In January this year Alzheimer’s Australia (Qld) and the University of Queensland (UQ) formalised our relationship with the signing of a Memorandum of Understanding (MOU) that will see an exchange of knowledge and skills between the two organisations.

We will collaborate on a range of initiatives that include joint research and consultancy projects, the development of student internships and placements, and co-hosting of workshops and seminars in promoting work with people with dementia and their carers.

Jan Samuels, CEO of Alzheimer’s Australia (Qld), says the collaboration with UQ is an important milestone after only five years of operation.

“Our relationship with UQ is very strong and this exciting new partnership will be of great benefit to people living with dementia and their families,” Jan says. “There is an urgent need for more research, supported by engaged, informed health professionals and service providers, if we are to address the enormous challenges ahead.

“Together we will be able to increase awareness and understanding of dementia among tomorrow’s leaders while working to reduce the impact of dementia on the community.”

UQ’s commitment to ageing related issues has been strengthened with the establishment of the Ageing Mind Initiative co-directed by Associate Professors Nancy Pachana (School of Psychology) and Gerard Byrne (School of Medicine), both of whom have collaborated with Alzheimer’s Australia (Qld) for several years.

Associate Professor Byrne believes the University’s relationship with Alzheimer’s Australia is significant.

“Alzheimer’s Australia has had an enormous impact on persons with dementia and their families. It has sponsored expert reports on the epidemiology of dementia in this country, provides services for people with dementia around the country and funds research grants and scholarships to investigate all aspects of dementia.

“It is a privilege to be involved in this new enterprise with Alzheimer’s Australia (Qld)” Professor Byrne said.

The partnership between UQ and Alzheimer’s Australia (Qld) will have several positive impacts. As the peak body we will benefit from improved access to UQ resources such as the Cybrary, as well as a closer relationship with UQ researchers. UQ’s Ageing Mind Initiative will improve links between clinical researchers and students, offering opportunities for projects and placements that capitalize on Alzheimer’s Australia (Qld)’s statewide network of clinical and community outreach programs.
Queensland CEO’s message

Since establishing Alzheimer’s Australia (Qld)’s statewide services in 2005 I have been deeply moved by the many stories I have been told and humbled by the courage of people facing up to what can be the worst news of their lives. But it seems a diagnosis of dementia can also bring out the best in us. I have met people who have celebrated finally having a name to put to “this wretched problem”, and have been heartened to see families plan for a future that values the individual and nurture their quality of life for as long as possible. I have also been reduced to tears by the tender care offered by one gentleman to his wife of more than 60 years. While she no longer recognized him, she certainly responded to his love.

Most members of our team hear similar stories every day. We are very aware of the privilege and responsibility we have in supporting people living with dementia, and our respect and admiration for families has undoubtedly shaped our organizational values and service models. I hope that our values continue to shine through in the way we work together on behalf of everyone who is affected by dementia in some way.

After five years as CEO of Alzheimer’s Australia (Qld) it is now time for me to hand over to our current GM Community Relations, Victoria Beedle. Victoria joined us in 2006 to develop our community relations, communications and awareness programs. She has also worked closely with our regional groups to ensure that awareness, information and peer support programs are available as widely as our limited funds allow. I have greatly valued Victoria’s strategic ability and strong business and NFP background and warmly welcome her as my successor.

As I now step down, I want to reflect on the tremendous progress we have made over the past five years and to thank every one of my team and our remarkable volunteers for their passion and commitment to our work. If I have learned anything, it is that taking time to connect with another person is among the greatest gifts one can give or receive.

Thank you for allowing me this amazing opportunity, and for sharing your lives, hopes and journeys with me. It has been a privilege that I will continue to treasure.

Jan Samuels, CEO

Alzheimer’s Australia launches $3 million National Quality Dementia Care Network

Alzheimer’s Australia has announced the establishment of the National Quality Dementia Care Network. The Network is a world first, bringing together researchers and industry and consumers as truly equal partners in dementia care.

The Network will promote collaboration between dementia care researchers, consumers and service providers with the objective of improving the quality of dementia care through the rapid dissemination and uptake of research evidence. Current and future research will be translated into education and training initiatives, policy recommendations and guidelines for best practice dementia care.

The Network will be funded through the generous support of the JO & JR Wicking Trust and Bupa, one of the world’s leading health care providers.

To build on the knowledge that Alzheimer’s Australia has developed over the past 10 years, and recognising the importance of collaboration, we started some two years ago to develop the concept of a National Quality Dementia Care Network. An additional impetus to go forward with the idea was the evidence that research findings tend to be slow to be translated into practice.

According to Alzheimer’s Australia’s national CEO, Glenn Rees: “The Network will not commission new research projects, but rather facilitate the translation of current and future research into education and training initiatives, policy recommendations and guidelines for best practice dementia care.

“There is also exciting potential for sharing knowledge between a consumer and community-based organisation such as Alzheimer’s Australia and Bupa, who have such a proud record of promoting research while providing aged care and dementia care services.”

The Network has been made possible because of the infrastructure established by the Federal Government through the Dementia Initiative, including the National Dementia Support Program, the Dementia Collaborative Research Centres and the Dementia Training Study Centres.
As a part of the Alzheimer’s Australia (Qld) team Sally Dunlop provides administration support for our Dementia Behaviour Management Advisory Service (DBMAS). But there is another side to Sally, as our clients discovered recently at the Brisbane Dementia Memory and Community Centre.

With the agreement of our carer support group and leisure program attendees, Sally and her greyhound, Peaches, ‘set up shop’ in the DMCC lounge for a bit of animal interaction better known as pet therapy.

Sally and Peaches have been volunteering with Delta Pet Partners since September 2006. The program promotes the social, physical and emotional benefits of interaction between people and companion animals.

“Before we could be a part of the program, Peaches was put through a temperament and behaviour assessment,” Sally explains. “This was to observe her reactions to exuberant and clumsy petting, angry yelling, staggering and gesturing, being bumped from behind, held by a stranger, crowded and petted; all situations that are likely to be encountered at some time during a visit.

“After some further training on how to conduct a visit and keep residents and your dog safe, we were accredited to visit children and adult hospitals, rehab units, mental health facilities, nursing homes and private residences.”

As well as visiting Alzheimer’s Australia (Qld), Peaches and Sally have been allocated to a nursing home in Brisbane, which they visit every second weekend for approximately 45 minutes to an hour.

Sally says: “During one of our recent visits one of the residents said ‘I feel safe when Peaches is here, she is my guard dog.’ We thoroughly enjoy our visits and it is fabulous to see the positive impact Peaches has on the residents and the staff.”

In the United States a pilot study\(^1\) showed significant decreases in agitated behaviors and a significant increase in social interaction in people with dementia who participated in a pet therapy program.

However, it is important to remember not everyone is a dog person (or cat person) so pet therapy is not for everyone.

If you care for someone who may be experiencing behaviours of concern and you feel they may benefit from this form of therapy please call our DBMAS team for further information. DBMAS can be reached 24 hours a day on 1800 699 799.

New website helps with behaviours of concern

Specialised help in caring for a person with dementia is now only a click away with the launch of the new Queensland Dementia Behaviour Management Advisory Service (DBMAS) website.

DBMAS provides clinical support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (BPSD) which are impacting on their care. In Queensland, this statewide service is provided by Alzheimer’s Australia (Qld)’s experienced health professionals.

Since its launch in 2007, DBMAS has helped carers all over the state with strategies to manage the behaviours experienced by people with dementia.

The website, www.dbmasqld.org.au, contains information about the service’s aims, how to contact the DBMAS team, and how we can help a person with dementia.

There is an area with the current and back issues of the popular Queensland DBMAS News which includes stories about therapies, profiles, case studies and articles written for DBMAS by affiliated academics and professionals working in dementia care.

DBMAS Manager Cathy Dancer says, “There are more than 46,000 people living with dementia in Queensland and that number is set to grow to 258,000 by 2050.

“Dementia can place an enormous challenge on families and professional paid carers who can find some behaviours of someone with dementia distressing or difficult to understand. Our team works directly with people to help them better understand the reasons and causes of behaviours and to care for people with dementia.”

For more information visit www.dbmasqld.org.au or call 1800 699 799 (24 hours a day).

Reform for Queensland justice system

The new Queensland Civil and Administrative Tribunal (QCAT) commenced operations on 1 December 2009. The new tribunal will provide a single gateway to increase community access to the tribunal system.

QCAT has taken over from several previous tribunals including the Health Practitioners Tribunal, the Nursing Tribunal and the Guardianship and Administration Tribunal.

A new registry, specifically designed for QCAT has been implemented to operate primarily from the Bank of Queensland Building on Queen Street in Brisbane. Justice Alan Wilson SC will be the new president of QCAT. He is joined by deputy president District Court Judge Fleur Kingham.

The number to call for guardianship matters will remain the same as for the former Guardianship and Administration Tribunal on 1300 780 666. For further information on QCAT and how to access the tribunal you can visit the website www.qcat.qld.gov.au.

Alzheimers

By Boyd Tarlinton

His memories,
Like stardust.
Slowly slipping away,
Into a black nothingness.

He grasps at them,
But they slide,
Twisting through his fingers,
Drifting out of reach.

Blown away,
On the wind,
Like dull Autumn leaves,
Until there is nothing left.

They scamper away,
Evading him,
Hiding in dark corners,
Taunting and teasing.

Who are the people who visit him?
Why do they stare?
Tears in their eyes.
Do they know him?

A glimmer of recognition,
A fleeting memory,
But like a candle in the wind,
It flickers, then fades.

Sometimes tantalisingly close,
Memories of a unique life.
Now only shadows and dreams,
Ghosts and whispers.

Boyd, aged 13, from Caboolture on the Sunshine Coast, won the 11 to 13-year-old category of the 2009 Ipswich Poetry Feast with his haunting poem.
Support Services

In the 2010 Support Services brochure you will find our workshops for people with dementia, their families and friends. These workshops are free for participants through funding from the Australian Government’s Dementia Initiative.

Valuable information and support can be found in the one-day family carer workshop which gives an introduction to the nature and impact of dementia as well as strategies that will help participants to care for a person with dementia.

There is also information about the three-day family carer workshop which provides a more in-depth look at dementia and provides practical strategies for caring for a person with dementia, as well as an opportunity to share common experiences.

Dates for our Living with Memory Loss program are also in the Support Services brochure. This program is specifically designed for people in the early stages of dementia and their family members. Described by one of our participants as “One of the lights that help you find your way after diagnosis”, Living with Memory Loss can be one of the most valuable tools for a person with dementia to help maintain their quality of life.

For a copy of the Support Services brochure call the National Dementia Helpline on 1800 100 500 or download it from our website at www.alzheimers.org.au (click on the map of Queensland and go to the Support Services tab).

New tool to help GPs

It is well known that the initial reaction to a diagnosis of a life-changing condition can vary greatly. As the peak body for people with dementia and their families Alzheimer’s Australia (Qld) supports hundreds of people who are living with dementia and the changes this brings to their health, wellbeing and capacity to live full lives. We also hear many stories of loss, grief and sometimes relief, as well as suggestions for how we can help ease the journey. Many people with dementia and their families have told us that the information provided during an initial appointment with their GP can be lost in the shock of the news.

Likewise, doctors around Queensland tell us they often do not have the time or tools to explain to their patients what is happening to their brains and what to expect.

In response to this Alzheimer’s Australia (Qld) has developed a booklet for GPs to give their patients after a diagnosis has been made. This booklet was developed in response to both GPs’ and patients’ requests for accurate, easy-to-understand information that can be provided at the time of diagnosis.

The booklet gives information about Alzheimer’s disease and other forms of dementia and the types of support that are available in Queensland. It also provides information about Alzheimer’s Australia (Qld) and the services we offer state-wide.

The booklet and a wealth of other resources are available free of charge from Alzheimer’s Australia website, www.alzheimers.org.au, or by phoning the National Dementia Helpline on 1800 100 500.
Alzheimer’s Australia (Qld) was pleased to receive funding from the Sylvia and Charles Viertel Charitable Foundation in 2009 to employ community liaison officers in regional Queensland.

Since their appointment, Carol and Cynthia have been out delivering community education sessions almost non-stop. They have spoken to more than 4,700 members of the community in the Rockhampton and Maryborough regions alone! Among participants in their sessions have been members of Country Women’s Associations, Probus, Lions and Lioness club members, the lovely ladies of the Red Hatters Society and many more local groups and clubs.

The primary purpose of the team is to raise awareness of dementia and possible risk reduction strategies through the Mind Your Mind health promotion program developed by Alzheimer’s Australia. In addition, an important part of the role is to refer people with dementia as well as their families and carers to support services in the region. This includes linking people into Alzheimer’s Australia (Qld)’s local member organisations, government funded Dementia and Memory Community Centres, and professional support services.

If your group is interested in receiving an information session, please contact the National Dementia Helpline on 1800 100 500.

Our community liaison officers are based in Rockhampton and Maryborough, although community information sessions are also offered across the whole state. To contact your local Alzheimer’s Australia group in Rockhampton phone 07 4928 1926 or in Maryborough phone 07 4123 5611. Please see the back page of this newsletter for a list of our other regional groups as well as details of how to contact our Brisbane service centre.

**Fundraising boost**

Alzheimer’s Australia (Qld) is delighted to have received some great fundraising news. The Danks Trust celebrated its 150th anniversary last year and asked 150 of their key customers to nominate a charity deserving of financial support. We were delighted when Plainlands Hardware and Rural Centre, located between Ipswich and Toowoomba, nominated Alzheimer’s Australia (Qld) for the funding and the Danks Trust donated $10,000 to support our services for people living with dementia.

In addition we recently received a phone call from Stephen Rule, director of Plainlands Hardware and Rural Centre, informing us that the company would be adding a further $5,000 to the donation, making a grand total of $15,000! We are very grateful for this fantastic generosity.

We have also received $30,000 from the Queensland Government’s Community Benefit Gambling Fund. This money will support our activities at the Brisbane Dementia and Memory Community Centre.

And we would also like to thank our many supporters for their generous response to our Christmas direct mail appeal. Your donations are still coming in and we are hugely grateful for your support in what has been a difficult financial year for many people.

Thank you all for giving us such a great start to fundraising in 2010!
Unconditional Love  By Jan Lepherd

I walk through the entry to the nursing home and look around for the lady I have been visiting for some 18 months.

Each week we sit together and I take her back to the days when she was young – a teenager, a bride, a young mother, her cooking expertise, and I can see her memory slowly forming the pictures in her mind of happier days when the whole world was there for her to take in her hands and use. But now she holds my hand and touches my face. If the weather is pleasant we can go for a short walk outdoors to look at and feel the texture of leaves on shrubs and touch the petals of flowers.

Now she is deteriorating, and the memories of youth have faded. She welcomes me with a smile but does not remember my name and as we sit together, she reaches for my hand, gazes at me continually and tells me she loves me, but cannot say anything else. She nurses a doll and constantly touches and cuddles it in her arms, the mothering instinct still being there, unbeknown to her. She cannot walk now; we cannot go outdoors to the beautiful garden, so I draw her eyes to the colours outside and speak of what I see.

Touch is so important to her. All humans need the touch of fellow travellers through this life and she is no exception. To brush the hair back from her forehead, to gently touch her face when she becomes distressed – probably with a fleeting elusive flash of memory that is gone before she can comprehend what it was – to simply hold hands and look into each other’s face and be close for a short time, all add up to answering the need to be lovingly touched, hugged and reassured that where she now is in her stage of life, is right for her.

When the time comes for me to leave, she becomes upset, and holds both my hands and raises them to her lips. This simple loving gesture is so touching, and makes it hard to leave her, but by my directing her eyes back to her ‘baby’, I gently free my hands so she can pick up the doll from her lap and cradle it in her arms. This brings her comfort. I know that by the time I reach the door she will have forgotten I was ever there; but that is not important.

The time together and the beautiful moving gesture to me creates a feeling that is indescribable. No matter how old, no matter what state of health we are in, no matter if we cannot communicate by speech, a sincere smile and touch means so much to my friend.

I drive home, dwelling on these things and on the special moment of love given to me. I had gone just to be with her for a while, but she, with her debilitating illness and state of detachment from this world, has given me so much more in return. How blessed I am.

At age 73, Jan Lepherd decided she had to keep her brain busy so joined the Camden Writers and Scribblers group, and over the years has self-published five children’s books. Jan was recently honoured with first place in the ASCCA competition for creative writers for her story ‘Unconditional Love’ which involves a visit to one of her ‘special ladies’, and what happened that day.

Please SUPPORT US
As a non-profit organisation, Alzheimer’s Australia (Qld) relies heavily on support from the community. Donations ensure we can continue to deliver our current services and grow to meet increasing demand. Donations to Alzheimer’s Australia (Qld) are always welcome – and your help truly will make a difference. Donations over $2 are tax deductible. Thank you so much for your support.
Alzheimer's Australia (Qld) Inc
Address: PO Box 9360, GCMC Qld 9726
Email: info@alzqld.asn.au
Website: www.alzheimers.org.au
Phone: 07 3895 8200
Facsimile: 07 5538 8225
ABN: 62 659 237 563
Dementia & Memory Community Centre
Address: Unit 2, 9 Hubert Street
Woolloongabba Qld 4102
Phone: 07 3895 8200

Regional community groups
Alzheimer's Australia Far North Qld Inc
Shop 6a, 151-159 Pease Street
Manoora Qld 4870
Phone: 07 4032 4884

Alzheimer's Australia North Qld Inc
Unit 1, 56 Thuringowa Drive
Kirwan Qld 4817
Phone: 07 4755 1177

Alzheimer's Australia Central Qld Inc
238 Richardson Road
North Rockhampton Qld 4701
Phone: 07 4928 1926

Alzheimer's Australia Mackay Region Inc
1A, 54 Gregory Street
Mackay Qld 4740
Phone: 07 4957 8799

Alzheimer's Australia Wide Bay & Burnett Inc
Level 1, 200 Bazaar Street
Maryborough Qld 4350
Phone: 07 4123 5611

Alzheimer's Australia Darling Downs & South West Inc
9C Bell Street
Toowoomba Qld 4350
Phone: 07 4613 0052

Alzheimer's Australia Sunshine Coast Inc
Reflections Respite Centre
8 Boxwood Avenue, Kuluin Qld 4558
Phone: 07 5476 7833

Alzheimer's Australia Gold Coast Inc
90 Allied Drive,
Arundel Qld 4214
Phone: 07 5594 0270

Our services include:
• Free community education sessions;
• Subsidised training for aged care, respite and community sector workers;
• The National Dementia Helpline (1800 100 500);
• Dementia Behaviour Management Advisory Service (1800 699 799) 24 hours;
• Support programs for people with dementia;
• Counselling and referral services;
• Regional support groups for carers;
• Drop-in Dementia and Memory Community Centres; and
• A varied calendar of events and activities.

For further information please call 07 3895 8200 or email info@alzqld.asn.au.

NATIONAL DEMENTIA HELPLINE
1800 100 500 8am - 5pm
Monday to Friday

More information is also available on our website www.alzheimers.org.au