



A publication of
Alzheimer's Queensland.

Dementia Matters

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Supporting Expressions of Sexuality

Sexuality is an essential part of being human for all age groups and persists throughout life for the person with dementia. Denying sexual identity can deny opportunities for relationships – old and new – leading to loneliness, boredom, frustration, insecurity, diminished self-worth, self-image and mental health. This can promote inappropriate behaviours as the person with dementia still seeks close continuing relationships and has a need for touch, comfort, genuine interaction with others, friendship and intimacy.

Dementia may produce changes to expressions of sexuality depending on the area of the brain affected, the progression of the disease, individual history, social context, age, gender, personality, memories and needs of the person. Behaviours that may be distressing for carers and staff might include inappropriate language, touch, disrobing, masturbating in socially unacceptable environments or with inappropriate people, seeking inappropriate, unplanned sexual encounters, misinterpreting environmental and sensory cues, jealousy and paranoia. Mistrust, resistance and aggression can occur when attempts by staff or carers are made to intervene or curb the behaviour.

Societal myths in relation to sexuality, sexual orientation, youth and ageing and negative attitudes and biases of staff and others can detract from holistic assessment related to sexuality. This detracts from the support and understanding extended to the person with dementia and their partners. To understand changes to expressions

of sexuality and demonstrate empathetic and respectful support, the sexuality of the person with dementia requires acknowledgment of their life story including cultural, sexual and emotional history, past patterns of behaviour, level of sexual drive, sexual orientation, valued roles and beliefs related to modesty, morality, fidelity and personality. This informed assessment must lead to the provision and evaluation of: open access to grooming, opportunities for enjoyment of private and public demonstrations of intimacy, touch, social interaction, roles and routines, pets, interactive virtual reality computer games, art and images, reading material, DVDs, music. In their long-term memory these may still remain significant for the person with dementia and improve their mood, confidence and sense of well-being.

Acceptance and valuing both the need for sexual expression and family cohesion requires a problem-solving approach and Alzheimer's Queensland have staff who can assist. Identifying and addressing triggers for the behaviour or inappropriate sexual arousal may include identifying: feeling too hot and disrobing; a typical time of day; acute illness e.g. infection, pain, dehydration; environmental cues, particular places and routines e.g. preparing for bed or receiving hygiene support; changes in routines; past valued relationships and isolation from family and spouse in residential care; history of sexual abuse; belonging to GLBTIQ community; absence of sensory input in their lives e.g. touch, hearing, smell, vision; sensory cues; night time disturbance and no recollection of previous sexual encounters.

Relationships, Autonomy and Decision-making

In problem solving and planning support for the person with dementia, informed choice and autonomy should be encouraged. The person may have capacity to initiate new relationships, understand the consequences of those relationships and consent to those relationships. Professional assessment of capacity may be necessary to ensure decisions are ethical and reflect the true competence of the person with dementia and decisions are in their best interest.

Education of both staff and loved ones and open discussion will improve support for and the valuing of sexual expression by people with dementia and their partners and expose potential feelings of shame, regret, loneliness, confusion and sadness that may accompany the many losses associated with dementia. Following assessment, non-pharmacological or behaviour strategies should be trialed prior to any medication treatment if behaviours are distressing to the person or others.



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:

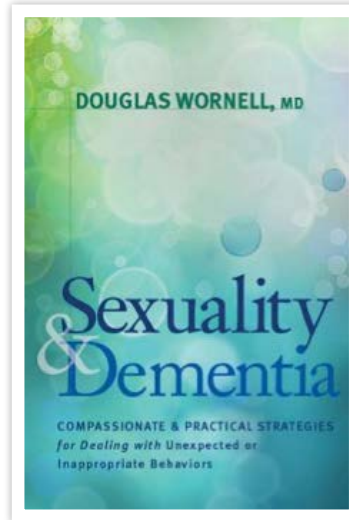
Statewide Information, Education and Support Services:

- 24 hour 7 days per week professionally staffed Advice Line (ph: 1800 639 331)
- Community education
- Library resources
- Interactive website at 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
Website: www.alzheimersonline.org
Dementia Advice line: 1800 639 331

New Books in Alzheimer's Queensland Library



Sexuality & Dementia Wornell, Douglas. (2013).

Compassionate and Practical Strategies for Dealing with Unexpected or Inappropriate Behaviors. New York: Demos Medical Publishing.

This book is available in the Alzheimer's Queensland library and is a comprehensive guide that discusses the effect of dementia on Sex, Intimacy, and Relationships.

Alzheimer's Queensland – a Good News Story.

Opportunities for meaningful social engagement in the community is an important part of Alzheimer's Queensland support for people living with dementia such as Arnold and Wayne.

Golf is Arnold's passion and he has enjoyed many golfing hours on different golf courses. Everyone who goes to the Driving Range with Arnold comments on how good he is. Wayne a newcomer to golf hasn't done much golf in the past, though still looks forward to his "Friday Driving Range activity". Wayne's skill has steadily improved due to Arnold's instructions and support. Despite the difference in their skill levels, they are both enjoying the opportunity of hitting a few balls together.



People living with Younger Onset Dementia (YOD) - A Minority Group

Of the 413,106 Australians with dementia, approximately 25,938 are people with Younger Onset Dementia (YOD). YOD occurs before the age of 65 years. Rarer forms of dementia can occur in the 30s, 40s and 50s e.g. familial Alzheimer's Disease (1 in 100 of all Alzheimer's Disease) where genetic testing and counselling can be offered. YOD is progressive and has no current cure. Changes both physical and cognitive may appear more marked in younger people and YOD may appear to progress more quickly than later onset dementia.

Delays in diagnosis are common and distressing for both the person and their families. Specialists including neurologists, geriatricians, geriatric psychiatrists will facilitate an early diagnosis through a multidisciplinary team approach with input from the person, family and carers. This is essential in order to exclude potentially treatable causes of cognitive changes including lesions, infection, inflammatory or metabolic causes among

others. Risk factors may include cerebrovascular, alcohol or malnutrition history, HIV/AIDS, head trauma or drug use.

With YOD a wider variety of causes and symptoms may present. Alzheimer's disease is the most common form of dementia for this group and is likely to present with memory changes. Behavioural symptoms in some dementias will present prior to memory or judgement changes. Frontotemporal lobe dementia is the second most common cause and the accompanying behavioural symptoms may be particularly challenging for carers. These changes may include lack of empathy, anxiety, decreased social engagement, compulsive, repetitive behaviours and changes to planning and sequencing. Strokes, Lewy Body Dementia, multiple sclerosis, HIV/AIDS together with rarer hereditary and genetic conditions of familial Parkinson's disease, Huntington's Disease and Down Syndrome are among other causes of YOD.



Younger Onset Dementia - Early signs and the Workplace

Changes noted in workplaces may include increased reliance on notes and word finding difficulty; self-doubt, anxiety and reduced confidence particularly with processing and storing new information, completing and sequencing tasks or increased workloads; reduced attention span,

flexibility, motivation and tolerance of others. Depression related to a degree of awareness of cognitive and functional changes is common. Peers and supervisors may notice a decline in productivity and efficiency compared to the person's historical performance.

Challenges for Carers and the Person with YOD

People with YOD and their families experience issues different to those with late onset dementia. They are more likely to be still employed, be physically fit and strong, have young families, elderly parents, financial commitments such as mortgages and school fees and unfulfilled lifetime goals and dreams. There is potentially greater family shock, stress and conflict related to symptoms and behaviours, skill loss, loss of autonomy, societal stigma, lack of appropriate information and referrals, and grief and loss related to altered relationships and roles. Siblings, parents, children and spouses may become carers with accompanying potential for feelings of denial, embarrassment, resentment, fear and confusion and pressures at school, in workplaces and within the extended family. Future planning decisions related to Enduring Power of Attorney, Advanced Health Directives, updating wills, getting financial advice including accessing superannuation, Centrelink and other welfare services or retraining as an option to early retirement from work put added stress on family units.

Age appropriate activities and goals are needed to enable retention of skills and capability and to avoid a premature decline in self-esteem, self-

worth, and unacceptable focus on deficits and losses. Needs include transport options, extended hours of support and a preference for in home support and client-initiated social engagement, improved interagency communication to meet the desired outcomes of the person and their young working partners and families.

Ageing parents supporting their children with YOD and those persons who are socially isolated without informal supports have special support needs. Potential for disadvantage also may exist for those in rural and remote areas, people who are Indigenous, homeless, from cultural and linguistically diverse backgrounds, people with pre-existing mental health conditions or intellectual impairment, GLBTIQ and Forgotten Australians. These special needs groups may have added challenges accessing individualised, essential supports including specialist care, education, family counselling, housing, community, residential and welfare services. Linking in with an organisation such as Alzheimer's Queensland who specialises in dementia care can assist the individuals and families with planning for the future and current supports required.

The National Disability Insurance Scheme and the Person with YOD

The National Disability Insurance Scheme (NDIS) which is not means tested and does not affect disability payments is continuing to roll out throughout different areas of Queensland for people under the age of 65 years who have a permanent disability. People with YOD and their families through accessing the insurance scheme will have greater choice and control of their funding and choice of service providers with an emphasis on retaining capacity and independence.

Registration for NDIS can be requested 6 months prior to the NDIS being operational in their area (Phone 1800 800 110). The National Access Team will check eligibility and the impact of dementia on the person's ability to meet their needs and achieve their goals of maintaining their independence, maximising capacity, participating socially and economically in their chosen life plan.

The person with YOD may ask for a face to face planning meeting rather than a phone meeting. Assistance will be given to identify cost effective, reasonable and necessary supports for the person with YOD and their informal support persons to live well with dementia and to achieve their goals.

Alzheimer's Queensland has multidisciplinary teams which provide person and family-centred support and aims to support the skills, capabilities, choices and quality of life decisions of people with YOD and their families. Alzheimer's Queensland advocates for individualised social engagement opportunities within their community and residential care services (Phone 1800 639 331). Additionally, the Ipswich Multiservice Centre has specialised funding through Queensland Health to support people under 65 with a diagnosis of dementia without being linked to the NDIA (Phone 1800 639 331).



Pin on your notice board

Alzheimer's Queensland Services and Contacts

www.alzheimeronline.org

Advice Line

1800 639 331

Open 24 hours a day, 7 days a week.

Free call from landline and public phones.

Or email: helpline@alzheimeronline.org

For information and emotional support for people with dementia, families, friends and staff. The

Advice Line 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.

AQ Rehab

In home - Physiotherapy

Occupational Therapy

Speech Therapy

1800 180 023

Care Services

Brisbane North, Brisbane South, Ipswich, Toowoomba
Seven days per week including:

- Personal Care; Domestic Assistance
- Social Support; Transport
- Allied Health Assessments
- Respite - Centre-based – day, overnight or emergency
- Respite for Working Carers
- Home Maintenance

Multi-Service Respite Centres located at:

- Gordon Park; Mt Gravatt; Ipswich; Toowoomba

Residential Aged Care located at:

- Garden City Aged Care Services, Upper Mt Gravatt
- Rosalie Nursing Home
- Windsor Aged Care Services

Home Care Packages at:

- Brisbane South
 - Logan River
 - Brisbane North
 - West Moreton
 - Darling Downs
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Call the Advice Line for vacancies for Home Care Packages and for Residential Aged Care both permanent and respite.

Carer Support Groups - 2017

Provide information and support for those caring for a friend or family member with dementia. Please phone 1800 639 331 for more information, or to be placed on the mailing list.

- **Toowoomba:** First Monday of month: 9:30am – 11:30am
Toowoomba City Library, Level 3, Cnr of Victoria & Herries Streets Toowoomba 4 Sept, 9 Oct (2nd wk), 6 Nov, 4 Dec
- **Ipswich:** Third Wednesday of every month: 10:00am – 12 noon
Calvary Baptist Church, 83 Chermerside Road, Ipswich 20 Sept, 18 Oct, 15 Nov, 20 Dec
- **Newmarket:** First Thursday of month: 10:00am – 12 noon
LifeTec, Corner Enoggera & Newmarket Roads, Newmarket 7 Sept, 5 Oct, 2 Nov, 7 Dec
- **Redcliffe:** First Thursday of month: 2:00pm – 4:00pm
Redcliffe Library Meeting Rooms, 476 Oxley Ave, Redcliffe 7 Sept, 5 Oct, 2 Nov, 7 Dec
- **Mt Gravatt:** First Friday of month: 10:00am – 12 noon
47 Tryon Street, Upper Mount Gravatt 1 Sept, 6 Oct, 3 Nov, 1 Dec
- **Garden City Evening:** 6:00pm – 7:00pm
52 Khandalla Street, Upper Mount Gravatt 20 September, 15 November
- **Gordon Park Evening:** 6:00pm – 7:30pm
45 Shamrock Street, Gordon Park 19 October
- **Qld-wide Telephone Support Group:** Last Wednesday of month: 1:00pm – 2:00pm
AAQ organises telephone link-up at no cost to members 27 Sept, 25 Oct, 29 Nov

For further details or to register please contact the Alzheimer's Queensland Advice Line.

