Younger Onset Dementia Summit

Maxine McKew lends support

Making memories with art

Changing hearts and minds

Groundbreaking research links blood pressure to dementia
The time to prepare for the dementia epidemic is now. Alzheimer’s Australia NSW has lodged its pre-budget proposal with the Australian Government in the lead-up to the 2009–10 budget process. We have requested a significant increase in funding for dementia as a National Health Priority for another four years.

Alzheimer’s Australia NSW made seven key recommendations to the Commonwealth Government:

- Continue to make dementia a National Health Priority.
- Boost the National Dementia Support Program (NDSP) by 23 per cent.
- Ensure Commonwealth control of dementia as a health priority for a seamless delivery of services.
- Double community care funding.
- Fund community and residential care places to reflect the real cost of care.
- Invest in effective early diagnosis and intervention strategies.
- Increase funding for carers of people with dementia.

Dementia can strike at any age. I went to the National Summit on Younger Onset Dementia at Parliament House in February. The summit discussed ways to improve the quality of life of those living with younger onset dementia. About 10,000 Australians under the age of 65 now live with the condition.

The needs of this group are special because there is low awareness, even among health professionals, that younger people can have dementia. People have a right to tailored dementia services regardless of age.

At the summit, a communiqué calling for priority actions was submitted to Justine Elliott, Minister for Ageing. Let’s hope it leads to significant action.

Alzheimer’s Australia NSW recently released the news that treating high blood pressure in Australians over 65 years of age may reduce the incidence of dementia by up to 50 per cent (see article on page 6). This brings enormous hope in the fight against the predicted dementia epidemic.

I continue to travel around NSW to meet with regional leaders, carers and people with dementia to gain a first-hand understanding of their needs. There is wonderful work happening across Sydney and regional NSW by Alzheimer’s Australia NSW. Our challenge is to broaden that work.

The Hon. John Watkins
Chief Executive Officer
Congratulations to our CEO, The Hon. John Watkins, who with Dr Michael Valenzuela, Tony Thirlwell, Chief Executive Officer of the Heart Foundation NSW, and The Hon. John Della Bosca, Minister for Health, held a very successful media event on the recent high blood pressure findings. Dr Valenzuela’s book, *It’s Never Too Late to Change Your Mind*, was launched at the same time on 27 January 2009.

The finding that reducing high blood pressure may decrease the incidence of dementia by up to 50 per cent, has resulted in significant national media coverage. This has helped to raise the awareness of both Alzheimer’s disease and our organisation.

Raising our profile
At the end of 2008, we had our local Federal MP, The Hon. Maxine McKew, and Senator Marise Payne visit the Vincent Fairfax Resource Centre at Cox’s Road in North Ryde. The extra contacts and links we gain are likely to help us perform better in our task of looking after more people.

We will soon be holding a seminar with Diana Kerr, an expert from Edinburgh University in the United Kingdom, who will speak on dementia and disability on 6 April. We urge you all to support the seminar with your presence.

Challenging times
The ‘economic meltdown’ has not passed us by. It has affected Alzheimer’s Australia New South Wales quite severely. We get a large amount of money from governments to do specific things – and that money continues unabated and we apply for grants (with some success) all the time.

We use such money strictly for the purposes for which it is given. But it is ‘soft’ in that we cannot depend on it year after year. We want to do other things too, and have some money that is ‘untied’ to particular governments – mostly money that we have accumulated and on which we earn interest.

We are particularly aware that some groups of people with dementia, and those caring for them, do not know that help is available. They do not come forward, do not use our services, do not get advice or help, do not get what they should from us, or from anyone. This causes unnecessary suffering and alienation.

We want to get to those people, and use our ‘untied’ money to allow us to do so. As economic conditions get seriously bad, some potential clients are likely to suffer because we cannot do everything that we would like. The organisation is doing what it can to find and include those people – we are running practical dementia education courses this year in many parts of western and south-western Sydney. This is likely to mean we get to more people who need and will benefit from our services.

We are well aware of our history and of the large numbers of people in our present area who turn to us for help – and we will not turn away from what we have traditionally done.

Thank you
We are lucky too, in the make-up of our Investment Advisory Committee, which has toiled to limit the damage to us from the bad economic times. One stockbroking firm has gone into voluntary liquidation (but the committee and staff quarantined our holdings so that we did not suffer from that event). Thanks to the members – both staff and volunteers – of the committee.

I would also like to thank everyone for their generosity with our Christmas appeal – times are hard and we are grateful to so many people for digging deeply to help us.

What everyone needs to know is that we regard the downturn seriously, that the CEO and staff are being sensible about dealing with it, that the Board is well represented (with the CEO and some staff) on the Investment Advisory Committee, but that our ‘outreach’ activities might be less this year than we would like.

Professor Peter Baume AC

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“**We are particularly aware that some groups of people with dementia, and those caring for them, do not know that help is available.**”

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2009 Alzheimer’s Australia National Conference
Adelaide Convention Centre, South Australia
2 – 5 June, 2009
Registrations now open
p: 08 8379 8222  e: events@plevin.com.au
Seniors Week

Seniors Week took place between 15 and 22 March, and it was a good opportunity to make improvements for a healthier lifestyle. There was a range of events at different venues across the State. During the NSW Premier’s Concerts at the Sydney Entertainment Centre, Alzheimer’s Australia NSW highlighted how people can look after their minds, and what to do if you’re worried about your memory or that of a loved one. You’re likely to read about this in a variety of related publications.

Alzheimer’s Australia recommends a ‘brain-healthy’ lifestyle, which means you’ll be less likely to develop Alzheimer’s disease and other types of dementia.

Brain-healthy lifestyle tips
• Get your blood pressure checked, if you’re concerned about your memory.
• Learn new skills to strengthen brain connections and promote the growth of new brain cells.
• Trust yourself more. If you feel you’re more in control of your life your brain chemistry improves.
• Relax and take your time. Tension may prolong memory loss.
• Make sure you get regular and adequate sleep.
• Eat a well balanced diet and avoid excessive drinking.
• Pay attention. Concentrate on what you want to remember.
• Use a notepad and carry a calendar.
• Organise your belongings: Use a special place for car keys and glasses.
• Repeat names of new acquaintances in conversation.

How can Alzheimer’s Australia NSW help you?
• Call the National Dementia Helpline on 1800 100 500 or visit our website for information about dementia.
• Enlist with Living with Memory Loss, a free Alzheimer’s Australia program for those diagnosed with dementia.
• Support groups.
• Private and confidential counselling.
• Other training and education programs tailored to carers and allied health professionals.

Disabilities and dementia seminar

Alzheimer’s Australia NSW will hold a full-day seminar on disabilities and dementia with renowned specialist, Diana Kerr (right), at Parramatta Leagues Club on Monday, 6 April.

Diana is a leading figure in the UK in the area of dementia and learning disability, and a Research Fellow at the University of Edinburgh.

Diana is author and co-author of several publications and her most recent work is Understanding Learning Disability and Dementia – Developing Effective Interventions, which addresses all the essential issues in supporting a person with a learning disability when they develop dementia.

A number of local experts will join Diana and make the seminar essential for families and professionals interested in the field.

Dr Seeta Durvasula from the Centre for Developmental Disability Studies, University of Sydney, will speak on distinguishing a deterioration in intellectual ability from dementia, and Christine Regan from NCOSS will describe a personal journey through the acute health system. Marti Travers and Tammy Gaylard work at the Sylvanvale Foundation and provide an update of a clinical trial involving one of their clients, and Pam Rogers will share her palliative care experiences at Sunshine Homes.

Registration includes lunch and is $65 for professionals or $55 for people with a disability or dementia, carers and the members of support organisations.

Please email education@alznsw.asn.au or phone Susan on 8875 4653.

ARJOHuntleigh support

AlzNSW would like to thank ARJOHuntleigh for its support of our Carer and Professional Education team.

The ARJOHuntleigh product range includes patient handling and hygiene, medical beds and therapeutic surfaces, wound healing, DVT prevention and disinfection.
Members enjoy discount rate from Accor partnership

Our members are set to benefit from the new national level partnership between Alzheimer’s Australia NSW and Accor Hotels, including Sofitel, Pullman, Novotel, Mercure, All Seasons, Ibis and Barrière hotels.

Members and consumers can now book nearly 1,300 Accor Australian hotels (and many Asian hotels) and get a five per cent discount below the best unrestricted rate of the day.

The rate is valid until 31 Dec 2009 and only available online. To make a booking, members must log on to www.accorhotels.com.au, go to the menu, click on ‘corporate’, and use the Accor id AS199679 and contract number 5000 to get the discount.

The offer is not available to staff of partner organisations, universities, Pfizer or Uniting Care.

Supporting our work

Running for awareness
Olivia Collier is running at three major events to raise funds for dementia awareness. In March, Olivia will run the 45km six-foot track in the Blue Mountains. In April, she will run the 50km Canberra Marathon, and in May, Olivia will tackle the North Face 100km trail run.

If you feel exhausted just reading this, why not support Olivia by going to the website www.everydayhero.com. Please follow the prompts on the website and make a donation that will come to Alzheimer’s Australia NSW.

Bowled over by gift
The Royal NSW Bowls Association selected AlzNSW as their charity for 2008 and has presented us a cheque for $15,000. Both our organisations consider that the demographics of bowlers in NSW are the people we wish to connect with in regards to dementia risk reduction and delivering our program ‘Mind your Mind’.

Christmas Prize winner
M. Russell of Wallsend (Ticket No: MST 01 641), won the Toyota Corolla. Meanwhile, B. Bush of Eastwood (Ticket RBR: 07247) won the AlzNSW Booksellers prize of a DVD player.

Recipes for a cause
A recipe book by a volunteer at AlzNSW will be available in time for Mother’s Day. This is a collection of favourite recipes and with the help of business support will be produced at low cost to assist our fundraising. The book costs just $10. Please call Christine on (02) 8875 4625 for more information.

Community Chest Raffle
A new Community Chest Raffle was launched recently, and it is your chance to win yet another Toyota Corolla valued at $25,000. Please call Christine Bauer on (02) 8875 4625 with your phone order and Chris will arrange tickets for you to on-sell. Tickets are still just $2 each and entries close 3 July 2009. Sell a book and win a DVD as well – good luck!

Entertainment Books
These will be on sale from 31 March with a fantastic array of bargains and discounts. They make a wonderful family gift and you will be helping us raise valuable funds. Just complete the enclosed order form – the discounts in this book represent up to $10,000 in value.

Thank you
A big thank you to all the members and friends of AlzNSW who generously supported our fundraising appeals last year. We also extend our gratitude to our regular pledge supporters who donate on a monthly or quarterly basis – knowing we have your support allows us to better plan our service delivery.

Become a pledge supporter
Pledge-giving is a convenient way to support AlzNSW and it helps us by reducing the number of appeal letters we need to send. If you would like to be a pledge supporter, please call Coralie Hicks on (02) 8875 4625.

(L–R) Brian Daniels, Manager Fundraising and Community Relations; Coralie Hicks, Development Officer; John Archer, RNSWBA State President; and Daniel Goldberg, Glaucoma NSW.
At a major media event in the NSW Parliament House, The Hon. John Watkins, Alzheimer’s Australia NSW Chief Executive, The Hon. John Della Bosca, NSW Minister for Health, Tony Thirlwell, Chief Executive Officer of the Heart Foundation NSW, and dementia expert, Dr Michael Valenzuela, called for blood pressure checks for every Australian over the age of 65. The call followed Dr Valenzuela’s groundbreaking medical finding that normalising blood pressure could cut the incidence of dementia by up to 50 per cent.

Alzheimer’s Australia NSW’s call for blood pressure checks made Alzheimer’s Australia NSW has called for blood pressure checks across the nation, following a groundbreaking medical finding that brings hope in the fight against dementia.

In the spotlight

The urgent call for blood pressure checks for all Australians over the age of 65 by Alzheimer’s Australia NSW was reflected in the story of Sandy Potter and his wife and carer, Mary. Sandy and Mary were present at the media event in the NSW Parliament House and also featured in a program by the ABC on Channel Two.

Sandy, 69, was told he had memory problems five years ago, but was diagnosed only last year with dementia. Sandy had high blood pressure for a number of years before his diagnosis.

The media coverage resulted in calls from friends including those unaware of Sandy’s condition. “We felt cherished by all the calls and it’s opened up opportunities for us to talk about Michael Valenzuela’s book,” Mary said.

“I was really comfortable with the media attention and I think it has been a very positive experience,” Sandy said.
headlines in Australia’s major newspapers, with TV stations, including Channels Two, Seven, Nine and Prime broadcasting the news to 7.5 million Australians.

The blood pressure finding was drawn from the recently published analysis of international research on dementia, *It’s Never Too Late To Change Your Mind* (see Resources, p.16), by Dr Valenzuela, Research Fellow at the School of Psychiatry at the University of NSW. Dr Valenzuela’s finding is based on more than 10 years of global research, and he argues that there are direct links between heart disease risk factors and developing dementia.

“The number one thing a person can do to help prevent dementia is to have their blood pressure checked regularly, and if it is high, to take the right measures to bring it under control,” Dr Michael Valenzuela states. All the same recommendations for avoiding cardiovascular disease apply to keeping the brain healthy.

The finding is a step forward in the difficult battle with dementia. More than 230,000 people now live with the condition in Australia. This number is projected to double by 2030, taking more lives than cancer and heart disease.

“At present, around 70 per cent of older people (from the age of 65) in Australia have high blood pressure,* and one in four over the age of 80 has dementia.”

**Check your blood pressure**

Alzheimer’s Australia recommends that you get your blood pressure (BP) checked annually and if your BP is too high, start with lifestyle changes (as detailed below) and then, if required, try medication through your GP.

- Ensure your weight range is within the healthy Body Mass Index (BMI)
- Exercise regularly
- Quit smoking immediately
- Maintain a healthy balanced diet, with plenty of brain and heart-friendly food
- Have your cholesterol checked
- Have your blood sugar checked

Dr Michael Valenzuela’s book, *It’s Never Too Late To Change Your Mind* published by ABC books, is available from the Alzheimer’s Australia NSW Library. To contact the library, please phone (02) 9888 4218, 9am–5pm, Monday to Friday.

Call for diversity in dementia research

One in five older Australians was born overseas. Persons with dementia from Culturally and Linguistically Diverse (CALD) backgrounds face additional challenges, as they often lose their English language abilities, have poorer knowledge of the disease and health system, and experience stigma in their communities.

In late 2008, a group of experts* from the Dementia Collaborative Research Centre reported a paucity of Australian and international literature on dementia in CALD.

The expert group reported that:
- There is a low quality of evidence to inform care to CALD groups.
- No dementia epidemiological study in Australia has included CALD persons with poor English skills – this limits service planning.
- Persons from CALD groups present later for assessment, usually at crisis point, and underutilise services.
- Diagnosis is complicated by a lack of language and culture-appropriate assessment tools. Medical management is based on research on predominantly Caucasian subjects.
- The level of cultural competency of medical and care staff is not known, and in Australia, a high proportion of care staff are from an ethnic minority.

A full review and recommendations are available from the DCRC website www.dementia.unsw.edu.au/DCRCweb.nsf/page/ResearchPDCRC.

Mid-life coffee drinking

According to two population-based studies in Finland, published in The Journal of Alzheimer’s Disease, people who drink coffee in mid-life have less risk of developing dementia than non-coffee drinkers and tea drinkers, although very few people were tea drinkers and were only asked whether or not they drank tea, not how much tea they drank. The optimum number of cups, according to the studies, were found to be between three and five.

To read more about the study, please visit www.j-alz.com/issues/16/vol16-1.html

Mediterranean diet: a healthy choice

Eating a Mediterranean diet appears to be associated with less risk of mild cognitive impairment (MCI) and MCI conversion to dementia, according to a report in the February 2009 issue of Archives of Neurology. The lead author also reported in a 2007 study, that a Mediterranean diet prolongs life in people with Alzheimer’s disease.

The Mediterranean diet includes fish, fruit and vegetables, unsaturated fats, regular moderate consumption of alcohol, little intake of dairy products, red meat and other sources of saturated fats. The diet has been associated with improving cholesterol levels, overall blood vessel function, inflammation reduction, and lower blood sugar levels, all of which could help preserve brain function.

The British Medical Journal (online edition, September 11, 2008) also reported a significant improvement in health status with a Mediterranean diet. Please visit http://oldwayspt.org/med_pyramid.html for more details on the Mediterranean diet pyramid.

Passive smoking and cognitive impairment

Researchers from the Peninsula Medical School, the University of Cambridge and the University of Michigan studied second-hand smoke exposure and cognitive impairment in non-smoking adults.

The research team examined saliva samples from almost 5,000 non-smoking adults over the age of 50. Cotinine, a product of nicotine, was found in mouths of non-smokers exposed to second-hand smoke. Individuals with cotinine in their saliva underwent a series of cognitive tests resulting in the finding that high levels of salivary cotinine in non-smoking adults may be associated with an increased risk of cognitive impairment.

To read more research news, please visit Alzheimer’s News at www.alznews.blogspot.com.

* The expert group convened by Dementia Collaborative Research Centre (Assessment and Better Outcomes) was drawn from Alzheimer’s Australia NSW, the Australian National University, Australian Nursing Home Foundation, Transcultural Aged Care Service NSW, Multicultural Mental Health Australia, University of New South Wales and University of Melbourne. The National Cross Cultural Dementia Network also participated in the review and is represented by members from Alzheimer’s Australia SA, Alzheimer’s Australia NSW and South West Sydney Area Health Service.
Too young for dementia?
National summit addresses issues of younger onset dementia

Over 100 people attended a national two-day summit held at Parliament House on 23–24 February to find ways to improve the lives of people living with younger onset dementia, and their families and carers.

A person diagnosed with dementia in their 40s or 50s may still have children living at home, be in the middle of their career, and have mortgage repayments stretching well into the future – very different issues from those faced by an aged person with dementia.

“For the 10,000 Australians under 65 years of age who have younger onset dementia, it is critical that policy makers and the wider community understand that life can never be the same after a diagnosis of dementia,” Glenn Rees, the National Executive Director of Alzheimer’s Australia, said.

“The reaction of doctors, health professionals, family and friends to younger people with concerns about dementia has often been ‘you’re too young for dementia’, because Australians associate the condition with older people,” Glenn said.

The discussions at the summit drew attention to the delays in diagnosis, access to services, and employment and financial issues of those with younger onset dementia. The summit also focused on stigma and social isolation, support services and respite care, and steps to make legal and administrative systems more user-friendly and responsive to their particular circumstances.

Representatives from all states and territories were present, as well as key partners, including Alcohol Related Brain Injury Australian Services (ARBIAS), Down Syndrome NSW, Parkinsons Australia and MS Australia – ACT, NSW and Victoria.

The Younger Onset Dementia Summit was made possible through Australian Government funding under the National Dementia Support Program, and is a joint initiative of Alzheimer’s Australia and the Parliamentary Friends of Dementia. The summit was co-convened by Sharon Grierson MP and Senator Marise Payne.

There were a number of members of Parliamentary Friends of Dementia at the Parliamentary event, including: Jodie Campbell MP, Yvette D’Ath MP, Senator Mark Furner MP, Gary Gray AO MP, Senator Bill Heffernan, Susan Ley MP, Kirsten Livermore MP, Brett Raguse, Member for Forde, Queensland, and Senator Dana Wortley.

The personal stories of many of those who attended will be included in a new Alzheimer’s Australia publication, In our own Words, launched at the summit.

The publication is available at www.alzheimers.org.au/youngerondementia.

Communiqué calls for action
Representative groups submitted a communiqué to Minister for Ageing The Hon. Justine Elliot, Shadow Minister for Ageing Margaret May, and Shadow Minister for Health Peter Dutton, at a presentation at Parliament House.

Joan Jackman, member of our Sydney consumer committee, spoke on behalf of all the summit participants and presented the communiqué to the minister. “The communiqué identifies that dementia can strike at any age. It affects the life of thousands of young Australians and their families every day. Our recommendations show how quality of life can be maintained and improved for people with younger onset dementia, their families and carers,” Joan said in her speech.

The communiqué called for six priority areas of action:
• Increase awareness to reduce stigma and social isolation
• Make timely and accurate diagnosis
• Access to appropriate services
• Employment and financial needs
• Legal and bureaucratic issues
• Increase investment in research

Joan Jackman of Carers NSW

(L–R) Joan Jackman; Minister for Ageing Justine Elliot; Shadow Minister for Health Peter Dutton; Shadow Minister for Ageing Margaret May.

Services (ARBIAS), Down Syndrome NSW, Parkinsons Australia and MS Australia – ACT, NSW and Victoria.

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Stealing memories

Her grandmother’s battle with Alzheimer’s disease drew artist Vanessa Pore to explore, through art, how the disease steals memories, depriving people of their identity.

“I believe that a person’s identity exists as an accumulation of memories,” says artist Vanessa Pore, who explores her grandmother’s identity in her art work, Last In, First Out (2008) at the College of Fine Arts, University of New South Wales.

Vanessa’s grandmother, a former seamstress, is represented in her work with the incorporation of thread, buttons, fabric, woollen garments and dressmaker’s books. In her works, Simplicity, Filed and Escape, Vanessa makes the association between the person’s mind and a book. “A person’s mind, as does a book, holds information and experiences that combine to form a whole. Cutting into and subtracting layers of a book renders it incoherent, much like a person’s mind when attacked by the perpetual nature of Alzheimer’s disease,” she says.

“It is my intention that the memory and identity of my grandmother may forever be preserved in my art and me. For only in the mind of others may one’s existence and former self live on.”

Thank you Flo

Flo Snell has, for over three years, devotedly knocked on many doors to take the Living with Memory Loss program to those living with the early stages of dementia.

After delivering 17 Living with Memory Loss programs in South Western and Western Sydney, Flo Snell left Alzheimer’s Australia NSW recently, to return to full time congregational life with the Sisters of St Joseph. As she said her goodbyes, Flo left colleagues with some words of wisdom worth remembering.

“There’s a fine line between helping and disempowering people living with dementia,” she said. While working on the program that aims to reduce isolation and connect people with local services, Flo learned that people with dementia have many remaining skills that can be easily overlooked.

“For example, allow them time to speak for themselves and let them do the tasks they’re still capable of doing. Also, do ask them for their opinion, especially when they’re still capable of being involved, or making a contribution. And don’t forget to laugh with them,” Flo said.

Farewell Flo, and thank you for your excellent work, commitment and ongoing support of those living with dementia.

Maxine McKew visit

Left: International Women’s Day at Alzheimer’s Australia NSW was celebrated with guest of honour Maxine McKew MP, Parliamentary Secretary for Early Childhood Education and Child Care, health professionals, carers and people living with dementia.

Right: Maxine visited the Alzheimer’s Australia NSW Vincent Fairfax Family Resource Centre at North Ryde. (L-R): Alzheimer’s Australia NSW CEO; The Hon. John Watkins; Maxine McKew; Chairman of the Board, Dr Peter Baume; and Nicky Hayward Wright, Acting Manager, Knowledge Services and Systems.
Alzheimer’s Australia NSW Diversional Therapist, Janet Godsell, has received an award for Professional Development from the Diversional Therapy Association of NSW. Janet facilitates the seven-week Living With Memory Loss (LWML) program at the Vincent Fairfax Family Resource Centre at North Ryde, and has worked for over 18 years with people who have dementia.

The annual Diversional Therapy Association award is given to members who have achieved a total of 100 points over two years. The award recognises Janet’s strong commitment to continually updating her professional knowledge and skills.

“Diversional therapists help people maximize their abilities and the programs that we do at AlzNSW help them maintain their participation in social and living skills to enhance their quality of life. This really helps maintain their self esteem and confidence,” Janet said. Janet also facilitates a Coming Together program for those who have completed the LWML program, as well as a follow-up group. She is also group leader for the Ryde Carer’s support group.

From all of us at AlzNSW – well done, Janet!

The NSW Ombudsman’s Office is one of the few agencies in the world that reviews the individual deaths of people with disabilities living in care. The aim of the review is to highlight the gaps in service practice, policy and systems, and drive service improvement from a grassroots level.

**The key concerns of the Ombudsman’s Office**

- As the number of older people with disabilities increases, the ability of services to meet the greater support needs of people with disabilities related to dementia and/or ageing with their existing resources will be challenging, particularly for smaller organisations.
- Disability staff, generally, do not have expertise in dementia and aged care and are unlikely to receive the necessary training and support.
- Access to community based aged care support, such as aged care packages for people with disabilities in care who have dementia, is hampered by the program, funding and policy separation between the disability (State) and aged care (Commonwealth) sectors.

**The main recommendations by the Ombudsman are:**

- It is important that people with an intellectual disability have a comprehensive assessment of memory, other cognitive functions and behaviours at least once in early adulthood to obtain a baseline of their level of functioning. A baseline makes it easier to identify changes and can be important in diagnosing dementia.
- For people with Down syndrome, best practice in diagnosing dementia includes assessment to determine any decline in the person’s functioning; medical tests to work out if decline is due to physical illness; psychiatric assessment to work out if decline is due to mental illness; and multidisciplinary assessments, including allied health involvement. Any reversible causes of decline need to be treated before a diagnosis of dementia can be made.
- The focus of caring for a person with dementia and Down syndrome should be on flexibility and meeting individual needs. The review found evidence of good practice by some of the services including changing personal care times and mealtimes, and adjusting routines to minimise stress, adapting the physical environment to ensure safety and ensuring that support was provided by familiar staff.
Call for funding in Armidale

The Hon. John Watkins, CEO, visited Armidale recently to meet health workers, people with dementia and their carers, in a bid to ensure continued government funding for those living with dementia in the region. Armidale, due to its older population, faces larger increases in the number of people with dementia than average in NSW. John met with local MP, The Hon. Richard Torbay, who has backed the call for government funding.

More than 650 people have dementia in the Armidale area and this number is expected to double by 2030. “In Armidale, the New England Division of General Practice in collaboration with the University of New England and Hunter New England Health, runs the Memory Assessment Program Support Service, one of the best models of dementia care in NSW,” John said.

“The response to John’s visit has been fantastic – people felt their needs were being taken seriously,” Sally Prowse, Dementia Support Officer, said. For more information on Armidale programs and groups, call (02) 6770 3826.

Alzheimer’s seminar

Over 120 people attended a one-day seminar hosted by Alzheimer’s Australia NSW at Port Macquarie recently. The seminar, Living with Dementia: Insights for Carers and Health Professionals, included a clinical overview of fronto-temporal dementia pathology and genetics by Professor John Hodges. Anthropologist, psychologist and art therapist, Dr Patricia Baines, also gave a talk, Living with Monsters: Restoring hope and humour in individuals living with dementia.

New Younger Onset service

Alzheimer’s Australia NSW will lend its expertise and practical support to a new Younger Onset Dementia Social Support Service launched by UnitingCare Ageing in February.

The service is the first of its kind on the Central Coast and is a response to the unique needs of people with dementia who are under 65 years of age.

Alzheimer’s Australia NSW will evaluate the service and monitor the impact of the program, as well as offer professional education courses for staff from the Central Coast through the Hunter and all the way to Armidale.

The service will operate once a week in partnership with the Terrigal Uniting Church and comprise individual outreach support, early intervention, monitoring of health and community participation. To contact the Younger Onset Dementia Social Support Service, please phone UnitingCare Ageing on (02) 4333 9142.

(L–R): Angie Robinson, Director of Community & Disability Services, UnitingCare Ageing; Dr Scott Whyte, Associate Professor, Gosford District Hospital; Rev Harry Herbert, Executive Director, UnitingCare Ageing; Margaret Johnston; and Brian Howell, Regional Director, UnitingCare Ageing.

Hunter painting toured Europe

The painting shows a woman wearing a bra on top of her ‘forget-me-not’ dress, clutching at photos spilling out of an album, the piano she has forgotten how to play in the background, her husband struggling to cope with it all.

It’s called Trapped in Her World, but the painting, which has a permanent home at the Hunter Centre, has been around the world and back.

Loaned to the Hunter Centre in late 2008, the painting by Emma Hamilton once toured Europe, beating entrants from 15 countries in 1996 to win an award in an international art competition, Perceptions of Alzheimer’s Disease.

The painting was part of Emma’s HSC work in 1995 and depicts her grandparents’ struggle with dementia.
Strong demand in Hunter for Mind your Mind program

By Beverley Watson

Over 3,000 people have taken part in the Mind your Mind program in the Newcastle, Lake Macquarie and Hunter regions during 2008. The national risk reduction program promotes the importance of making lifestyle changes to reduce one’s risk of dementia.

As well as discovering the seven signposts of Mind your Mind, those who attended the program gained a greater understanding of dementia – and with greater knowledge, hopefully, comes less stigma.

Dementia is not an older person’s disease and we encourage Hunter corporate organisations, community groups and anyone in their 40s or older, to discover how they can ‘Mind your Mind’.

To make a reservation, please contact the Hunter Dementia & Memory Resource Centre on (02) 4962 7000.

Program to fight cognitive decline

By Deanna Sue

The Hunter Dementia and Memory Resource Centre teamed up with Alzheimer’s Australia Tasmania and the University of Tasmania on a research project, the Active Cognitive Enhancement (ACE) program.

Dr Sarah Elder from Alzheimer’s Australia Tasmania and Anna Wolf, a Master of Psychology student at the University of Tasmania, conducted the program.

Designed to boost memory and mental fitness, the program aims to combat cognitive decline. Participants had to be 55 to 80 years of age and have no diagnosis of dementia. The first phase of the 10-week program had 17 participants.

The project investigated the effects of a variety of tasks that train:

• Verbal and visual memory.
• Information processing speed, attention and reasoning.

Activities at the program included:

• Challenging mental exercises, puzzles and games.
• Education on normal ageing, healthy ageing, diet and physical exercise, how to maximise brain health and manage stress.
• Mindfulness meditation.
• Novel and fun activities such as getting dressed with your eyes closed or brushing your teeth with the other hand.

Another 10-week program starts in March 2009 and data once again collected for the project. Hopefully the program will produce some positive findings in the battle against cognitive decline.

For more information about the ACE program, contact Deanna at The Hunter Dementia and Memory Resource Centre on (02) 4962 7000.
<table>
<thead>
<tr>
<th>DATE</th>
<th>TOPIC</th>
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### CARER

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<td>10am-3pm, every Wed</td>
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In touch Autumn 2009 www.alzheimers.org.au
In memoriam

We offer our sympathies to the families who have lost their loved ones. We also thank the friends and families who have donated to Alzheimer’s Australia NSW in their memory.

Jan Arnold
Edie Bailey
Phyllis Irene (nee Poole) Baker
Martin Bambey
Noel Booth
Dr William Herbert Boydell
Raymond Frederick Broadby
Owen George Brooker
Eric Canfield Brown
Marie (Kavanagh) Bruton
Bill Bullock
Joan Burgess
Bernice Lily Burton
Joan Evelyn Callanan
Giovanni Casamento
Elma Fay “Ellie”Castor
Norman Allen Collins
Zoe Constantopedos
Phyllis Cornford
Mustafa Cosic
Norma Crampton
Gregory Criticos
Hugh Cumming
Antonios Daras
Giovanni Nicola De Grandis
Billie Dick
Maurice Doyle
Dennis Druce
Mrs Beryl Ebzery
Joseph Francis (Frank) Fay
Erta Luigia Fiorio
Nick Giataganellis
Gordon Harold Gillespie
John Kenneth Campbell Grace
Alvin Leslie Grey
Joan Gumb
Patricia Lilian Hanlan
George Harle
Ethel Isabel Hearsch
Phillip Heath
Noreen Hickey
Moira Sarah Houghton
Wendy Howell
Gladys Lillian Hughes
Ernest John (Jack) Idiens
Eileen Merriel Johnson
Eric Jones

Robert Jones
Narelle Dorothea Jory
Dorothy Therese Kelly
Pamela Kunze
Elspeth Agnew Leadbeater
Rodney Lowe
Nance Alice Elizabeth MacDonald
Maria Mackell
Joseph Makhlouf
Adrian Don McCloskey
Jean Marie McEwen
Bob Mcgready
Reginald Clyde McMillan
Brian Malcolm Meredith
Raymond Metcalfe
Antonia Mico
Betty Mihailovich
William Gordon Minto
Clarence Walter Moate
Jeanette Morris
Marguerite Ethel Munce
Charles Murphy
Gaetano Natoli
H Nesbitt
Cyril Newlands
Nancy North
Leo Wilson O’Brien
Bill Ohlsen
Roy Parnell

Miranda Petrus
Dr Suzy-Erica Phillips
Lawrence Keith Pittman
Giovanni Pizzale
Kenneth Alan Price
Giacinto ‘Cinto’ Raccanello
Gaetano Raffaele
Dorothy Redford
Liborio ‘Bo’ Riccobono
Monica Amelia Rodgers
Reg Ryan
Donald Brian (Don) Sargent
Hermann Ernst Schietinger
Angela Yam Yuen Shiu
Roy Neville Sillick
Leo Dallas Simmons
Gordon Simpson
Lois Simpson
Chloris Joyce Smith
Sheila Anne Sutherland
Hilda Taylor
Arthur Thane
Sheila Tulley
Salvatore Venuto
Miranda Vici
Mary Waters
Dorothy Beatrice Wiseman
Eileen Woolford
Danny Zanella

www.alzheimers.org.au
What’s Never too Late to Change your Mind

By Nicky Hayward Wright

The Alzheimer’s Australia NSW main library is located at the Vincent Fairfax Family Resource Centre in North Ryde. Our other libraries are located at Bega, Port Macquarie and Newcastle. The library and resource centre is an invaluable benefit to our members. No matter where you live in NSW, you can contact our library staff between 9am and 5pm, Monday to Friday on (02) 9888 4218, or email lis@alznsw.asn.au. We also post information resources to our members.

To see all the resources you can borrow, including full text online resources, please see the library catalogue at www.catalog.nsw.alzheimers.org.au/Library3/default.htm

It’s Never too Late to Change your Mind is a review of global scientific literature on dementia by Dr Michael Valenzuela, Research Fellow at the School of Psychiatry, University of New South Wales. Dr Valenzuela’s groundbreaking finding that treating high blood pressure cuts the incidence of dementia by up to 50 per cent, is drawn from this book.

Still Alice is a compelling debut novel about a 50-year-old woman’s sudden descent into early onset Alzheimer’s disease, written by first-time author Lisa Genova, who holds a PhD in neuroscience from Harvard University. This title was first published in 2007 and is also available in audio CD. Both formats are available to purchase through the Alzheimer’s Australia online bookshop at www.alzseekbooks.com.au

Life in the Balance: a physician’s memoir of life, love, and loss with Parkinson’s disease and dementia is the personal memoir of Thomas Graboy, who at the age of 49, is battling an aggressive form of Parkinson’s disease and progressive dementia. Thomas is a clinical professor of medicine at Harvard Medical School.

How to Make your Care Home Fun. The book includes chapters on the value of activities, how to program and organise activities, talking and listening, as well as detailing various therapy-based activities.

In Full Bloom. A brain education guide for successful ageing discusses the important interconnection between body and brain, provides a fully-illustrated series of physical exercises to keep both body and brain in top condition, and explores the brain’s ability to evolve, adapt, and learn at any age.

Communication Disability in the Dementias offers evidence-based practice in relation to speech and language therapy and a multidisciplinary team approach to service delivery and care.

Musical Memories: for people who remember the 50s to 70s is a sing-along DVD, with large words appearing on the screen (karaoke style). The three-set DVD contains songs popular with people who grew up with 50s to 70s music.