorway to dementia + Applying person-centred communication

Our intensive value-packed Package & Save study days combine two of our most-popular workshops for a cost-effective, intensive and rich learning experience.

Doorway to dementia provides you with knowledge of dementia and its implication for practice. Learn about specific approaches and strategies to support a person living with dementia and their families.

Consolidate your foundation level knowledge of person-centred communication and learn more advanced strategies to support a person living with dementia and their carers.

Cowes Tuesday 8 March
Sunshine North Wednesday 20 April
Shepparton Wednesday 25 May
FREE

Geelong Wednesday 13 April
Drouin Wednesday 13 April
Bendigo Tuesday 19 April
COST $120

Bookings: vict.fightdementia.org.au/education | vic.education@alzheimers.org.au | 03 9816 5708
What the Hell Happened to My Brain? Dementia and Me
Kate Swaffer (2016)

Kate Swaffer was 49-years-old when diagnosed with a form of younger onset dementia. In this book, she offers an all-too-rare first-hand insight into that experience, sounding a clarion call for change when it comes to how we ensure a better quality of life for people with dementia. Kate describes vividly her experiences, exploring the effects of memory difficulties, loss of independence, leaving long-term employment, the impact her diagnosis had on her teenage sons, and the enormous impact of the dementia diagnosis on her sense of self.

Our dementia resources blog
dementiaresources.org.au

We will update you every three to four weeks with a different topic. Some recent posts have been on spirituality and dementia, how to design a more dementia-friendly home, younger onset dementia, films and fiction that have a theme of dementia, along with many others. Take a look and if it is of interest to you please sign up for regular posts.

Our library catalogue
dementialibrary.org.au

This national catalogue contains information about items held in the Victorian collection along with other states and territories. You can visit online or call the library if you would like to check something.

Before I Forget
How I Survived a Diagnosis of Younger-Onset Dementia at 46
Christine Bryden (2015)

When she was 46, Christine Bryden – Science Advisor to the Prime Minister and single mother to three daughters – was diagnosed with younger onset dementia. Doctors told her to get her affairs in order as she would soon be incapable. Twenty-years later she is still thriving, still working hard to rewire her brain, even as it loses its function. The unusually slow progress of her condition puts Christine in a unique position to describe the experience of dementia.

People with Dementia Speak Out
Edited by Lucy Whitman (2015)

Twenty-three people from diverse backgrounds share their experiences of living with dementia. The contributors are honest about the frustrations and fears they face, but overall there is remarkably little self-pity and a great deal of optimism. Their personal accounts demonstrate that with the right support at the right time, and above all with opportunities to continue to contribute to society in a meaningful way, it is possible to live well with dementia.

Nothing about us, without us! 20 Years of Dementia Advocacy
Christine Bryden (2016)

A dementia advocate for 20 years, Christine Bryden has been instrumental in ensuring people with dementia are included in discussions about the condition and how to manage and think about it. This collection of hard-hitting and inspiring insider presentations promotes self-advocacy and self-reflection. Provocative and insightful, the pieces included in the book address the issues that demand attention.
FUNDRAISING IN THE COMMUNITY

Enjoy an Afternoon Tea to Remember with Ita Buttrose AO, OBE

Don’t miss out on this unique opportunity to join Australian icon and Alzheimer’s Australia Ambassador Ita Buttrose for an ‘Afternoon Tea to Remember’, at Melbourne’s most renowned grand hotel, The Windsor.

Meet the legendary media editor, business woman, TV personality and best-selling author. Upon arrival, enjoy a glass of French sparkling wine before indulging in exquisite pastries, traditional scones and ribbon sandwiches, presented on three-tiered stands in the splendid, heritage-listed Grand Ballroom.

In Melbourne for only two days, Ita will host a weekend of afternoon teas, during which she will share stories about her incredible experiences and mingle with guests to create a truly memorable experience.

All profits raised from the events will support the ongoing work of Alzheimer’s Australia Vic.

Secure your ticket for this rare chance to meet Ita Buttrose, while supporting an important cause. The events will take place on Saturday 19 March and Sunday 20 March between 2.30 and 4.30pm, and tickets cost $99. Limited seats are available, so be quick!

To book, call 03 9633 6004 or email reservations@thw.com.au

Are you ready to Run Melbourne?

Alzheimer’s Australia Vic has been selected as a Champion Charity for this year’s Run Melbourne! Register for the half-marathon, 10km or 5km runs, get fit and raise vital funds to help fight dementia.

The event is scheduled to take place on Sunday 24 July. For more information visit bit.ly/vicrunmelb16

Hair-raising exploit to help fight dementia

Community fundraiser Amy Saunders recently had her head shaved courtesy of her CEO, in aid of Alzheimer’s Australia Vic. Amy raised an incredible $3,323 - a figure her employer iSelect subsequently promised to match.

Amy’s effort was in honour of her Granddad, who is living with Alzheimer’s disease.

Alzheimer’s Australia Vic would like to thank Amy, iSelect and everybody else who showed their support.

The head-shave can be seen in full, thanks to a special YouTube video. You can check it out by visiting bit.ly/vicamysaunders

Experience A Trek to Remember this October

Alzheimer’s Australia Vic brings you the latest in our A Trek To Remember series, presenting two unique opportunities to combine raising money for Alzheimer’s Australia Vic and conquering a physical challenge in Tanzania or Vietnam.

These once-in-a-lifetime opportunities will both held in October 2016. Choose between trekking Kilimanjaro in Tanzania, the iconic highest peak in Africa and highest free-standing mountain in the world and trekking, cycling and kayaking amongst Vietnam’s beautiful rural landscape.

For more information contact Kristin Marshall, Alzheimer’s Australia Vic Community Fundraising Officer on 03 9816 5746.

Below: A selection of the creative tea cosies up for auction
Why is leaving a gift in your Will to a charity like Alzheimer’s Australia Vic so important?

Gifts in Wills are increasingly common as more and more Victorians realise that it is their opportunity to leave a legacy and make a difference to the lives of others when they are gone.

Known as a bequest, a gift in your Will helps to ensure Victorians receive the best services and most cutting edge programs available. It will also help improve the quality of life of people living with dementia and fund crucial research to ensure future generations can look forward to a life without dementia.

When you think about it, a bequest costs you nothing now, but will have a lasting impact in the future.

You may ask, how can my bequest make a difference?

To Alzheimer’s Australia Vic, every gift – no matter how large or small – is incredibly important. Some bequests we have received have been set up as educational grants and enabled members of the aged care profession to attend important conferences or undertake vital studies to assist people with dementia. Other gifts have seen researchers create new ways to diagnose dementia or develop virtual learning environments. But most importantly, each gift has been used to help others and is bringing us one step closer to creating a future without dementia.

As you would have read on pages four and five of this publication, the number of people being impacted by dementia is rapidly increasing in Australia. It is the second leading cause of death and there is no cure.

But together we can beat dementia. Including Alzheimer’s Australia Vic in your Will is the ultimate gift you can make to enhance the lives of all Victorians living with dementia.

For a confidential discussion on leaving a bequest please call Natalie Sikora, Planned Giving Manager, on 03 9816 5776

“For sure there’s a lot of research that needs to be done but we need to have the everyday coping mechanism and support. “Just to ring up and talk to someone. I know your organisation will help. That’s what I want my bequest to do.”

Alison Ingamells

“Because of the help I received when this disease struck down my beautiful wife, I’ve included Alzheimer’s Australia Vic in my Will. They changed my life. I believe in them, they are a wonderful organisation.”

Les Courtney

“Gifts in Wills allow us to keep progressing, to support people living with dementia and provide them with the best possible services.

“Every bequest will help secure our future”

Barbara Potter

“For your free copy of our Will Instruction Booklet, information about bequests, or a confidential discussion please contact Natalie Sikora on 03 9816 5776 or natalie.sikora@alzheimers.org.au

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Improving the lives of people with dementia is important to me.

Please accept my donation of $_________

☐ My cheque is enclosed OR ☐ Please debit my credit card

Please debit the above amount from my credit card:

☐ Monthly ☐ Quarterly ☐ Half yearly ☐ This time only

Card details

☐ Mastercard ☐ VISA ☐ AMEX ☐ Diners

Expiry date ___________________ CCV ___________________

Cardholder’s name _______________________ 

Signed ________________________

☐ 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

Title ________________________ First Name ________________________

Family Name ________________________

Organisation (if applicable) ________________________

Address ____________________________________________

Postcode ________________________

Telephone ________________________ Mobile ________________________

Email ____________________________________________

Donations of $2 or more to Alzheimer’s Australia Vic are tax deductible.

Please send your donation to:
Alzheimer’s Australia Vic
Locked Bag 3001, Hawthorn 3122

For more information contact:
Telephone 03 9815 7800 Facsimile 03 9815 7801

ARBN 0013779R | ABN 1467 184 0186