

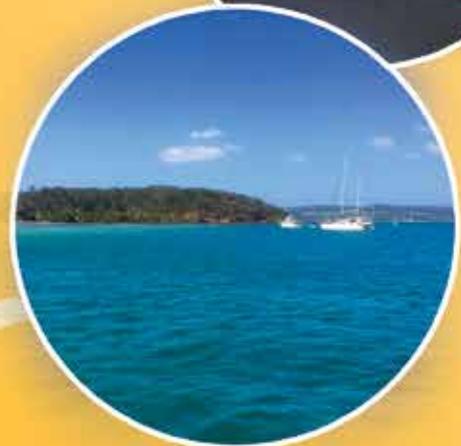


A publication of
Alzheimer's Queensland.

Dementia Matters

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Swallowing Difficulty, Communication and Speech Pathologists

The speech pathologist at Alzheimer's Queensland supports the person experiencing a life-limiting illness. The values, cultural background and goals of the individual and their caregivers are taken into account.

Swallowing difficulties are often a symptom of an underlying condition such as dementia, Parkinson's disease and strokes and may result in frequent coughing, chest infections or choking. The speech pathologist may recommend compensatory strategies to guide safety with oral intake. This may include optimal positioning, changes to feeding techniques, food texture modification and changed fluid consistencies. The person can still enjoy their preferred flavours and choices with food and fluids. If swallowing problems are very severe, the person may still be able to enjoy the taste of a familiar food. Oral hygiene is essential for optimising swallowing competence and comfort. A speech pathologist provides education and may also be involved in decision-making regarding non-oral feeding.

If a person is finding it more difficult to communicate, the speech pathologist may suggest ideas for augmentative or alternative communication so the person can direct their care and engage in discussions with family and others. Some communication aids may include spelling boards, communication books, talking apps for iPads or chat books. Techniques to facilitate optimal interactions for caregivers may include gaining the attention of the person, using short, simple sentences, touch and gesture, pictorial or written cues.



Social and Psychological Support

Support strategies with family engaged in decision making may include: regular explanation of care, flexible visiting times and private spaces, calm speech, touch; soft, indirect lighting; favourite items, music; reduction in noise; dressing in own clothes; skilled aromatherapy and massage, awareness of sensory impairment.

Increasing levels of fatigue and need for rest may limit participation in interactions but hearing may be retained and familiar voices and touch may comfort. Individualised spiritual support should be offered to both the person with dementia and their support network.

Loss and Grief

Loss and grief and emotional distress is experienced by both carers and the person with dementia related to changes to personality, relationships, friendship groups, as well as moving into Residential Care and at end of life. Experiences and responses will vary depending on individual differences including values, beliefs, culture, life story and the causes and symptoms of dementia. The uncertainty in relation to the progression of the illness may diminish hope and increase a sense of fear and vulnerability for all involved.

Carer Support Groups, community and residential care services and the 24 hour Advice Line provided by Alzheimer's Queensland provide opportunities to gain practical assistance, discuss feelings and to reduce the risk of depression.



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:

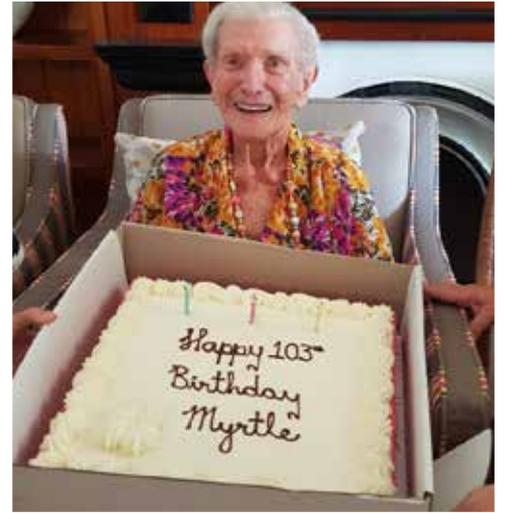
- 24 hour 7 days per week professionally staffed Advice Line (ph: 1800 639 331)
- Community education
- Library resources
- Interactive website at www.alzheimersonline.org
- Professional education
- Family carer education
- Support groups – face to face and telephone support groups
- Individualised support
- 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**

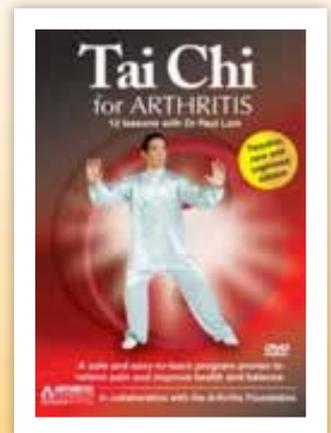
Alzheimer's Queensland A Good News Story

Myrtle, a long-time client of the Ipswich Alzheimer's Queensland Multi-Service Centre, has recently celebrated her 103rd birthday. The celebration was attended by the Ipswich City Council Mayor, family, the cottage's clients and staff. Myrtle was an employee of the Prince Alfred Hotel and Booval Racecourse, a member of the Labor Party for 5 years, and was the president of the Swifts Bowls Club. Now at 103, Myrtle is showing no signs of slowing down – remaining actively involved through volunteering with Meals on Wheels, visiting the Swifts Bowls Club, and attending church every Sunday. She attends our respite centre multiple times a week and loves participating in bingo and regular craft groups. Myrtle says that the key to ageing well is to be active in both body and mind.



Alzheimer's Queensland Tai Chi Groups

Please contact 3812 2253 if you would like to join a Tai Chi group in Ipswich run by the Occupational Therapists at Alzheimer's Queensland. Separate groups are available for the general public, carers and persons living with dementia. Tai Chi may help to relieve pain, and improve health and balance. A Tai Chi DVD is available in the Alzheimer's Library.



Dementia and Palliative Care

Dementia is the 2nd leading cause of death in Australia and has no cure. Unlike cancer or other life limiting diseases the decline is slow over many years. Individuals with dementia will differ due to the different causes of dementia; the progression of the disease and symptoms such as loss of function, cognition and behaviour; age of onset, overall health status, multiple medications, values, beliefs, preferences and treatment goals.

Palliative Care Approach

A palliative care approach for the person with dementia and their families aims to improve their quality of life and prevent and relieve distress. Early assessment, anticipating problems and flexible treatment options are essential e.g. for physical, psychological, social, spiritual, cultural issues. Involvement of families and substitute decision-makers as advocates for their loved ones is essential along the care pathway and is not restricted to the last days or weeks of life.

Early, compassionate information sharing and honest, two way discussion strengthens trusting relationships with the health team and supports end of life care decisions and an understanding of the consequences. Treatment options include behavioural strategies, complementary therapies such as music, massage, aromatherapy and skilled personal care. Medication will be used if needed for symptom control where symptoms are distressing and complex and not responding to other treatment options.

Specialist palliative care will include team referrals for focused specialist assessment and guidance from medical staff, nurses and allied health professionals with high levels of palliative care expertise. The Palliative Care Teams work alongside families, General Practitioners, trained registered nurses and personal carers. All staff should also have palliative care skills when working in community, residential aged care facilities and hospital or hospice settings.

Regular reviews of the person's physical, emotional and spiritual comfort and the support needs of the family are essential in the final days or weeks of life when giving person-centred end of life terminal care.

Though resources are limited, justice and equity demand that palliative care is accessed by people with dementia. Currently people with dementia are less likely to be referred to specialist palliative care services or die in a hospice or be effectively treated for pain. This occurs even though over 52% of people in residential aged care facilities have dementia and the average length of stay is only 2-3 years and 17% of people living in their own homes and receiving community services have dementia (2013-14).

Most people with dementia die in Residential Aged Care Facilities where there is limited after hours support and specialised training. Alzheimer's Queensland liaise with specialist hospice care staff and provide annual staff education. Staying at home is complicated by the burden on ageing carers who may not have the required skills or training or access to GP home visits or equipment to manage the changing behaviours and needs - physical and psychological - associated with end of life. Benefits at home include the familiarity of environment and people and more flexible routines at home if adequate support is available.

Care Needs at End of Life

The person with dementia may decline slowly or their death may be precipitated by events such as falls, recurrent pneumonia or deterioration of multiple organ systems associated with frailty. In the final months of life the more common issues of concern will include eating and swallowing difficulty, pneumonia and febrile episodes. The risk of dyspnoea (difficulty breathing), aspiration of food or fluid into airways, pressure sores and pain and anxiety all increase towards the end of life.

Difficulty Breathing and Skin Care

Breathing may become noisy, slower and less regular but suctioning is avoided at end of life. Medication and side lying to aid drainage may assist. Fear and anxiety exists for both the person and their family and explanation and reassurance are needed. Oxygen therapy is not necessarily recommended.

Mouth care and eye care is assisted at end of life to promote comfort and reduce tissue dryness and ensure that causes of dental pain are identified. Urine output will reduce. Checking skin integrity continues as the risk increases of pressure sores occurring at end of life when blood circulation, nutrition and hydration reduces. Gentle repositioning should continue with use of pressure relieving mattresses and cushions and potentially pain relief prior to movement.

Pain, Anxiety and Distress

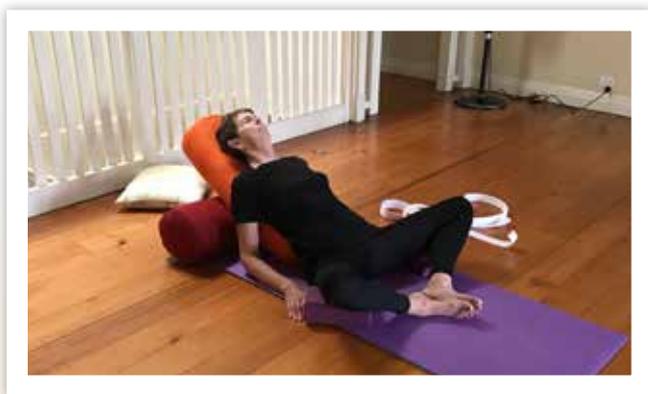
Symptoms such as pain, anxiety and distress may be expressed differently e.g. in moderate/severe dementia a person may be unable to verbalise pain or discomfort or accurately give yes/no answers. Needs may be expressed by behaviours such as crying, groaning, frowning, restlessness, increased confusion. It is well documented that pain is underreported, underdetected and undertreated in the person with dementia. Behaviours and actions must be seen as a form of communication and require a response.

The source of pain can vary due to chronic illnesses e.g. arthritis; acute illnesses such as infection, sore gums; pressure sores, wounds, constipation, urinary retention and contractures. Therefore treatment will vary. Treatments for pain can be non-pharmacological or pharmacological (drug) and must be regularly observed, reviewed and documented regarding effectiveness. Medication

may be more effective when administered regularly with additional pain medication as needed e.g. prior to movement or hygiene care if discomfort is predicted.

Potentially hospital admissions can be avoided if behaviours are understood and causes of pain and distress appropriately identified and treated. The stage of dementia and goals of care must be considered before choosing to transfer to hospital where the risk of delirium and adverse events is high. Relieving pain and distress and not starting or continuing life-prolonging treatment may shorten life but can ensure dignity and comfort to the dying person.

Restlessness, agitation and confusion occurs for some people in the last days of life. A calm, familiar environment and potentially medication may enhance comfort.



Medication, Nutrition and Hydration

Medication side effects should always be considered if changes to behavior occur.

Medication reviews by accredited pharmacists are available without charge in both Community and Residential Aged Care Facilities by referral from the treating Medical Provider – GP or specialist.

Medications may be ceased under medical supervision when it is prolonging life and not decreasing sufferin e.g. Antibiotics may be given if they relieve the symptoms of infection and the goal is to increase comfort at end of life.

Nutrition and hydration is essential and beneficial earlier in dementia often supported with expert advice from dietitians and speech pathologists. However at the end of life attempts to maintain artificial nutrition or hydration may cease when distress and discomfort occurs, there is no

reversible cause and there is no swallow or gag reflex.

Medical decisions should reflect previously stated views of the person with dementia for example in an Advanced Health Directive where discussion of the potential outcome of ceasing care or medications was previously discussed. Views and beliefs should be documented while the person still had capacity for independent decision making. Family members are grieving and stressed from their caring roles and are influenced by their own religious, cultural, views and beliefs and potentially family conflict and guilt. Unless previously discussed they can find decision-making challenging when trying to weigh life expectancy, care goals, quality of life and the benefits and side effects that can result from end of life treatment such as resuscitation or hospitalisation.



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 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 14 May (due to public holiday), 4 June, 2 July, 6 Aug, 3 Sept, 1 Oct, 5 Nov, 3 Dec.
- **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 Chermide Road, Ipswich 16 May, 20 June, 18 July, 22 Aug, (NB: 4th week due to public holiday), 19 Sept, 17 Oct, 21 Nov, 19 Dec.
- **Newmarket:** First Thursday of month: 10:00am – 12 noon
LifeTec, Corner Enoggera & Newmarket Roads, Newmarket 3 May, 7 June, 5 July, 2 Aug, 6 Sept, 4 Oct, 1 Nov, 6 Dec.
- **Redcliffe:** First Thursday of month: 2:00pm – 4:00pm
Redcliffe Cultural Centre, Terry Walker Room, Downs Street Redcliffe, 3 May, 7 June, 5 July, 2 Aug, 6 Sept, 4 Oct, 1 Nov, 6 Dec.
- **Mt Gravatt:** First Friday of month: 10:00am – 12 noon
47 Tryon Street, Upper Mount Gravatt 4 May, 1 June, 6 July, 3 Aug, 7 Sept, 5 Oct, 2 Nov, 7 Dec.
- **Garden City Evening:** 52 Khandalla Street, Upper Mount Gravatt 6:00pm – 7:00pm
16 May, 16 August, 21 November.
- **Gordon Park Evening:** 45 Shamrock Street, Gordon Park 6:00pm – 7:30pm
17 May, 16 August, 18 October.
- **Qld-wide Telephone Support Group:** Last Wednesday of month: 1:00pm – 2:00pm
AAQ organises telephone link-up at no cost to members 18 April, (NB: 3rd week due to public holiday), 30 May, 27 June, 25 July, 29 Aug, 26 Sept, 31 Oct, 28 Nov

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

