



A publication of
Alzheimer's Queensland.

Dementia Matters

In this edition...

- **Alzheimer's Queensland Good News Stories**
 - Ipswich Carer Support Group
 - Mt Gravatt Carer Support Group
 - Alzheimer's Queensland (AQ) Homes
- **Transition to Residential Care**
- **Younger People with Disability**
- **Future Planning**
- **Resistance to Residential Care**
- **Questions to Ask?**
- **Your Observations**
- **Loss and Grief**





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 Good News Stories

Ipswich Carer Support Group

Alzheimer's Queensland facilitates Carer Support Groups in Ipswich, Toowoomba and Brisbane. Experienced professionals present an hour of dementia-related education at each monthly meeting. Recently one of Alzheimer's Queensland's Occupational Therapists in Ipswich presented on the topic of Transitioning to Residential Care – Strategies to support the person living with dementia and their carers.

This type of education empowers families to confidently make informed decisions and to address current and future needs. The social support and helpful strategies that carers share at the meetings contributes to the person living with dementia maintaining independence and staying at home longer and supports the health, well-being and resilience of carers.

Mt Gravatt Carer Support Group

The Upper Mount Gravatt Carer Support Group provided an opportunity for four carers to present and share their stories in caring for themselves and their loved ones. In dealing with the inevitable loss and grief experienced by carers and the person living with dementia, the carers identified the need for meaningful interaction with their loved ones through shared, joyful experiences but also through maintaining their own social roles, relationships and activities outside their carer's role. Activities for Will, Richard, Brenda and Graham ranged from a shared passion for cinema, writing a memoir, exercise and joining a ukulele group.



Alzheimer's Queensland (AQ) Homes

Alzheimer's Queensland has four residential care homes in Upper Mt Gravatt, Rosalie and Windsor in Brisbane including an additional new nursing home at Upper Mt Gravatt.

All our residents benefit from Alzheimer's Queensland distinctive knowledge, skills and expertise in dementia care. Our education program ensures that the skills of our staff are maintained. Familiar activities reminiscent of everyday home life are incorporated in our lifestyle program. We offer access to a range of professionals including registered nurses, physiotherapists, speech pathologists, occupational therapists, and podiatrists.

Transition to Residential Care

Most people choose to remain in their own homes for as long as possible and only a small percentage of the older population live in residential aged care. The average age at entry to residential care is 82 for men and 84.5 for women and the average length of stay is 34.6 months.

The risk of transition to a residential care home increases with age, chronic illness, dementia, hospitalisation, being female, living alone or being socially isolated. Long waiting periods for appropriate and timely community support also increases risk. Alzheimer's Queensland provides community support through My Aged Care and the National Disability Insurance Scheme (NDIS) to assist people to remain living in their own homes.

When deciding to live in residential care, potential impediments may include a perceived loss of dignity or lack of respect for individual characteristics and life experiences; loss of autonomy, freedom of movement, security and privacy; separation from family; fears related to affordability, accessibility and ownership of an asset; absence of the familiarity and emotional attachment to home, contents and community. Supporting individualised, meaningful lifestyles in residential care and avoiding a one size fits all approach will address these concerns of carers and people living with dementia and also reduce depression, loneliness, agitation, challenging behaviours and the use of antipsychotic medication.

The decision to live in a residential aged care home is often distressing for carers and the person living with dementia even when it is a planned decision. Feelings of grief, loss and guilt are overwhelming and often persist. The eventual decision to move is based on a variety of reasons

including a progressive but marked reduction in independent mobility, personal care or toileting, or behavioural issues that are difficult for carers to manage on a full-time 24/7 basis. Behavioural issues may include agitation, wandering, night-time waking, verbal or physical abuse, resisting care, incontinence or hallucinations and delusions that are distressing for the person living with dementia and their carer.

Moving into residential care can be an unplanned decision following a hospital admission. The person living with dementia may not return to their pre-admission level of physical or cognitive functioning; the level of carer stress is impacting on the health and well-being of the carer or there is a significant decline in the carer's health or death of a carer.

Residential care can provide a supportive environment for the individual, ensuring that all their care and social needs are met. It allows the carer to return to the role of family member and enjoy quality time with the individual.



Younger People with Disability

In September 2018 there were 5,905 people with disabilities including dementia under 65 years of age living in residential aged care homes across Australia due to their complex care needs or lack of appropriate specialised disability housing. An Aged Care Assessment Team (ACAT) approval is required to enter residential aged care together with a letter from the National Disability Insurance Scheme (NDIS) stating that the person cannot be supported outside residential care. NDIS for those under 65 years of age in residential aged care homes

assists with means-tested care fees and daily accommodation payments and funds reasonable and necessary support not provided under the residential aged care home funding.

Through an NDIS Complex Support Needs Pathway, Specialist Disability Accommodation (SDA) funding can be incorporated into the NDIS support plan to assist young residents in aged care, or currently in hospital settings and at risk of entering aged care to find suitable accommodation and supports in the community.

Future Planning

The decision to live in Residential Care is made easier by future planning and reducing the risk of uninformed decisions in crisis situations. For permanent residential care or residential respite care an approval letter from the Aged Care Assessment Team (ACAT) is required. An ACAT assessment can be arranged through registration with My Aged Care (Phone 1800 200 422). Consumers are eligible for 63 days per year of subsidised residential respite and can be asked to pay the basic daily fee to cover day-to-day living costs.

The consent of the person with dementia is required for a referral to ACAT. Referrals and decisions can be made by an Enduring Power of Attorney for lifestyle decisions if the person has lost capacity for decision-making. A letter from a doctor is required in relation to capacity.

An Enduring Power of Attorney for decision-making related to finances and assets may be involved in managing residential care costs. An independent financial planner with experience in aged care may assist with these financial decisions as well as discussions with the residential care home as costs will vary e.g. Refundable Accommodation Deposits, non-refundable Daily Accommodation Payment or a combination of both and daily extra services fees.

Additional means tested fees may be required. For more information contact the Department

of Human Services 1800 227 475 or go the website humanservices.gov.au/agedcare. (This assessment is not required for Residential Respite Care). The information you provide is used to calculate aged care fees and charges. The assessment will remain current for 120 days and a letter will be sent to you. Basic daily Fees (up to 85 per cent of the single person rate of the basic age pension) covering living costs, food, laundry, cleaning and personal care are paid by all residents. The residential agreement is a legal document and should be read carefully and understood.

Financial hardship assistance may be available if eligibility criteria are met.

Where there are no Enduring Power of Attorney/s appointed and the person lacks decision-making capacity, an application to the Civil and Administrative Tribunal may be made. If there are no family or significant others available to be appointed by the Tribunal, potential outcomes may include the Adult Guardian making lifestyle decisions and the Public Trustee making financial decisions. An Advanced Health Directive made when the person had capacity can assist substitute decision-makers to make health decisions that reflect the person's goals, values, beliefs and preferences.

For further information on Alzheimer's Queensland residential homes phone 1800 639 331.

Resistance to Residential Care

Individual preparations and responses will vary. Establishing a relationship with the residential care home prior and discussing transition strategies and support on the day will make the transition smoother. You may like to discuss your time of arrival, length of your stay, a contingency plan for leaving if loved ones want to come home; setting up the room with familiar and currently meaningful objects – life story books, photographs, art, doonar, pillow, alarm clock, favourite chair, religious icons, music, snacks, perfumes – putting clothes and items in places that are familiar to the person and replicate the cupboard contents, layout, tidiness at home. Unnecessary clutter and new clothes or furniture may not reassure the person.

Consider the feelings and the reality of the person living with dementia - listen patiently,

acknowledge feelings, reassure, redirect or distract with empathy and be flexible. Potentially it may be days or months before the person can accept their changed circumstances and feel that they are valued, heard and are not disempowered. Avoid phrases like 'this is your new home' as this may not reflect the reality or the feelings of the person and may increase anxiety, insecurity, confusion, frustration and even anger.

During visits regularly take the person for walks and participate socially in the residential home to foster positivity and orientation to the environment, routines and people. Genuine regard, touch, a hug, hand or leg massages and familiarity may promote positive emotional feelings and be as meaningful as words.

Questions to Ask?

Knowing what to look for in a residential aged care home increases the likelihood of the home meeting the individual needs of the person living with dementia, their family and significant others.

The care and services provided must meet the new Aged Care Quality Standards and the Charter of Aged Care Rights effective from 1st July 2019. Any concerns about the care or services in residential aged care should be discussed initially with the aged care provider. However, the National Aged Care Advocacy Line 1800 700 600 and the Aged Care Quality and Safety Commission 1800 951 822 can support consumers who have concerns that are not addressed to their satisfaction.

Alzheimer's Queensland's homes provide consumer directed care that values and respects carers and the person living with dementia and maximises independence, autonomy, comfort, dignity and quality of life. Carers and the person with dementia should ask the home how they will be engaged in collaborative decision-making to plan, implement and monitor care. A list of your priority potential needs – physical, social, spiritual, cultural, emotional – should be a point of discussion when carers and the person with dementia are engaged in decision-making and care planning. Enquire how feedback is sought in relation to processes and outcomes within the aged care home for example through complaints, compliments and regular resident and carers' meetings with management and staff.

Other discussion may relate to dietary options, personal care routines such as waking times, toileting regimes, time of shower, perfumes used; nursing care for wounds, diabetes, medication. Staffing questions should include consistency of staff and relationship-building; are registered nurses on site 24/7 to ensure prompt response to needs; access and costs related to physiotherapy, occupational therapy, speech pathology, podiatry, pharmacy, palliative care staff; visits by doctors (including after hours) and appointment processes for carers and reporting of changes to health status and incidents; are leisure and lifestyle staff on site 7 days.

AQ Homes ensure meaningful social, cultural and spiritual rituals and symbols are valued to promote a sense of belonging and place, to increase social engagement and to reduce stereotypes about disability, frailty or ageing. Daily, varied and individualised social programs include easy access to regular exercise and exposure to sunlight, plants and animals. AQ's activities respect and reflect diversity, valued roles, hobbies and life story. They foster feelings of hope, achievement, usefulness and connection with others including an ability to help others, to participate with family and friends and to express sexuality and intimacy. Residents are not passive recipients of care. Open visiting hours and opportunities for community outings and overnight stays outside the aged care home are welcome.

Your Observations

Do you see, hear and feel a relaxed, friendly, social and physical environment reflected in smiles and greetings, colour, lighting, music, quiet areas with calming outlooks? Do staff use language that is not labelling or condescending e.g. a wanderer, demented, the burden of caring? Do residents appear engaged in a variety of settings, relationships and activities and receive a prompt response to their needs?



Loss and Grief

Counselling and strategies to deal with loss, grief and changed circumstances can assist carers to adapt, particularly when their carer role and close relationships have been long term. Typically social isolation, depression and neglect of their own health is common for carers and there is a need to

retain and/or rebuild a life outside the carer role. The frequency of visits is a decision for the carer and there are many variables including the carer's health, distance and transport options. Phone the Alzheimer's Queensland Advice Line 1800 639 331 for information about counselling and carer support.



Pin on your notice board

Alzheimer's Queensland Services and Contacts

www.alzheimeronline.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@alzheimeronline.org

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

The Dementia Advice Line has a database of services 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
- NDIS Support
- 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
 - Gold Coast to Byron Bay
-

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

Carer Support Groups - 2019

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. Blue Care Community Training Room, Ramsay Street Toowoomba. 2 Sept, 14 Oct, 4 Nov, 2 Dec
- **Ipswich:** Third Wednesday of month: 10:00am – 12 noon. The Cottage, 85 Chermerside Road, Ipswich. 18 Sept, 23 Oct, 20 Nov, 18 Dec
- **Windsor:** First Thursday of month: 10:00am – 12 noon. Windsor Aged Care Services. 26 Palmer Street, Windsor (Enter via Reception). 5 Sept, 3 Oct, 7 Nov, 5 Dec
- **Redcliffe:** First Thursday of month: 2:00pm – 4:00pm. Redcliffe Entertainment Centre, Terry Walker Room, Downs Street Redcliffe. 5 Sept, 3 Oct, 7 Nov, 5 Dec
- **Mt Gravatt:** First Friday of month: 10:00am – 12 noon. 47 Tryon Street, Upper Mount Gravatt. 6 Sept, 4 Oct, 1 Nov, 6 Dec
- **Mt Gravatt Chat Group:** 2nd Wednesday of month: 10 am – 12 noon. The Coffee Club, The Village, Upper Mount Gravatt: 32/1932 Logan Road, Upper Mt Gravatt. 11 Sept, 9 Oct, 13 Nov, 11 Dec
- **Garden City Evening:** 52 Khandalla Street, Upper Mount Gravatt 6:00pm – 7:00pm. 21 August, 15 November
- **Gordon Park Evening:** 45 Shamrock Street, Gordon Park 6:00pm – 7:30pm. 17 October
- **Qld-wide Telephone Support Group:** Last Wednesday of month: 1:00pm – 2:00pm. AAQ organises telephone link-up at no cost to members. 28 Aug, 25 Sept, 30 Oct, 27 Nov

