IN TOUCH
THE QUARTERLY NEWSLETTER OF ALZHEIMER'S AUSTRALIA NSW
WINTER 2013. ISSUE 85

KICKING GOALS
FOOTBALL AND HEAD INJURIES DISCUSSION PAPER RELEASED

RUN FOR LIFE
AL THE ELEPHANT LEADS A RECORD 2000 ALzNSW SUPPORTERS AROUND THE BAY RUN

18 COURSES FOR CARE WORKERS, VOLUNTEERS, CARERS AND SUPPORT GROUP LEADERS

IN THE BLOOD ONE GIANT LEAP CLOSER TO EARLY DETECTION

NEWS • EDUCATION • FUNDRAISING • SERVICES • Q&A

FIGHT ALZHEIMER'S SAVE AUSTRALIA FIGHTDEMENTIA.ORG.AU
3 CHAIR’S AND CEO’S MESSAGES

4 NEWS
• FOOTBALL AND HEAD INJURIES DISCUSSION PAPER RELEASED
• YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM
• MEMORY VANS
• VISITING DEMENTIA EXPERTS TALK ABOUT INTERVENTION AND CARE
• MCA LAUNCHES GUIDED TOURS FOR PEOPLE WITH DEMENTIA
• FINANCIAL PLANNING

8 COVER STORY
SYDNEY 2013 MEMORY WALK & JOG

11 EDUCATION
COURSES FOR CARE WORKERS, VOLUNTEERS, FAMILY CARERS AND SUPPORT GROUP LEADERS

12 RESEARCH
• EARLY DETECTION DEBATE: BEHAVIOUR AND BRAIN INFLAMMATION, OR BIOLOGICAL MARKERS?
• GENETIC RISK MARKERS IDENTIFIED
• RESEARCH OVERHAUL NEEDED
• HOW TO CREATE AN ENABLING ENVIRONMENT

13 SERVICES
• 10 WAYS ALzNSW CAN HELP
• Q&A

14 FUNDRAISING
HOW YOU CAN HELP ALzNSW

15 IN MEMORIAM

16 RESOURCES
• ALzNSW LIBRARY
• CROSSWORD
We continue to build momentum for a strong 2013.

In the past three months I have visited our offices in the Hunter and Port Macquarie regions and was delighted to meet our wonderful and committed staff, as well as many people living with dementia, their families and carers. I also met with the NSW Advisory Council, which is comprised of eminent Australians who share a passion to further our great cause, and visited the Alzheimer’s Australia office in Queensland to give support and advice to those working there as they consider restructuring their organisation to meet future challenges.

It is pleasing to see that Australia has been recognised on the world stage as the global leader in addressing dementia. The 2013 Alzheimer’s Disease International Award recognised the Minister for Ageing, Mark Butler, for Australia’s “efforts in improving the lives of people with dementia and their carers”. Those efforts include the Fight Dementia campaign, making dementia a National Health Priority Area through the Council of Australian Governments and the Federal Government’s $3.7 billion Living Longer. Living Better. aged-care reforms, which provide a big boost to dementia funding and the broader aged-care system.

Alzheimer’s Australia National President Ita Buttrose presented Minister Butler with the award. “[The award] recognises Australia as leading the world and it was thanks to the whole community’s efforts to draw attention to the issue and demand better resourcing and support,” Minister Butler said.

While this award is an outstanding contribution to the overall mission of achieving greater recognition of dementia, there is still much to be done. On 24 April, Ita launched the Fight Dementia Election 2013 manifesto, which calls for a bipartisan approach to build on the past achievements and to develop an inclusive society, one that values the strengths and contributions of its citizens regardless of age, disease or disability, while also respecting choice and social inclusion rather than institutionalism and isolation.

In order to provide greater choice and better care and support for people living with dementia, their families and carers, we need:
- access to high quality dementia care and support services
- a health system prepared to confront the issue of timely diagnosis
- hospitals that meet the needs of people with dementia
- greater investment in dementia research

The manifesto, which you can find at www.campaign.fightdementia.org.au, outlines what Alzheimer’s Australia believes is urgently needed from the Australian Government to support people living with dementia, their families and carers. It also calls on all candidates to commit themselves publicly to our cause.

Jerry Ellis AO, Chair, AlzNSW

CEO’S MESSAGE

BUSY TIMES

We have had a full schedule of events in recent months and the trend is set to continue, with the Alzheimer’s Australia National Conference, Sydney Memory Walk & Jog and a discussion paper launch all wrapped up, and Dementia Awareness Week on the horizon in September. AlzNSW was well represented at Alzheimer’s Australia’s 15th National Conference in Hobart last month. There were a number of staff members presenting at the conference on a range of topics including addressing the needs of people with disabilities, maintaining life skills through creative engagement, engaging male carers and men in early-stage dementia through Men’s Sheds, enhancing the capacity of communities to improve responsiveness to dementia, individual art therapy for carers of people with dementia, creating multimedia resources to engage with CaLD communities, and a multimedia campaign inspiring GPs to make a difference by detecting signs of Alzheimer’s disease and dementia early.

With such a strong field of staff presenting on such a diverse range of topics, it is clear that we are blessed with a passionate and knowledgeable team in NSW.

A record number of people joined us for the annual Sydney Memory Walk & Jog around the Bay Run in Lilyfield in May. The atmosphere on the day was just fantastic and, with more than 2000 people taking part, it was our most successful event yet.

The record crowd was a testament to the community’s willingness to support loved ones, family and friends in their fight against dementia. It was a great day with families, groups and individuals supporting one another. We were blessed with wonderful weather and the event raised $160,000 online, which will continue to support AlzNSW’s education and support services for people living with dementia, their families and carers.

Thank you to everyone who took part, helped raise funds and supported us on the day; we look forward to the Hunter and Illawarra Memory Walk & Jogs later in the year – see page 9 for details.

Head injuries caused by football continue to be an issue and the launch of AlzNSW’s discussion paper Football, Head Injuries and the Risk of Dementia in March ensures we are at the forefront of this important debate. We must ensure that all football codes continue to work to ensure player safety and to minimise players’ risk of concussion.

The Hon. John Watkins, CEO, AlzNSW
US EXPERT TALKS DEMENTIA INTERVENTION

Noted psychologist Dr Cameron Camp is visiting Australia from July to September as part of the National Quality Dementia Care Initiative project Relate, Motivate, Appreciate: Restoring Meaningful Engagement with People with Dementia in Care.

Dr Camp conducts workshops on designing cognitive and behavioural interventions for dementia.

His current research includes the use of Montessori-based activities as rehabilitative interventions to enable care residents with dementia to lead activities for other residents with dementia, interventions to enable therapists to apply memory improvement techniques, and the use of cognitive rehabilitation via telecommunication to enable adherence to medical regimens.

These interventions are designed to reduce challenging behaviours and improve the functioning of people with dementia.

COSTS OF AGED CARE

PHILLIP CORMACK FNIA; SF FIN; ADFF (FP)

The fees charged by aged care facilities differ according to the level of care required and the resources of the resident.

Low-level care facilities (hostels) provide accommodation and assistance with personal care, while High-level care facilities (nursing homes) cater for those with higher degrees of frailty, often requiring continuous care.

While the federal government provides some funding for residential aged care facilities, those who can afford it are expected to contribute to the cost of their care. Either Centrelink or the Department of Veterans’ Affairs are able to assess assets to determine the level of contributions. The table below summarises the main fees and costs a resident may be asked to pay.

An accommodation bond may be payable in low-level care or extra-service facilities. There is no set amount. Each bond is negotiated with the facility based on assessable assets. The bond can be paid as a lump sum, periodic payments or a combination of both.

An accommodation charge is a daily fee charged in a high-level care facility based on assessable assets and capped at a maximum rate (currently $33.29 per day).

A basis daily fee is usually payable by all residents as a contribution towards daily living costs such as nursing, personal care and meals, depending upon the resident’s status. The current rate for a standard resident is $44.54 per day.

A daily income-tested fee may be payable in addition to the basic daily fee and is based on the resident’s assessable income. The fee is currently capped at $70.74 per day.

An extra services fee may be payable by residents of both low and high-level care facilities to cover the costs of some additional services provided. There is no set amount; the fee can vary from home to home and it is not income tested. This is a very brief explanation of the various charges and costs that may be applicable, and the individual circumstances of each resident will have a direct bearing on charges and costs.

There are strategies to reduce the accommodation bond, charges and daily income-tested fees. A financial planner with experience and expertise in aged care can assist with these strategies and provide guidance.

Phillip Cormack FNIA; SF Fin; ADFF (FP)

T: (02) 9231 5611
E: pcormack@godfreypembroke.com.au

Phillip Cormack is a Financial Planning Specialist with Godfrey Pembroke Limited and has had a long association with Alzheimer’s NSW as a voluntary member of its Investment Advisory Committee. The views expressed are solely those of the author. Readers should consider their own situations before seeking financial planning advice. Any advice in this communication has been prepared without taking account of your objectives, financial situation or needs. Because of this you should, before acting on any advice, consider whether it is appropriate to your objectives, financial situation and needs. Godfrey Pembroke Limited ABN 23 002 336 264, registered office 106-163 Miller Street North Sydney NSW 2093, is an Australian Financial Services Licensee and member of the National Australia Bank group of companies.

### Table: Costs of Aged Care

<table>
<thead>
<tr>
<th></th>
<th>Low-level care (hostel)</th>
<th>High-level care (nursing home)</th>
<th>Extra service facility (low level)</th>
<th>Extra service facility (high level)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation bond</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation charge</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic daily-fee</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily income-tested fee</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extra services fee</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
All football codes must strictly enforce concussion guidelines to minimise the risk of brain injury and cognitive impairment, according to a new discussion paper. The paper also calls on codes to review their rules to minimise the risk of concussion and contribute to further research about dementia in retired football players.

These are among a raft of recommendations in Football, Head Injuries and the Risk of Dementia, prepared by AlzNSW.

AlzNSW CEO The Hon. John Watkins said a growing body of research and anecdotal evidence linking concussions and other head injuries sustained in football to the development of later-life cognitive impairment was a cause for concern.

“The codes have a responsibility to their players to undertake much more research in this area, particularly with retired football players, to see if there is evidence of post-career cognitive impairment, and even the development of dementia, as a result of multiple concussions sustained during their careers,” John said.

Read the full discussion paper on the AlzNSW website.


DEMENTIA CARE: A UK PERSPECTIVE

In June, AlzNSW will welcome Professor Julian Hughes, one of four international guest speakers to present for AlzNSW this year.

Prof. Hughes is an old-age psychiatry consultant and Honorary Professor of the Philosophy of Ageing at Newcastle University, UK. He will hold two seminars titled ‘Models of dementia care: Can we do it better?’

Prof. Hughes will discuss dementia care at the end of life, palliative care in people with dementia, pain and stress management, and ethical issues.

SYDNEY
When: 25 June, 10am-12pm
Where: Theatrette, NSW Parliament House, Macquarie St, Sydney
RSVP: by 21 June to (02) 9805 0100 or NSW.Reception@alzheimers.org.au

NEWCASTLE
When: 26 June 10am-12pm
Where: Noah’s on the Beach, Shortland Esplanade, Newcastle
RSVP: by 21 June to (02) 4962 7000 or NSW.Hunter@alzheimers.org.au
A DAY AT THE GALLERY

The Museum of Contemporary Art (MCA) in Sydney, with guidance from AlzNSW, is now offering guided tours and hands-on art experiences to small groups of people living with dementia.

When a person with dementia connects to their creativity through an activity that is meaningful to them, the positive outcomes are far-reaching. During this time there is no focus on dementia and no stigma, as the activity engages the person at their individual level.

The MCA was interested in inviting people with dementia into the gallery to experience the artwork and approached AlzNSW for support. AlzNSW Social and Therapeutic Activities Coordinator Denise Herman and Educator Pam Davis prepared an education session for staff of the MCA.

In conjunction with Alzheimer’s Australia ACT, AlzNSW developed the Guiding Visitors with Dementia manual – a handbook for art gallery tour guides. Pam delivered the Understanding Dementia course and Denise delivered the Engaging People with Dementia with Art course to give MCA staff the understanding and skills they needed to offer tours and group activities for people living with dementia. Denise and AlzNSW clients with dementia visited the MCA four times after the MCA staff training was complete.

MCA Public Engagement Manager Georgie Meagher is now working with MCA Art Educators David Capra and Elspeth Grew to improve the quality of life for people living with dementia and, indirectly, their carers and families by providing an enjoyable and stimulating environment in which they are actively engaged with other people and art.

Where: 140 George Street, The Rocks, Sydney

More information: To find out more or book a tour, contact MCA Public Engagement Manager Georgie Meagher. T: (02) 9245 2462

Guiding Visitors with Dementia handbook, contact Denise Herman.
E: denise.herman@alzheimers.org.au

POSITIVE IMAGES OF DEMENTIA

An international photography exhibition that seeks to broaden the understanding of dementia is coming to Sydney in November.

American photographer and sociologist Cathy Greenblat’s exhibition Love, Loss and Laughter illustrates stories of people living with dementia, including Australians photographed in March and April this year.

A professional and personal connection to dementia adds a personal element to her photography, and her depth of understanding is evident in her work.

Featuring more than 85 photographs taken in the US, France, India, Japan, the Dominican Republic, Canada, Monaco and Australia, the Love, Loss and Laughter exhibition will visit most capital cities in Australia between May and November.

If you have photos that capture the experience of living with dementia, submit them to be displayed at the Love, Loss and Laughter exhibition when it visits Sydney. Visit the Fight Dementia website, complete the form and upload an image by 4 November.


When: 7-27 November
Where: Parliament House, Sydney
Times: Monday-Friday, 9am-5pm
Contact: Alzheimer’s Australia National Office, 1 Frewin Place, Scullin, ACT 2614
T: (02) 6254 4233
E: nat.admin@alzheimers.org.au
IN TOUCH
WINTER 2013
7

LIBRARIANS MAKE HOUSE CALLS

AlzNSW Library and Information Services Coordinator Michelle de Mari and Educator Donna Moore recently created a presentation about dementia, which Michelle delivered to librarians from the Home Library Service. Offered through public libraries, the Home Library Service delivers library items to people who are housebound due to poor health, disability or frailty, residents in aged-care facilities and carers. To join, contact your local library.

BRAIN-SAVING HABITS

Port Macquarie-Hastings Council Mayor Peter Besseling and councillors recently took up the Heart Your Brain Challenge: 21 Days to Brain Healthy Habits. The challenge is part of Alzheimer’s Australia’s Your Brain Matters program, an evidence-based initiative that demonstrates ways to help retain and build brain cells. The councillors added fun brain-training exercises to their daily routines and took simple steps to improve brain health.

The challenge is as simple as learning a new task, organising a social event, going for a walk or making simple changes to your diet,”

AlzNSW congratulates Port Macquarie-Hastings Council and thanks others who have participated.

NEW YOD KEY WORKERS

AlzNSW will welcome 11 key workers to assist people living with younger onset dementia (YOD) and their families access vital services and support. A national team of 40 is being recruited through the National YOD Key Worker Program.

“The key worker will be a primary contact for a person with dementia,” said The Hon. John Watkins, CEO of AlzNSW. The key worker will provide information and advice as an initial point of contact, and help families engage with support and care options by providing direct services and linking them to relevant services.

“Support will be individualised and person-centred, which will help to improve the quality of life for people living with YOD, their families and carers,” John said.

Minister for Ageing The Hon. Mark Butler MP announced $16.8 million funding for the program as part of the $3.7 billion Living Longer, Living Better, aged care reforms.

The location of key workers has been determined by analysing ABS data for people living with dementia in the 35-64 years age group and identifying locations with high concentrations of people living with early onset dementia.

In NSW, key workers will be located in Western Sydney, Central Sydney, Southern Sydney, Wollongong, the Hunter Valley, Central Coast and Mid-North Coast. More details about the program and how to contact key workers will be in the next edition of In Touch.

We are currently recruiting for participants

This study being run from the University of Sydney is a trial to test a program aimed at improving the quality of life of people with dementia by providing meaningful activities tailored to their abilities.

For more information, please contact:
Tara-Lea McAleer Tel: (02) 9351 9594 or Email: tara.mcalceer@sydney.edu.au

BRIGHTSKY

specialist healthcare products at your door

Everyday & hard-to-find healthcare products home-delivered

- Continence
- Wound care
- Nutrition
- Respiratory
- Personal service
- Discreet packaging on request
- Clinical nursing advisory service
- Online shopping

Managing your CAPS and other payments is easy with the BrightSky Card!

To find out more, contact us on:

1300 88 66 01
orders@brightsky.com.au
www.brightsky.com.au

LIBRARIANS MAKE HOUSE CALLS

[Image of a book]

BRAIN-SAVING HABITS

[Image of a brain with arrows]

NEW YOD KEY WORKERS

[Image of a key worker]

The Tailored Activity Program

[Image of a group of people]
A record 2000 participants took part in Memory Walk & Jog on Sunday 5 May.
Runners and walkers of all ages laced up for the 2km and 7.5km walks, as well as the 7.5km run around the beautiful Bay Run at Lilyfield.
The Sydney Memory Walk & Jog was the first event to kick off the 2013 season, with regional walks to be held later in the year in the Hunter, Port Macquarie and Illawarra. Runners as well as walkers will be invited to complete the track at the regional events.
This year’s annual fundraising event was the most successful yet.
“More than $160,000 has been raised online so far for Alzheimer’s Australia NSW to help us to continue to provide much-needed support for people in need,” AlzNSW CEO The Hon. John Watkins said. “This is a wonderful effort and I’d like to congratulate and thank everyone involved.”
Organisers and participants could not have asked for a more pleasant day, with the sun coming out for the event. Participants took advantage of food stalls and coffee carts in the registration area to fuel up before the official start, and 2013 Australian of the Year and Alzheimer’s Australia National President Ita Buttrose thanked the crowd for supporting AlzNSW’s efforts to assist people with dementia, their families and carers.
Ita’s long association with Alzheimer’s Australia is partly a result of her own experience living with her father who had dementia. Bupa Ambassador and former World Ironman Champion Guy Leech also showed his support, joining the crowds for the fun.
“Memory Walk & Jog is a great event because it not only raises money and awareness for such a good cause, it also promotes healthy and active lifestyles,” Guy said.
Race participant Kate Galea described the electric energy at the start line as everyone joined in a group warm-up.
“There was a great atmosphere at the start line as everyone milled around getting ready for their turn to set off,” she said. “So many people had invested time and effort in creating team outfits, which really helped the vibe around the park.”
Volunteers stationed along the route offered runners and walkers words of encouragement as they passed.
“Along the route everyone was encouraging and friendly,” Kate said. “I wouldn’t have even minded doing another lap!”
The fun continued at the finish line where a jumping castle awaited any children with excess energy to burn off, while a clown and stilt walker entertained those who preferred to sit and watch.
Every participant was cheered across the finish line and given a gift bag packed with information and gifts from event sponsors.
“I’d like to acknowledge and thank our major sponsor, Bupa aged care, without whom we could not have put on such a successful event,” John said.
“I’d also like to thank our city supporter Guardian Funerals, and our community supporters Share and Leichhardt Council.”

SYDNEY’S 2013 MEMORY WALK & JOG WAS A ROARING SUCCESS, WITH RECORD NUMBERS OF PARTICIPANTS AND A GREAT DAY OUT FOR ALL.
GET INVOLVED
Show your support for people living with dementia and their carers by participating in an upcoming Memory Walk & Jog.

Hunter Memory Walk & Jog
Sunday 8 September
Speers Point Park
W: memorywalk.com.au/hunter

Illawarra Memory Walk & Jog
Sunday 13 October
Stuart Park
W: memorywalk.com.au/illawarra
Noel Hackett and Jenny Fitzpatrick enjoyed a sunny day by the bay, raising money and awareness for AlzNSW in the process.

CRUNCH THE NUMBERS

36,000,000
THE NUMBER OF PEOPLE WORLDWIDE WHO LIVE WITH DEMENTIA

2021
THE NUMBER OF PARTICIPANTS IN THIS YEAR’S MEMORY WALK & JOG

$160,000
THE AMOUNT RAISED ONLINE SO FAR

$7135.35
THE AMOUNT RAISED BY THE TOP INDIVIDUAL FUNDRAISER, SIMONA BEVILACQUA

310,000
THE NUMBER OF AUSTRALIANS CURRENTLY LIVING WITH DEMENTIA

900,000
THE NUMBER OF AUSTRALIANS EXPECTED TO HAVE DEMENTIA BY 2050

1,200,000
THE NUMBER OF AUSTRALIANS WHO CARE FOR SOMEONE WITH DEMENTIA
THE ALzNSW EDUCATION PROGRAM OFFERS COURSES FOR CARE WORKERS, FAMILY CARERS, VOLUNTEERS AND SUPPORT GROUP LEADERS.

SUPPORT GROUP LEADERS’ WORKSHOP
Group Leaders’ Forum (for current, experienced group leaders)
North Ryde  17 June
Coffs Harbour  22 July

Loss and Grief in a Carer Support Group
Mt Druitt  8 and 9 July
North Ryde  5 and 6 August
Queanbeyan  9 and 10 September

Introduction to Group Work Leadership
Mt Druitt  19 and 20 August
Wollongong  14 and 15 October

Advanced Group Leadership
Coffs Harbour  28 and 29 October
Mt Druitt  14 and 15 November
Queanbeyan  25 and 26 November

For more information or to register for a Support Group Leaders’ Workshop, contact Monica Cole.
T: (02) 8875 4682
E: GroupDevelopmentNSW@alzheimers.org.au

FAMILY CARER EDUCATION
Three-day Carer Course
North Ryde  8, 15 and 22 July
Goulburn  11, 18 and 25 July

Sons and Daughters or Family and Friends
North Ryde  3 September

Newly Diagnosed Course
Forster  8 August

One-day Carer Course
Forster  19 September

Two-day Carer Course
Port Macquarie  17 and 24 September

Dates and locations may be subject to alteration. For more information or to register, contact the AlzNSW Education team.
E: nsw.education@alzheimers.org.au
T: (02) 8875 4640 or (02) 8875 4651

VOLUNTEER COURSES
Volunteer Education
Banora Point  19 June
North Ryde  31 July and 5 November

Dates and locations may be subject to alteration. For more information or to register, contact the AlzNSW Education team.
E: nsw.education@alzheimers.org.au
T: (02) 8875 4640 or (02) 8875 4651

CARE WORKER COURSES
Intellectual Disability
Forster  27 June
Coffs Harbour  September

Physical disability
Central Coast  19 June
Tweed Valley  31 July – 1 August
Bankstown/Liverpool  11-12 August

Understanding Dementia and Communicating with a Person with Dementia
North Ryde  16 July

Experiencing Dementia
Hunter  17 July
Tea Gardens  25 July

Communication
Tea Gardens  25 July
Port Macquarie  8 August

What is Dementia?
Port Macquarie  8 August

Experiencing Dementia and Challenging Perceptions of Behaviour Associated with Dementia
North Ryde  22 August

Meaningful Engagement in Leisure Activities
North Ryde  26 June and 2 September

Dates and locations may be subject to alteration. Fees apply for some courses. For more information or to register, contact the AlzNSW Education team.
E: nsw.education@alzheimers.org.au
T: (02) 8875 4640 or (02) 8875 4651
RESEARCH

RECENT STUDIES

AUSTRALIAN RESEARCHERS HAVE IDENTIFIED EARLY BIOLOGICAL MARKERS OF ALZHEIMER’S DISEASE, BRINGING US A BIG STEP CLOSER TO SCREENING TESTS FOR EARLY DETECTION.

CLOSER TO A BLOOD TEST

Australian scientists have identified blood-based biological markers that can appear years before Alzheimer’s disease symptoms are evident and associated irreversible brain damage has occurred. The biological markers are associated with the build-up of beta amyloid proteins, and their identification brings researchers a step closer to developing screening tests for early detection.

Amyloid beta levels become abnormal as early as 17 years prior to the appearance of dementia symptoms, Dr Noel Faux, from the Florey Institute for Neuroscience and Mental Health explained. “This gives us a much longer time to intervene to try to slow disease progression.”

The results have been published in the journal Molecular Psychiatry.

Read more: goo.gl/EV7nX

THE OTHER SIDE: ‘PLAQUE COMES LATER’

Another Australian study has shown that the build-up in the brain of amyloid plaques may occur later in the progression of Alzheimer’s disease.

PhD student Amanda Wright and Dr Bryce Vissel from Sydney’s Garvan Institute aimed to identify early versus late Alzheimer’s disease mechanisms and markers. They found that significant loss of brain cells and a range of associated disease processes (including inflammation) began at an early stage of the disease, at around the same time as the first signs of subtle memory problems. Amyloid plaques occurred much later, after significant memory loss had occurred.

“Our study supports the increasingly common view that treatment should start much earlier in the disease process,” said Dr Vissel. The findings also suggest that brain inflammation, cell loss, mild memory loss and behavioural changes may be early indicators of disease.”

Read more: goo.gl/vN1Yo

GENETIC RISK MARKERS

New genetic markers that could help highlight who is at risk of developing Alzheimer’s disease have been identified by US scientists.

A team of researchers led by Dr Alison Goate performed the largest ever genome-wide association study of protein markers found in cerebrospinal fluid. Researchers found that one of the genetic markers had a strong association with increased Alzheimer’s disease risk.

Read more: goo.gl/vN1Yo

RESEARCH OVERHAUL NEEDED

The Strategic Review of Health and Medical Research – Better Health through Research, led by 2011 Australian of the Year Simon McKeon, has been released by the Australian Government. The report features a 10-year strategic plan to maximise Australia’s capacity to produce world-class health and medical research.

The plan sets out recommendations that will build research capacity in health priority areas such as dementia and support an increased focus on priority-driven research by establishing set research agendas, evaluating outcomes and leveraging funding.

The report also recommends the establishment of a leadership body to work with key organisations to better deliver healthcare services. The recommendations are part of a three-tier vision that calls for strengthened partnerships between researchers, health professionals and the wider community.

Read more: www.mckeonreview.org.au

ENABLING ENVIRONMENTS

Alzheimer’s Australia WA and the NSW Dementia Training Study Centre at the University of Wollongong have developed a national project focusing on translating research into practice to create enabling environments for people with dementia.

The Dementia Enabling Environments Project (DEEP) uses evidence-based principles that will provide design professionals, carers and aged-care staff with practical information and advice on creating ‘dementia-friendly’ environments.

W: www.enablingenvironments.com.au
Q&A

Q MY WIFE HAS DEMENTIA AND HAS TO GO TO HOSPITAL FOR MINOR SURGERY IN A FEW WEEKS. DO I TELL HER ABOUT THE HOSPITAL SO SHE CAN GET USED TO THE IDEA?

A Telling a person with dementia about going to hospital can be difficult. The decision about what to say and when to say something will depend on a few factors. These can include, for example, the extent of your wife’s memory loss and how anxious you think she will be about going into hospital.

It would be useful to talk this issue over with one of our National Dementia Helpline counsellors on 1800 100 500. They will be able to help you make the decision that best suits your wife.

Q MY FATHER IS CARING FOR MUM, WHO HAS DEMENTIA, AND I WORRY THAT IT IS ALL GETTING A BIT MUCH FOR HIM. DO YOU HAVE ANY SUGGESTIONS THAT MIGHT HELP HIM?

A Caring for someone with dementia can be demanding and challenging, particularly if it has meant that your dad has had to learn new skills. Carers’ groups can be very supportive during this time and the National Dementia Helpline can give you contact numbers for groups in your dad’s area.

AlzNSW also has help sheets with ideas that may be useful for your dad. These are available from our website or by calling the National Dementia Helpline on 1800 100 500.

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.

NEED ANSWERS?

Do you have a question for AlzNSW? Contact the National Dementia Helpline. E: nsw.helpline@alzheimers.org.au T: 1800 100 500

↑ Courses 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.

Q CROSSWORD SOLUTION
FUNDRAISING

LIFE SUPPORT

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

BEQUESTS

As our population ages, we need to extend our services to meet growing demand. Leaving AlzNSW a gift in your will can give us the long-term financial confidence to maintain and extend our vital support services, continue to educate carers and health professionals, and invest in research to stop this deadly disease.

Make a will or update your existing will and include a bequest to AlzNSW.

You should always seek the services of a solicitor or trustee company to prepare your will to ensure that it is correctly drafted and is practical in meeting your wishes.

To find out more about how you can help AlzNSW by leaving a gift in your will, contact Diana Waring.

T: (02) 8875 4631
E: diana.waring@alzheimers.org.au

IN MEMORIAM DONATION

By making a donation in memory of a loved one, you ensure his or her memory lives on by helping others. You can also celebrate the life of a loved one by asking for a donation to AlzNSW in lieu of flowers.

In memoriam envelopes can be made available at a funeral, church, wake or service where friends and family can make a donation to AlzNSW.

A receipt will be sent to the donor and, with their permission, a letter will be sent to the family to advise them of the kind gift. The amount of the gift will remain confidential and gifts $2 and higher are tax deductible.

T: (02) 8875 4673
E: marina.agostino@alzheimers.org.au

SEND US YOUR STORY

Some members help our fundraising and awareness-raising efforts by sharing their stories of dementia, whether funny, tragic, empowering, uplifting, inspirational or sad.

If you would like to help our fundraising and awareness-raising efforts by telling your story, please contact Karen.

T: 1300 636 679
E: karen.carran@alzheimers.org.au

BRING IT TO THE TABLE

We are bringing the fight against dementia to the nation’s tables with a get-together with a difference.

Members of the community, carers and supporters will host events, such as high teas or board game dinners, and raise the conversation about dementia while raising much-needed funds for Alzheimer’s Australia. Bring It To The Table launched in April with events throughout June. If you would like to know more about this great fundraising initiative please contact Donor & Community Development Executive Megan Thomas.

E: megan.thomas@alzheimers.org.au
T: (02) 8875 4625

COMMUNITY FUNDRAISING

Planning a fundraiser in your local community or workplace? We are revitalising our community fundraising program and are looking for support from passionate fundraisers. We can guide and support you in preparation for your event, from morning teas to gala balls.

T: 02 8875 4625
E: megan.thomas@alzheimers.org.au

TRUSTS AND FOUNDATIONS

It has been a great year with many trusts and foundations coming on board to support us in our fight against dementia.

They have enabled AlzNSW to deliver education workshops for carers and volunteers, pilot new programs to promote health and wellbeing, update our vital library resources and information, send out the Memory Van to discuss the risks of dementia, and work with Indigenous communities to increase the understanding of dementia and ways in which one can delay or even prevent it.

We have been able to achieve tremendous results and continue to fight dementia thanks to the following foundations:

- IMB Foundation
- Aussie Farmers Foundation
- Give2Asia/State Street Foundation
- Mumbulla Foundation
- Foundation for Regional and Rural Renewal
- AMA (NSW) Charitable Foundation
- The Raymond E Purves Foundation

T: (02) 8875 4652
E: serena.stewart@alzheimers.org.au

STAY IN TOUCH

If you are not already on our email database and would like updates about all the news on our upcoming events, please contact Megan.

T: (02) 8875 4625
E: nsw.events@alzheimers.org.au
IN MEMORIAM

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.

Evangelia Acon
Erika Agoston
Wendy Ayres
Helen Batsios
Flo Jo Birkin
Elsie Josephine Brien (nee Munday)
Robin Madeline Broose
Patricia Joy Bullow
Marjorie Byrnes
Harry Cargill
Judith Elaine Collins
Cecily Jean Connolly (nee Dempsey)
Robert (Bob) Corbett
Sylvia Muriel Cottee
Constantino Cuccuru
Enrico Damiano
Douglas Neate Dark
Mrs M Delbello
Faye Irene Donaldson
Joan Merle Doswell
Heather Jane Druce
Elaine Evans
Isabella Fazzalaro
Maraleen Joyce Felshaw (nee Mason)
Frederick Edward Flowers
Kevin John Francis Folkes
Maria Francipane
June Ellie Fraser
Ouraania Georgiou
Joan Gilbert
Walter Gillespie
Ada Giesson
Jocelyn Glencross
Robert Glover
Simone Giuette Gluck (nee Larroumet)
Rev Tom Gordon
Edward Leon Green
Isabel Hamilton
Grace Hampton
Colleen Patricia Hansell
William “Bill” Hanson
Douglas Bernard Hardes
Wendy Harper
William "Bill" Harris
Pixie Heginbotham
Dulcie Heiningar
John Houston

Carmelina Iacono
Frederick Jarrett
Gertrude Kaliri
Marjorie Kearton
Thomas Frederick (Tom) Kelly
Ditrios Konakas
Ruth Edith Eva Laanema
Jack Wilmay Lamont
Mary Laurentia Lateo
Patricia Lovell AM, MBE
Vittorio Maganja
Joseph Mangraviti
Barbara Mary Martin
Henry Maxwell “Max” Mayo
Susan McBride
Patricia Imelda McDonald (nee Kearney)
David Miller
Arthur George Mison
Leona Jean Mobbs
Frank Murrell
Lorina Olive Murrell
Agnas (Nan) Mushet
Valda Lenore O’Connor
Franco Osbich
Frosa Paparestis
Patricia Elizabeth Parsons
Mary Grahame Peterson (nee Revill)
Jessie Mabel Podmore
Pat Primmer
Michael Punturiero
Norma “Junie” June Putland
Margot Veronica Rabbridge (nee Bond)
Denis Francis Reid
Enid June Ross
Jim Roussis
Carmela Rufo
William “Bill” Wallace Russell
Annunziata Salzano
Giovanni Sapuppo
Lorraine Savage
Keith Kee Lock Seeto
Terence Robert Shute
Jean Smith
Ken Smith
Mollie Smith
Mrs Starr
Mary Sternbeck

George Stimitiotis
Gerald McDonald Stoddart
Gbor Szilvassy
Dawn Toys
Vasiliki (Vicky) Theodore
Francis Sidney (Frank) Thomas
Neofita Tikkis
Miloslav Charles Vaughan
Thomas Wells
Noelene Joyce White
Malcolm Max Wilson
Neville Wilson
Pearl Withington

Alzheimer’s Australia would like to acknowledge and thank families and executors for 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
NEW ADDITIONS TO THE ALzNSW LIBRARY.

Forget Memory: Creating better lives for people with dementia
By Anne Davis Basting
The fear and dread of losing our memory makes the experience of the dementia worse than it needs to be, according to cultural critic and playwright Anne Davis Basting. Based on 10 years of practice and research in the field, Basting's study gives specific examples of innovative programs that stimulate growth, humour and emotional connection, translates into accessible language a wide range of provocative academic works on memory, and addresses how advances in medical research and clinical practice are already pushing radical changes in care for people with dementia.

Enhancing Cognitive Fitness in Adults: A guide to the use and development of community-based programs
By Paula E. Hartman-Stein and Asenath La Rue
This book takes a wellness-support rather than a disease-based approach to its subject, presenting a wide range of promising interventions among the diversity that is currently being offered – from intergenerational volunteer programs, writing workshops and multimedia strategies to meditation, biofeedback, nutrition, and exercise. Introductory chapters discuss the findings driving the cognitive-wellness movement, and the possible roles such programs may have in preserving critical brain resources, increasing cognitive flexibility and avoiding devastating brain decline for improved quality of life in older adults. Areas of coverage include: research bases for cognitive wellness interventions; social programs designed to improve and sustain cognitive function; enhancing cognition through the arts and cultural activities; cognitive wellness interventions for adults with memory impairment, and community-based programs with positive societal impact.

Dementia: The journey ahead – A practical guide for in-home caregivers
By Susan Kiser Scarff and Ann Kiser Zultner
Within a year of receiving her husband's diagnosis, Susan Kiser Scarff had a classic case of caregiver burnout. She couldn't concentrate at work. Friends drifted away. Overwhelmed, she struggled to make the transition from Red's wife to his protector, nurse and mother. Susan's experiences as a first-time caregiver, which are recorded in these pages with grace, wisdom and humour, prove just how much there is to learn: finances have to be handled a different way in case the person with dementia decides to make a lone trip to the bank, aggressive behaviour is a constant threat and safety becomes a concern in every aspect of daily living.

NEED ASSISTANCE?
NOT SURE WHAT YOU WANT?

ASK THE LIBRARY!
Monday to Friday 9am–4pm
E: nsw.library@alzheimers.org.au T: (02) 9888 4218

Keep up to date with all new items in the Library, including books, DVDs and journal articles by visiting the Library News blog.
W: www.alzheimersnswlibrary.blogspot.com

Choose from more than one million general titles, as well as a wide range relating to dementia and Alzheimer’s disease, at the Alzheimer’s Australia Online Bookshop.
W: alz.seekbooks.com.au T: (02) 8206 9035

CROSSWORD

ACROSS
1 Short of wind
6 Dog parasite
10 Sacred book
11 Ate outside
12 In adjacent house (4,4)
14 Spree
16 Absurdly
18 Plays at, ... in
20 Re-create (scene) (2-5)
22 Drink chiller (3,4)
23 Lustrous gem
25 Cloudy
28 Drive
29 Physicist, ... Newton
31 Lump
32 Lighter than air

DOWN
1 Newborn
2 Fade away
3 Indulgence
4 Tropical disease
5 Tethered
7 Show as similar
8 Postal recipients
9 South Africa’s neighbour
13 Duck and weave
15 Confusion
17 Sending electronic messages
19 Yobs
21 Deceive (lover) (3-4)
22 The Titanic hit one
24 Curved over
26 Film star, ... Eastwood
27 Behaves
30 Reverence

IN TOUCH WINTER 2013