10 WAYS ALZNSW CAN HELP

Let the training begin! Getting pumped for this year’s #MEMORYWALK

So many great memories from my wedding day – including these shoes! #MEMORYWALK

One of the highlights of visiting nanna? Her amazing slipper collection… #MEMORYWALK

BARE YOUR SOLE FOR #MEMORYWALK

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instagram.com/alzheimersnsw
CONTENTS

3 CHAIR’S AND CEO’S MESSAGES

4 NEWS
  • NEW BRING IT TO THE TABLE AMBASSADOR
  • DEMENTIA IN PRISONS
  • START2TALK PROGRAM
  • MEMORY VAN
  • CARER COACHING
  • DEMENTIA CARE IN HOSPITALS SYMPOSIUM

8 COVER STORY
  • MEMORY WALK & JOG A RUNAWAY SUCCESS

10 SERVICES
  • FINANCIAL ADVICE COLUMN
  • 10 WAYS ALzNSW CAN HELP
  • Q&A: YOUNGER-ONSET DEMENTIA AND GOING INTO HOSPITAL

12 EDUCATION
  2014 COURSES

13 RESEARCH
  • PARTICIPATING IN RESEARCH TRIALS
  • PAIN RELIEF MEDICATION AND DEMENTIA
  • MUSIC AND EXERCISE – A WINNING COMBINATION
  • LONG LIVE THE NAKED MOLE RAT

14 FUNDRAISING
  HOW YOU CAN HELP ALzNSW

15 IN MEMORIAM

16 RESOURCES
  • IN THE LIBRARY
  • CROSSWORD

READERSHIP SURVEY 2014 – WE WANT TO HEAR FROM YOU!

Here at In Touch, we’re conducting a Readership Survey to make sure we’re giving you the best member magazine we can and we’d love to hear from you.

What you think about the publication? What would you like to see more (or less) of? Is what we put in the publication relevant, useful, interesting and helpful? Would you like to continue to receive it in its current form, or would you prefer to receive it by email or access via our website?

We’ve enclosed a short survey with this publication, and we’d love it if you could take a moment to fill it in and return it to us in the reply paid envelope, also enclosed.

Or you can take the survey online at: surveymonkey.com/s/In-Touch-Survey

We really appreciate you taking the time to do this and will let you know the results in the Summer 2014 edition of In Touch, due to come out in December. Thank you!
CHAIR’S MESSAGE

CARE AND COMPASSION

Over recent months I visited a number of residential aged care facilities with Ms Eesa Witt, one of my board colleagues at AlzNSW. In March I had the opportunity to visit one in West Ryde.

We were struck by the high level of care and compassion evident, from the management team, nursing and care staff, to the cooks and cleaners. Despite being an older facility, the quality of innovative dementia care and empathy was first rate. The visit was insightful and improved our understanding of issues relating to the provision of aged care.

In recent months there has been considerable media attention on the issue of the use of physical and chemical restraints in residential care homes. The recent Alzheimer’s Australia report, The use of restraint and psychotropic medications in people with dementia, looks at the current practices of physical and chemical restraint in aged care facilities. The paper looks at the prevalence of their use, consequences and the legal implications. It particularly highlights the importance of considering psychosocial approaches, including person-centred care and recreational therapies when restraint is being considered.

The report, written by Associate Professor Carmelle Peisah (UNSW School of Psychiatry) and Dr Ellen Skladzien (National Policy Manager at AA), was developed with input from Nick O’Neill, Alzheimer’s Australia NSW Board member and former president of the NSW Guardianship Tribunal, who has expertise in the medico-legal issues of aged care; and Eesa Witt who is a Registered Nurse and Alzheimer’s Australia NSW Board member who has extensive clinical experience in caring for people with dementia.

Our role as a peak body is to advocate for all persons with dementia - no matter where they reside. It is not our role to micro-manage how aged care providers run their business, but to ensure that we advocate for the highest standards of care for people with dementia.

My recent visits to a number of care homes illustrated to me that there are many wonderful examples of quality care practices, and that we need to congratulate those providers who seek to deliver best practice person-centred care to their residents.

Jerry Ellis AO, Chair AlzNSW

CEO’S MESSAGE

STAY IN TOUCH

You will see that with this issue of In Touch comes a Readership Survey. We would love to hear your thoughts on In Touch and what we can do to ensure it is relevant, interesting and informative. I encourage you to take a moment to fill in the survey, either via the hard copy enclosed to send back in the reply-paid envelope, or online at: surveymonkey.com/s/In-Touch-Survey

We value your thoughts and look forward to hearing what you have to say.

I had the pleasure of meeting children’s author Debra Tidball recently. Debra presented AlzNSW with a copy of her illustrated children’s book When I See Grandma, inspired by her own children’s visits to their grandma. We thank Debra for this fantastic resource and for her generosity in donating royalties to dementia research through the Hazel Hawke Alzheimer’s Research and Care Fund.

Recently, AlzNSW has held a series of symposiums, the most recent of which was the Dementia Care in Hospital Symposium last month. We heard from some of the strongest researchers in the field of dementia care in the hospital setting and were fortunate enough to have flagged some really practical suggestions for improving dementia care in our hospitals. There’s already some great work being done in this area, but there are always things we can improve, as the forum highlighted.

Congratulations goes to the Bega team on their outstanding and continued effort to support people living with dementia, their carers, family and friends in the Bega Valley, racking up 40 years of combined service between them. All members of the AlzNSW team do a tremendous job in working to support people living with dementia, but to be celebrating 40 years of combined service is an especially impressive effort. So to Barb Williams, Nola Hergenhan, Lizzie Simkus, June Madden and Samantha Joyce – well done.

As you read this, members of the AlzNSW team are working hard in preparation for Dementia Awareness Month, coming up in September. There will be a number of events for people to take part in, including four Memory Walk & Jog events across the state. We will have more details for you in the next edition but, in the meantime, keep in touch via our website fightdementia.org.au, our Facebook page facebook.com/alznsw or our Twitter account @AlzheimersNSW

The Hon. John Watkins, CEO, AlzNSW
CAFÉ CONNECT

Café Connect enables people living with dementia, their carers, family and friends to get together for a coffee and chat.

SOUTH SYDNEY

ST GEORGE
3rd Tues. of the month, 10–11.30am
Café Brasserie, Beverly Park Golf Club

SUTHERLAND
4th Tues. of the month 9.30–11am
The Tea House, cnr President Ave & Kareena Rd, Caringbah

Contact Julie Sinnis
T: (02) 9531 1928
E: NSW.stgeorgesutherland@alzheimers.org.au

ST GEORGE & SUTHERLAND
YOUNGER ONSET DEMENTIA
FAMILY SUPPORT MORNING
2nd Sat. of the month, 10–11.30am
Hazelhurst Gallery Café

Contact Pam Mcdonagh
T: (02) 9531 1928
E: NSW.stgeorgesutherland@alzheimers.org.au

HUNTER

MAITLAND
3rd Thurs. of the month, 10am–12pm
Central Park Café & Function Centre, cnr High Street & New England Hwy

NELSON BAY
2nd Thurs. of the month, 9.30–11am
Little Nel Café at The Nelson Resort

TORONTO
4th Thurs. of the month, 10am–12pm
Toronto Workers Club

RAYMOND TERRACE
4th Thurs. of the month
Cravins Café, 2/26 Sturgeon St

WARNERS BAY
1st Wed. of the month, 10–11.30am
Wanrers at the Bay, Hillsborough Rd

Contact Hunter Dementia and Memory Resource Centre
T: (02) 4962 7000

NORTH COAST

COFFS HARBOUR
3rd Wed. of the month, 10–11.30am
Shearwater Café, The Promenade, 321 Harbour Drive

Contact Marg Coutts
T: (02) 6651 7101

SOUTHERN TABLELANDS

YASS
3rd Mon. of the month, 10am–12pm
Kaffiene Café, Comur St

Contact Libby Smith
T: (02) 6241 0881

CROOKWELL
3rd Wed. of the month, 10.30am–12pm
Chat-A-Way Café, 87 Goulburn St

Contact Nina or Jane
T: (02) 4869 5651

WINGECARRIBEE

WERAI
1st Thurs. of the month, 10.30am–12pm
Werai Teahouse and Nursery

BOWRAL
3rd Thurs. of the month, 10.30am–12pm
Peppers Craigieburn

Contact Nina or Jane
T: (02) 4869 5651

RACHEL LITHERLAND SPEAKING TOUR ON DEMENTIA-FRIENDLY COMMUNITIES

Visiting speaker Rachael Litherland was a hit with her expertise on dementia-friendly communities when she held workshops in Sydney and Port Macquarie in April 2014.

Rachael was visiting Australia from the UK as part of a national lecture tour for Alzheimer’s Australia. She conducted a series of workshops with practical strategies and approaches for creating dementia-friendly communities and organisations.

She said ‘dementia-friendly’ was a relatively new concept for Australia, but one that has been used to educate and create more inclusive communities for people living with dementia in the UK for some time. “For too long people all over the world have treated dementia as taboo, but it’s now time to bring the condition out of the shadows and engage with people living with dementia,” Rachael said.

Rachael said that people living with dementia and their carers had to be at the heart of any community strategy and that a dementia-friendly community was one that helped a person living with dementia retain their social networks, feel safe and access local services. “Improving the physical environment of public spaces and services such as banks, shopping malls and public transport by using signage that is simple, clear and uncluttered is one way to improve accessibility for people with dementia.”

The Port Macquarie workshop was held as part of a project led by Member for Port Macquarie Leslie Williams, in conjunction with AlzNSW, to turn Port Macquarie into a dementia-friendly community. It was the last stop on Rachael’s national tour, which included Brisbane, Darwin, Perth, Adelaide, Melbourne, Canberra, Hobart and Sydney.

GAME ON!

Twelve lucky people attended a Sydney Football Club (FC) versus Adelaide United soccer game at Allianz Stadium in Sydney on 8 February.

The group included people with dementia and their partners, family and friends, as well as Anne Tunks from the Inner West Dementia Advisory Service and Grace Burgess.

Grace is a Registered Nurse who works with people with dementia and their support networks. She recognised that there were people who have always loved sport, but may now find it challenging to make their own arrangements to attend games. Through liaison with Sydney FC staff, the group was able to use a private box provided through the generosity of the club.

Attendees were contacted about the game through AlzNSW Younger Onset Dementia Key Workers, the Dementia Advisory Services throughout Sydney, the Ella Centre and Hammondcare.

All thanks go to Sydney FC for their understanding and support of the first game in this exciting project.

DEMENTIA IN PRISON

Dementia in Australia’s prisons is a growing problem, with the ageing population in the country’s correctional facilities increasing at a higher rate than the general population, according to a new discussion paper released by AlzNSW.

The paper, Dementia in Prison, notes that corrective service authorities across Australia need to respond to this urgent issue. “Just as people in prison are treated for health conditions such as cancer and diabetes, so too are they entitled to appropriate care if they have a diagnosis of dementia,” said AlzNSW CEO, The Hon. J ohn Watkins.

To read the full paper online, visit: fightdementia.org.au/new-south-wales/research-nsw.aspx
NEW BRING IT TO THE TABLE AMBASSADOR

AlzNSW is excited to have Courtney Roulston join us for Bring it to the Table. The Master Chef Series Two contestant joined the national fundraising initiative, throwing her support behind the campaign to raise funds and awareness for people living with dementia, their carers, family and friends.

Courtney said when she signed up to become a Bring it to the Table ambassador, she had been unaware dementia was the third leading cause of death in Australia.

“We are often quiet when it comes to dementia. Nobody likes to talk about it, and while this is the case we will never find a cure,” she said.

“I’m on board as an ambassador for Bring it to the Table as this will bring people together to discuss dementia and bring some awareness to the silence.”

Courtney joins existing ambassadors Rebecca Sullivan and Alice Zaslavsky, who ask that you join them and bring it to your table in June.

It’s not too late to host an event and raise some money for AlzNSW. We have host packs and loads of ideas to help you get started.

To register your event, visit www.bringittothetable.com.au

YOU MIGHT LIKE TO TRY...

Bring it to the hotplate
Hold a party where the guests cook for you! You judge each chef on their creations and choose the prize, but the chefs must donate to eliminate the competition.

Bring it to the hammer
Hold an auction with a difference. Ask guests to bring along something important to them. They will think they are doing some sort of show and tell, but really you are going to make them buy their items back!

Bring it to the bowl
Make your pooch part of your fundraising efforts and host a pet party. All entrants must pay the registration fee to be part of the event.

Bring it to the big screen
Host a movie matinee or hold an outdoor cinema night. Make guests feel included in the movie choice by letting them choose the movie. The catch? They have to pay to vote. The more votes, the better chance of getting the movie they want!
WESTERN NSW DEMENTIA OUTREACH PROGRAM

To assist people living with dementia, their carers, family and friends in Western NSW, AlzNSW, with the support of the Vincent Fairfax Family Foundation, has developed a Dementia Outreach Program for the region.

A new Project Officer role has been created that will see Jenny Roberts supporting AlzNSW’s presence in Western NSW for the next 12 months, operating out of Dubbo.

The project will work in partnership with local service providers to make dementia awareness and education programs more available in the region.

AlzNSW currently works with Catholic Community Services (Dubbo), Orana/Far West Dementia Respite Services and Department of Family and Community Services (Mudgee); and the Greater Western Area Health Service (Orange).

MERCI BEAUCOUP

AlzNSW received a generous $500 donation from The Alliance Française de Port Macquarie in February. Alliance president, Jean Jaraczewski, visited the Port Macquarie office to make the donation personally.

Jean said the Alliance has always tried to donate any money raised from their fundraising activities to associations that are in need both of money and recognition for the services they provide.

Jean said he would have been grateful for the type of support offered in Port Macquarie when his mother was diagnosed with Alzheimer’s 25 years ago in northern France.

AlzNSW thanks Alliance Française de Port Macquarie for their contribution.

40 YEARS IN THE BEGA VALLEY

The AlzNSW team is celebrating 40 years of combined service in the Bega Valley. The team (pictured) offers a range of services including information, support and practical advice to the approximately 1500 people living with dementia in the Bega electorate.

START2 TALK

Do your loved ones know what you would want if dementia, another chronic disease or an accident prevented you from making end-of-life decisions?

While no one likes to think about end-of-life issues or dementia, the reality is that difficult financial, lifestyle and medical decisions are often left up to others to make on our behalf.

To help make discussing end-of-life care with loved ones easier, a new website www.start2talk.org.au has been launched.

Dr Chris Shanley from Liverpool Hospital in Sydney developed the Start2Talk program for Alzheimer’s Australia after national consultations with consumers, Alzheimer’s Australia organisations, guardianship officials, healthcare providers and policy makers.

The website can help you to make your wishes known and features practical, up-to-date information for each state and territory, available in 30 languages. Have your questions answered by experts, post your story or read about the experiences of others.

Worksheets help you plan for yourself or others, which can be a great way to start a conversation with a loved one or a professional about your wishes. You can choose to complete and store the worksheets online, or print them and complete them by hand.

The website also has a section for health and community care workers, with information for GPs and Aboriginal Health and Multicultural Workers.

To Start2Talk, visit www.start2talk.org.au, or for more information contact info@start2talk.org.au.

CARER COACHING

A new course has been developed to support staff who work with people living with dementia to help family carers understand and deal with behavioural changes. Most importantly, the course focuses on implementing a ‘Purposeful Thinking’-based approach in relation to behavioural change.

The Purposeful Thinking approach encourages carers to stop and think about the behaviour concerning them, in a bid to work through the issue in a more effective way. This helps to reduce family stress and increases the wellbeing of the carers and the person living with dementia.

The course was developed with support from the NSW Government, Department of Family and Community Services, Ageing, Disability and Home Care (ADHC), and with the advice and feedback from a range of aged care and disability service providers and family carers.

The ongoing delivery of these education sessions will be through AlzNSW education and group development services.

For more information, please contact Judy Bartholomew or Marg Coutts:
E: Judy.Bartholomew@alzheimers.org.au T: (02) 6651 6415
E: Marg.Coutts@alzheimers.org.au T: (02) 6651 7101
THE NEW NATIONAL YOUNGER-ONSET DEMENTIA KEY WORKER PROGRAM

The new national Younger Onset Dementia Key Worker program has been making its mark across NSW, as the team prepares to celebrate the program’s first anniversary on 1 July.

Families and supporters of people living with dementia have become familiar with the new program and what it has to offer, which includes support and care for younger people diagnosed with dementia, their carers and families, and assistance for people navigating complex health and community service systems.

Since the program began NSW has received more than 370 referrals, with more than 300 currently being managed by key workers. Many of the referrals have come via the National Dementia Helpline. Those who have difficulty referring by phone can email: NSW.ReferalYODKW@alzheimers.org.au

Feedback has been positive about the flexibility of the program with different methods of engagement such as phone, email and Skype or face-to-face meetings. Consumers report feeling listened to and acknowledged, with Key Workers recognising the wishes of the individual, and providing empowerment through advocacy and education.

The program also raises awareness of the incidence of Younger Onset Dementia. To contact the Younger Onset Dementia Key Worker program in NSW, please call the National Dementia Helpline on: T: 1800 100 500

HARMONY DAY

A morning tea to celebrate Harmony Day was held by the Far North Coast Multicultural Working Party at the Murwillumbah Community Centre on 19 March.

A Your Brain Matters presentation from AlzNSW highlighted the importance of brain health at any age, and the morning ended with cake and a rousing chorus of We are Australian. Harmony Day is celebrated annually as a day of cultural respect for everyone who calls Australia home. The central message of the day is that ‘everyone belongs’.

DEMENTIA ADVOCATES

One reason for AlzNSW’s success in its advocacy for people with dementia, their carers and families in recent years has been our ability to tell the stories of our carers and families in recent years.

Members of the Dementia Advocates program help us to spread the word by sharing their story in the media, on social media, as part of a fundraising appeal, or by participating in our research projects.

If you would like to find out more about becoming involved, please contact J o-Ann Brown: T: 02 8875 4636 E: J o-Ann.Brown@alzheimers.org.au

DEMENTIA CARE IN HOSPITALS

AlzNSW was delighted to have Conjoint Professor in the School of Psychiatry at the University of NSW, Dr Brian Draper, for the Dementia Care in Hospitals Symposium in Randwick, Sydney, in April.

Dr Draper was joined at the symposium by a number of high-profile researchers in dementia to discuss the latest Australian research on dementia care in hospitals, including the latest findings on falls, delirium and interventions to improve quality care. Alzheimer’s Australia National President Ita Buttrose AO OBE (pictured, above-right) chaired the panel discussion on strategies to improve dementia care, based on the current research.

ILLAWARRA DEMENTIA FORUM

The Illawarra will host a ‘Living Positively with Dementia’ forum this J uly at The Builders Club, Church Street, Wollongong on 30 July, from 10.15am to 2pm.

For more information or to attend, please contact Michelle Brownlee T: 02 8875 4663 E: Michelle.Brownlee@alzheimers.org.au

THANK YOU FOR PARTICIPATING

The AlzNSW research team wishes to thank all the people with dementia, carers and service providers who recently participated in the ‘Meeting the Transport Needs of People with Dementia’ project.

The team is analysing all of your feedback and in the process of contacting those who have won gift vouchers. The results will be available once they have been written up. Thank you for your generosity. Your input is greatly valued.

DEMENTIA AWARENESS MONTH

Preparations are underway for a fantastic Dementia Awareness Month this September.

Last year, Dementia Awareness Week was bursting at the seams with awareness-raising events and activities across Australia. So, to fit everything in this year, it has grown to a full month, with a focus on creating dementia-friendly communities and initiatives to improve inclusiveness for people living with dementia, their carers, family and friends.

Activities and events will include a visit by international guest speaker Steve Milton, one of three directors of Innovations in Dementia, a UK not-for-profit organisation. The organisation has successfully influenced the British government to create dementia-friendly communities. Steve will be visiting Kiama, Sydney and Port Macquarie in NSW as part of a national tour during Dementia Awareness Month.

AlzNSW will keep you informed of all the events and activities planned for Dementia Awareness Month in the next edition of In Touch. We will also be updating the website so check www.fightdementia.org.au for events and activities near you.
WELCOME MESSAGE FROM LOUIS DUDLEY.

Bupa is delighted to be the official aged care partner of the NSW Memory Walk events for the third year in a row. A large proportion of Bupa’s 6000 residents are living with a diagnosis of dementia, so we are acutely aware of the valuable work done by Alzheimer’s Australia and the need to rally behind the fight against dementia.

We are excited to see the reach of the Memory Walks expanding this year with a new event to be held in Port Macquarie. Staff, friends and family at Bupa Kempsey are eager to ensure the local event is a big success.

As the largest private aged care provider in Australia and New Zealand, Bupa specialises in dementia care, working with families and our residents to personalise care and make each day the best it can be.

Bupa’s support for Alzheimer’s Australia extends beyond the NSW events, with plans for up to 20 Bupa homes across Australia to conduct fundraising Memory Walks in their local communities. With 62 homes stretching from Cairns to Hobart, there is likely to be a Bupa Memory Walk near you – watch out for these events in September.

As part of our focus on person-centred dementia care, we introduced medical care into 10 of our homes in 2013. This initiative has improved the health and wellbeing of our residents and given our staff the opportunity to advance their clinical expertise. We are keen to build on the success of this program with plans to employ more GPs to work in our homes this year.

I appreciate that moving into residential aged care is a major decision for any family. I encourage you to visit the Bupa Aged Care website to access a range of useful resources including our Choosing a Care Home app and the booklet ‘Caring for Someone Living with Dementia’, which was produced in collaboration with Alzheimer’s Australia. Visit www.bupa.com.au/agedcare

Please say hello to our friendly Bupa team at any of the Memory Walk events you attend – you can’t miss them, they will all be wearing their bright blue Bupa t-shirts.

I look forward to seeing you there!

Louis Dudley
Managing Director
Bupa Care Services Australia

MEMORY WALK & JOG A RUNAWAY SUCCESS

THE AlzNSW MEMORY WALK & JOG EVENT IS GROWING, WITH A NEW EVENT LAUNCHED IN PORT MACQUARIE IN APRIL.
MEMORY WALK & JOG is off to a flying start, with Member for Port Macquarie Leslie Williams MP unveiling the new-look Port Macquarie Memory Walk & Jog at an event in April.

The Parliamentary Friends of Dementia co-convenor and chair of the Port Macquarie Dementia Friendly Steering Committee officially launched the fundraising and awareness-raising event by asking the community to sign up for AlzNSW’s Memory Walk & Jog, and to join her in the race against dementia.

“This is a great way for people to get involved, show support of people living with dementia, help raise some much-needed funds and do something good for your health at the same time,” Leslie said.

“Funds raised will go towards helping AlzNSW provide vital support services for people living with dementia,” she added.

Memory Walk & Jog entrants can do a 2km or 7.5km walk or a 7.5km run in four locations across NSW, with participants encouraged to raise money to help reach a fundraising target of $750,000 across the state.

AlzNSW CEO, The Hon. John Watkins said this year was already shaping up to be an exciting and successful one for Memory Walk & Jog.

“We are so lucky to have such wonderful community support for this important cause. It is fantastic to see good friend of the organisation Leslie Williams MP join us again this year in supporting the Port Macquarie Memory Walk & Jog,” he said.

“All funds raised from Memory Walk & Jog will help increase AlzNSW’s ability to provide vital support services, such as counselling, support groups, education to help family carers and professional training. These services reduce feelings of isolation and empower people living with dementia and those caring for them.”

Port Macquarie joins Hunter, Sydney and Illawarra on the Alzheimer’s Australia NSW’s Memory Walk & Jog circuit.

The 2014 Memory Walk & Jog is again proudly supported by Bupa. For more information, visit www.memorywalk.com.au

BARE YOUR SOLE

#MEMORYWALK

As part of Memory Walk & Jog, this year we want you to help us start a social media revolution.

By snapping a pic of your shoes and sharing your story you can help raise funds and awareness for people living with dementia, their carers, families and friends.

It’s easy! To get involved all you have to do is take a picture of your shoes and upload it to Facebook, Instagram or Twitter using the hashtag #memorywalk.

There are many ways to bare your sole:
1. Show us how your training is going for Memory Walk & Jog;
2. Let us know your special reason for taking part this year;
3. If you are a person living with dementia, carer, family or friend of someone who is living with dementia, let us know what it is like to ‘walk in your shoes’;
4. Sign up to Memory Walk & Jog and let everyone know by posting a pic of your joggers and a link to your fundraising page;
5. Share a favourite memory of a loved one who bought you your shoes;
6. Remind your friends of that crazy thing you did while wearing your shoes!

Shoes hold decades of memories, so bare your ‘sole’ and share a story to help support people with dementia. Remember to #memorywalk with your posts.

If you’re not active on social media and still want to take part, send us your pic and a short memory and we can post it for you.

For more information and post ideas, go to: www.memorywalk.com.au/myshoes

MEMORY WALK & JOG DATES

24 AUGUST
Hunter Memory Walk & Jog
Speers Point Park, Lake Macquarie

31 AUGUST
Port Macquarie Memory Walk & Jog
Westport Park, Port Macquarie

14 SEPTEMBER
Sydney Memory Walk & Jog
Leichhardt Oval #3, Lilyfield

12 OCTOBER
Illawarra Memory Walk & Jog
Stuart Park, North Wollongong
In the winter 2013 edition of In Touch I discussed the various fees charged by aged care facilities, depending on the level of care required and the resources of the resident. However, in June 2013, the Federal Government passed a number of laws affecting the aged care system with the objective to:
- Increase the options available for those requiring aged care;
- Provide flexibility and choice on how residents can pay their accommodation costs; and
- Align the fees charged for aged care services more closely to individual circumstances.

While these reforms affect the entire aged care system and some changes have already commenced, the key changes will affect new residents entering aged care after 1 July 2014.

WHAT IS CHANGING?
From 1 July, new residents will be able to elect to pay any accommodation payment of the residential aged care costs by way of a refundable lump sum (currently classified as a bond), a periodic payment (currently referred to as a charge), or a combination of both.

The current system of having payments based on the type of care (low or high level) will be removed and the resident, rather than the facility, will decide how to pay. New residents will have 28 days after entering aged care to determine how the payment will be made. Should the payment be by way of lump sum or component thereof, no retention amount can be withheld, unlike current arrangements.

**MINIMUM ASSET AMOUNT**
Residents must be left at least 2.25 times the basic age pension amount at the time of entry. This amount will be determined each quarter.

**PRICING OF PAYMENTS**
Accommodation payments will need to be published in advance from 19 May in each aged care facility website, the My Aged Care website and in written form to prospective residents and their families. The publication will be required to detail payment options for lump sum and periodic payments and a combination of both as well as a description of the key features of each type of room.

Depending on the resident’s financial position, the Government may provide a supplement or part supplement to the facility following assessment. From 1 July, this assessment will be based on a combined income and assets test rather than just the current assets test.

There are other important aspects of the changes which should be considered by prospective residents and their families, including the interaction of accommodation payments and other fees which may have a bearing on the calculation of the amount payable for accommodation.

A financial planner with experience and expertise in aged care can provide guidance and advice on these changes.

You can also contact the Centrelink Financial Information Service on 132 300.

Phillip Cormack FNA;
SF Fin; ADFS (FP)
Financial Planning Specialist
Authorised Representative
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Any advice in this publication is of a general nature only and has not been tailored to your personal circumstances. Please seek personal advice prior to acting on this information. The information in this document reflects our understanding of existing legislation, proposed legislation, rulings etc as at the date of issue. In some cases the information has been provided to us by third parties. While it is believed the information is accurate and reliable, this is not guaranteed in any way. Opinions constitute our judgement at the time of issue and are subject to change. Neither, the Licensee or any of the National Australia group of companies, nor their employees or directors give any warranty of accuracy, nor accept any responsibility for errors or omissions in this document. Phillip Cormack is an Authorised Representative of Godfrey Pembroke Limited ABN 23 002 336 254, an Australian Financial Services Licensee, Registered office at 105 –153 Miller St North Sydney NSW 2060 and a member of the National Australia group of companies.

Phillip has had a long association with AlzNSW as a voluntary member of its Investment Advisory Committee. The views expressed in this column are those solely of the author.
**Q&A**

**Q** I am 56 years old and have just been diagnosed with younger onset dementia – I am in a state of shock. What can I do for myself?

The counsellors on the National Dementia Helpline can help you explore your feelings and they can provide contact information about services that are available for you, such as the Library, the Younger Onset Dementia Key Worker program, Living with Memory Loss program, counselling, and relevant supports in your local community. Call the National Dementia Helpline on 1800 100 500 or visit www.fightdementia.org.au/NSW

**Q** It has been recommended that my 84-year-old husband with dementia who lives in a nursing home have surgery for a skin lesion on his face. Should I discuss this with someone beforehand?

It would be good to talk to your husband’s doctor to get the correct medical information. To talk about the dementia specifically, it would be useful to call the National Dementia Helpline on 1800 100 500. They can talk about such things as whether your husband may become anxious about the procedure, how he might respond to pain or to the change in his routine and environment. They will also talk about ways that you can make the procedure easier for him.

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**10 WAYS AlzNSW CAN HELP**

AlzNSW is here to support people with dementia, their families and carers. Let us count the ways!

1. Support at time of diagnosis helps you and your family to make sense of the diagnosis and the next steps.

2. Practical advice helps you minimise the impact of dementia.

3. Living with Memory Loss programs for people in early-stage dementia increase knowledge and confidence for managing memory loss.

4. Individual and family consultations help you plan for the future.

5. Education programs help you understand and live well with dementia.

6. Up-to-date information and resources about dementia and access to the members’ lending library keeps you and your family informed.

7. Connections with other people living with dementia enable you to share information and experiences.

8. Social and creative activities provide opportunities for meaningful participation.

9. Recommendations and advice about dementia support services in your area ensure suitable care.

10. Our provision of information to GPs and other health care providers helps them improve their care and support for you.

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**NEED ANSWERS?**

Do you have a question for AlzNSW? Contact the National Dementia Helpline.

E: nsw.helpline@alzheimers.org.au

T: 1800 100 500

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**CROSSWORD SOLUTION**

[Crossword puzzle image with clues and answers]

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[Course and special events increase knowledge about dementia risk reduction and treatments.]

[AlzNSW campaigns rally the public and lobby the government to improve dementia funding and care.]
2014 COURSES

THE ALzNSW EDUCATION PROGRAM OFFERS COURSES FOR CARE WORKERS, FAMILY CARERS AND VOLUNTEERS.

SUPPORT GROUP LEADERS WORKSHOPS 2014
Introduction to Group Work Leadership
North Ryde 28 and 29 July
Newcastle 9 and 10 September

Advanced Group Leadership
North Ryde 18 and 19 August
Tamworth 10 and 11 November

Loss and Grief in a Carer Support Group
Tuggerah 21 and 22 July
North Ryde 13 and 14 October

Group Leaders’ Forum (for current, experienced group leaders)
Port Macquarie 16 June
Wollongong 4 August
Queanbeyan 24 November

FAMILY CARER EDUCATION
One-Day Carer Education
Griffith 19 June
North Ryde 17 July and 15 October
Taree 5 August
Newcastle 13 August

Two-Day Carer Education
Port Macquarie 22 July

Three-Day Carer Education
Goulburn 10 July

Four-Evening Carer Education
Sylvania 16 June

Family and Friends
North Ryde 2 July
Sanctuary Point 15 September

Caring for People who have an Intellectual Disability and Dementia
Port Macquarie 19 J une

Volunteer Courses
Interacting with a Person with Dementia
Yamba 23 J une
Tamworth 2 July
Coffs Harbour 11 August
Port Macquarie 21 August

CARE WORKER COURSES
Dementia, Sexuality and Care
North Ryde 30 September

Working with Families
North Ryde 25 July
Newcastle 16 J uly

A Positive Approach to Understanding, Effective Communication and Behaviour Changes
North Ryde 27 August

Meaningful Engagement in Leisure Activities
Mudgee 3 September
Huskisson 16 September
Newcastle 17 September

A Positive Approach to Understanding Dementia, Effective Communication and Behaviour Changes
Griffith 18 June

Experiencing Dementia and Communicating with a Person with Dementia
Forster 5 August

Coffs Harbour 9 and 10 July
Milperra 23 and 24 July
Taree 6 and 7 August
Goonellabah 3 and 4 September
Hurlstone Park 17 and 18 September
Queanbeyan 15 and 16 October
Dubbo 5 and 6 November

Working with People who have an Intellectual Disability and Dementia
Griffith 17 June
Tamworth 1 July
Sydney City 6 August
Mudgee 2 September
Hamilton 16 September
Cooma 29 October
Grafton 6 November
Campbelltown November

Caring for People who have an Intellectual Disability and Dementia
Port Macquarie 19 J une

For more information or to register, please contact:
E: nsw.education@alzheimers.org.au
T: (02) 8875 4640
RESEARCH

LATEST STUDIES

PARTICIPATING IN TRIALS, PAIN RELIEF AS POSSIBLE DEMENTIA TREATMENT, AND THE BENEFITS OF MUSIC AND EXERCISE.

RESEARCH TRIALS

The population is ageing and the numbers of people with dementia, principally Alzheimer’s disease (AD), will balloon over the next generation. Everyone with AD or a greater risk of developing AD wants a cure, and the pharmaceutical industry is investing billions in finding one.

Yet there is a curious paradox. Trials of potential disease-modifying treatments struggle to recruit eligible participants. Evidence suggests that participation in drug trials itself, regardless of receipt of active trial drug or placebo, is beneficial.

At the Sydney Centre for Clinical Cognitive Research at Prince of Wales Hospital, my team has been conducting trials of drug treatments for AD and memory loss since 1987. Patients and their family carers receive close attention, thorough medical checks and continued support, which for most more than compensates for the time spent attending appointments.

We are excited about new prospects in the fight against AD. We are currently trialling two drugs that aim to prevent the build-up of abnormal proteins that are toxic to brain cells. The first drug blocks an enzyme that releases the harmful Aβ protein, which clumps together and eventually results in amyloid plaque deposition in the brain.

There will be two trials with this drug, one for patients with AD and another for people with possible pre-Alzheimer’s. The second drug aims to prevent the abnormal formation of tau protein accumulating.

We are also trialling another type of drug designed to make nerve cells communicate more efficiently with each other rather than to block the pathology of AD piling up in the brain.

With monthly inquiries from industry interested in starting new trials, the Sydney Centre for Clinical Cognitive Research can choose to accept only those trials that we think have a good chance of success and little risk for patients. We look forward to working together to fight Alzheimer’s and find effective treatments.

For more information, contact us via phone 02 9382 3733 or email: lynne.seifman@sesiabs.health.nsw.gov.au

Scientia Professor Henry Brodaty AO, Honorary Medical Advisor to AlzNSW

PAIN RELIEF AND DEMENTIA

The National Ageing Research Institute in Melbourne is leading a trial to see whether pain relief medications could reduce the severity of behavioural and psychological symptoms in older people with dementia.

Participants will be split into groups that will receive either a placebo, paracetamol, or a paracetamol and codeine treatment, and will be monitored over a six-week period. The study is generating international interest, with the researchers hoping to attract new funding to broaden the work.

MUSIC AND EXERCISE

A Japanese study has found that people who exercised while listening to music performed better on some measures of cognition than those who exercised without listening to music.

One hundred and nineteen people aged 65–84 who did not have dementia took part in the study over the course of a year. Eighty exercised for an hour a week with a trainer – half listened to music, half did not. There was also control group that did no exercise.

Neurophysical assessments found those who listened to music had enhanced ‘visuospatial’ function (sense of depth, distance and spatial awareness) compared to those who did not. However both groups had enhanced motor function – reinforcing the benefits of exercise for the brain.

LONG LIVE THE NAKED MOLE RAT

Named ‘2013 Vertebrate of the Year’ by the journal Science, the South American Naked Mole Rat is the longest-lived member of the rodent family with a lifespan of up to 32 years.

There are many hypotheses as to why it lives longer, including its ability to slow its metabolism in times of reduced food, which could reduce age-associated oxidative stress in the brain.

Could the distinctive burrowing rodent shed light on longevity and age-related diseases in humans?

US Researchers recently found that the rodent’s longevity might be linked to a specific ‘chaperone protein’ called HSP25 (or HSP27 in humans), which is found in much higher levels in this rodent species compared to others.

HSP25 is a so-called ‘heat-shock’ protein which can help cells deal with different kinds of stress, effectively performing a ‘quality-control’ function.

The researchers believe that trying to increase the human form of protein could be a key to preventing neurodegeneration in the brain and potentially regulate cell development.

MORE INFO

Stay up to date with the latest dementia research, visit: dementiaresearchfoundation.org.au
FUNDRAISING

LIFE SUPPORT

DONATE, LEAVE A GIFT IN YOUR WILL OR FUNDRAISE THROUGH ACTIVITIES. NO MATTER HOW YOU DO IT, SUPPORTING ALzNSW FINANCIALLY WILL HELP THOUSANDS OF PEOPLE.

BEQUESTS
Please consider making a gift in your Will to help us extend our services to meet growing demands. This kind and generous gesture will ensure people with dementia, their carers and families are provided access to vital support services, as well as education of carers and health professionals and investment in research.

We recommend seeking the services of a solicitor or trustee company to prepare your Will, to ensure it is correctly drafted and clearly states your wishes.

If you would like to know more about how you can help AlzNSW by making a gift in your Will, please contact Yvonne Hamilton:
T: 02 8875 4606
E: yvonne.hamilton@alzheimers.org.au

COMMUNITY FUN-RAISING
Wanting to plan an event to raise funds for AlzNSW? Maybe a morning tea or gala ball? We can guide and support you in your preparation for your event. Contact Megan Thomas:
E: megan.thomas@alzheimers.org.au

TRUSTS AND FOUNDATIONS

The Aged Persons Welfare Foundation has generously supported a series of Dementia Cafes and Carer Wellness Workshops for people with dementia, their families and carers in the Hunter and Port Macquarie areas.

For more information on how your trust or foundation can help AlzNSW, please contact Trust and Foundations Manager Serena Stewart:
T: 02 8875 4652
E: serena.stewart@alzheimers.org.au

TEAM MEMORY JOGGERS
Team Memory Joggers has kicked off the running season with a strong effort. We have been chosen as one of the charity partners for this year’s Color Run nationwide, with events being held in most capital cities over the next 12 months.

Our runners have been part of the Fitness First Corporate Triathlon in Sydney on 18 April; the Color Run in Wollongong on 4 May and in Newcastle on 11 May; and the Sydney Morning Herald Half Marathon on 18 May. Upcoming events are the Sydney Harbour 10k on 13 July; the Sun-Herald City2Surf on 10 August; and the Blackmores Sydney Running Festival on 21 September.

The Team is still looking to recruit more runners and volunteers. To get involved, contact Megan Thomas:
E: megan.thomas@alzheimers.org.au

DEMENTIA FIGHTER

Do you want to be able to make a difference to dementia each month? The Dementia Fighter program has been set up for our supporters to be able to give a scheduled gift from their credit card or bank account and to be part of the fight against dementia each month. If you would like to more, contact Megan Thomas:
E: megan.thomas@alzheimers.org.au

WORK PLACE GIVING

Would you like to make a difference through your workplace? Contact Megan Thomas to find out more about our workplace giving program.
E: megan.thomas@alzheimers.org.au

GENERAL

If you would like to know more about any of the opportunities to get involved and support AlzNSW financially through bequests, trusts and foundations or fundraising, please contact AlzNSW. T: 1300 636 679

SPECIALIST DEMENTIA EDUCATION FOR BUSINESS AND WORKPLACES

As the peak body for dementia, Alzheimer’s Australia is at the forefront of dementia knowledge and quality care.

We design education and engagement programs from foundation learning to specialist care that meet a variety of service and educational outcomes.

We also offer consultancy services for businesses that desire to be recognised as industry leaders.

Alzheimer’s Australia provides nationally recognised dementia training to:
• Improve employee confidence, skills and capacity to engage with people with dementia
• Make your organisation more dementia-friendly
• Help your employees to lead a brain-healthy lifestyle

Get in early, make dementia education a top priority for your staff in 2014.

Contact the Alzheimer’s Australia NSW education team: nsw.education@alzheimers.org.au or phone 8875 4840 or 8875 4851.

THE NATIONAL DEMENTIA HELPLINE
1800 100 500

Understanding Alzheimer’s is Australia’s top priority for your staff in 2014.

The National Dementia Helpline is an Australian Government initiative. Alzheimer’s Australia NSW ABN: 21 109 831 475 Photo © Jonathan Daley Photography

14 IN TOUCH WINTER 2014
WE OFFER OUR CONDOLENCES TO THE FAMILIES WHO HAVE LOST THEIR LOVED ONES. WE ALSO THANK THEIR FRIENDS AND FAMILIES WHO HAVE DONATED TO ALZHEIMER’S AUSTRALIA NSW.

Annetta Barone
Barry (John) Benjamin
Joan Muriel Besters
Norma Lynne Bonnitcha
Edgar Johannes Wilhelm Bosholm
Edmund Bourke
Tom Breaden
Edna Bruce
Nola Brunton (nee Forster)
Edmund Peter “Eddie” Burke
Judith Anne Butcher
Jeanette Campbell
Joyce Mary Casey
(Arthur) Dennis Cleaton
Margaret Marion Cole
Kenneth Colebourn
Perce James Cooley
Peter Cornwall
Robert William Fairfax Cousins
Mary Imelda Cray
Alberto D’Alessandro
Peter Del Ben
Alan Jack Denney
John Kevin Dowd
Eileen Leith Draeger
Heather Dunbar
Joan Marianne Dunlop
Sylvia Spence Edgar
Evelyn Emery
Heather Fair
Lloyd Wheaton Fletcher
Caterina Gennusa
Lorna Ethel Gillam (nee Hanby)
Kevin Clarence Hankinson
Josie Howkins
Dorothy Hubbard
Joan Mildred Hubbard (nee Barwick)
Bridget Anne “Bud” Hyem (nee Macintyre)
Noreen Joyce Jackson
Ida Hilda (Susie) Jansson
Lola Elaine Johnston
Marian Johnston
Donald James Kerr OAM
Mary Margaret Kirley
Bessie Linsell
Maja Iliga Lobb
Robert William (Bobby) Mara
John Martin
Olwyn Mather (nee O’Grady)
Moya Therese McKinnon
Antonio Modderno
Colin Frederick Moore
John Henry Morgan
Janet Morris (nee Plowman)
Carmela Moschella
Harry Murphy
Annie Noreen Nunan (nee Dorahy)
Joyce Evelyn Oakes
Reginald William Oliver
Charles Edward O’Regan
Elizabeth Patterson
Bonnie Pereira
John Press
Betty Prodes
Chris Rementzoulas
Carmela Ricca (nee Moschella)
Lorna Margaret Robin
Betty Elsie Rudd
Stamata Skibosios
Cornelia Janette Smart
Phyl Smyth
Stefania Sochan
Fran Spooner
Nancy Hope Stenning (nee Ford)
Joan Storey
Noel Dudley And Nancy Tanswell
Betty Taranto
Harry Tavener
Janet Thornton
Antonius Bernardus (Tony) Verhey
David Boyd Watt
Frank Wilson
Alan Wooding

Alzheimer’s Australia would like to acknowledge and thank the families and executors of the recently received bequests from which people with dementia, carers and their families have received lasting benefit.
RESOURCES

AlzNSW LIBRARY

LIBRARY AND INFORMATION SERVICES
COORDINATOR MICHELLE DE MARI REVIEWS THE
NEW ADDITIONS TO THE ALZNSW LIBRARY.

BOOKS AND CDs FROM ALZHEIMER’S AUSTRALIA

Green Vanilla Tea
By Marie Williams

When Marie Williams’ husband Dominic started buying banana Paddle Pops by the boxful it was out of character for a man who was fit and health conscious. Dominic, Marie and their two sons had migrated to Australia to have a life where they shared more family time, when gradually Dominic’s behaviour became more and more unpredictable. It took nearly four years before there was a diagnosis of early-onset dementia, coupled with motor neuron disease. Marie says she began to write as a refuge from the chaos and as a way to make sense of her changing world. Her book, Green Vanilla Tea, has recently been named winner of the 2013 Finch Memoir Prize.

Don’t Sweat The Small Stuff … And It’s All Small Stuff: Simple Ways To Keep The Little Things From Taking Over Your Life
By Richard Carlson [available in book or CD format]

Learn to put things in perspective by making the small daily changes suggested in this book, including: “Think of your problems as potential teachers”; “Remember that when you die, your inbox won’t be empty”; and “Do one thing at a time”.

You can also try to live in the present moment, let others have the glory at times, and lower your tolerance to stress.

These resources are available for loan to members of AlzNSW. If you would like to reserve them, please email the library at nsw.library@alzheimers.org.au

BOOK DONATED TO ALZNSW

AlzNSW had a special visit by children’s author Debra Tidball who presented AlzNSW CEO The Hon. John Watkins with a copy of her first children’s book When I See Grandma. Inspired by her own children’s visits to her mother in an aged-care facility, When I See Grandma is a warm and uplifting story that Debra hopes will offer purpose and a way of engaging children in the care of their loved ones.

Debra has generously offered to donate royalties from the sale of her book to the Hazel Hawke Alzheimer’s Research and Care fund. When I See Grandma is available from bookstores or at wombatbooks.com.au

CROSSWORD

ACROSS
1. Most significant
5. Baking chamber
7. Appeal
8. Lack of response
9. Squeaks and rattles
12. Of the senses
15. Line of Chinese emperors
19. Higher-priced
21. Long-necked animals
22. Secluded place
23. Pecans or almonds
24. Arm/torso joint
11. Shady trees
12. Recite
13. Letter
14. Across
15. Fire-breathing monster
16. Church tables
17. Robberies
18. Stocks & shares agent
19. 70s dance music
20. Declare void

DOWN
1. Staring open-mouthed
2. Collect
3. Leaves room
4. Hypnotic state
5. River creatures
6. Roman XC
10. Smooth out (shirt creases)

RESOURCES

CROSSWORD

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