



A publication of  
Alzheimer's Queensland.

# Dementia Matters

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# LASA Q Excellence in Care awards finalist Rosa Janice (Janice) and Julie Firth

**Alzheimers Queensland was excited that two of their staff were selected out of hundreds of applicants to be one of the finalist for the individual excellence in care awards at the LASA Q conference on the 19th March.**

## Rosa Janice (Janice)

Janice, an Occupational Therapist for Alzheimer's Queensland at the Garden City Aged Care Services home, was nominated for her compassion, empathy and desire to give the best to the residents that she works with. Janice has devoted time and effort to connect and care for each individual person.

In 2014, a new falls prevention program for people with severe dementia was piloted at Garden City Aged Care Services. The pilot was the first of its kind in Australia that we could identify. The pilot involved a program that developed functional exercise as part of everyday life. Janice embraced the challenge of this innovative project.

This new program saw a 66% reduction in falls and 65% reduction in behaviours. Whilst the program was designed by the Director of Care and the Allied Health Manager, it was Janice who carried out the bulk of activities and served as the glue for the team.

Janice has continued the program after the initial pilot. The program continues to change and grow under her guidance.

Janice led a multidisciplinary team, developed and delivered training sessions, supported and mentored both staff and family, all the while maintaining her usual workload. Working through this program, Janice demonstrated that people with severe dementia can participate in activities that are typically labeled as risky activities for example, cooking at the stove and grocery shopping at the local supermarket.

Janice's willingness to engage staff and families in the program has changed the perception of what is perceived safe for people with severe dementia in Palm Court. Her work has led to a rejuvenation of everyday life for the residents of Palm Court who despite severe dementia are now benefitting from an environment where staff are now 'doing with' rather than 'doing for' the residents.

## Julie Firth

Julie performs a vital role in administration with Alzheimer's Queensland, Toowoomba. Acting as the face and voice of our organisation, she provides not only exceptional administrative service, she regularly goes above and beyond the call of duty.

Julie acts as an interface between our care staff, clients and carers, other service providers and other stakeholders. She is able to provide the caller with the right information or support.

Julie adopts an "accidental counsellor" role in many situations. She provides a compassionate, confidential listening ear, always acknowledging the very real challenges facing the clients and carers of Alzheimers Queensland. This helps defuse situations, allowing people to work through what their needs are, and to be directed to the best possible service or resource.

When potential clients phone to find out about our services, Julie understands the anxiety and stress that accompanies a first call. Most people wait for a crisis before they take the step of asking for help. An understanding and empathetic voice on the other side always makes a difference and Julie's ability to calmly listen and respond with the necessary information and guidance, makes a world of difference to the person.





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

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

Helpline: 1800 639 331

# Identifying Apathy to Improve Person-centred Care in Frontal-Temporal Dementia

*Taken from Massimo, Evans & Gossman in 2014*

The article discusses the importance of understanding, diagnosing and treating apathy in people with Frontal-Temporal Dementia. Carers for people with Frontal-Temporal dementia often misinterpret apathy as resistive behaviour. The article suggests apathy is an important, but often overlooked side effect of the disease, even though it affects almost 90% of individuals with frontal-temporal dementia. A clinical diagnosis for apathy is important to ensure behaviours can be distinguished apart from other causes.

Apathy is a lack of goal-directed behaviours comprised of three main components – initiation, planning and motivation – which are performed through commands from different areas of the brain. The area of the brain that is affected will lead to different presentations and thereby different treatment and intervention options. Massimo, Evans and Grossman (2014) suggest there should be diagnostic criteria to confirm if one has apathy comprising of the identification of three domains: diminished motivation for at least four weeks; reduction in two of the three components (initiation, planning and/or motivation); and a functional impairment that is attributed to the behaviour.

Treatment and intervention options are available, however it is suggested these should take a multi-faceted approach to ensure the treatment is individualised. An example is if difficulties with planning arise, then the intervention would be for the person to simplify complex tasks. The article concludes by suggesting people with Frontal-Temporal dementia who display apathy should receive person-centred intervention to ensure health professionals can recognise the unique needs of the individual. This method ensures that family members, carers and staff provide the best possible care for the person with dementia.

# Let's talk about Sex

**The following article is specifically meant for Service Providers and in particular to challenge staff to think about the following:**

Are the rights of people living with dementia being overlooked or are we curtailing residents' rights to sexual expression by hiding behind our duty of care and refusing to accept non-verbal cues when it comes to sexuality?

Sex and intimacy should be a normal part of life. Are the policies in your organisation clear regarding sexual expression and do they cover privacy, give guidance to staff on how to assess non-verbal cues and discuss opportunities for people to express their sexuality in a safe and private place?

The sad reality is that sexual expression by people with dementia can be a source of humour, disgust, fear and conflict and staff may laugh and ridicule the person. Family members may also fear that their mother (usually) is being molested, and conflict can result.

Often, when care workers are asked what they think of older people having sex, the response is often "yuk" or "it does not happen".

Some wonder about the ability to determine whether people with dementia can give consent. Yet, we all know

that people with dementia are capable of expressing consent non-verbally. They make decisions every day using non-verbal cues about what they eat etc. Just because someone loses the ability to communicate verbally, doesn't mean that they can no longer let you know what they would like and whether they are enjoying something. Being able to interpret body language and facial expressions is one of the most important tools when caring for someone with dementia.

In my opinion, people with dementia, are more often interested in intimacy than sex, however, the question still remains, how are we managing the issue about sex in aged care?

## **Treat men as men and women as women.**

What role are we playing in blurring the lines of gender? Are we allowing men to feel and act like men and the same for woman?

Do we dress care recipients in ways that would make our lives easier, or do we think about the impact on a person's emotional status?

How do we style their hair? What about those unsightly little hairs that we often see on older women's faces? If they were aware of it, would they ask for it to be removed?

If a person wore makeup and dressed feminine all their lives, or if a man wore a suit and tie most of his life, how do they feel if they have to walk around in track pants every day?

If you think that spending time on your appearance is not important, does that mean that the person you care for now have to change their ways, even if appearance has always been an important part of their lives....and vice versa?

## **Remember that it is all about the person.**

How do we treat couples if one is in care and the other visits? Do we give them time alone and do we provide opportunities for intimacy or allow them to cuddle or hold hands?

How do we as staff then act around them when they show affection to each other?

If we are practicing "Person Centred care", is the person we care for not supposed to come first? Do we not have a commitment to maintain the personhood?



## Let's talk about Sex cont...

### What about same sex relationships?

The things that same sex couples wonder about:

*Will people welcome us as a couple and respect our need to be together?*

*Will carers listen to what we know about each other?*

*Will they accept our need to physically hold and love each other?*

*Will we feel comfortable as an older, homosexual couple expressing who we are in a fearless way?*

Can we answer these questions honestly?

### The question about protection?

Obviously regardless of age one can still get sexually transmitted diseases.

According to England's Family Planning Agency (FPA), the number of reported cases of STDs among 50-to 90-year-olds has more than doubled in the past decade. Are we in future going to remind people to use a condom?

### And now we have Viagra.

How many people in facilities are already on Viagra or similar medication?

How are we reacting when we have to administer these meds?

Fact is that as many as 25 percent of 65-year-old and older men may experience erectile dysfunction and they don't like it!

### Learn from the older generation

An older nurse told me once, "Nothing is as overrated as sex and as underrated as a good bowel movement. It took years for me to understand it, but now that I am getting older, I get it!"

*Theresa Buys*

*Community Service Manager Toowoomba*

# Dementia: Another Way of Living

"Dementia: Another Way of Living" education days were conducted with family carers and service providers in the Toowoomba and Darling Downs region. We had a number of very informative speakers on a variety of hot topics including 'sex in dementia'.

Ann Hopper and Linda Lau from Salem Lutheran Rest Home discussed Dementia and changes to the aged care system in response to government changes in funding. This was well received with a number of questions clarified. AQ Occupational Therapist, Cindy Wilesmith talked about the dignity of risk and how everyone should have the option to participate in daily tasks rather than having roles taken away from them.

Over the two days a number of Alzheimer's Queensland staff spoke on a variety of topics. Morgan-Lee Goodsell spoke regarding mobility and pain, and medications in dementia management. Theresa Buys provided new insights for all attendees during her 'Sexuality and Dementia' and 'Maintaining Smart Skills' presentations.

Nutrition, dementia and swallowing were covered by AQ Speech Therapists Caylie Field and Jessie Cutler, while Daniel Biernoff, a naturopath, discussed the need for good nutrition in order for our brains to function at their best. He noted that people with dementia already have some cognitive impairment and having inadequate nutrition can further reduce one's cognitive capacity.

Two representatives from Queensland Health discussed the region's Older Persons Mental Health Service and the unique needs of people with younger onset dementia. Palliative Care and Making the End Count was a presentation by Sue Thonell which is often an area where quality of life can be overlooked.

Rob McGrigor, a music therapist, discussed ways of using music when reminiscing to connect with people who have dementia. Finally Berit Munro, a wellness advocate from doTERRA Essential Oils presented to the audience a practical session on the need to look after oneself so that they can continue in the caring role.

Overall the feedback from the education day was extremely positive with all involved looking forward to next year's program. Community education sessions for families and service providers are of great benefit to all, increasing the understanding of dementia and promoting awareness in the community. If any of these topics are of interest to you or your organisation training can be arranged by contacting AQ on 1800 639 331.





Alzheimer's  
QUEENSLAND



## 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 - 2015

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  
4 May, 1 Jun, 6 Jul, 3 Aug, 7 Sep, 12 Oct (NB: 2nd week  
due to public holiday), 2 Nov, 7 Dec

**Qld Wide Telephone Support Group**  
Last Wednesday of each Month 1.00pm – 2.00 pm:  
AQ organises telephone link up at no cost to participants  
29 Apr, 27 May, 24 Jun, 29 Jul, 26 Aug, 30 Sep,  
28 Oct, 25 Nov

**Evening:** 2nd Wednesday of every 2nd month  
6.00pm – 8.00pm: 47 Tryon St, Upper Mt Gravatt  
13 May, 8 Jul, 9 Sep, 11 Nov

**Newmarket:** 1st Thursday of every month 10am – 12 noon:  
LifeTec, Cnr Enoggera & Newmarket Rds, Newmarket  
7 May, 4 Jun, 2 Jul, 6 Aug, 3 Sep, 1 Oct, 5 Nov, 3 Dec

**Ipswich:** 3rd Wednesday of every month  
10.00am – 12 noon: Calvary Baptist Church,  
83 Cherside Rd, Ipswich  
20 May, 17 Jun, 15 Jul, 19 Aug, 16 Sep, 21 Oct,  
18 Nov, 16 Dec

**Redcliffe:** 1st Thursday of every month 2pm – 4pm:  
Redcliffe Library Meeting Rooms, 476 Oxley Ave, Redcliffe  
14 May, 4 Jun, 2 Jul, 6 Aug, 3 Sep, 1 Oct, 5 Nov, 3 Dec

**Mt Gravatt:** 1st Friday of every month  
10am – 12 noon: 47 Tryon Street, Upper Mt Gravatt  
1 May, 5 Jun, 3 Jul, 7 Aug, 4 Sep, 2 Oct, 6 Nov, 4 Dec

**Weekend:** 2nd Saturday of every 2nd month  
10am – 12 noon: LifeTec, Cnr Enoggera &  
Newmarket Rds, Newmarket  
13 Jun, 8 Aug, 10 Oct, 12 Dec

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