



A publication of  
Alzheimer's Queensland.

# Dementia Matters

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# Commonwealth Home Support Program

Over the past 12 months there has been a lot of discussion regarding changes to aged care services in the community. Due to the rapidly ageing population the Australian Government has reformed the aged care system in an attempt to make it easier for clients and carers to access services that are high quality, client-centred, respond to the changing needs of the individual and maximise the individuals' independence. This reform has been labelled the Commonwealth Home Support Program (CHSP).

The CHSP will provide basic maintenance, care, support and respite services for older people living in the community, and their carers. For the majority of clients with alzheimers, no change has been noticeable and the cost of respite and attendance will remain the same. However, the CHSP is not designed to support high level care needs, such as in-home support with personal care, wound care, medication prompts etc. As a result, clients with more complex needs will be supported to transition to more appropriate levels of care such as Home Care Packages.

## 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 Dementia Helpline (ph: 1800 639 331)
- Community education
- Library resources
- Interactive website at [www.alzheimersonline.org](http://www.alzheimersonline.org)
- 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](mailto:helpline@alzheimersonline.org)

Website: [www.alzheimersonline.org](http://www.alzheimersonline.org)

Dementia Helpline: 1800 639 331

## Home Care packages program - Gordon Park

The Home Care Packages program have replaced the existing care programmes– Community Aged Care Package (CACPs), Extended Aged Care at Home (EACH) and the Extend Aged Care at Home Dementia (EACHD). Gordon Park on the Brisbane North side offers level 1 and 2 packages.

Home Care Packages offer four levels of care:

- |                          |  |
|--------------------------|--|
| <b>Home Care level 1</b> | To support people with basic care needs.                                     |
| <b>Home Care level 2</b> | To support people with low level care needs (equivalent to the former CACP). |
| <b>Home Care level 3</b> | To support people with intermediate care needs.                              |
| <b>Home Care level 4</b> | To support people with high care needs (equivalent to the formed EACH).      |

The Home Care Packages program has been developed to assist older Australians to remain in their homes, particularly targeting frail older people. People can access respite through their packages of care, however will need to negotiate with their provider for this service to be provided. Home Care Packages are about getting the services you want and most need. The aim is the package should be driven by you and not the service provider.

If you would like more information regarding the Commonwealth Home Support Program or Home Care Packages, please go to [www.myagedcare.gov.au](http://www.myagedcare.gov.au) or live in Brisbane North contact Lyndsey Hawthorne 07 38572191.

# Education Days 2015

During November, we were inspired by speakers from within our local community at our two day annual Darling Downs Region Dementia Education Days.

Both days were extremely successful and everything went according to plan, with more than 80 Carers and 120 Service Providers attending. The Middle Ridge Golf Club was an excellent venue and we have received positive feedback from all the attendees and delegates who displayed their trade tables and promoted other services and products.

These Education Days delivered tools, resources, fresh ideas and thinking that will help deliver specialised Dementia Care to our community. That process helped the continuation of our agenda and has helped to shape new strategies that will enable us to respond to caring and working with people with dementia.

The Carers education “Dementia: The Carer’s Journey”, was opened by Derek Tuffield, CEO of Lifeline Darling Downs and South West Queensland. Derek is well known in the region for his involvement in many projects to ensure that Toowoomba and the surrounding areas provide a helping hand and an understanding ear where needed.

Discussions on the day were specifically aimed at the Carer and included topic such as; ‘Busting Dementia Myths’, ‘Understand Me!’, Navigating My Aged Care and Consumer Directed Care Packages, The Transition to Permanent Placement, ‘Sharing is Caring’ and an open panel discussion session with Q&A’s. The highlight of the day was a personal journey and a transparent and honest discussion by two carers, who knows what it is like to live with and care for someone you love with dementia. Thank you Lori Greer and Margaret Neville for the heart felt messages. It helped everyone realise that they are not alone and that others are facing similar challenges.

The Service Providers education “Dementia: A Life Worth Living” was a jam packed informative day. Prof Scott Kitchener, the Clinical Sub-Dean from the Rural School of Medicine at the Griffith University opened the day with an inspiring message. Topics included, Medical Management of Difficult Behaviours in Dementia, ‘The Cutting Edge’ Current Dementia Research, ‘A Life Worth Living’ Activities, Tools and Technology and ‘The Flip-side’ The Dementia Journey From A Carer’s Perspective. Many professionals shared their knowledge on the day and it was well received by all.

Dr Nisal Gange, Geriatrician, Stroke and Rehabilitation Physician provided us with cutting edge information and food for thought about diagnosing and medicating people with dementia.

Community carers and aged care providers should not underestimate the degree of change required to successfully care for people with Dementia. Our aim is to unite everyone as we believe together we can achieve quality outcomes by supporting people in our community. The aged care system is often difficult to navigate, has had limited choice for consumers and variable quality. Through these Education Days we provided access to support and reinvigorated everyone’s thinking to care for people with dementia and to enable them to build new partnerships so that together we can shape the next generation of community care.



Alzheimer’s Queensland’s Toowoomba Multi-Service Centre is committed to the sector developing solutions that will ensure people are able to be cared for in their homes and residential facilities with flexible, innovative options that are based on choice and independence. We will continue to discuss sector trends more broadly and that that our service innovation is likely to grow and continue.

## Free education sessions

Hervey Bay  
Dementia: A life Worth Living  
15th March 2016  
Hervey Bay Boat Club

Brisbane North  
Service Providers  
16th March 2016  
Kedron Wavell Services Club

Brisbane North  
Carers  
17th March 2016  
Kedron Wavell Services Club

# Occupational Therapy Updates: Falls prevention

Having recently spent a night in the emergency department with a relative who had had a significant fall at home, I've been considering what is available when it comes to preventing and managing falls. Here are a few things which can be done when it comes to falls prevention and management:

- It is helpful to have a current medical summary with medical history and current medications close at hand to give to ambulance officers and medical staff. In my case, my relative who had fallen was not able to give a coherent medical history and in the middle of the night, rifling around through papers to find it was not practicable;
- Don't hesitate to call the ambulance to assist you when someone has fallen and is injured and/or can't get up;
- Getting a thorough medical review is important to find out if there is a medical reason for falls happening. A thorough medication review is also important as various medications can contribute to falls. In my relative's case, the falls were due to severe osteoarthritis in one hip causing stiffness and pain which resulted in poor movement, balance and coordination and muscle weakness. On review by a geriatrician, my relative had two medications ceased which were thought to possibly be contributing to the regular falls;



- Physiotherapists and occupational therapists can assist with falls prevention and management. Falls prevention programs run throughout Queensland over a number of weeks and comprises both a balance and strengthening exercise component and an education component which covers topics such as appropriate footwear and trip hazards in the home.
- There are numerous watches and pendants on the market where if the wearer falls, they can push a button on the pendant/watch to summon help. These devices vary in their features and can include: being waterproof (so they can be worn in the shower); long-life batteries and short charging times (so minimal time where the device is not being worn); GPS trackers (so the wearer can be located wherever they have fallen); monitoring (some devices are monitored 24/7 through monitoring centres which action any calls for assistance sent from the devices); two-way communication with the device (like a mini mobile phone, you can talk to the wearer through the device and they can talk to you); an automatic fall alert (so even if the wearer is unconscious after a fall, an automatic alert is sent out that the person has fallen). These devices vary in price with a top-of-the-range watch costing around \$500 with \$50 per month in monitoring fees. However, there are less expensive devices available, particularly where no monitoring is used.

# Posterior Cortical Atrophy - a rare form of dementia

Posterior cortical atrophy (PCA) is an atypical form of dementia primarily affecting sight rather than memory. It is a progressive condition where the degeneration and loss of brain cells is found mostly in the back (posterior) part of the brain.

In most cases, the same pathological changes that are seen in Alzheimer's disease (loss of brain cells associated with the presence of amyloid plaques and neurofibrillary tangles) are also found in the brains of people with PCA. PCA is therefore considered to be an unusual variant of Alzheimer's disease.

Although the same disease process occurs in both Alzheimer's disease (AD) and PCA, the effects of these two conditions are markedly different. In AD, deterioration in memory, language, perception and insight are typically seen. In PCA, however, memory, insight and language tend to be preserved (at least in the early stages) but there is a specific decline in vision and literacy skills such as spelling, writing and arithmetic. The reason for this difference is that AD-related changes occur across most brain areas whereas PCA-related changes are restricted to the rear of the brain where visual processing, literacy, numeracy and motor planning and execution (praxis) are focussed.

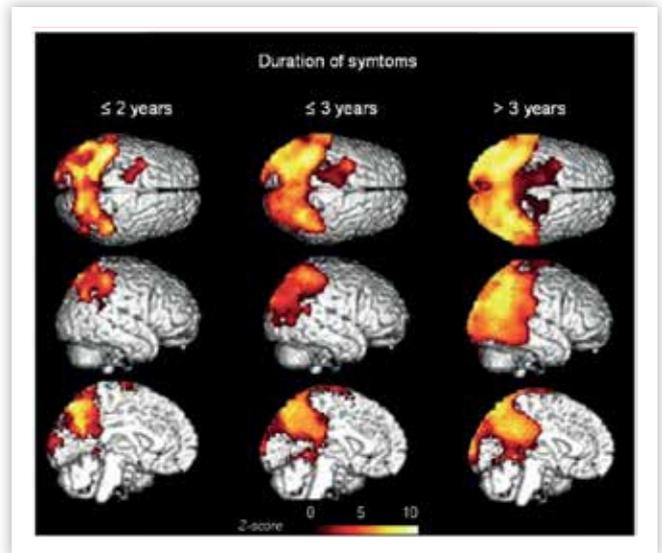
Initial symptoms of PCA often include difficulties with driving (including judging distances and speed), fine spatial judgements (e.g. missing when reaching out to pick something up), recognition of what or where objects are (e.g. difficulty recognising common household items in a catalogue) and deterioration in reading, writing, spelling and counting abilities.

Because the most common problems noticed by individuals with PCA are with vision, people with PCA often first consult their optometrist or ophthalmologist. However, the difficulties being experienced are not related to the eyes but to the back part of the brain which cannot correctly process the information sent to it by the eyes. PCA is therefore not a problem of eyesight but of brain function.

PCA often occurs in younger people, with the early symptoms often presenting in the 50s and 60s.



Sir Terence David John "Terry" Pratchett, OBE, English author of fantasy novels, diagnosed with PCA in 2007 (Source: Dementia Vision, <http://livingwelldementia.org/2014/05/16/terry-pratchett-norman-mcnamara-shibley-rahman-living-well-with-dementia/>)



(Source: Dementia Vision, <http://livingwelldementia.org/2014/05/31/meeting-other-people-living-with-posterior-cortical-atrophy/>)

Because PCA often occurs in younger people and has an unusual presentation, diagnosis of PCA is often slow and frustrating for the person affected. Early symptoms are often attributed to other causes such as impaired eyesight, anxiety, depression, menopause or even malingering and typically time to diagnosis of PCA from the onset of symptoms is one to three years.

In the moderate stages of PCA, common problems include: difficulty navigating between rooms or locating particular places such as the bathroom; difficulty recognising even very familiar faces; movement problems such as being able to walk but not sit down; difficulty with spatial commands or actions such as "turn around" or "shuffle forward"; and difficulties with handwriting, mental arithmetic and spelling.

In the later stages of the condition, word-finding, day-to-day memory and general cognitive functions can become affected. Jerking movements of the limbs (myoclonus) and occasionally seizures may also occur at this late stage. Further information on the symptoms of PCA can be found in "The Stages of PCA" available at <https://www.ucl.ac.uk/drc/pcasupport/stages-of-pca>

While there is no medication available to treat PCA specifically, there is some evidence to support the use of the medications available to treat AD, namely donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). Although these medications are not a cure for PCA, they are designed to treat the symptoms of the condition.

Because people with PCA often show relatively preserved insight into their condition, peer support groups, group, couple and individual psychological therapies and use of practical aids such as talking clocks/watches, mobile phones with simplified displays, talking books and voice recognition software can be of benefit.

References can be obtained by contacting 1800 639 331.



## Pin on your notice board

# Alzheimer's Queensland Services and Contacts

[www.alzheimersonline.org](http://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](mailto:helpline@alzheimersonline.org)

For information and emotional support for people with dementia, staff and anyone interested. The

Helpline has a database of services in Queensland to provide information and referrals.

Call for free information

e.g. fact sheets or brochures to be mailed out.

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### AQ Rehab

In home - Physiotherapy

Occupational Therapy

Speech Therapy

1800 180 023

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### 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

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## Carer Support Groups - 2016

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

#### Toowoomba: 1st Monday of month:

1:30pm – 3:30pm: The Rose Cottage, Newtown Park, off Pottinger St, Toowoomba  
7 March, 4 April, 9 May (NB: 2nd week), 6 June, 4 July, 1 Aug, 5 Sept, 10 Oct (NB: 2nd week public holiday), 7 Nov, 5 Dec

#### Ipswich: 3rd Wednesday of every month:

10:00am – 12 noon: Calvary Baptist Church, 83 Cherside Road, Ipswich, 16 March, 20 April, 18 May, 15 June, 20 July, 17 Aug, 21 Sept, 19 Oct, 16 Nov, 21 Dec

#### Newmarket: 1st Thursday of month:

10:00am – 12 noon: LifeTec, Corner Enoggera & Newmarket Roads, Newmarket, 16 March, 20 April, 18 May, 15 June, 20 July, 17 Aug, 21 Sept, 19 Oct, 16 Nov, 21 Dec

#### Redcliffe: 1st Thursday of month:

2:00pm – 4:00pm: Redcliffe Library Meeting Rooms, 476 Oxley Ave, Redcliffe, 3 March, 7 April, 5 May, 2 June, 7 July, 4 Aug, 1 Sept, 6 Oct, 3 Nov, 1 Dec

#### Mt Gravatt: 1st Friday of month:

10:00am – 12 noon 47 Tryon Street, Upper Mount Gravatt,  
4 March, 1 April, 6 May, 3 June, 1 July, 5 Aug, 2 Sept, 7 Oct, 4 Nov, 2 Dec

**Garden City Evening:** 52 Khandalla Street, Upper Mount Gravatt 6:00pm – 7:00pm 16 March, 18 May, 13 July, 14 September, 16 November

**Gordon Park Evening:** 45 Shamrock Street, Gordon Park 6:00pm – 7:30pm Feb 18, May 19, Aug 18, Nov 17

**Qld-wide Telephone Support Group:** Last Wednesday of every month: 1:00pm – 2:00pm AAQ organises telephone link-up at no cost to members 24 Feb, 30 March, 27 April, 25 May, 29 June, 27 July, 31 Aug, 28 Sept, 26 Oct, 30 Nov

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

