



A publication of
Alzheimer's Queensland.

Dementia Matters

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Abuse Neglect and Exploitation

Violence, abuse, neglect and exploitation is more likely if a person has an intellectual disability, dementia or cognitive impairment. The risk is also high for other special needs groups such as Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds and the LGBTIQ community. Ageism, social isolation and relationships of dependence contributes also to the risk of elder abuse. Elder Abuse often leads to the appointment of decision makers such as guardians and/or administrators and investigations by the Office of the Public Advocate.

The person's ability to act in their own best interests is eroded over time by the action of abusers. Abusers may be a family member, supported decision maker, staff member, a payment nominee for a social security recipient or a recipient

of a carer allowance or carer payment who is not providing adequate care or when coercion is used to make contributions, withdrawals or transfers from superannuation funds. Financial dependence e.g. for a person without residency or eligibility for an aged pension, increases the risk for the person with dementia. For private family agreements where property title is transferred or granny flat or co-occupancy is agreed in exchange for long term housing and support, the person with dementia may not have any legal protection. The person with dementia should seek independent legal advice. Also people must have capacity to make particular decisions or transactions such as making an Enduring Power of Attorney, a Will or signing agreements and contracts.



Government Subsidized Services and Decision-Making.

My Aged Care (MAC) and the National Disability Insurance Scheme (NDIS) mark a shift to greater control and choice by consumers over lifestyle options, the services which meet their individual needs and how these services are managed. The NDIS funds clients under 65 years of age and 89% of NDIS participants are identified as having some form of cognitive impairment. NDIS participants will include people with Younger Onset Dementia. The rights of clients of MAC and the NDIS to participate in decision making are protected in the core principles of legislation (NDIS Act and Aged Care Act).

MAC is a central point of contact for people over the age of 65 years who require support services. By mail, fax or phone the person with dementia can appoint a regular representative - family member, carer or someone they trust - to speak and act for them. However, if a doctor's letter states that the

person is unable to act on their own behalf, then legal documents must be provided to MAC before an authorised representative can speak on their behalf (Phone 1800 200 422). Health professionals can make referrals to MAC with the client's consent.

Apart from supports such as family, friends, peer groups, and independent advocates, the NDIS participants can ask that a correspondence nominee or a plan nominee be appointed by the National Disability Insurance Agency which administers the NDIS in cases where it is not possible for participants to be assisted to make decisions for themselves. Guardians and administrators may also be involved where appropriate to support decision making. Nominees, guardians and administrators are obliged to ensure maximum participation, choice and control by the NDIS participant.



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

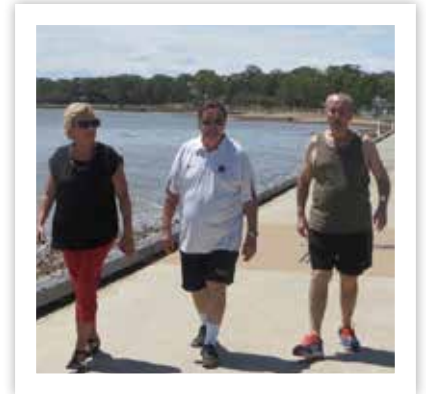
Alzheimer's Queensland – A Good News Story for the Tai Chi Group

Between October and December 2017, Alzheimer's Association QLD's (AAQ) Tai Chi instructors, Christina Robb and Zoe Samuels successfully completed an 8-week Tai Chi for Arthritis and Falls Prevention pilot program, "Move for Life". The program was run from AAQ's Ipswich Multi Service Centre and involved 7 participants.

Instructors were conscious of the expressed needs and goals of the participants and modified the program to optimise engagement, comfort levels and involve carers. Movements were modified, for example, seated vs standing and a smaller range of movement.

Participants had a choice to engage in the program or not; and could stop and rest at any time.

The feedback from participants and carers was very positive, it included: "I found it came naturally, the graceful movement"; "It's an exercise I can continue to do and to enjoy a calmness and feeling of relaxation"; "I go home really peaceful". It also provided an opportunity for both carers and the person with dementia to share a positive experience.



Pre-and post program evaluations were completed to provide information on ways to modify the program to enhance participant benefits in the subsequent groups planned for early 2018. The shared goal is to improve confidence for moving and walking; reduce fears of falling; to provide participants with a set of skills that can help manage pain and stress; all within a relaxed, social atmosphere.

Please contact Ipswich Multi Service Centre on 07 3812 2253 for more information on how to get involved!

Decision-making – A Basic Human Right

The person living with dementia retains a basic human right to be engaged in autonomous decision-making, to have freedom of speech and movement and to participate in balancing reasonable risk with opportunities for inclusion, participation, joy and personal goal achievement. Words, equipment or environments which restrict this ongoing engagement may result in outcomes such as frustration, boredom, agitation, anxiety, withdrawal or depression. Distress, grief, fear and loss of self-worth can result for both carers and the person living with dementia. Prevention and advocacy require appropriate use of words, actions and environments that promote a gentle, familiar rhythm to daily routines that reflects the full extent of the ability and understanding of the person with dementia. The person has a right to be engaged from a social, psychological, emotional, cultural and/or spiritual perspective and have their physical needs and quality of life supported.

Communication and Barriers to Decision Making

Negative language which is used both in the community and health settings contributes to the attitudes which damage the personhood or identity of the person with dementia. Words such as 'victim', 'tsunami of dementia', 'demented', 'not right in the head', 'burden on the health budget' 'the burden of caring' and 'a wanderer' are among terms/phrases which demean, humiliate and set people apart as does the medical model focus and statistical data on 'numbers of dementia sufferers'.

Individual differences and positive images such as people interacting and contributing to family, community and society are not at the forefront of media reporting. Stereotypes including ageism and misinformation about dementia continue to socially isolate, embarrass and frighten the person with

dementia, their carers and families. If viewed in this negative light, the person living with dementia is often not heard, listened to nor empowered to maintain function, independence and autonomy or to communicate their needs and preferences.

Non-verbal communication becomes increasingly important as dementia progresses and words may become less meaningful. Communication barriers such as invading their personal space, a condescending tone of voice, frowning, avoiding eye contact or touch, rushing, not responding to the person's body language or expressions of emotion which may reflect their discomfort or confusion can be demeaning and impact negatively on the mood, feelings, dignity and responses of both the person with dementia and their carers.

Person-Centred Care and Informed Consent

Person-centred care is promoted within community services, Residential Aged Care Facilities and health services. Central to this is to act in the best interests of the client and adhere to complex ethical and legal elements of informed consent and supported decision-making. Reflecting the individual beliefs, preferences and priorities of the person living with dementia in areas such as health, finances and personal matters should ensure the person's proper care and protection, and maintain optimal decision-making ability, independence and autonomy. Capacity can vary under different circumstances e.g. capacity may exist for making simple decisions but not complex decisions. For example, where there are complex situations and disharmony among family members then appointing an Enduring Power of Attorney may be overwhelming for the person living with dementia.

The capacity and skills for decision making will decline as the disease progresses. However, the focus must also be on strengths and wellness and simplifying discussions to enhance understanding and engagement. It is within the capacity of many people with dementia to participate in discussions and decisions regarding the benefits, risks and alternatives of their care and to have trusting relationships with

service providers. Lack of trust can result not only from reduced insight due to dementia but also the personal background of the individual such as refugee status and previous trauma or past experiences within the health system or with authority figures e.g. previously institutionalised people. The risk of harm to self or others is a consideration while also taking all steps to support the person with dementia's autonomous decision-making.



Service providers and those supporting the person with dementia may often fear mistakes, poor choices and the client declining support or forgetting that they have consented or giving too much information causing stress. These concerns may lead to a reduction in autonomous decision-making for the person with dementia, particularly where capacity is borderline or fluctuating and changes to care require review of consent. Geriatricians, psychiatrists or neurologist can assist to assess

capacity and give a second opinion. A valid Advanced Health Directive or Enduring Power of Attorney can also support decision-making as would engaging those who are regularly supporting the person with a diagnosis of dementia. Use of familiar, appropriate communication strategies including interpreters is needed.

Environments and Decision-Making

Decision-making participation can be enhanced by environments which reassure and not challenge the safety, security and well-being of the person with dementia. Environments must support the person to meet their needs such as for rest, nutrition, hydration, toileting, exercise, love, belonging and safety. Lighting including sensor lighting, colour contrast, signage/pictures, toilet access, freedom of movement and exercise areas/activities, noise and temperature control, privacy, familiarity of equipment such as furniture, bedding, photographs, familiar and symbolic clothing can all contribute to allaying anxiety and confusion which can impact on participation.

To support the continuation of valued roles, routines and rituals, families and those who know the person well play a vital part in informing service providers of significant physical, social, spiritual, cultural and emotional profiles including personality type in order to avoid triggers which may result in unwanted outcomes or distress. Reversible and treatable issues or triggers such as inadequate pain management, infection, medication interaction or side effects, fatigue, alcohol, can also contribute to the agitation of the person with dementia and reduce their ability to participate and enjoy daily interactions, experiences and decision-making.

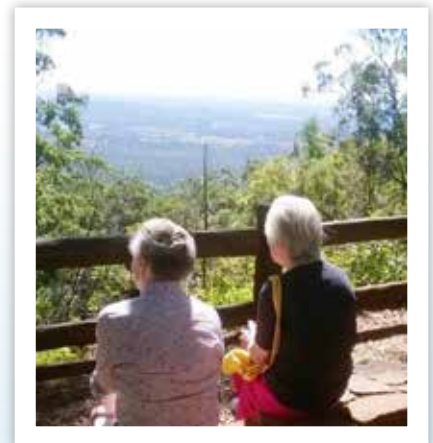
Capacity and Substitute Decision Makers

Each individual's symptoms of dementia will vary and fluctuate as the cause of dementia, the area of the brain effected and the progression of the disease is different. For those without supporters or representatives and with reduced capacity in some areas, substitute decision makers may be required to try to support decision making with input from the person with dementia in all aspects of their life. When the task specific capacity for decision making reduces in areas such as finances, health or lifestyle, the doctor may complete assessments to determine if the person is no longer able to make decisions independently. A multidisciplinary team is often involved such as an occupational therapy assessment for fitness to drive or ability to manage finances. A valid Advanced Health Directive should inform decisions as it is a legally binding document. Certified copies of the Enduring Power of Attorney and Advanced Health Directive will be needed e.g. for your general practitioner, hospital admissions, Residential Aged Care Facilities and any appointed attorneys.


The complexities of both Home Care Packages and residential aged care placements can lead to an application by family, significant others or staff in hospitals for a substitute decision maker through the Queensland Civil and Administrative Tribunal (QCAT). Substitute decision makers with legal authority such as a guardian or administrator appointed by the Tribunal/court or an Enduring Power of Attorney or a statutory health attorney (such as a spouse) can then support the person living with dementia who should still be

appropriately informed and participate in the process to the full extent of their capacity.

A substitute decision-maker will assist the person most effectively if they have an understanding of both dementia and the person. Even longer-term carers and service providers can benefit from building their communication and



behavioural support skills to promote maximal engagement and good quality of life of the person with dementia. The professional staff at Alzheimer's Queensland are able to offer individualised or group education sessions to any interested Residential Aged Care Facilities, community groups or individuals. The Alzheimer's Queensland 24hour Dementia Advice Line offers education and support to people living with dementia and their carers. Education forms part of the monthly Alzheimer's Queensland Carer Support Group meetings and the Alzheimer's Queensland website provides information in relation to other planned education opportunities Phone 1800 639 331 or check <https://www.alzheimersonline.org/page/our-services/Education-Training/>



Pin on your notice board

Alzheimer's Queensland Services and Contacts

www.alzheimersonline.org

Dementia Advice Line

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, 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
-

Call the Advice Line for vacancies for Home Care Packages and for Residential Aged Care both permanent and respite.

Carer Support Groups - 2018

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
Park Motel, 88 Margaret Street, Toowoomba 5 Feb, 5 March, 9 April (due to public holiday), 14 May (due to public holiday), 4 June
- **Toowoomba Men Only:** 11:30-13:30 (includes lunch)
For venue and Dates please contact 07 4635 2966
- **Ipswich:** Third Wednesday of every month: 10:00am – 12 noon
Calvary Baptist Church, 83 Chermerside Road, Ipswich 17 Jan, 21 Feb, 21 March, 18 April, 16 May, 20 June
- **Newmarket:** First Thursday of month: 10:00am – 12 noon
LifeTec, Corner Enoggera & Newmarket Roads, Newmarket 4 Jan, 1 Feb, 1 March, 5 April, 3 May, 7 June
- **Redcliffe:** First Thursday of month: 2:00pm – 4:00pm
Redcliffe Library Meeting Rooms, 476 Oxley Ave, Redcliffe 4 Jan, 1 Feb, 1 March, 5 April, 3 May, 7 June
- **Mt Gravatt:** First Friday of month: 10:00am – 12 noon
47 Tryon Street, Upper Mount Gravatt 5 Jan, 2 Feb, 2 March, 6 April, 4 May, 1 June
- **Garden City Evening:** 6:00pm – 7:00pm
52 Khandalla Street, Upper Mount Gravatt 21 Feb, 16 May, 16 Aug, 21 Nov
- **Gordon Park Evening:** 6:00pm – 7:30pm
45 Shamrock Street, Gordon Park 17 May, 16 Aug, 18 Oct.
- **Qld-wide Telephone Support Group:** Last Wednesday of month: 1:00pm – 2:00pm
AAQ organises telephone link-up at no cost to members 31 Jan, 28 Feb, 28 March, 18 April (due to Public Holiday), 30 May, 27 June

For further details or to register please contact the Alzheimer's Queensland Dementia Advice Line 1800 639 331

