The future of dementia care – a time to make choices

“I am a daughter, sister, nurse, mother and grandmother and now, at my age, face one of the most challenging roles of all as a carer.”

These are the articulate words of Kerrie Barnes, pictured above with her husband Robert at their rural property one hour south-east of Melbourne. Robert was diagnosed with Alzheimer’s disease four years ago at the age of 63. Kerrie is now his full-time carer.

With the number of people with dementia increasing in Australia, we will continue to rely on people like Kerrie and this important group of our workforce – our carers – into the future. A new Access Economics report has confirmed the growing social and economic problem this presents to Australian society in coming decades.

Launched in May, the Making Choices – Future Dementia Care report found that without policy changes or a medical breakthrough, Australia will face a shortage of both paid and unpaid carers of 153,000 by 2029. Of these carers, there will be a shortage of nearly 60,000 paid staff in high care residential aged care facilities and a shortfall of 94,000 unpaid family carers.

“These new and disturbing figures call for action from governments, business and the community about how we are going to manage future dementia care needs in this country,” Glenn Rees, Chief Executive Officer of Alzheimer’s Australia said.

The report found that our current workforce of paid and family carers of people with dementia will need to increase significantly – by 76 per cent within two decades – to meet the anticipated rapid rise in demand for dementia care services over this time.
Like many charities across the country, Alzheimer’s Australia Vic was founded by volunteers. Many of our members would know that in 1983 a group of carers concerned about the lack of information and support available to people living with dementia, volunteered their time to set up a support group for carers.

Thanks to the passion of those volunteers, Alzheimer’s Australia Vic was born and today we are an independent, not-for-profit organisation and Victoria’s peak body for people living with dementia. Last year we supported 30,000 people across the state – so we certainly owe a great deal to the volunteers who founded our organisation 26 years ago.

Today, the ongoing sustainability and day-to-day operations of our organisation continue to be supported by our dedicated volunteers.

In May we recognised the contribution our volunteers make with a special thank you afternoon tea during National Volunteers Week.

Last year our 100 plus volunteers clocked up an incredible 5,500 hours of time working with us. Some of these volunteers work as Helpline advisers on our National Dementia Helpline, others assist with vital administrative work or undertake public speaking engagements and share their personal experiences with dementia.

Whatever their job, our organisation would not function or exist without them and I would like to personally thank all of our volunteers for the time and energy they commit to their work with us.

While we have a strong and dedicated team of volunteers we’re always looking for more. If you’re interested in becoming a volunteer or would like to know more about volunteer opportunities with us, contact our Coordinator of Volunteers, Judith Allen on 03 9815 7847.

I hope you enjoy reading the June 2009 issue of The Memory Matters.

Lynette Moore
Executive Director

Ps. As this newsletter was going to print, the Victorian and Commonwealth budgets had just been handed down. Both, at first glance, seemed silent on dementia. But at Commonwealth level 2010 is our year of ‘big expectations’ for dementia. And at State level we are following through on the detail. I’ll report back to you on this in the next edition of The Memory Matters.
“This clearly highlights that workforce issues, both in respect to paid and unpaid carers, must be given centre stage in current policy thinking to address how we will care for the predicted 465,000 Australians who will have dementia in 2030,” Mr Rees said.

In addition to the startling figures about the lack of carers available in coming decades, the Making Choices report also presented the results of a survey of family carers.

“As we look at the future economic and social issues surrounding dementia care, it’s critical that we look at what is working for family carers now. So Access Economics surveyed carers about their preferences on the range of community and residential services that are currently available to them,” Mr Rees said.

“The survey found that a service option which includes home support services such as shopping, transport and cleaning rated highly among carers, along with access to respite care. When looking at residential care, privacy, dignity and an understanding about the impact of dementia on a person rated highly.”

Mr Rees says the survey results indicate that there is a need for radical new thinking in terms of how family carers are supported, “...as well as the choices that they, and the people they care for, are able to make between the mix of community and residential care services available,” he says.

Kerrie and Robert are yet to decide on the home support services they will need to manage Robert’s illness into the future. They live at home and manage to get by with regular support from their family and friends. But looking at the Access Economics report recommendations, Kerrie believes a key priority for governments should be increasing the training and education available to carers, particularly unpaid carers.

“I’m a trained nurse and my daughters are nurses so I’m lucky – I have some knowledge and get support,” Kerrie says, “But with more support and training on strategies Robert and I can put in place to manage his illness and care, the less stress will be placed on the community into the future.”

The Making Choices – Future Dementia Care report was presented to the federal, state and territory governments and opposition parties in May. The report identified key recommendations that Alzheimer’s Australia believes must be addressed to ensure the future care needs of Australians with dementia, and the carers who support them, are met.

Some of the key recommendations presented to governments from the Making Choices – Future Dementia Care report include:

- Expand the availability of community and residential care services for people with dementia.
- Increase access to information to enable people with dementia and their carers to make informed choices.
- Improve workforce training to create a skilled paid and informal dementia care workforce.
- Better assist carers to balance their work and caring responsibilities, including through access to long day respite care and greater workforce flexibility.
- Increase investment in dementia research – whether cause, cure or care – as this is a key strategy for addressing the epidemic.

For a full copy of the report and recommendations please visit www.alzheimers.org.au. Alzheimer’s Australia thanks Pfizer for funding half the cost of Making Choices – Future Dementia Care through an unconditional grant.
International Conference on Alzheimer’s Disease 11–16 July
As a member of Alzheimer’s Disease International, Alzheimer’s Australia will be paying close attention to the International Conference on Alzheimer’s Disease (ICAD) being held in Vienna from Saturday 11 July to Thursday 16 July. Over 4000 people are expected to attend this year’s conference to hear top dementia researchers from around the world present revolutionary and exciting information from latest research. This annual conference is known as the world’s leading forum on dementia research. For more information about the conference visit the ICAD website at www.alz.org/icad.

National Missing Person’s Week 3–9 August
Alzheimer’s Australia will work with the Australian Federal Police on their National Missing Person’s Week campaign this year. Held in early August, the focus for the 2009 campaign is the elderly population and in particular, people with dementia who are a key group at risk of going missing.

Four families of missing persons will be used as the ‘face’ of the National Missing Persons Week media advertising campaign, sharing their story of not knowing where their loved is, the ongoing darkness that surrounds this, and the glimmer of hope that keeps them going day-to-day.

Along with Homelessness Australia, we look forward to being one of the Australian Federal Police’s key partners on the National Missing Person’s Week 2009 campaign.

For further information about Alzheimer’s Australia Vic’s involvement with the campaign in Victoria, contact Michelle Low on 03 9816 5741 or mlow@alzvic.asn.au.

Wandering and going missing is quite common among people with dementia and can be very worrying for families and carers. We produce a Help Sheet that looks at reasons for wandering and suggestions on how to manage it. Visit www.alzheimers.org.au or call our National Dementia Helpline on 1800 100 500.

Dementia Awareness Week 2009
Plans for Alzheimer’s Australia’s annual Dementia Awareness Week are well underway. Our national awareness week is held each year to raise awareness about dementia and raise funds to support the work of Alzheimer’s Australia.

The week coincides with World Alzheimer’s Day which is held on 21 September each year.

This year Dementia Awareness Week will run from Tuesday 15 to Friday 25 September (yes, we know – it’s actually a ten day week!) and a variety of events and activities are being organised by Alzheimer’s Australia across the country.

Professor Constantine Lyketsos

Professor Constantine Lyketsos MD from the United States has been invited by Alzheimer’s Australia to speak in each capital city as a central figure in activities for 2009. An active clinician, teacher and researcher, Dr Lyketsos is based at the Johns Hopkins University, America’s first research university. An expert in the care and treatment of patients with Alzheimer’s and related dementias, Dr Lyketsos has carried out pioneering work regarding epidemiology and treatment of neuropsychiatric features of Alzheimer’s disease. He has been cited in ‘America’s Top Doctors’ and ‘Best Doctor in America’ and has authored more than 250 publications, book chapters, commentaries and guest-edited several journal special issues.

Dr. Lyketsos will be in Melbourne on Thursday 17 September to speak at an event organised by Alzheimer’s Australia Vic. Further details will be announced soon. Dr. Lyketsos’ time in Australia will culminate with a presentation at the National Press Club in Canberra on Wednesday 23 September.

For further information about Dementia Awareness Week activities in Victoria contact Kate Morton on 03 9816 5772 or kmorton@alzvic.asn.au.

Popular DVD updated
Our Understanding Dementia DVD, produced in 2005, provides an introduction to dementia for family carers and service providers. In the DVD medical professionals explain dementia’s causes and symptoms and people living with different stages of the condition speak about how it affects their lives. We updated the popular DVD in 2006 to make it available in a variety of community languages. We’re pleased to announce that the Understanding Dementia DVD now includes an English caption – making it suitable for people who are deaf or hearing impaired.

To loan or purchase a copy of the Understanding Dementia DVD or to find out what other DVDs and video resources we have please contact our library on 03 9815 7800.

Research goes global
We were pleased to learn that research findings commissioned by Alzheimer’s Australia Vic recently appeared in the Journal of Chinese General Practice. In 2005 we commissioned Victoria University to undertake a study to examine the effectiveness of community based public health interventions in producing lifestyle changes. The results of the research were used to inform the progress of dementia risk reduction strategies that contributed to development of Alzheimer’s Australia’s Mind your Mind program (see page 12). The report findings were recently published in the Journal of Chinese General Practice. It is great to see Australian research on dementia risk reduction available internationally.
New board member

In May we welcomed Fiona Mason to the Alzheimer’s Australia Vic’s board.

We look forward to the wealth of knowledge and experience Fiona will bring to our organisation. Fiona’s professional experience is built upon 25 years in media and marketing positions within the advertising and banking industries. Starting her career in advertising at Clemenger and then Ogilvy and Mather she then took up the position of Marketing Manager for the Bank of Melbourne for a seven-year period. In 1995 she founded The Marketing Bank, providing strategic marketing services and an outsourced marketing function to clients in both private and public companies across a broad range of industries.

Fiona is currently the Strategic Planning Director for Hayes Berry Tehan an Australian advertising agency, developing marketing strategies for growth for her clients.

Ethnic radio campaign on the airwaves

Alzheimer’s Australia Vic has received a one-off grant from the Victorian Department of Human Services to develop and implement an ethnic radio campaign to raise the awareness of dementia in three ethnic communities: Chinese (both Cantonese and Mandarin speaking), Greek and Vietnamese.

The campaign will consist of one 45 second community service announcements in each language and a series of interviews. The audio material is currently being produced in partnership with the Chinese Community Social Services Centre, Australian Greek Welfare Society and the Australian Vietnamese Women’s Welfare Association.

Stay tuned for further details about the campaign. For more information contact Natalija Nesvadba on 03 9816 5786 or nnesvadba@alzvic.asn.au

Sweet Memory rose

Released in 2007 and named for Alzheimer’s Australia Vic to raise awareness about dementia, the ‘Sweet Memory’ rose is available from Treloar Roses. The bare root plants are available throughout winter and ten per cent of proceeds from each rose is donated to Alzheimer’s Australia Vic. Order your rose online at www.treloarroses.com.au or call 03 5529 2367 or purchase from your local nursery. Alzheimer’s Australia Vic gratefully acknowledges the support of Treloar Roses.

That’s entertainment!

We are pleased to offer our members the 2009/2010 Entertainment™ Book. The book is now on sale for $65.00 and it offers big discounts on restaurants, hotels, sports and leisure activities. We receive 20 per cent of the price of every book sold, so it’s an important source of funding for us.

To order your copy, please visit www.alzheimers.org.au and download an order form or contact Asha Sandifer on asandifer@alzvic.asn.au.

The Memory Matters goes green

As a member of Alzheimer’s Australia Vic, you would be well aware that one of your membership benefits is receiving this newsletter, The Memory Matters, four times a year. As part of our organisation’s ongoing commitment to the environment we’re pleased to announce that The Memory Matters is going green. We can now offer our members the opportunity to receive future issues of The Memory Matters electronically.

Sending the newsletter out electronically is not only good for the environment but it will also mean we can re-direct printing costs to services that directly assist people with dementia, their families and carers.

Of course, if you prefer to continue to receive printed copies of the newsletter – this will not change.

If you would like to receive future copies of The Memory Matters electronically, please email Kate Morton at kmorton@alzvic.asn.au.
Combination therapy may slow Alzheimer’s decline

Two recently reported studies from the US involving hundreds of people with Alzheimer’s disease, found that a combination of two drugs worked best in slowing decline in daily life activities and in cognitive function. Currently cholinesterase inhibitors (Aricept, Exelon and Reminyl) are prescribed in early stage Alzheimer’s and memantine (Ebixa) is prescribed in later stages. These recent studies suggest that a combination of a cholinesterase inhibitor and memantine may be the most effective treatment for all stages of Alzheimer’s.

These findings will likely spark a new debate about how and when memantine should be prescribed. It is an expensive drug and is currently only subsidised in Australia for use on its own in more advanced Alzheimer’s disease. We will keep you up to date with any future changes to the approvals and subsidies for the Alzheimer’s drugs in The Memory Matters.

No evidence that ‘brain training’ can prevent dementia

Two recently published reviews examined studies of cognitive interventions, or ‘brain training’, in healthy older people. These interventions are structured programs, often computer based, purported to be designed to improve brain function. They do not include everyday brain activities such as crosswords and reading. One review included ten studies and the other seven, so not a lot of research has been completed in this area to date. Some of the studies have found small improvements in cognitive skills following training, mostly in the areas of cognition that were trained. Whether cognitive training can slow decline in general cognitive skills and daily functioning or prevent progression to dementia has not been determined.

The authors of both reviews concluded that there is no evidence yet that structured brain training programs can delay or prevent the onset of dementia, and that future research should address this with well designed trials. The authors of both reviews concluded that there is no evidence yet that structured brain training programs can delay or prevent the onset of dementia, and that future research should address this with well designed trials.

The future for early detection of Alzheimer’s disease

Diagnosis of Alzheimer’s disease and other forms of dementia currently relies predominantly on the clinical symptoms and history of the person, and the skills of the doctor. The Journal of Nutrition, Health & Aging recently published a special issue focussing on promising new techniques for the early detection of Alzheimer’s. These include brain imaging methods to look at atrophy (shrinking) in specific brain regions or the amount of amyloid (protein) build up in the brain, and measuring changes in protein levels in the blood or cerebrospinal fluid.

This area of research is very important as it will lead to being able to detect the presence of Alzheimer’s disease before symptoms are apparent. When disease modifying treatments become available they will need to be given as early as possible to prevent the onset of dementia.

The impact of residential respite on people with dementia and their carers – La Trobe University

This project is recruiting people with dementia (any type) and their carer, who are planning to use residential respite. The study involves interviews with the person with dementia and their carer before and after the episode of respite. The study will investigate the impacts of residential respite on both family carers and people with dementia.

Contact Bridget Ryburn: 03 9479 5769.

Wayfinding while driving, differences between age groups and with and without dementia – Monash University

This project is recruiting people with dementia (any type) who are currently driving and also people who are a regular passenger in a car driven by someone with dementia. The participant will be sent a questionnaire to complete at home. The study will investigate how drivers with dementia find their way and the relationship between drivers and passengers.

Contact Kelly Bryden: 0466 329 875.
Clinical trials of potential medications for Alzheimer’s disease – Austin Health

This is not an individual project but an ongoing call for participants for clinical trials of new medications. The Medical and Cognitive Research Unit at the Austin Hospital has several trials running and is always looking for more participants. The unit is recruiting people diagnosed with Alzheimer’s disease, who have a carer who can accompany them to study visits, and who are fluent in English.

Contact Jenny Cvetkoski: 03 9496 4243.

Balance and exercise for people with Alzheimer’s disease

La Trobe University and the National Ageing Research Institute (NARI) are collaborating on a project comparing two home-based programs for people with mild to moderate Alzheimer’s disease.

One program involves a physiotherapist monitored six-month home exercise program and the other, an occupational therapist delivered home-based program of information and education. All participants will have a balance assessment at NARI in Parkville initially, then after six months and 12 months.

For further information please contact Plaiwan Suttanon: 03 8387 2383.

Did you know?

- In Australia 234,640 people have dementia with the number expected to be 731,030 by 2050 unless there is a medical breakthrough.
- One in four Australians with dementia are Victorian. That’s 60,000 people, with the number expected to be 84,000 by 2020 and 176,000 by 2050.
- There are 141 new cases of dementia every day in Australia, 41 new cases in Victoria.
- One in six people with dementia in Victoria are from an ethnic background and do not speak English at home.

IN THE COMMUNITY

Victorian Senior of the Year Awards 2009

Do you know a Victorian resident aged 60 years and over who is making an extraordinary difference to their community? Nominate them for Victorian Senior of the Year.


Younger Onset Dementia specialist diagnostic services

The Eastern Cognitive Disorders Clinic at Box Hill Hospital offers a diagnostic service for people with younger onset dementia.

Call the Outpatients Department: 03 9896 3353. For appointments (Thursday mornings only) fax your referral to 03 9895 4852.

The Royal Melbourne Hospital Neuropsychiatry Unit is a state-wide specialist service that also offers a diagnostic service for people with younger onset dementia.

Contact the Neuropsychiatry Unit: 03 9342 8750 or email info@neuropsychiatry.com.au or visit www.neuropsychiatry.org.au

Living with Memory Loss programs

Alzheimer’s Australia Vic runs Living with Memory Loss programs for people with younger onset dementia. We cover topics including understanding younger onset dementia, developing strategies to deal with memory loss and other changes, latest developments in treatment and preparing for the future.

Call the National Dementia Helpline: 1800 100 500.

Tastes to Remember events

This series of multicultural events raise awareness about dementia in a culturally appropriate way. The events combine social activity (entertainment and food) and information about memory changes, dementia and support services available. A variety of events are planned across Victoria in 2009 and Alzheimer’s Australia Vic thanks State Trustees for its generous support.

Call Natalija Nesvadba: 03 9816 5786 or nnesvadba@alzvic.asn.au
Richard Buxton: on a journey for a cure

Managing Director of Melbourne-based Buxton Construction and Property Group, Richard Buxton has a love and passion for adventure. Since 2001 he has focused this passion – and his boundless energy and determination – towards raising awareness and significant funds to find a cure for dementia.

It all began with a desire to replicate the voyage undertaken by explorer Matthew Flinders over 200 years ago. Richard has since circumnavigated the Australian coastline – a journey of 12,000km – twice. It started with a flying journey around Australia in 2002 and 2003, followed by a voyage by yacht from 2005 to 2007. His adventures have now culminated in a book If Matthew Flinders Had Wings. Richard has made a significant commitment to our organisation – he has pledged the first $500,000 in proceeds from the book to go to Alzheimer’s Australia to fund research into a cure for dementia.

When did you get the idea to travel around Australia to raise money and awareness about dementia?

Richard: My dream of circumnavigating the country started well before I had a connection with Alzheimer’s disease or mental health issues in general. But it was in 2001 when I was planning my trip to fly around the country that a friend suggested I use my journey as a way to raise awareness about Alzheimer’s disease and funds for research. I thought at the time: ‘There’s something in this.’ And there was. It turned out we had a great deal of media coverage on that first trip . . . in print, radio and television news around the country about the flight, Alzheimer’s disease and our plan to raise money for research.

When you got back from your flight around Australia your involvement with dementia became personal – what happened?

Richard: When I got back my mother was not as well as when I left. She had become quite ill. It turned out she had dementia and other health complications.
The Big Interview

Mum was always so mentally active her whole life. To see her suffer and lose herself and her lifestyle disappearing was hard. It really affects you. For her to then confuse me with someone else was upsetting. And the fighting and aggravation that used to come and go – from her frustration at what was happening to her – I wanted that to go away. It made me realise that you can take medication for a number of ailments and illnesses to extend life – but once your brain is gone, you go too.

Following your mother’s illness, you became even more motivated to find a cure for dementia? Is this when you began planning your second trip?

Richard: Yes, around that time I was also opening Rylands, our independent retirement facilities. Combined with what Mum was going through with dementia, my travels around the country and my business entering into a new area of national retirement homes – it all came together.

In 2003 I realised I wanted to make a bigger thing of it. I wanted to take a second journey around Australia – this time sailing – to raise even more funds for dementia research. So that’s exactly what we did in 2005 to 2007.

Richard: I think it’s about a lack of understanding and awareness. And it’s not just about dementia – it’s about mental illnesses in general. I think they’re all connected, but there is a sense that it should be swept under the carpet. I have personally had epilepsy all my life and I’m happy to talk openly about it.

In the past Alzheimer’s Australia Vic has had trouble finding people, particularly those who have a high profile, willing to make public their personal experience with dementia – whether it’s their partner, parent or grandparent. Why do you think that is?

Richard: I think it’s about a lack of understanding and awareness. And it’s not just about dementia – it’s about mental illnesses in general. I think they’re all connected, but there is a sense that it should be swept under the carpet. I have personally had epilepsy all my life and I’m happy to talk openly about it.

Do you think the corporate sector could do more to raise awareness about dementia?

Richard: We certainly have to get more corporations on board. There’s long been favour by corporations for other causes, such as cancer, heart disease etc. And yes all illnesses deserve attention but dementia has always been put in the background. But I think corporations are now at the point where they know the illness is important and needing support. And the more we can get from corporations to support and participate in this cause – if we can get just five per cent of corporate and philanthropic donations – the greater the chance we have of finding a cure.

In isolation, general awareness about all mental illnesses is spread thinly. But I really think if we all put in together and use our voices to speak up about dementia and mental illnesses I think we can make a difference and have an impact.

So what do you see as the answer to the dementia epidemic?

Richard: When it comes down to it, it’s about money. Researchers have an idea on how to get there, on how to find a cure for dementia, but they haven’t got the money. We need to find the money. We need to fund research for a cure, so this illness won’t be a problem for future generations.

Copies of Richard Buxton’s book If Matthew Flinders Had Wings are now on sale. To purchase a copy go to www.epsilonresearch.com.au and fill in an online order form, email emoffat@buxtongroup.com.au or call Lib Moffat on 03 9644 7000.

Alzheimer’s Australia thanks Richard for his significant commitment to supporting dementia research in Australia.
In conversations and interactions with people living with dementia, the lack of respect they feel they sometimes receive from within the community, including at times from their own friends and family members, seems to be foremost on their minds. Members of our Consumer Reference Group identified ‘respect’ as a topic in need of awareness. Member of the group Pamela Hore, pictured below, wrote this poem about respect following her experiences caring for her father.

**Respect**
*by Pamela Hore*

As I wend my way onwards take time to talk with me to find out who I have become; search slowly for who I was and find out what makes me tick so you may know how I feel today; love me, laugh with me, ask me about times past to discover my interesting news; listen to what I have to say, touch me carefully, hold my hand, treat me like a real person who is living a full and happy life; if I am tired and sleepy reminisce in your own mind about the good times we have had; never let me feel old and useless and above all the thoughts you have respect me; respect my family; ask them for their knowledge so they can help you care for me because I deserve dignity as I age and depend upon others to provide respect to keep me safe and warm.

In response to Pamela’s poem, below are some comments from consumers living with dementia, their family and carers about their experiences with respect or a lack of respect.

“It is so easy to be disrespectful to a person with dementia as their reaction to your attitude is often so far ‘under the surface’ it is hard to see. I find showing respect is a two step process. It involves honouring the person they were while at the same time respecting the person they have become. This can at times be difficult to do – but is always worth the effort!”

“Lack of knowledge about Alzheimer’s makes friends withdraw from you as they don’t know how to treat you.”

“A peaceful and happy community depends largely on the respect held by its citizens. When respect breaks down, problems arise. Lack of respect of other people’s age, state of health, religion, race, colour and occupation are just a few instances where this can occur. Pamela Hore’s beautiful poem expresses so well ways by which we can understand another human being, particularly one who is suffering with dementia.”

**THE BIG QUESTION**

**What is … promoting continence?**

For many people with dementia the prospect and reality of losing control of their bladder and bowel function is frightening and humiliating. Likewise for carers, managing and promoting continence can seem like a daunting and stressful challenge.

The reality is that people with dementia, just like other adults, are susceptible to the physical processes of ageing that can cause a loss of bladder and bowel function. Dementia adds an extra dimension and means the person may have other difficulties such as finding the toilet, putting all the activities of toileting in the right sequence or remaining seated long enough to finish the task. The good news is that many people with dementia recognise the urge to go to the toilet until quite late in the disease process so helping them with these other things can sometimes prolong continence.

When incontinence occurs the first step is to consult your doctor to obtain a full medical assessment. You may want to consult a continence nurse at this stage too.

If you’re caring for someone, promoting continence may seem like a difficult task. But there are measures that can be taken to promote and manage continence of the person you care for. Remember everyone is different so these are just some suggestions that may help.

- Ensure adequate fluids are being consumed – preferably water – from five to eight glasses a day (jelly, ice cream or custard can also be substituted).
- Reduce caffeine intake by using decaffeinated coffee and tea.
- Observe toilet patterns and suggest the person you care for uses the toilet at regular times based on their pattern.
- Help the person to find the toilet by leaving the door open or using signs or pictures and leaving the light on at night.
- Use a raised toilet seat if the person has trouble getting on and off the toilet.
- Losing control of your bladder and bowel can be humiliating and embarrassing for the person with dementia and their carer but try not to worry too much. Keeping the person clean and making light of the situation may help alleviate anxiety.

You can get help managing continence in a number of ways. Alzheimer’s Australia Vic runs a Promoting Continence in the Home course for family members and friends. We run a separate course called Promoting Continence in People with Dementia for aged care workers. See pages 15 and 16 for course dates and details.

Information about promoting continence is also available on our Continence Help Sheet. Visit www.alzheimers.org.au or call our National Dementia Helpline on 1800 100 500.

Confidential advice and information is also available from the Continence Foundation of Australia. Contact their helpline on 1800 330 066 or visit www.continence.org.au
George Bernard Shaw wrote ‘Life does not cease to be funny when someone dies any more than it ceases to be serious when someone laughs’ giving a nod to the old adage that laughter is often the best medicine.

In the case of Alzheimer’s disease this message is of particular importance as the person is not lost once, but is lost numerous times throughout their journey. Put simply, dementia is fraught with feelings of loss, pain, anger and guilt. All of which, at various times, can become overwhelming. The outlook, sadly, is no better as there is little anyone can do but sit back and watch as their loved one fades before their eyes.

For me, it was no different. My father, Alan Watt, was a prominent doctor until one day at the age of 54 he was diagnosed with younger onset Alzheimer’s disease. Understandably his diagnosis left a void in my life and in the lives of my family, and over the seven years which followed the diagnosis feelings of loss, pain, anger and guilt became entrenched within each of us. However, after a number of years something happened. The laughter began to return. At first it was fired in small embarrassed bursts, but very quickly the sense of humour that had permeated from the family before Alzheimer’s disease had joined us was back and flourishing.

For me, the sense of humour helped me to survive what I consider to be the most difficult years of my life. I was only 18 when my father was diagnosed and humour gave me a lifeline in those darker times. However, it was my father’s cheeky sense of humour that really made the journey bearable. As after seven years – despite his inability to talk coherently or recognise any one of us – his eyes will still sparkle on occasion as he grins at a joke only he knows, allowing us to see him clearly one last time.

I write this with the realisation that humour may not be your first point of call in dealing with Alzheimer’s disease or other forms of dementia, but please don’t let it be the last point either. Just as you have given yourself permission to grieve, it is also important that you give yourself permission to laugh. Laughing during these hard times should not be viewed as a sign of weakness nor neuroticism (although in the case of my family I’m not so sure), but as a sign that you are coping with some happiness intact. Laughter can be a way of maintaining connections with those around you going through a similarly difficult time. It can enable people to have more frank discussions about life and death and what comes next by breaking through the associated taboos. And more importantly laughter enables those caring for a loved one to face the challenges ahead with some degree of hope.

So I do not write this to say that you must laugh and joke your way throughout this journey, as at times there will be nothing to do but cry. Instead I write this to say that often the fondest memories are created when good friends laugh together. So laugh with your mother, laugh with your father and laugh with your friends, and who knows it might just make this journey a little bit more bearable.

Andrew Watt
Health checks are important for your heart AND your brain

Almost everyone understands the importance of having healthy blood pressure and healthy blood cholesterol for a healthy heart. But very few people know these are also really important for reducing dementia risk.

A Newspoll study undertaken for Alzheimer’s Australia found that less than one per cent of people who believed it was possible to reduce dementia risk, knew that reducing high blood pressure and reducing high blood cholesterol could help reduce dementia risk. And it’s not only blood pressure and cholesterol that are important - it’s also important to have a healthy blood sugar level and body weight.

Mind your Health Checks is one of the signposts in Alzheimer’s Australia’s Mind your Mind dementia risk reduction program.

“In Mind your Health Checks, we encourage people to have their blood pressure, blood cholesterol, blood sugar and weight checked, and if they are too high to have them treated”, says Cathy Cooper, National Dementia Risk Reduction Program Manager.

“If everything is fine, you should ask your doctor when these factors need to be checked again,” she said. For brain and heart health, it’s important to have regular check ups and follow any treatment advice for the long-term.

“We know from research that high blood pressure, high blood cholesterol, high blood sugar and obesity particularly during mid life increase dementia risk”, said Cathy. But there is some good news. Research has confirmed that treating high blood pressure helps to reduce dementia risk. At this stage we don’t have enough evidence to know for certain if treating high blood cholesterol, high blood sugar and obesity will reduce dementia risk, but it is likely that it will. So it’s very important to have these checked and treated if they are too high.

If you don’t know if your blood pressure, blood cholesterol, blood sugar and weight are at a healthy level for you, make an appointment to see your doctor. Your brain and your heart will thank you for it.
**How to … plan for the future**

Regardless of your age, health or life circumstances it’s a good idea to plan for your future as early as possible. This means making sure your financial and legal affairs are in place – for example having a Will and a Power of Attorney (financial) – long before any health issues arise.

If you have been diagnosed with dementia or if you’re caring for someone with dementia, planning for the future is something you need to consider and talk about. Sadly, the reality is that sooner or later the person with dementia will find their abilities decline and they will be unable to make their own decisions about their own financial, medical and legal affairs. For this reason it can, and will, make it much easier if you plan for the future.

**If you have dementia** you can make sure your future is in good hands by taking part in the planning of your affairs as early as possible in the course of your illness. You can make your own decisions and make sure that your future wishes are carried out in the way you would like. Talking with your family about your preferences for the future will also assist them to help you in the way you have chosen.

**If you are caring for someone with dementia**, planning for the future with your loved one will mean you are much better placed to cope with the changes that will occur to your situation and circumstances. By understanding what your loved one wants you will also have peace of mind that you are following their wishes as the illness progresses.

**Planning ahead means:**

1. **Having joint signatures on all financial accounts.** If a bank account is in joint names, the family member of the person with dementia can continue to operate it without any change in arrangements.

2. **Making sure all your important documents are the way you want them to be** – such as insurance policies, mortgage, superannuation and financial papers. Tell someone you trust where they are kept.

3. **Discussing your future financial affairs with a financial adviser, your family and friends.**

4. **Having a Will and making sure it is up-to-date** and the way you want it to be. It’s also important to know who the executor is and letting them know where your Will is kept.

5. **Signing an Enduring Power of Attorney (financial).** This is a legal document that enables you to nominate someone to look after your financial and legal affairs.

6. **Signing an Enduring Power of guardianship.** This enables you to nominate someone to make medical and lifestyle decisions for you. At some point in the future you may need extra assistance or care services in your home or it may be necessary to move into a residential facility. By signing an enduring power of guardianship you can make sure that your future wishes are carried out.

For further information on how to plan for your future call our National Dementia Helpline on 1800 100 500 or visit our website at www.alzheimers.org.au.

State Trustees can also guide you through the important legal and financial decisions for you and your family. For more information on State Trustees visit their website at www.statetrustees.com.au or call them on 03 9667 6444. Residents outside of the Melbourne metropolitan area should call 1300 138 672.

When Bill was initially diagnosed with dementia he created and activated an Enduring Power of Attorney (Financial) to help organise his financial needs.

Bill did not want to burden his family and appointed State Trustees – an independent and impartial Trustee company – to act as his Attorney.

Bill gave instructions to State Trustees on how he would like his financial and legal affairs managed. As Bill’s Attorney, State Trustees used their skills, knowledge and time to manage his affairs including payment of accounts and bills, liaising with Centrelink on entitlements, protection of his assets and any complex financial affairs.

Bill now has peace of mind that his finances are being managed by professionals so he can spend time with those close to him.

We thank State Trustees for providing this case study.
What’s new in the library?

Our library sits within the Dementia and Memory Community Centre at 100 Riversdale Road, Hawthorn. It’s packed with books, videos, DVDs and journal articles. Here are a few of our newest items. Why not pay us a visit?

Dementia, Design and Technology


This anthology answers an increasing need to understand design that supports the daily life of people with dementia. The aim of this book is to support the emerging research and development around this topic, which has stressed innovation and participation in the design process, as well as technical competence and the physical environment. However, the main focus is learning to understand the person affected by dementia as well as his or her subjective needs and desires.

Still Alice


(Fiction)

Neuroscientist and debut novelist, Genova, combines years of experience in her field to craft a realistic portrait of early onset Alzheimer’s disease.

The character Alice Howland is an esteemed psychology professor at Harvard, living a comfortable life in Cambridge with her husband, John, when the first symptoms of Alzheimer’s begin to emerge.

I’m still here: A Breakthrough Approach to Understanding Someone Living with Alzheimer’s


I’m Still Here is a glass-half-full look at Alzheimer’s disease that shows how to connect with someone through the fog of dementia and build a relationship with the person within. In I’m Still Here, Zeisel outlines his approach and demonstrates how people can incorporate it into their relationships with those who have Alzheimer’s.

LETTERS TO THE EDITOR

In the last edition of The Memory Matters, an anonymous writer to Letters to the Editor asked, “With so much information in the media about dementia, how do I determine what is good information that can help people, as opposed to what I should take with a grain of salt?”

Editor: Alzheimer’s Australia Vic recognises the vital role that journalists play as they work to disseminate health information and latest news and research about dementia. Through their reporting journalists can raise public awareness about the prevalence of dementia and can encourage community understanding so we certainly do all that we can to assist journalists in this regard. The reality however is that many journalists writing or producing media stories about health issues and medical research findings are generally not experts. Unfortunately, this means that on occasion media reports on dementia research can be exaggerated, misleading or inaccurate. Our advice is to never make any decisions about medical care or treatment based on what you hear or read in the media. While media reports are vital to make us aware about latest health news and advances in dementia research, it’s critical that you always speak to your doctor first.

A call out for letters – from the editor

Dear readers

As the new editor of The Memory Matters, I am keen to hear what you think about the newsletter – what you like or dislike, what questions you’d like answered or information you would like to see in future editions. I encourage you to write to me. I look forward to hearing from you.

Kind regards, Michelle Low

email mlow@alzvic.asn.au

Submitting letters

Whether you wish to comment on issues covered in The Memory Matters or wider topics to do with dementia, your letters are extremely welcome. Please try and keep them to under 200 words, and note that they may be edited for publication. Submit your letters for the September edition to Kate Morton at kmorton@alzvic.asn.au or Locked Bag 3001, Hawthorn 3122, by Friday 3 July 2009.
Alzheimer’s Australia Vic is a Registered Training Organisation (RTO) offering a range of courses, workshops, traineeships and distance education. Most workshops and courses take place at our head office at 98–104 Riversdale Road, Hawthorn (Melway ref: 45 D12) unless otherwise advised.

Bookings are essential. For more information or to register call 03 9815 7808 or send an email to edu@alzvic.asn.au Registration forms and details are also available at www.alzheimers.org.au

### June – August 2009

**Workshop for volunteers**

**Working as a Volunteer**

Overview of dementia and communication, the value of volunteering, approaches to volunteering and volunteer issues.

**Note:** This course is for volunteers working with people with dementia in an agency or the aged care sector generally. It’s not for people wanting to volunteer for Alzheimer’s Australia Vic specifically.

**Friday 10 July**

10:00am–3:00pm

**FREE**

**Workshops and courses for family members and friends**

**For friends of people living with dementia**

Dementia and its causes, how dementia may affect the person and tips and guidelines for maintaining friendships and providing support.

**Wednesday 15 July**

1:00–3:00pm

**FREE**

**Information sessions**

An introduction to dementia including the many types and causes. The session covers the different services and support available through Alzheimer’s Australia Vic.

**Thursday 16 July, 1:00–3:00pm OR**

**Thursday 27 August, 1:00–3:00pm OR**

**Tuesday 4 August, 6:00–8:00pm**

**FREE**

**Drawing the Threads Together**

Four x three hours

Small groups give everyone the chance to have individual issues addressed and ongoing support networks are offered.

**Tuesday 4, 11, 18 & 25 August**

10:00am–1:00pm

**FREE**

**Promoting Continence in the Home**

How dementia affects continence, using a problem solving approach towards toileting and continence and practical strategies to support the person with dementia to remain continent.

**Wednesday 5 August**

1:00–4:30pm

**FREE**

**Managing change**

Learn why behaviour can change in a person with dementia, how to adapt your approach to communication and solve problems.

**Wednesday 12 August**

6:00–9:00pm

**FREE**

**Food for Thought**

A seminar on nutrition and healthy eating tips

**25 June 2009, 10:00am–12:30pm**

**FREE**

Please mention this is a Dementia & Memory Community Centre course when booking

**Photograph by Lynton Crabb**
## DIARY DATES

### Workshops and courses for staff

<table>
<thead>
<tr>
<th>Workshop</th>
<th>Description</th>
<th>Date</th>
<th>Time</th>
<th>Fee</th>
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<tbody>
<tr>
<td>Protective Behaviour – P3</td>
<td>Prevent – initiation and escalation of aggressive and other behaviours of concern. Protect – staff, residents and others from the impact of aggressive and other behaviours of concern.</td>
<td>Tuesday 7 &amp; 14 July 9:30am–4:00pm</td>
<td>$290</td>
<td></td>
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<tr>
<td>Dementia and Changes in Sexual Behaviour</td>
<td>Learn about the issues of dementia and changes in sexual behaviour and help to identify appropriate responses and resources. Content includes sexuality defined, why sexuality and ageing is a taboo subject, capacity to consent to some ethical issues and the impacts on individuals and their families.</td>
<td>Monday 17 August 1:30–4:30pm</td>
<td>$110</td>
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<tr>
<td>Person Centred Care – What is it really?</td>
<td>Learn to support people with dementia to continue to answer questions and put person-centred care into practice.</td>
<td>Thursday 7 May 9:30am–12:30pm</td>
<td>$110</td>
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<tr>
<td>Dementia Education in Acute Care Settings</td>
<td>Increase your knowledge of good dementia care principles and consider how these may be applied in acute hospital settings. Learn about the holistic approach that is important for people living with dementia.</td>
<td>Monday 20 July 1:30–4:30pm</td>
<td>$110</td>
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<tr>
<td>Depression, Dementia &amp; the Cornell Scale</td>
<td>Gain a greater understanding of depression in the elderly with dementia and the use of the Cornell scale as part of the Aged Care Funding Instruments (ACFI).</td>
<td>Monday 20 July 9:30am–12:30pm</td>
<td>$110</td>
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<tr>
<td>Promoting Continence in People With Dementia</td>
<td>Learn practical strategies to help a person with dementia to remain continent, including how to use a problem-solving approach towards toileting and continence.</td>
<td>Friday 17 July 1:00–4:00pm</td>
<td>$110</td>
<td></td>
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<tr>
<td>Dementia Education for Non-Nursing Care Staff</td>
<td>Suitable for hospitality, maintenance, laundry, cleaning &amp; other non-nursing care staff who work in residential care settings.</td>
<td>Friday 17 July (Castlemaine) 9:30am–4:00pm</td>
<td>FREE</td>
<td></td>
</tr>
<tr>
<td>Dementia education for care managers – General</td>
<td>Two days</td>
<td>Tuesday July 21 &amp; 28 9:15am registration 9:30am–4:30pm</td>
<td>$290</td>
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### Guest Speaker Series

<table>
<thead>
<tr>
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<th>Description</th>
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<th>Cost</th>
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</thead>
<tbody>
<tr>
<td>Interventions in Social Isolation</td>
<td>Learn about the feelings of loss associated with key life changes, programs which effectively reduce social isolation and strategies that have positively addressed this important issue.</td>
<td>Wednesday 19 August 1:30–4:30pm</td>
<td>FREE</td>
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<tr>
<td>Safer Communities for Older People</td>
<td>Held during National Missing Person’s Week this seminar will discuss issues relevant to older people including personal safety, home security and missing from home safety strategies.</td>
<td>Wednesday 5 August 5:15pm-6:15pm</td>
<td>FREE</td>
<td></td>
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</tbody>
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For more information or to register for a course or workshop:
Call: 03 9815 7808
Email: edu@alzvic.asn.au
Visit our website: www.alzheimers.org.au

### Thank you to our supporters
Alzheimer’s Australia Vic is grateful for ongoing support from: