

ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

ABOUT DEMENTIA

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHTDEMENTIA.ORG.AU



An Australian Government Initiative

Enquiries

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Disclaimer

This information provides a general summary only of the subject matter covered. Any person with dementia or a carer for a person with dementia should seek professional advice about their specific case.

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THANK YOU FOR PICKING UP THIS BOOKLET AND FOR ALLOWING US TO SHARE OUR KNOWLEDGE AND EXPERIENCE WITH YOU. BEING WORRIED ABOUT YOUR MEMORY OR DEMENTIA CAN BE HARD BUT WE HOPE YOU WILL FIND THIS INFORMATION HELPFUL AND REASSURING.

This information booklet has been written for people with Alzheimer's disease and other forms of dementia, their families and carers.

Much is still unknown about dementia, but we do know that support and assistance can greatly benefit all people who are affected by the condition.

If you are worried about memory loss or dementia, it is important to learn more about it, and how to get help. This booklet provides a starting point with information about dementia, services and resources that are available to assist you.

Just as Alzheimer's disease and other dementias affect people differently, the support you will need will vary over time.

The information in this booklet will be useful at different times. We encourage you to share it with family and friends and keep it for future reference.

You can also find out more by contacting Alzheimer's Australia (Qld) on the National Dementia Helpline 1800 100 500 or visiting www.fightdementia.org.au



DEMENTIA IS THE TERM USED TO DESCRIBE THE SYMPTOMS OF A LARGE GROUP OF ILLNESSES WHICH CAUSE A PROGRESSIVE DECLINE IN A PERSON'S FUNCTIONING. IT IS A BROAD TERM WHICH DESCRIBES A LOSS OF MEMORY, INTELLECT, SOCIAL SKILLS AND WHAT WOULD BE CONSIDERED NORMAL EMOTIONAL REACTIONS. FOR A LONG TIME, THE PERSON MAY LOOK HEALTHY, BUT ON THE INSIDE THEIR BRAIN IS NOT WORKING PROPERLY.

UNDER

STAND

WHAT IS DEMENTIA?

Dementia is not a normal part of ageing and affects people of all ages although it becomes more common as we get older.

There are a number of different forms of dementia. The best known is Alzheimer's disease. This is also the most common, accounting for between 50% and 70% of all cases. Alzheimer's disease is a progressive, degenerative disease that affects the brain.

Vascular dementia is the second most common form of dementia. Other forms of dementia include Fronto-Temporal Lobar Degeneration, dementia with Lewy bodies and alcohol-related dementia (Korsakoff's syndrome). There are other forms of dementia that are quite rare. A person may have more than one type of dementia, for example some people have both vascular dementia and Alzheimer's disease.

Memory loss

One of the main symptoms of dementia is memory loss. We all forget things from time to time, but the loss of memory with dementia is different. It is persistent and progressive, not just occasional. It may affect the ability to continue to work, or carry out familiar tasks. It may mean finding the way home is difficult. Eventually it may mean forgetting how to dress, bathe or carry out other activities of daily living.

Examples of normal forgetfulness are walking into the kitchen and forgetting what you went in there for, or misplacing the car keys. A person with dementia, however, may lose the car keys and then forget how to use them.

Description	Person with dementia	Older person
Events	May forget part or all of an event	Memory may sometimes be vague
Words or names for things or objects	Progressively forgets or cannot recall	Sometimes may forget; words or names are on the tip of the tongue
Written and verbal directions	Increasingly unable to follow	Able to follow
Words or names for things or objects	Progressively forgets or cannot recall	Sometimes may forget; words or names are on the tip of the tongue
Stories on TV, in books or movies	Progressively loses ability to follow	Able to follow
Stored knowledge	Over time loses known information such as historical or political information	Although recall may be slower, information is essentially retained
Everyday skills such as dressing and cooking	Progressively loses capacity to perform tasks	Retains ability, unless physically impaired

Who gets dementia?

Dementia can happen to anybody, but it is much more common after the age of 65. For people 85 years and over, one in four will have dementia. In some cases it affects people in their 30s, 40s and 50s.

Can dementia be inherited?

This depends on the cause of the dementia, so it is important to have a firm medical diagnosis. If there are concerns about the risk of inheriting dementia, consult your doctor or contact Alzheimer's Australia. Most cases of dementia are not inherited.

Progression of dementia

Every case is unique. A person's abilities may change from day to day, or even within the same day. What is certain though is that the person's abilities will deteriorate, sometimes rapidly, and in other cases more slowly, over a number of years.

What can be done to help?

At present there is no cure for most forms of dementia. However, medications and alternative treatments have been found to relieve some of the symptoms for some people. Your doctor will be able to provide advice about these.

Support is available for the person with dementia and their families, friends and carers. This support can make a positive difference to coping with dementia and continuing to get the most out of life for as long as possible.





THE EARLY SIGNS OF DEMENTIA

The early signs of dementia can be very subtle and vague, and may not be immediately obvious. Early symptoms may also vary a great deal. Usually though, people first seem to notice that there is a problem with memory, particularly in remembering recent events.

COMMON SYMPTOMS CAN INCLUDE

- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to do everyday tasks

Sometimes people fail to recognise that these symptoms indicate that something is wrong. They may mistakenly assume that such behaviour is a normal part of the ageing process. Or symptoms may develop gradually and go unnoticed for a long time. Sometimes people may not want to act even when they know something is wrong.

Many conditions have symptoms similar to dementia, so it is important not to assume that someone has dementia just because some of the symptoms are present. Stroke, depression, alcoholism, infections, hormone disorders, nutritional deficiencies and brain tumors can cause similar symptoms to dementia. Many of these conditions can be treated, so it is very important to seek medical advice if at all concerned.

Only a medical practitioner such as your local doctor or specialist can diagnose dementia. If a diagnosis has been made, it is helpful to find out about dementia and the support that is available to help you manage.

WARNING SIGNS

- Memory loss that affects day-to-day function
- Difficulty performing familiar tasks
- Confusion about time and place
- Problems with language
- Problems with abstract thinking
- Poor or decreased judgement
- Problems misplacing things
- Changes in personality or behaviour
- A loss of initiative

*Based on information from
Alzheimer's Association USA*

As a first step it is important that you see your doctor as other conditions can have similar symptoms to dementia. If you do receive a diagnosis of dementia there is support and assistance available through the National Dementia Helpline **1800 100 500**.

SUPPORT

NATIONAL DEMENTIA HELPLINE 1800 100 500

Alzheimer's Australia (Qld)'s mission is to reduce the impact of dementia on the community. We offer a range of services for people with dementia, family carers, industry workers and anyone who wants to know more about memory loss, dementia or good brain health.

The National Dementia Helpline is a confidential, free government funded telephone information and support service that is available Monday to Friday 8.30am to 4.30pm. It is staffed by trained and experienced advisors. Many of our staff have personal experience in dementia care.

National Dementia Helpline Provides

- Understanding and support
- Practical information and advice
- Up-to-date written material about dementia
- Access to telephone counsellors
- Information about other services
- Details of the full range of services provided by Alzheimer's Australia

A large number of Help Sheets are available free of charge for people with dementia, their families and carers. These Help Sheets provide specific information across a range of topics including:

- About Dementia
- Caring for someone with dementia
- Looking after families and carers
- Driving
- Residential care and dementia
- Changed behaviours and dementia
- Young people and dementia
- Younger onset dementia (people under 65)
- Information for people with dementia

Contact the National Dementia Helpline on **1800 100 500** for copies of the Help Sheets, or visit **www.fightdementia.org.au** to download free copies.

INFORMATION EDUCATION AND SUPPORT PROGRAMS

Information sessions

Alzheimer's Australia (Qld) holds regular public information sessions for anyone who wants to learn more about memory and ageing, dementia and the services available in their community. These sessions are free of charge.

Support for people with early stage dementia

When a diagnosis is confirmed, people in the early stages of dementia can benefit greatly by receiving information, practical advice and emotional support. This can help with adjusting to living with the illness and planning for the future.

Individual or family counselling is available. Provided by professional staff, it is confidential, sensitive and free of charge.

Alzheimer's Australia has a special program for people with early stage dementia. The Living with Memory Loss Program provides opportunities for both people with a diagnosis and family members to maintain a sense of control, obtain information and talk through issues in a group environment.

The program provides information about the brain and dementia and focuses on maintain abilities and developing strategies for living with dementia. During the sessions the group breaks into two (one for carers and one for people with dementia). This way there are opportunities for people to share their issues or concerns privately with others in the same situation. The program incorporates ongoing support so that social contact is maintained and further educational or support opportunities can be offered.

Counselling and individual support

Professional staff are available to provide individual support and practical advice to people with dementia, their families and carers.

Counselling may involve:

- Identifying strategies for managing and living with dementia
- Planning for the future
- Dealing with feelings of stress
- Resolving conflicts within families (when this relates to a diagnosis of dementia)
- Helping to obtain an appropriate service or practical assistance

The service is confidential, sensitive and free of charge. Call the National Dementia Helpline on 1800 100 500 to arrange a counselling session.

Practical education programs for families and carers

A range of education courses and workshops are available for families and carers. These provide useful information and practical suggestions for living with dementia. These programs are conducted by professional educators with experience in dementia care. They are held regularly across Queensland and are free of charge.

Information about dates and times of programs can be obtained by contacting the National Dementia Helpline on 1800 100 500 or by visiting www.fightdementia.org.au and selecting Queensland as your state.

Community awareness

To increase community awareness about dementia and risk reduction strategies, professional staff and trained volunteers are available to speak to organisations and interested groups of people.

Website

For the latest information about Alzheimer's Australia (Qld) visit www.fightdementia.org.au

The website contains information about our services, events, current information about dementia and links to other useful sites. Help Sheets and other excellent publications are also available to download from the website.

Dementia and Memory Community Centres

Dementia and Memory Community Centres are a Commonwealth government funded initiative. They provide a gateway to information, support, referrals and advice relating to memory concerns and dementia.

The Brisbane Dementia and Memory Community Centre is located at Alzheimer's Australia (Qld), 825 Stanley Street,

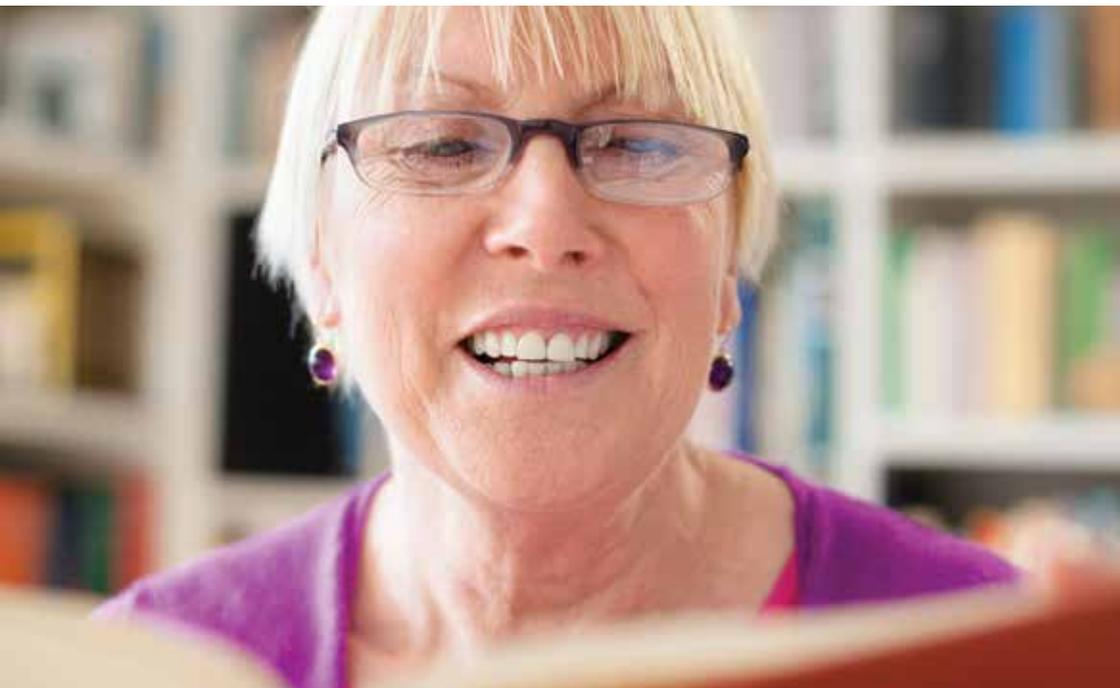
Woolloongabba and is open from 9.30am to 4.30pm Monday to Friday (excluding public holidays). No appointment is necessary, visitors are welcome to drop in and access the following services:

Library: The library holds an extensive collection of books, brochures, journals and DVDs about dementia. Dedicated computers are available for community users to browse the internet for further information about dementia, with access to experienced staff if needed.

Everyone is welcome visit the library to browse or study.

Activities: The Brisbane Dementia and Memory Community Centre organises a varied program of activities and events throughout the year for people with dementia and their carers. These activities can include carer support groups, therapy programs, tai chi, counselling and forums with specialist guest speakers.

For more information or to book a place please contact the Brisbane Dementia & Memory Community Centre by calling **1800 100 500**.



Dementia Behaviour Management Advisory Service

Queensland Dementia Behaviour Management Advisory Services (DBMAS) is coordinated from Alzheimer's Australia (Qld) offices in Woolloongabba, Brisbane and delivers service across Queensland.

We provide services to care workers, aged care service providers and carers of people with dementia who receive support through Australian Government funded aged care services.

Our aim is to improve the quality of life for people with dementia whose behaviour is having an impact on their care by improving the capacity of care workers, family carers and service providers to meet their specific needs.

The DBMAS office is staffed by qualified clinicians between 8.30am and 4.30pm on weekdays. After hours support and assistance is available on 1800 699799. The national after hour's telephone service.

DBMAS is a multidisciplinary team of clinicians including registered nurses, endorsed enrolled nurses, psychologists, physiotherapist and diversional therapists who work collaboratively to deliver a diverse service. The team's functions include the provision of education and tailored information workshops, assessments, assistance with case management, care planning, mentoring and modelling of behaviour management techniques.

More general issues relating to dementia care, support and education are managed through the National Dementia Helpline 1800 100 500. As this service is also operated by Alzheimer's Australia (Qld), there is an opportunity to provide an integrated service both to people living with dementia and their family carers as well as supporting professional care workers.

To contact DBMAS call **1800 699 799** (24 hours) or email **qld.dbmas@alzheimers.org.au** or you can visit **www.dbmas.org.au** for more information.

Multicultural services

Alzheimer's Australia (Qld) is committed to meeting the language and cultural needs of all members of the community. Information about dementia is available in a range of community languages and can be obtained by contacting the National Dementia Helpline on 1800 100 500 or by visiting www.fightdementia.org.au.

Interpreters can be arranged for all of our services including counselling.

If you or someone you know has difficulty communicating in English, ring the Translating and Interpreting Service on 131 450 and ask to speak with the National Dementia Helpline in Queensland.

Keeping in touch with us

Alzheimer's Australia (Qld) produces an electronic newsletter with the latest news of interest in Queensland, nationally and internationally. Articles on events, research, programs and activities keep you in touch with what our organisation is up to as well as letting you know how you can contribute to advocacy, political and fundraising campaigns. You can sign up for our newsletter on the resources page of our Queensland website area at www.fightdementia.org.au.

REGIONAL AREAS

Regional Dementia & Memory Community centres are located around the state and hold a variety of activities and support groups in their surrounding regions. Alzheimer's Australia (Qld) also has regional community groups across the state:

**Alzheimer's Australia
Far North Queensland Inc**
Shop 6a, 151 – 159 Pease Street,
Manoora QLD 4870
Phone: (07) 4032 4884

**Alzheimer's Australia
North Queensland Inc**
1-56 Thuringowa Drive,
Kirwan QLD 4817
Phone: (07) 4755 1177

**Alzheimer's Australia
Mackay Region Inc**
1A, 54 Gregory Street,
Mackay QLD 4740
Phone: (07) 4957 8799

**Alzheimer's Australia
Central Queensland Inc**
238 Richardson Road,
North Rockhampton QLD 4701
Phone: (07) 4928 1926

**Alzheimer's Australia
Wide Bay & Burnett Inc**
Level 1, 200 Bazaar Street,
Maryborough QLD 4650
Phone: (07) 4123 5611

**Alzheimer's Australia
Darling Downs & South West Inc**
9C Bell Street,
Toowoomba QLD 4350
Phone: (07) 4613 0052

**Alzheimer's Australia
Gold Coast**
Rosemary House,
20 Allied Drive,
Arundel QLD 4214
Phone: (07) 5594 0270

YOUR RIGHTS AND RESPONSIBILITIES

You have a right to:

- Receive quality services
- Be treated with respect, dignity and courtesy
- Have your needs assessed to determine the right service for you
- Be informed about and participate in the decisions that affect you
- Have someone represent you (an advocate or support person) who participates in decisions relating to your care if you do not have the capacity
- Have your privacy and confidentiality respected
- Access personal information kept about you
- Make a complaint, without retribution, if we do not meet your expectations

It is your responsibility to:

- Treat staff with respect and courtesy
- Be accountable for your own actions and decisions
- Provide enough information to assist staff to assess and determine appropriate services
- Inform our staff if there is any change in your condition

Our commitment to you is to:

- Respect your personal beliefs, privacy and confidentiality
- Treat you with courtesy and respect
- Acknowledge and include any person you choose to act on your behalf
- Inform you of our full range of services and relevant services of other organisations
- Respect and value your language and cultural needs
- Provide you with access to interpreters if required
- Have any complaint acknowledged and investigated fairly and confidentially with a view to resolving the issue promptly

How to make a complaint, compliment or comment

We welcome your feedback, whether it is in the form of a complaint, a compliment or a comment because it will help us to improve our services.

If you wish to contact us about your experience of our service, you have a right to have a person of your choice to assist you in this regard or to act on your behalf.



You can send your complaint, compliment or comment directly by:

Writing to PO Box 8141
Woolloongabba Qld 4102

Email qld.general@alzheimers.org.au

Phone 07 3895 8200

Fax 07 3895 8266

In person to any Alzheimer's
Australia (Qld) staff member

If you have a complaint it is always a good idea to raise your concern with us as soon as possible so that we can investigate and respond quickly. All complaints will be dealt with promptly, fairly and confidentially.

As an alternative you may also contact

Aged Care Complaints Scheme

Phone 1800 550 552

Email agedcare.complaints@govspace.gov.au

Queensland Aged and Disability
Advocacy Inc (QADA)

Phone 1800 818 338

Your Privacy

It is necessary for us to collect and record some of your personal information so that we can provide the best possible service.

Please be aware that:

- Any information you provide will be treated confidentially
- In general, we will not disclose your personal information to anyone without your consent.
- We are occasionally required to collect non-identifying information for some government-funded services.
- If you are receiving services, there are times when your personal information may be shared with other staff, so that we can provide you with the best information and support available.
- There are also occasions, though uncommon, when the law requires us to disclose confidential information.
- This might occur when the health or wellbeing of a person is threatened and thus there is a strong public interest in disclosing that information.
- Our staff can answer any questions you have.
- You may remain anonymous if you prefer when using our services.

Dementia is the third biggest killer in Australia and your support is vital to help us tackle this devastating condition.

GET INVOLVED

MORE THAN 53,000 QUEENSLANDERS ARE ALREADY LIVING WITH DEMENTIA AND YOUR HELP WILL TRULY MAKE A DIFFERENCE IN THEIR LIVES.

THERE ARE LOTS OF WAYS YOU CAN BECOME INVOLVED WITH OUR WORK. FOR EXAMPLE

- Your financial gift will help us to provide information, education and support for people living with dementia and their families.
- Your voice and energy will help to raise awareness of dementia in the community and reassure people living with dementia that they are not alone.

HERE ARE SOME OF THE WAYS YOU CAN HELP

- Become a regular giver
- Make a one-off donation
- Make a gift in memory of a friend or relative
- Celebrate a special occasion (weddings, birthdays, anything!)
- Leave a bequest
- Fundraise for us
- Hold an event
- Buy some of our merchandise
- Become a sponsor
- Become a dementia champion
- Buy an Entertainment Book

CONTACT OUR FUNDRAISING TEAM TODAY

(07) 3895 8200

qld.donations@alzheimers.org.au

Let's work together to reduce the impact of dementia on the community.

You can find more information online at **www.alzheimers.org.au/queensland**

Over time a person with dementia will require increasing support and care from family and friends. Often partners and children provide significant amounts of care on a daily basis as a person's dementia progresses.

TALK

FAMILY AND FRIENDS

Family and friends can play an important part in the lives of people affected by dementia. They provide valuable links to past experiences, and enable the person with dementia to continue to be a loved and valued member of the family and circle of friends.

Family and friends can also provide invaluable support to carers. Whilst studies confirm high rates of depression, anxiety and even physical illness in families where someone has dementia, support from others can reduce the impact of the disease.

Unfortunately, many people with dementia and their carers find that family and friends stay away from them after dementia has been diagnosed. Some people are frightened or embarrassed by dementia. Some are afraid of saying or doing the wrong thing.

Ways to help

Family and friends can support people affected by dementia in a variety of ways:

- Learning about dementia is always a good starting point. This includes understanding that while outwardly the person may look fine, they do have a condition that affects the brain. This is not contagious.
- Encouraging all involved to have a break or just a change of scenery.
- Being available for a chat from time to time
- Bringing a meal, or helping with gardening or shopping.

Helping the person with dementia do the kind of things that they enjoyed doing before dementia was diagnosed can be helpful. Outings, fishing, walks, or drives in the country are all activities that may still be enjoyed. Remember that many people with dementia do not enjoy crowds or noisy environments. Activities may need to be

adapted but it is important to keep doing them for as long as possible. Enjoyment does not require memory, so it is important to remember that even if an outing is soon forgotten, it is still worthwhile.

Ask about specific ways you can help. Be aware that many people are often reluctant to admit that they need help until the need becomes desperate.

Communicating effectively

Losing the ability to communicate can be one of the most frustrating and upsetting problems for people with dementia, and can also add to the difficulty of maintaining friendships for family and friends.

Remember that people retain their feeling and emotions even though they may not understand all that is being said or cannot express things easily. It is important to always maintain their dignity and self-esteem. Be flexible and always allow plenty of time for a response. Using touch to keep the person's attention and to communicate feelings of worth and attention may be helpful.

It is important to talk in a gentle, matter of fact way and to keep sentences short, focusing on one idea at a time. Always allow plenty of time for what you have said to be understood. Silence provides time to think and respond.

Alzheimer's Australia has a number of Tip booklets for families and friends. These include information on how friends can make a difference, how to make the most of a visit with a person with dementia, ideas for helping with the holidays and tips on using art and music at home. These are available by phoning the National Dementia Helpline on **1800 100 500** or you can download them at www.fightdementia.org.au.

