On the move

Memory Walks to end dementia

Raise the bar

New framework set to improve dementia services

• Dementia Awareness Week
• World Alzheimer’s Day
• Australian entertainment legends perform for AlzNSW
We have had a busy and satisfying quarter. So much is happening and all of it is good. Dementia Awareness Week (DAW) was supported financially by Ageing, Disability and Home Care, Department of Human Services NSW, and Home and Community Care (HACC), and the active program included a national television campaign.

During DAW we had a successful meeting of the NSW Parliamentary Friends of Dementia; it is pleasing that interest in this important activity in Parliament House is increasing.

We also released a discussion paper on stigma associated with dementia. Congratulations to Lisa Langley and Jo-Ann Brown who prepared this excellent paper on an important subject.

September’s Memory Walk in Parramatta was a great day – numbers were up and it was financially successful.

Advisory Committee
The excellent Advisory Committee that meets each quarter has done some new and different things. They have had a ‘brainstorming’ session in which ideas for the Association are thrown around and they plan to have another such occasion. They are eminent and busy people and their ideas are most appropriate and welcome.

New resources
Our staff members have produced some new resources during the quarter. They include new resources on ‘ Worried about your Memory?’, as well as information for GPs and pharmacies.

Our Helpline is receiving an increasing number of calls, which pleases us because it is there precisely to help people.

We are also taking steps to increase our activities in areas of high population growth, and therefore dementia growth – they are the Tweed, the Illawarra, the Central Coast and South-West Sydney in the first instance.

Nationally the IT project continues to advance, although it has been delayed a bit, and we in NSW will derive benefit when it is online. One of our staff members, Amanda Allen, is helping drive it.

Ministerial update
Following the Federal election, we have a new Minister for Ageing, The Hon. Mark Butler MP from South Australia, with whom to liaise. We are also aware that change in our area is ‘on the table’.

The first major event, we expect, will be a report by the Productivity Commission early next year. We are waiting for that report and will study it closely.

Financial matters
As the stock market continues to recover, so our investment portfolio becomes healthier and has more value. We maintain a model of a desirable asset balance between shares, cash and fixed interest investments.

Since some recent bequests came to us in the form of shares, we have had to integrate those into our model. This has necessitated buying and selling.

Board news
The Board had the chance to meet regional staff at a picnic in September and we thank those who made this possible. We certainly appreciated it.

John Watkins has accepted the position of Chair of the Little Company of Mary Health Care Limited, however he will remain CEO of our organisation.

We expect that his new position will demand up to two days a week. Accordingly, his time at AlzNSW has been reduced and plans have been made for others to take up extra duties.

John’s new position commenced in November 2010.

The Hon. Prof. Peter Baume AC
Chairman
CEO’s message

It has been a busy three months here at AlzNSW, with Dementia Awareness Week (DAW), the launch of a new Ambassador Program, the release of a discussion paper on stigma and, of course, our continued delivery of vital services to people in need.

The NSW Dementia Services Framework 2010–2015 was also launched by the State Government during DAW, at our Parliamentary Friends of Dementia event.

The Framework is a comprehensive initiative by the NSW Government to improve services for people with dementia across the state and we are confident it will lead to better services and care.

DAW events

DAW was again a big success in NSW and around the country. We were able to reach hundreds of thousands of people and raise awareness about dementia and the importance of early diagnosis.

This year, for the first time, Alzheimer’s Australia launched a national television advertising campaign which ran during prime time around the country.

This was very successful and allowed us to spread the word to a much larger and varied audience.

It led to a significant increase in calls to our National Dementia Helpline and in awareness about memory problems and dementia.

Ambassadors

We also launched our first Ambassador Program. Ita Buttrose AO OBE, PJ Lane, Doris Younane, Natarsha Belling and Maxine McKew have all joined us as Ambassadors and have already been working hard to help us raise awareness.

We are also excited that Sir Michael Parkinson has come on board as an Honorary Ambassador; we look forward to February’s fundraising lunch with Sir Michael.

Discussion paper

We also released a discussion paper on stigma that highlights serious issues many people with dementia and their carers face.

Read more about our many other wonderful events throughout this issue of In touch.

All of us here at AlzNSW hope you have a safe, restful and happy Christmas, and look forward to seeing you in the new year.

The Hon. John Watkins
Chief Executive Officer
Chinese Dementia Helpline to expand

The relocation of a dementia-specific helpline for Chinese-speaking communities in NSW, provided by AlzNSW, is expected to lead to longer operating hours and a better service.

The CEO of AlzNSW, The Hon. John Watkins, said the relocation of the service to the Australian Nursing Home Foundation in Burwood is a significant milestone in the provision of the service. “The Helpline will be situated within a major Chinese community in Sydney, which means staff and volunteers will be better supported.”

The relocation of the service was marked by an official handover function at the Citymark Marigold Restaurant in Sydney on 14 October.

About the Helpline
Callers who ring the Chinese Dementia Helpline have access to trained, Chinese-speaking volunteers and staff who can give them appropriate, relevant and up-to-date information on memory loss and dementia.

This includes on-the-spot telephone counselling and support, and callers can also receive important printed resources about dementia, as well as the services available to help them, in their own language.

“Dementia will continue to have a major impact on Chinese-Australian families – both on those individuals who will develop dementia and on their families and carers,” John explained. “That’s why the Chinese Dementia Helpline is so important.” AlzNSW will continue to support staff and volunteers with training, clinical supervision and resource material to ensure a high standard of service.

The Helpline is funded and supported by the Federal Government’s National Dementia Support Program through AlzNSW, and is part of the National Dementia Helpline, which is operated by AlzNSW.

Chinese Dementia Helpline: 1800 300 386
National Dementia Helpline: 1800 100 500
Hunter garden

AlzNSW’s Hunter Region Dementia and Memory Resource Centre’s new Rotary Garden was officially opened in September by the CEO of AlzNSW, The Hon. John Watkins, and the President of the Rotary Club of Newcastle Inc, Tony Rhodes. A lunch in the garden celebrated the opening.

“This garden is a wonderful extension of our Dementia and Memory Resource Centre,” John said. “It has already proven popular as a tranquil space for people with dementia, their carers, families and friends to sit and relax.”

Rotary’s contribution

The Rotary Club of Newcastle Inc donated $29,000 for the construction of the garden.

“On behalf of all our members and visitors to the Centre, I would like to sincerely thank the members of the Rotary Club of Newcastle Inc for all their hard work,” said John.

The funds were raised by the Rotary Club of Newcastle Inc at the annual Race Day at the Newcastle Jockey Club, and through donations received from other Rotary Clubs, service organisations and individual members of the Hunter community.

The President of the Rotary Club of Newcastle Inc, Tony Rhodes, said the club was pleased to be able to continue its support of the Dementia and Memory Resource Centre with such a wonderful addition to the centre.

“The Rotary Garden is a great space for visitors to the centre to relax and take some time out,” he explained.

“We hope it will become a sanctuary for people with dementia, their families and carers and friends.”

The Rotary Club of Newcastle Inc also raised a substantial amount of money to help in the construction of the Dementia and Memory Resource Centre, which opened in April 2008.

The garden

The Rotary Garden contains plants to stimulate the five senses, including herbs, fruit trees, lavender and flowers, and all are safe to eat.

It will also be used by the Centre’s social groups for special functions and barbecues, and for dementia awareness activities. It is fully wheelchair accessible.

The number of people with dementia in the Hunter region is expected to quadruple by 2050, when the population will reach 32,000.1

The Hunter Dementia and Memory Resource Centre provides support and advocacy for people living with dementia. It offers a counselling service, social groups, education programs, and an extensive library of community resources. Contact the Centre for more information.

T: (02)4962 7000


Bang the Drum

Our Bang the Drum competition is going full steam ahead with elephants and other AlzNSW merchandise popping up in Australia and overseas.

This issue’s top entries see the Memory Walk bottles getting a workout on the South Australia/Northern Territory border and our elephants climbing mountains in England’s Lake District.

Keep sending in your photos of AlzNSW merchandise wherever you are, winners will be announced in In Touch Winter 2011. Good luck!

To enter:
Send your entries to Andrew Mills.
E: amills@alznsw.asn.au
P: Andrew Mills
Alzheimer’s Australia NSW
PO Box 6042
North Ryde, NSW 2113

Keep Up!
Get all the latest news from AlzNSW on Twitter and Facebook, and see event photos on Flickr.

Facebook: facebook.com/alznsw
Twitter: twitter.com/alznsw
Flickr: flickr.com/photos/alznsw
AlzNSW has welcomed its second Memory Van. The new Memory Van, based in the Hunter, travels up and down the North Coast. It has already visited Newcastle, Lake Macquarie and Dungog.

The other Memory Van has been out in western Sydney visiting Vietnamese, Indian, Greek, Italian and Assyrian communities.

To find out where the Memory Vans will be in coming months, contact AlzNSW.

To invite a Memory Van to a community event in the Hunter region, contact Kim Wilson, or Susan Newton if your event is elsewhere in NSW.

Hunter and Mid North Coast: Kim Wilson
T: (02) 4962 7000
E: kwilson@alznsw.asn.au

Rest of NSW: Susan Newton
T: (02) 8875 4637
E: snewton@alznsw.asn.au
AlzNSW Ambassador PJ Lane’s October concert honoured his father Don Lane, as well as raising awareness of dementia and funds for AlzNSW.

PJ gathered together the cream of the Australian entertainment crop at the State Theatre on 25 October for the Memory Lane Concert – a fantastic night of song and dance, along with plenty of laughs. An audience of hundreds was treated to the talents of entertainment legend Rhonda Burchmore; the fabulous ‘Candy Man’ Wayne Scott Kermond; the divine Liza Minelli and Shirley Bassey courtesy of the very talented Trevor Ashley; the witty stand-up ventriloquist Darren Carr; the wonderful songstress Trisha Crowe; and the astonishingly adept and entertaining juggler Joel Salom. The ever-popular David Campbell finished off the night’s stellar performances.

PJ not only created the event, he also hosted it and opened the show with a song, and all the headline performers donated their time and talents.

“The Memory Lane Concert was a wonderful way for PJ to honour his father and to help people with dementia and their families and carers,” said The Hon. John Watkins, CEO of AlzNSW.

“On behalf of all our members, I want to thank PJ and all the artists for donating their time and talents to help the more than 80,000 people with dementia in NSW, as well as and their families and carers.”
Australian identity Ita Buttrose AO OBE, entertainer PJ Lane, actress Doris Younane, Channel Ten newsreader Natarsha Belling and former MP Maxine McKew have come together to raise awareness of Alzheimer’s disease and other forms of dementia as AlzNSW’s inaugural Ambassadors.

Well-loved international media identity Sir Michael Parkinson has also joined the program as an Honorary Ambassador.

The CEO of AlzNSW, The Hon. John Watkins, said the program was an important step forward in raising much-needed awareness of dementia and its impact on the more than 250,000 Australians currently living with the illness.

“We are excited that Sir Michael and these great Australians are so willing to use their personal experience with dementia to help the tens of thousands of people living with the disease, and their families, in NSW,” John said.

“We thank them all for giving up their valuable time to help raise awareness and understanding of dementia and we look forward to working with them to do just that.”

Ita Buttrose

“It is a regular visitor to Australia and we are delighted that he has accepted our invitation to help raise awareness of dementia while he is here.

“Sir Michael’s mother had dementia and he has been a passionate advocate for better care for people in hospital and in aged care facilities, most recently, as the National Dignity Ambassador for the British Government’s Dignity in Care Campaign.”

As an Honorary Ambassador, Sir Michael will be the guest speaker at a special fundraising lunch for AlzNSW in February.

He was delighted to accept the invitation to be part of AlzNSW’s inaugural Ambassador program.

“This is an issue that I hold dear to my heart. Everyone deserves to live their life with dignity and raising awareness about dementia is an important way we can help ensure those affected by the illness are treated with compassion, understanding and care.

“I hope that as an Honorary Ambassador for AlzNSW, I am able to help alleviate some of the stigma associated with dementia and contribute to a much greater understanding of the illness and its impacts.”

PJ Lane, Ita Buttrose and Doris Younane.
People power

Lunch with Sir Michael Parkinson

AlzNSW Honorary Ambassador Sir Michael Parkinson will be the guest speaker at a special fundraising lunch in Sydney on Friday 25 February.

It promises to be a wonderful event and one not to be missed. Numbers are limited and bookings are essential. We expect tickets to sell out fast. To book, contact AlzNSW.

Where: Strangers Dining Room at NSW Parliament House, Macquarie Street, Sydney

When: Friday 25 February.

Cost: $135 per person (AlzNSW members); $150 per person (non-members); table of 10 $1350

E: reception@alznsw.asn.au

T: (02) 9805 0100

“People need to know where to go to get help. No one has to walk the journey alone.”

PJ Lane

PJ Lane, whose father, popular entertainer Don Lane, was lost to dementia last year, said it was an honour to be associated with AlzNSW as an Ambassador.

“My dad developed dementia and I know firsthand the difficulties associated with the illness and, in particular, for those caring for someone with dementia,” PJ said.

“I will do whatever is possible to promote awareness of Alzheimer’s disease and dementia. It is important people realise life does not stop with a diagnosis of dementia and that there is help available.”

Doris Younane

Actress Doris Younane, whose mother has dementia, hopes that as an Ambassador she is able to help promote a better understanding of dementia in the community.

“Dementia is so prevalent it’s almost inconceivable that it has remained a taboo illness for so long,” said Doris, well-known from her roles in McLeod’s Daughters, Seachange and the 2009 film The Combination.

“It’s not until you have been touched personally by the disease that you begin to understand just how common it really is and how many families it affects,” Doris explained. “Thankfully there is support available for those trying to deal with an ever-changing illness.

“I cannot stress enough how beneficial it has been to talk to professionals and counsellors from Alzheimer’s Australia who can guide you through the often rugged terrain of Alzheimer’s disease.”

Natarsha Belling

Like thousands of other Australians, Channel 10 newsreader Natarsha Belling has had experience with people living with dementia and she said it was imperative that awareness of the disease is raised in the community.

“Alzheimer’s disease does not only affect the elderly, it can also strike the young. As the people with dementia are affected, so are their loved ones and family,” she said.

“It’s critical we fund vital research for a cure, but we also need to raise awareness about this debilitating disease, ensuring a growing number of Australians with the illness, and their families, receive the best possible treatment and support.”

Maxine McKew

Maxine McKew said she was pleased to be able to help raise awareness of dementia and the issues those living with the illness face.

“I have met many people over the past four years who are caring for a loved one with dementia and have heard firsthand of the challenges involved,” she said.

The Ambassador Program was launched during Dementia Awareness Week.

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The Ambassador Program was launched during Dementia Awareness Week.
A discussion paper released by AlzNSW in September, *Addressing the Stigma Associated with Dementia*, found that stigma can have a profound effect on people with dementia and their loved ones. It also found that dementia is the second most feared disease among seniors.

The CEO of AlzNSW, The Hon. John Watkins, said the stigma associated with dementia often leads to exclusion, discrimination and disempowerment for both the person with dementia and their family members or carers.

“It can also affect whether people with genuine worries about their memory seek medical help early, which is a big concern,” John said.

“If the symptoms are caused by dementia, getting a diagnosis as early as possible is important in helping to get the right information, treatment and support.”

To combat this, AlzNSW has called for a national campaign to increase the understanding of dementia and to ensure the retained abilities of people with dementia are recognised so they can participate in mainstream community life.

“What we have found is that a lack of understanding of dementia and fear of dementia are the major causes of stigma,” John explains.

“The fear ranges from ignorance and fear of the illness itself, to fear of how to communicate and interact with a person with dementia.”

**Sources of stigma**

In surveys conducted for the discussion paper, carers of people with dementia talked about the negative community attitudes towards the person with dementia.

“I explained my husband’s problem; the response was ‘If you are going to have an idiot on the street put a muzzle on him’, ” one carer said.

Carers also talked about the isolation and loneliness that can be associated with dementia. A carer said: “People become very clever at being able to avoid you. It becomes a very lonely experience for many years.”

“Friends stayed away and treated the person as ‘contagious’, ” said another.

“People with dementia can continue to lead a fulfilling and rewarding life and should be encouraged and supported to continue to participate in mainstream community life.”

The surveys also found that 61 per cent of people did not believe the general public had an understanding of dementia and that dementia is the second most feared disease after cancer.

As well, 76 per cent of carers surveyed stated they had, at some time, felt embarrassment or shame for the person they care for because of inappropriate social behaviour caused by the dementia – an aspect of the illness which is not well understood by the general public.

Many carers reported ignorance of dementia as a major reason for people’s negative attitudes.

If you enjoy a good read, appreciate humour with honesty, are not afraid to weep, are worried about your loved one’s behaviour and your role in caring for them, or if you are a professional carer who takes the job seriously, then this book is written for you.

Jim Connor shares his own experiences in dealing with his wife’s Alzheimers. This book is for everyone who is trying to cope with dementia and similar wretched diseases. in the sincere hope that their lives will become enriched.

To order, call 1800 628 058 or visit our secure web order page www.funnythinghappened.com.au
Key recommendations

1. **National dementia awareness campaign:** Australian Government to develop and fund a national dementia awareness campaign to increase understanding of dementia and to decrease stigma.

2. **Social inclusion initiatives:** Australian and NSW Governments to fund social inclusion initiatives such as leisure and access programs that recognise the retained abilities of people with dementia and enable them and their carers to participate in mainstream community life.

3. **Legislated dementia care standards:** Australian Government to amend aged care legislation to include enforceable quality dementia care standards, such as those developed by Alzheimer’s Australia, which can be applied across aged care services.

4. **Early diagnosis and timely referral:** Australian and NSW Governments to fund programs for early diagnosis and timely referral to dementia support services to avoid the impact stigma has in delaying access to diagnosis and medical support.

5. **Dementia-specific education and training:** Australian and NSW Governments to fund and support dementia-specific education and training for all personnel working in dementia care services to reduce prejudice and stereotyping among dementia care workers.

6. **Further social research:** Australian Government to invest in further social research into the effect of stigma on the lives of people living with dementia, their carers and families.

**Increasing awareness**

Many people with dementia interviewed as part of the survey believe the community needs to recognise that a person in the early stages of dementia still retains many of the abilities that allow them to participate meaningfully in everyday life.

“People with dementia can continue to lead a fulfilling and rewarding life and should be encouraged and supported to continue to participate in mainstream community life,” said John.

An estimated 257,000 Australians currently live with dementia, and, without a significant medical breakthrough, this figure is expected to soar to almost one million by 2050.

“There is an urgent need for a national dementia awareness campaign to increase understanding of dementia and to decrease stigma,” John said.

“The number of people with dementia is only going to increase and, as physical disability has been increasingly integrated into mainstream society, so too should dementia.”

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s cognitive ability. Alzheimer’s disease is the most common type of dementia.

Dementia is not a normal part of ageing.

*Addressing the Stigma Associated with Dementia* was launched at the start of Dementia Awareness Week 2010, which ran from 16-26 September.

Dementia Awareness Week is supported by Ageing, Disability and Home Care, Department of Human Services NSW, and Home and Community Care (HACC).
Dr Andrew Rochford has urged those worried about their memory to seek help sooner rather than later.

Dr Rochford, National Ambassador for Dementia Awareness Week, made the call at the launch of Alzheimer’s Australia’s new publication, Worried About Your Memory? on 21 September. The new Federal Minister for Mental Health and Ageing, The Hon Mark Butler, also joined the event.

The launch coincided with World Alzheimer’s Day and the launch of a new report released by Alzheimer’s Disease International, which estimates that 35.6 million people live with dementia globally, a figure expected to increase to 115.4 million by 2050.

“I encourage people who have concerns about their memory to contact Alzheimer’s Australia on the National Dementia Helpline for help and support, or to seek medical help,” Dr Rochford said.

Timely diagnosis

“It is important that when someone has a genuine concern about their memory, or that of a loved one, they act sooner rather than later as this will help in getting a diagnosis as early as possible,” Dr Rochford continued.

“Early diagnosis is important in helping to get the right support, information and treatment. Some medications are also at their most beneficial in the early stages of dementia.”

Timely diagnosis is also important when planning for future care needs and making sure financial and legal matters are in order.

Dr Rochford said it was also important for people living with dementia, as well as their carers and families, to know help is available.

“Alzheimer’s Australia is a great resource for people living with dementia. It can help with information about dementia, including help sheets, education for carers and professionals, counselling, support, the early intervention Living with Memory Loss program, social and therapeutic activities, and more,” he said.

“The National Dementia Helpline is the best way to contact Alzheimer’s Australia throughout the country.”

Publication launch

A new publication for GPs, No time like the present, was also launched at the event.

AlzNSW Honorary Medical Advisor Professor Henry Brodaty, Director, Aged Care Psychiatry and Head of the Memory Disorders Clinic, Prince of Wales Hospital, said the publication would help GPs provide a timely diagnosis for their patients worried about their memory. Timely diagnoses are a high priority for patients, but all too often are not achieved.

“We need to take patients’ concerns about their memories seriously,” Professor Brodaty said. “Some symptoms similar to dementia can be caused by other...
conditions and may be treatable; in those cases where it is dementia, a timely diagnosis is one of the first steps to understanding and managing the condition. We need more education for GPs and other health professionals and better support through assessment, diagnosis and ongoing management.

“Every GP, practice nurse and other health professionals working in the area should have a copy of No time like the present to act as a reference point for further clarification or to refresh their memory about the common issues with timely dementia diagnosis.”

The CEO of AlzNSW, The Hon. John Watkins, said the release of the World Alzheimer’s Report 2010 is yet another wake-up call for governments around the world to develop comprehensive plans to combat dementia.

These plans should include action on issues such as timely diagnosis and awareness, as well as access to dementia services, and research into prevention, cause and cure.

“The World Alzheimer’s Report 2010 estimates the costs of dementia worldwide at US$604 billion, which is more than the annual revenue of Wal-Mart, one of the world’s largest companies, at US$414 billion,” John said.

“Australia laid a basis for action on dementia in the 2005 Dementia Initiative but there is an urgent need to address new health and care priorities as the numbers of Australians with dementia grow at an ever increasing rate.

“About 257,000 Australians have dementia today and this is set to escalate to almost one million by 2050. We only have a short window of opportunity to act.”

For more information on memory loss, contact the National Dementia Helpline.

T: 1800 100 500

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Alzheimer’s Australia has, for the first time, launched a national television advertising campaign. It urges people with concerns about their memory to seek help.

Called There’s a difference, the advertisement explains the differences between what is considered ‘normal’ memory loss that may happen with age and memory loss associated with Alzheimer’s disease and other forms of dementia.

The advertisements were screened during prime time over two weeks in September on the Seven Network.

“It is important for people to understand the difference between normal memory loss and dementia.”

With more than 250,000 Australians already estimated to be living with dementia, and with the ageing population set to see that figure rise to almost one million people by 2050, AlzNSW CEO The Hon. John Watkins believes it is more important than ever that people know the warning signs and get help.

“If the symptoms are caused by dementia, getting a timely diagnosis is important in helping to get the right information, treatment and support. As well, it gives people an opportunity to plan ahead and make decisions about their future care and finances,” John said.

“It is also important for people to understand the difference between normal memory loss and dementia.”

Alzheimer’s Australia engaged the services of international branding agency, Interbrand, to create the ad and help promote the message.

“It’s not often that we get to use our creative skills for a community cause,” says Chris Maclean, Creative Director at Interbrand Australia. “Our creativity wasn’t limited and we created a visually stunning ad that speaks to a genuine insight.”
Dementia Services Framework

Following consultation with people with dementia and their carers, a new framework for dementia services was launched at September’s NSW Parliamentary Friends of Dementia forum.
AlzNSW has welcomed the State Government’s commitment to improve services for people with dementia with the launch of the NSW Dementia Services Framework.

With the number of people with dementia set to soar over the next 40 years, it is critical that services are able to meet the expected demand, said AlzNSW CEO The Hon. John Watkins.

“The NSW Dementia Services Framework 2010-2015 is a comprehensive initiative to improve dementia services across the state,” John said.

“It is based, for the first time, on extensive consultations with carers and people who are living with dementia.”

“There has been a wide-ranging examination of what works and what is there for people with dementia across the spectrum, from community awareness to palliative care.

“We are confident this will ultimately lead to better services and care for people with dementia in NSW.”

There are an estimated 88,000 people with dementia in NSW.1 Without a significant medical breakthrough, that is expected to soar to about 300,000 by 2050. This increase is largely driven by the ageing population.

Dementia is already the third leading cause of death in Australia, after heart disease and stroke.2

John said he welcomed the commitment of the NSW Minister for Health, The Hon. Carmel Tebbutt and the Minister for Ageing and Disability Services, The Hon. Peter Primrose, to providing better access to much-needed services and support for people with dementia and their families and carers.

“This framework is an important strategic initiative that promotes a coordinated approach and further direction for the improvement of dementia care services,” John said.

“It addresses a wide range of care needs, including knowing where to go for help, keeping healthy, obtaining a diagnosis, living with dementia, obtaining more support, managing illness, managing behaviour and personality changes, transition to residential care, and access to palliative care.”

“There has been a wide-ranging examination of what works and what is there for people with dementia across the spectrum, from community awareness to palliative care.”

The NSW Dementia Services Framework was launched during AlzNSW’s twice-yearly NSW Parliamentary Friends of Dementia forum at NSW Parliament House on 22 September. The forum was held as part of Dementia Awareness Week, which was held from 16-26 September.

People who are worried about their memory, or that of a loved one, are being encouraged to seek help, either by seeing their doctor or by calling the National Dementia Helpline on 1800 100 500.

“It’s important that people who do have genuine concerns about their memory seek help sooner rather than later,” John said.


On the move to end dementia

This year’s Dementia Awareness Week was the biggest yet, with activities throughout the state raising awareness of dementia and funds for people living with dementia.

A major initiative of this year’s Dementia Awareness Week (DAW) was a new television commercial, ‘There’s a difference’, which was run during prime time on the Seven Network around the country. See page 13 for more details.

There were also Memory Walks, the 10th Annual Memories Service, a Badge Day, a cocktail fundraising event and more.

DAW Picnic
In St George and Sutherland, World Alzheimer’s Day was commemorated with a picnic attended by members of the Friends and Leisure, Café Connects and Younger Onset Dementia Activity groups.

The barbecue lunch at Dolls Point was attended by 25 people and was followed by a game of quoits.

Memory Walks
Sydney
Hundreds of Sydneysiders joined AlzNSW Ambassadors in raising awareness of and funds for dementia at the third annual Memory Walk at Parramatta Park on Sunday 26 September.

Ita Buttrose AO OBE, PJ Lane, Doris Younane and Maxine McKew led the record number of walkers in the event. We were also very pleased to have the NSW Minister for Ageing and Disability Services, The Hon. Peter Primrose, take part in the Walk and raise funds for AlzNSW.

An estimated 500 walkers took part in the Memory Walk and participants raised almost three times as much money as last year. Check out photos from the day or register your interest in taking part in next year’s event at the Memory Walk website. We look forward to seeing you all there next year!

W: www.memorywalk.com.au

Wollongong
The second annual Memory Walk in the Illawarra was held at Galvin Park in Wollongong on Saturday 11 September.

The event, organised in conjunction with the Multicultural Communities Council of Illawarra, was again a great success with more than 600 registered walkers, which included our very own Al the Elephant!

Port Macquarie
The Port Macquarie Triathlon Club hosted a Fun Run and Walk on Sunday 26 September, with proceeds donated to AlzNSW.

This is the second year the Triathlon has generously run the event to help raise funds and awareness of dementia.

About 150 people took part in the event, with local member Peter Besseling MP doing the honours and starting the race.

Other locations
More than 100 people took part in the Memory Walk at Albury, held by the Albury Dementia Service Network, and Peninsula Village also again held a very successful ‘Walk to Remember’ to help raise funds for AlzNSW.

Thanks
Thank you to everyone who took part in all the Memory Walks and fundraising walks and runs in NSW.

Your participation and contribution has helped make a difference to the lives of people with dementia, their families and carers in NSW.

Badge Day
More than 100 volunteers and staff took to the streets on World Alzheimer’s Day, 21 September, to sell a range of merchandise. They raised funds to provide support and services for people with dementia and their families and friends, and to raise awareness.

Volunteers were stationed in the Sydney and Parramatta CBDs and at train stations at Milsons Point, North Sydney, Gordon, Hornsby, Wahroonga and Turramurra.

The day even got a plug on national TV, thanks to AlzNSW Ambassador Ita Buttrose AO OBE, who wore a gold elephant badge on her regular segment on the popular Network Seven show Sunrise.

Ita also encouraged viewers to buy a badge to support people with dementia and gave host David Koch his very own squeezy elephant.

A big thanks also to all our volunteers who sold merchandise on the day, in particular to students and staff from Burwood Girls High School, St Andrew’s Cathedral School, Loreto Kirribilli, Shore School, Ravenswood School for Girls, Knox Grammar School, Abbotsleigh, Normanhurst Boys High School and Macarthur Girls High School.

Thank you also to Sydney Fast Ferries, who brought one of our sellers on board their ferry to sell to commuters between Manly and Circular Quay, and to RailCorp, who gave us access to their train stations, as a preferred charity, to sell merchandise. »
“An estimated 500 walkers took part in the Memory Walk, and participants raised almost three times as much as last year.”
Forget Me Not

All dressed up and looking fabulous, 250 people converged on the Museum of Contemporary Art on 25 September to help raise more than $26,000 for research into Alzheimer’s disease.

The money will go to the Hazel Hawke Alzheimer’s Research and Care Fund, which contributes to the care of those with dementia, their families, carers and care workers, and helps in the search to find a cure.

The event was a result of the hard work of The Forget Me Not Girls – Andrea Britz, Annabelle Boyd-Jones, Sophie Pieters-Hawke and Tess Paul. The women are also behind the Forget Me Not website, a space for young people who have had a relative affected by dementia to share their stories.

Congratulations on a fantastic night and thank you to all who contributed to the fundraising efforts.

Dementia Adventure

The annual ‘Dementia Adventure’ symposium was held at the Epping Club on 16 September. With the theme of ‘Thinking outside the square’, the symposium attracted a diverse range of speakers.

Anne Cumming from the NSW Dementia Policy Team presented on the NSW Dementia Services Framework 2010-2015; Dr Bob Russell, Staff Specialist of Psychogeriatrics at Royal North Shore Hospital examined the ‘Dilemma of Dual Diagnosis’; and Danielle McIntosh and Fiona Darrow from Hammond Care showcased Streeton Cottage, a new model of residential care based in Horsley for clients with younger onset dementia.

Susan Graham from Catholic Community Services then explored the absorbing world of squalor and hoarding, and Professor Wendy Rogers from Macquarie University provided a thought-provoking session on ethical decision-making.

Following lunch, BASIS Clinicians Laura Hill and Sharonne Pearce presented two very practical sessions on ‘Why showers hurt’ and ‘The role of pharmacological treatments in dementia care’.

The final speaker, carer Robyn Austin, gave a moving account of her personal experiences caring for her sister Kaye who was born with Down syndrome. Kaye has since developed a range of other conditions, including schizophrenia, epilepsy and, most recently, dementia.

More than 190 people attended the popular annual event, which is hosted by the Dementia Advisory Services of the Northern Sydney Metro area.
Fundraising walk

An amazing 51 walkers joined Hunter resident Amanda Percival for her second annual 26km fundraising walk from Mulbring to Maitland on Saturday 18 September.

Perfect weather helped all enjoy a wonderful day, and over $2700 was raised for AlzNSW.

A big thank you to Amanda and to all who took part and donated, and thanks to Michel’s Patisserie in Maitland for supporting the walk.

Hunter Celebrates 10 Years

The Hunter’s 10th annual Memories Service was held on Sunday 19 September at Newcastle’s magnificent Christ Church Cathedral on the Hill.

The Anglican Dean of Newcastle, The Very Reverend Dr James Rigney, warmly welcomed our approach to join in the cathedral’s Sunday morning choral eucharist.

UnitingCare’s Reverend Gwen Graham, along with 2009 NSW Senior of the Year Lynn Thorpe and her husband David, all contributed to the service on the day.

As the congregation departed the cathedral, they enjoyed sweet music from a small group of the Percy Street Singers, a choir made up of people with dementia, their carers and other community members.
Weigh It Up Australia
An eight-week healthy lifestyle challenge called ‘Weigh It Up’ is raising funds for AlzNSW.
Launched on 10 October by Abundant Media, along with several media partners including News Ltd, the program is based around sensible eating, exercise and positive thinking.
To register for Weigh It Up and raise money for AlzNSW, visit the Weigh It Up website.
W: www.weighitup.com.au

Charity Challenge – Climb Kilimanjaro!
AlzNSW, in conjunction with Inspired Adventures, is running its very first charity challenge. The 12-day adventure will leave Australia on 14 September 2011.
Join Climb2Remember Ambassador adventurer Matt McFadyen and Climb Champion Emma Lovell to scale Mt Kilimanjaro in Tanzania.
Challenge yourself while raising much-needed funds for essential support services for people with dementia and their families and carers in NSW.

The Climb2Remember is already gathering interest so don’t miss out – there are limited spaces available.
Visit the Climb2Remember website to register, and follow AlzNSW on Twitter and Facebook for the latest news and updates.
Twitter: twitter.com/alznsw
Facebook: facebook.com/alznsw

Blackmore’s Sydney Running Festival
AlzNSW was an official supporter charity for the Blackmore’s Sydney Running Festival, held on Sunday 19 September.
There were four events, giving people of all ages and abilities the once-a-year opportunity to run, jog or walk over the Sydney Harbour Bridge and finish at the equally iconic Sydney Opera House.
We had 144 people running for AlzNSW, and they raised two and a half times more than last year’s total – a fantastic result.
Thanks to all who participated and their sponsors.
AlzNSW Christmas Cards
A great selection of AlzNSW Christmas Cards is still available, but they are selling fast. Contact Chris Bauer to place your order before they sell out!
T: (02) 8875 4625

Support opportunities
We have a number of opportunities for business to partner or assist us in our fundraising ventures.
Our events include Dementia Awareness Week activities, the Memory Walk, seminars, corporate golf days and more. We are also seeking donations of high-level auction items and raffle prizes for community-driven fundraising events.
If your company or business wants to support the work of AlzNSW, please contact Andrew Mills, Manager Fundraising.
T: (02) 9805 0100

Thank you
We extend a big thank you to all the members and friends of AlzNSW who generously supported our 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.

WIN!
A CHRISTMAS TREASURE TROVE
Over $25,000 in prizes is up for grabs in the Christmas Treasure Trove Raffle! Tickets are just $2 each – don’t miss out.
1st prize: Toyota Yaris
2nd prize: Netbook Computer
3rd prize: Jewellery to the value of $1000
The raffle will be drawn on 19 January 2011.
For more information or to purchase tickets, see the flyer inside this edition of In touch or contact Chris Bauer.
T: (02) 8875 4625
E: cbauer@alznsw.asn.au

AD-HOC events
The Alzheimer’s Disease – Help Our Carers group (AD-HOC) holds monthly meetings for AlzNSW members and their friends. All events are held at the Vincent Fairfax Family Resource Centre, Dementia & Memory Community Centre located on the Macquarie Hospital Campus, corner Cox’s & Norton Roads, North Ryde. All events begin at 12.30pm and cost $10.
RSVP to Chris Bauer:
T: (02) 8875 4625
E: cbauer@alznsw.asn.au

DATES
29 January: Barbecue
26 February: Luncheon
26 March: Garden Party
30 April: Luncheon
28 May: Barbecue
25 June: Luncheon
A day in the life of... a Library and Information Services Coordinator

AlzNSW’s Library and Information Services Coordinator Michelle de Mari is kept busy at the helm of Australia’s largest dementia-specific resource library, linking healthcare professionals and community carers to an ever-expanding catalogue of resources.

“I am in the privileged position of being able to guide carers and healthcare professionals through AlzNSW’s wealth of dementia resources, essentially supporting the old adage that ‘knowledge is power,’” Michelle says.

“We really do canvass the A to Z; from dealing with dementia in its early stages, to coping with grief and loss.”

AlzNSW’s library recently integrated the reserves of its Western Australian, Victorian, South Australian and Northern Territory counterparts, with Queensland set to follow suit. The move means that Michelle now has nearly 11,000 resources at her fingertips.

“As you can imagine, it’s a lot of information to juggle, but it is well worth the effort. It means I can tailor my advice to each person, develop unique one-on-one relationships and navigate carers towards the best resources to suit their needs.”

Constant contact

While those in Sydney are encouraged to use the library in person, Michelle stresses that her help and the library’s resources are available to everyone in NSW.

“We mail out resources free of charge to anyone who wants to borrow them, and I can walk people through the offerings over the phone or via email. The library is set up to be truly accessible, no matter where you are, even if you’re in regional NSW.”

Borrowers can also access the library’s online news blog, which publishes a list of its newest additions, including books, DVDs and research papers.

Those who sign up can be notified of any new arrivals via email, with Michelle encouraging people to use the online reservation and borrowing service. For anyone wanting to actually purchase material, the library also hosts an online bookshop.

Why wait?

“If I could say one thing to people it would be to use the library now, not tomorrow. The library is here to support every stage of dementia and knowledge, and can make such a difference to that journey,” says Michelle.

“The carers I come into contact with use strength and humour to overcome very difficult circumstances. It is a privilege to share insights into their life experiences.”

Access to the AlzNSW library is free to members of AlzNSW. See page 24 for details of how to access the library and blog.

Courses

<table>
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<tr>
<th>LOCATION</th>
<th>WORKSHOP</th>
<th>DATE</th>
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<tbody>
<tr>
<td></td>
<td>Professional education Workshops cost $75 each. Contact Gail Longhurst: (02) 9805 0200 or <a href="mailto:education@alznsw.asn.au">education@alznsw.asn.au</a></td>
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<tr>
<td>North Ryde</td>
<td>Understanding Dementia and Person Centred Approach</td>
<td>2 Feb</td>
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<tr>
<td></td>
<td>Experiencing Dementia and Person Centred Approach to Managing Behavioural Symptoms</td>
<td>10 Mar</td>
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<td></td>
<td>Pharmacological Treatment and Dementia</td>
<td>6 Apr</td>
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<td>Intellectual Disability and Dementia</td>
<td>20 Apr</td>
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<tr>
<td>North Ryde</td>
<td>Sons and Daughters</td>
<td>23 Feb</td>
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<td></td>
<td>Understanding Grief and Managing Transition into Care</td>
<td>16 Mar</td>
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<td></td>
<td>3 Day Carers Course</td>
<td>5, 12 &amp; 19 Apr</td>
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<tr>
<td></td>
<td>Understanding Grief and Managing Transition into Care</td>
<td>11 May</td>
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<td></td>
<td>4 Session Evening Carer Program</td>
<td>8, 15 &amp; 22 Feb, 1 March</td>
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<td></td>
<td>Special programs</td>
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<tr>
<td>North Ryde</td>
<td>Mind your Mind Presentation</td>
<td>9 Feb</td>
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<tr>
<td></td>
<td>Interacting with the Person with Dementia</td>
<td>16 Feb</td>
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<tr>
<td></td>
<td>Memory and Ageing Presentation</td>
<td>13 Apr</td>
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</tbody>
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Janet de Bres (reference and research librarian) and Michelle (right)
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.

Janice ‘Jan’ Adderley
Fotini Alexopoulos
Ivan Anthony Almeida
Edna Mary Anderson
Stella Aquilina
Eileen Martha Bennett
Irene Berenyi
Zoi Bonaventura
Jean Alice Bowley
Lilian Therese Bracken (nee Mungovan)
Dorothy Brightwell
Ronald Henry Briley
Elizabeth ‘Betty’ Margaret Brotherton
Gwendoline Alice Brown
William Bucknell
Clifford Alan Burgess
John Moore Buxton
Brian Byrne
Clarence ‘Jim’ Cairney
Jean Mary Cairns
Marion Cameron
Kevin John Casey
Marjorie Chaffey
Antonietta Ciaglia
John Robert Claypole
Jean Campbell Cleary (nee Paton)
Hazel Marie Cleur
Beryl Hilda Conyers (nee Cooper)
Kingston Herbert Cottam
Norman John Cottrell
Jean Crawford
Hilary Ivy Daley
Mary Therese ‘Maureen’ D’Arcy
Jean Death
Tamara Dolhun
Laurel Douglas
Eileen May Down
Dorothy Downes (nee Crofts)
James Anthony Edmunds
David William Ewing
Venturino Fagnano
Joyce Farrell (nee O’Brien)
Aarón Feldman
Doris May Fleming
Peter Alexander Foster
Jack Frater
Doreen Ellen Fry
Elise Winifred Fursman
Efstratios Gazlais
Kevin James George
Betty ‘Olga Bessie’ Gibson (nee Wellham)
Milton Verus Gray
Thomas Arthur Grunsell
Ethel Gertrude Hamilton
Amyce Handicott (nee Wallis)
Edna Joyce Harris
Caryll Hearm
Fay Helm
Pamela Hennes
Alma Hobgbin
Loyd Stanley Howarth
Mervyn ‘Merv’ Hoy
Antonio Ingegneri
Raymond Glyn James
Betty Eileen Johnson
Veronica Johnson
Irene Jordan
Catherine ‘Kate’ Mary Kelly
Robert Bruce Kenney
Ann Margaret Kirby
Neil George Kirk
Isabella Bell Craigie Kisky
Ernest Jan Kokot
Audrey Stella Lamrock
Dulcie Irene Lennon
Cathy Lerchner
David Tony Lewis
Stuart Strong Lowe
Olive Enid Lusher
A.G. Maitland
Carmen Mamo
Max Edward Mannall
Angelo Martignago
Geoffrey Mason
Neville McCarthy
Brenda McHutchison
Janet Margaret Miller
Eunice Alice Morgan
Evripidis Mougios
Lyle ‘Bonnie’ Granville Muir
Jennifer ‘Shen’ Myers
John Neave
Russell Herbert Nichols
Geoffrey Charles North
Eileen Mary Oliver
Elia Palmucci (nee Bedini)
Audrey Fay Payne
Freda Pearce
Arthur ‘Jack’ John Puttock
Janet Paterson Rankin
Gloria Wilhelmina Reeves
Kenneth Alwyn Rhodes
William ‘Bill’ Henry John Rixon
Arthur Robinson
Kenneth Bruce Rodgers
Maria Rossello
Rosina Ruggero
Kevin Ryan
Thelma Therese Ryan
Raymond Saywell
Vincenzo Sellarò
Wynne Shih
Marlene Shipley
Kenneth Simpson
Ian Sloan
Herbert ‘Bill’ William Smith
Margaret ‘Migs’ Isabel Gwyn Smith
Norm Smith
Mr Shars
Reg Sonter
Phyllis Ruby Spanko
Mildred Veronica Steele
Peter Stevens
Francis ‘Frank’ Kevin Stewart
Margaret Still
Kenneth Francis Stone
Judith Dorothy Taylor
Keith Taylor
John Elliott Thompson
John Trotter
Leslie William Vagg
Hans van Bilsen
Ovidio Vici
Heidi von Rhedey
Dulcie Walsh (nee Rowsell)
William John Walton
James ‘Kanga’ Watson
Patricia Dawn Watson
Douglas Wilkins
Yvonne Beatrice Williams (nee Cossart)
Margaret Catherine Wilson
Kevin Winterbottom
Ngaire Thelma Young

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

In touch Summer 2010
What’s new on the bookshelf...

...with AlzNSW Library and Information Services Coordinator Michelle de Mari

Tracy & Jess: Living with Early Onset Alzheimer’s (DVD)
Dir. James Dreyer

Five to ten per cent of people diagnosed with Alzheimer’s disease develop symptoms before the age of 65, and experts estimate half a million people in their 30s, 40s, and 50s have Alzheimer’s disease or dementia.

Tracy & Jess is the amazing story of two women diagnosed with the disease at early ages.

The film focuses on the challenges and triumphs of Tracy, Jess and their families.

Total Relaxation: Healing Practices for Body, Mind & Spirit
By John Harvey

Symptoms of tension affect the muscles, the autonomic nervous system, emotions, mind and spirit. Symptoms include chronic tension in the neck and shoulders; a nervous stomach; a residue of anxiety, worry, sadness or anger; a racing mind; and a lack of direction or purpose in life.

A build-up of tension can cause physical illness, create mental stress, and limit creativity and self-development. This book offers easy-to-master relaxation techniques and features a symptom checklist.

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness
By Hank Dunn

Hard Choices covers the most common medical treatment decisions faced by those living with a life-threatening illness and their carers.

Resuscitation efforts (CPR), artificial feeding, hospitalisation of an ill person, shifting to a hospice approach and end-of-life decisions are all considered in depth.

Need assistance; not sure what you want? Ask the Library!

Hours: Monday to Friday 9am–4pm
T: (02) 9888 4218 E: lis@alznsw.asn.au

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: www.alz.seekbooks.com.au

T: (02) 8206 9035
Access latest research, care practices and more by visiting Alzheimer’s News.

W: www.alznews.blogspot.com

Crossword

Across
1. Chastising (7,3)
6. Sore crust
10. Facial hair
11. Pub game target
12. Tailless felines (4,4)
14. Inhabit,... in
16. Motivate
18. Gracefully stylish
20. Highest in status
22. Army toilet
23. Skinflint
25. Alert
28. Cleopatra actress (3,6)
29. Overhaul
31. Fragrant flower
32. Generous (4-6)

Down
1. Vats
2. Meadow
3. Tabulated list
4. British anthem, ...
   The Queen (3,4)
5. Envisage
7. Run after
8. Linen
9. Compliant
13. Ancient Greek writer
15. Different
17. Dairy treat (3,5)
19. Foreign
21. Wrap around
22. Ankle shackle (3,4)
24. Dimensions
26. Immature insect
27. Pedigree farm
30. Fashion

SOLUTION ON PAGE 11