SPRING 2014

A publication of Alzheimer's Queensland

Dementia Matters

In this edition...

- **Upcoming Education**
- Pain and Dementia
- My Aged Care
- What are our staff up to?
- **Research Update**
- Tapping into our senses



Alzheimer's QUEENSLAND





Alzheimer's Queensland

Alzheimer's Queensland is Queensland's largest not-for-profit community organisation whose primary aim is to maintain the quality of life of people with dementia and their caregivers. We support the desire of most people to remain living in their own home as long as possible and assist families and caregivers to facilitate this.

We aim to do this by offering the following:

Statewide Information, Education and Support Services:

- 24 hour 7 days per week professionally staffed Helpline (ph: 1800 639 331)
- Community education
- Library resources
- Interactive website at www.alzheimersonline.org including carer support chat lines
- Professional education
- Family carer education
- Support groups face to face and telephone support groups
- Individualised support
- Fact sheets and specific information requests posted as required
- Dementia Matters newsletter

Alzheimer's Queensland

47 Tryon Street Upper Mt Gravatt Qld 4122 Telephone: (07) 3422 3000 Fax: (07) 3343 2557 Email: helpline@alzheimersonline.org Website: www.alzheimersonline.org Helpline: 1800 639 331

Upcoming Education:

Community Awareness Programs

Don't forget that Alzheimer's Queensland (AQ) run free community awareness sessions to people in the community to improve the general understanding about dementia. AQ have been speaking to various social and cultural groups about dementia for a number of years, and are keen to continue this valuable service to the general public to help to reduce the stigma about the condition in the wider community.

Please call the **Dementia Help Line** on **1800 639 331** to make an enquiry for a guest speaker from AQ to talk to your community group about dementia and have an opportunity for a discussion and to ask questions.

Paid Education Series

For service providers, the following paid education series for the second half of 2014 is held at the Alzheimer's Queensland Resource Centre at \$40 per person per topic.

Topics and Dates:

Dementia & Intellectual Disabilities

9.30am-11.30am, Tuesday 9th September 2014

Dementia & Behaviours of Concern

9.30am-11.30am, Tuesday 14th October 2014

Manual Handling for Frail Aged Persons

9.30am-11.30am, Tuesday 4th November 2014

Dementia & Design

9.30am-11.30am, Tuesday 2nd December 2014

For more information about or to register for any of the above education sessions, please phone the Help Line on **1800 639 331**

What are our staff up to?

Education Forums

Alzheimers QLD Occupational Therapist, Marnie Combes and Speech Pathologist, Gemma Willis presented a series of annual education forums in North QLD in June. Topics included, Understanding Dementia, Communication, Dementia and challenging behaviours and Designing Activities for People with Dementia. These sessions were all successfully attended by 60+ participants, of varying backgrounds i.e. family members, support workers, nurses and allied health. Feedback was positive with overwhelming appreciation for the practical approach to the theory, and allowing application to a variety of different environments. A big thank you to participating guest speakers, Lifetec in Townsville, Carers QLD in Cairns and Ozcare in Hervey Bay.



International Dementia Conference 'Risky Business 2' in Sydney on 26th and 27th of June 2014

Gemma Willis was a concurrent speaker on the topic of "Risk versus Benefit of Oral Feeding in Advanced Dementia: A Carer's Perspective". The presentation discussed how to balance quality of life with safe eating and drinking during the advanced stages of dementia. Brooke Suess, Alzheimer's Queensland' state manager presented on Smart Assistive Technologies (SAT). She provided an overview of SAT, and shared AQ's experiences giving a reflective framework for the application and prescription of smart assistive technology solutions.

Falls Prevention Program

As mentioned in the last edition Garden City Aged Care Services, an Alzheimer's Queensland residential facility, has implemented a falls prevention program. This intervention has recently finished, and the preliminary results of the program attest to its great success with a 78% reduction in falls. It has been a rewarding process for staff and residents to see improvements in engagement and quality of life. Family members of residents also supported the program.

"The Falls Prevention Program which has been running recently has benefited my husband by increasing his functional activities. I felt when I saw him during this period he was functioning with a purpose. Seemed keen to help making beds and washing up, checking up on people etc. I think he felt at home and in control to some extent. The atmosphere seemed alive, with everyone participating in some way and communicating with each other. Motivation and stimulation is important and at the time I felt this was achieved. Every day is different of course with Alzheimer's however I would fully support this program to continue" – from a family member.

Research Update Tapping into our senses

Eyes are windows to the soul – and our brain too.

One of the hallmarks of Alzheimer's disease is the build-up of amyloid beta protein deposits, also known as amyloid plaques, in the brain. As the retina of the eye is part of the central nervous system (the brain and spinal cord), recent research has shown that this amyloid build up can be identified through special retinal scans.

In an Australian study conducted by the CSIRO, participants were given curcumin, a component of the spice turmeric, which stains the amyloid plaques and allows it to be detected by new optical imaging devices.

Participants in the trial were given more extensive testing, such as PET (positron emission tomography) scans and CSF (Cerebrospinal Fluid) testing to confirm the findings of the retinal scans. Initial results indicate that the retinal scans correctly identified 100% of participants with Alzheimer's disease in the study, and correctly identified 80% of people who did not have Alzheimer's disease. This method is still in the trial phase, and is not available to the general public.



Another innovative approach being investigated at the moment is the link between our sense of smell and Alzheimer's Disease. One study found that structures in the brain that are important to our sense of smell are often damaged in the early stages of Alzheimer's Disease, such as the hippocampus and entorhinal cortex. The researchers checked people's sense of smell using a test known as the University of Pennsylvania Smell Identification Test (UPSIT). They then proceeded with extensive cognitive and neurological tests. More damage to the hippocampus and entorhinal cortex led to worse smell identification. Another study followed a group of 757 people over time, and found that lower scores on the UPSIT measure were linked with the transition to Alzheimer's Disease.



Whilst a smell test is unlikely to become a single diagnostic measure for Alzheimer's Disease, it could become a very inexpensive way to identify those at risk of Alzheimer's disease.

These tests are not in widespread use as they are currently in the trial phases, and there is no estimated timeframe for public access. However this research is promising for the future and could help lead to the development of non-invasive, fast and inexpensive tests for Alzheimer's Disease that can help provide a diagnosis earlier. Early diagnoses can allow different treatments and therapies to be trialled at an early stage, before more extensive damage has occurred to the brain, which may result in more favourable outcomes.

If you have any questions about this research, or any other dementia related issue please contact the Dementia helpline on **1800 639 331**.

Pain and Dementia

Previously it has been thought that people with dementia do not feel pain in the same way as people who do not have dementia. Now research has shown that this is not the case. People with dementia do experience pain, however they are less able to communicate this to family, carers and medical professionals. As dementia affects the brain, there is a generalised deterioration of a person's ability to communicate and understand what is happening around them.

There are a number of reasons that pain in a person with dementia may not be treated. Some of these include:

- Person with dementia being unable to communicate that they are in pain. This may be due to a decline in speech
- Pain is perceived differently by everyone
- Medication to reduce pain may not be taken regularly (often due to family / carer perceptions)
- Due to poor memory.

There are many signs that a person may be in pain. These may include facial expressions (grimacing), an area that is hot to touch or swollen, changes in behaviour (aggression, agitation, wandering etc.), or changes to mood. When a person with dementia is in pain they may not be able to communicate this. This poor report of pain can lead to poor pain management including irregular pain relief (medication, heat packs etc.). If pain is left untreated the person with Dementia can be left suffering unnecessarily. Untreated pain can cause decreased mobility and increased risk of falls, aggression and challenging behaviours, changes in sleep patterns, anxiety and agitation and increased confusion and a decreased quality of life.

Pain can be managed with pharmacological or non-pharmacological interventions. Pharmacological interventions include pain medications or analgesic. Non-pharmacological interventions include heat and ice packs, massage, physiotherapy, gentle exercise or stretching and relaxation services. There is a need for carers to be intentionally observant for nonverbal signs that a person with dementia is in pain. Carers need to become the voice of the person with dementia if they have trouble communicating their needs and concerns to doctors and other health professionals.

My Aged Care

My Aged Care has been established by the Australian Government to help you navigate the aged care system, and is made up of a website and a national contact centre. Together they can provide you with information on aged care, whether for yourself, a family member, friend or someone you're caring for. The contact centre can be phoned on 1800 200 422 between 8.00am and 8.00pm on weekdays and between 10.00am and 2.00pm on Saturdays.

My Aged Care provides:

- Information on aged care, which can be made available:
 - in other languages if you speak another language
 - in other formats if you have hearing difficulties or vision impairment
- Help to find Government-funded aged care services.
- Prompt resolution of any complaint or concern you have with My Aged Care.







Pin on your notice board

Alzheimer's QUEENSLAND

Alzheimer's Queensland Services and Contacts www.alzheimersonline.org

Helpline 1800 639 331

Open 24 hours a day, 7 days a week.

Free call from landline and public phones.

Or email: helpline@alzheimersonline.org

For information and emotional support for people with dementia, staff and anyone interested. The Helpline has a database or services in Queensland to provide information and referrals. Call for free information e.g. fact sheets or brochures to be mailed out.

> AQ Rehab In home - Physiotherapy Occupational Therapy Speech Therapy

1800 180 023

Respite and Care Services

Seven days per week including:

- Centre Based Day Respite
- Overnight Respite
- Respite for Working Carers
- Emergency Respite
- Personal Care
- Home Maintenance
- Allied Health
- Social Support

Multi-Service Respite Centres located at:

- Gordon Park
- Mt Gravatt
- Ipswich
- Toowoomba

Residential Care

- Garden City Aged Care Services
- Rosalie Nursing Home
- Windsor Aged Care Services

Call the Helpline for vacancies for permanent and respite care

Carer Support Groups - 2014

Providing information and support for those caring for a friend or family member with dementia.

Toowoomba: 1st Monday of every month

1.30pm – 3.30pm: Jacaranda Room, Grand Central Shopping Centre, Toowoomba
1 Sept, 13 Oct (NB: 2nd week due to public holiday), 3 Nov, 1 Dec

Qld Wide Telephone Support Group

Last Wednesday of every month 1.00pm – 2.00pm: AQ organises telephone link up at no cost to members 27 Aug, 24 Sept, 29 Oct, 26 Nov, 17 Dec (NB: 3rd week due to public holidays)

Evening: 2nd Wednesday of every 2nd month 6pm – 8pm: 47 Tryon Street, Upper Mt Gravatt 10 Sept, 12 Nov

lpswich: 3rd Wednesday of every month 10am – 12 noon: Calvary Baptist Church, 83 Chermside Road, Ipswich 20 Aug, 17 Sept, 15 Oct, 19 Nov, 17 Dec **Newmarket:** 1st Thursday of every month 10am – 12 noon: LifeTec, Cnr Enoggera & Newmarket Rds, Newmarket 4 Sept, 2 Oct, 6 Nov, 4 Dec

Redcliffe: 1st Thursday of every month 2pm – 4pm: Redcliffe RSL, Irene Street 4 Sept, 2 Oct, 6 Nov, 4 Dec

Mt Gravatt: 1st Friday of every month 10am – 12 noon: 47 Tryon Street, Upper Mt Gravatt 5 Sept, 3 Oct, 7 Nov, 5 Dec

Weekend: 2nd Saturday of every 2nd month 10am – 12 noon: LifeTec, Cnr Enoggera & Newmarket Rds, Newmarket 11 Oct, 13 Dec

For further details or to register please contact the Dementia Helpline.