ABOUT DEMENTIA

Alzheimer’s disease and other dementias

A guide to help inform and support people with a diagnosis of dementia

Alzheimer’s Australia Qld
Living with dementia

An Australian Government Initiative
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Alzheimer’s Australia (Qld) Inc
PO Box 9360, GCMC Qld 9726
ABN 62 659 273 563
www.alzheimers.org.au

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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.
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 dementias and 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 know 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 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 by visiting www.alzheimers.org.au
What is dementia?
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 could be considered normal emotional reactions. For a long time, the person may look healthy, but on the inside their brain is not working properly.

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 there to do, 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
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 person 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 family, 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.
What are the early signs?
The early signs of dementia are 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.

Other 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 refuse or be afraid 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 with misplacing things
- Changes in personality or behaviour
- A loss of initiative

(Based on information from the Alzheimer’s Association, USA)
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.

**National Dementia Helpline (1800 100 500)**

The National Dementia Helpline is a confidential, free government funded telephone information and support service that is available Monday to Friday 8am to 5pm. It is staffed by trained and experienced advisors. Many of our staff have personal experience in dementia care.

National Dementia Helpline advisors provide:

- 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.alzheimers.org.au to download free copies.
Information and education 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.

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.alzheimers.org.au then clicking on the map of Queensland.

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.

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 also 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 people with a diagnosis and family members to maintain a sense of control, obtain information and talk through issues in a group program. The program provides information about the brain and dementia and focuses on maintaining 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 opportunities can be offered.
**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 dementia and Alzheimer’s Australia (Qld) visit www.alzheimers.org.au.

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

**Support groups**

Support groups are meetings of family members, friends or neighbours who are affected by dementia. They meet regularly at a local venue to share their experiences and support each other in working towards overcoming the problems and challenges they face as carers.

Support groups vary in size and some have special memberships. For example some may be for people of a specific cultural background. Others may be primarily for people who are in the younger age groups, for example under 65. There may also be some groups specifically for males.

**Dementia and Memory Community Centres**

Dementia and Memory Community Centres are an Australian 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), Unit 2, 9 Hubert Street, Woolloongabba and is open from 8.30am to 4.00pm 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, videos and DVDs about dementia. Dedicated computers are available for community users to browse the internet for further information about dementia, with experienced staff to assist you if needed.

Everyone is welcome to 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, yoga from a chair, tai chi, therapy programs, counselling and forums around Brisbane.

For more information, or to book a place, please contact the Brisbane Dementia and Memory Community Centre by calling 1800 100 500.
Regional areas

Regional Dementia and 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) 4041 3052

**Alzheimer's Australia North Queensland Inc**
Unit 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 Sunshine Coast Inc**
Reflections Respite Centre, 8 Boxwood Ave, Kuluin QLD 4558
Phone: (07) 5476 7833

**Alzheimer's Australia Darling Downs & South West Inc**
9C Bell Street, Toowoomba QLD 4350
Phone: (07) 4613 0097

**Alzheimer's Australia Gold Coast Inc**
Rosemary House, 20 Allied Drive, Arundel QLD 4214
Phone: (07) 5594 0270
Dementia Behaviour Management Advisory Service

The Dementia Behaviour Management Advisory Service (DBMAS) supports carers of people with dementia whose behaviour is having an impact on their care. This statewide service is provided by experienced health professionals who are part of the Alzheimer’s Australia (Qld) team and understand the complexities of caring for a person with dementia.

Family carers and industry workers can contact DBMAS at any time of the day or night (except public holidays). Situations are assessed free of charge and appropriate referrals to other support services can also be made if necessary.

DBMAS consultants can travel anywhere in Queensland and the team has helped people all over the state. This free clinical service assesses each person’s needs and makes suggestions to support both carers and the person with dementia. Where appropriate, DBMAS consultants can revisit to give support and help to the carer and the person with dementia with ongoing strategies to help everyone become more comfortable and confident.

To contact DBMAS call 1800 699 799 (24 hours) or email dbmas@alzqld.asn.au or visit www.dbmasqld.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.alzheimers.org.au.

Alzheimer’s Australia (Qld) also welcomes opportunities to work with other services to raise awareness of dementia and the help available.

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.
In addition to the services provided by Alzheimer’s Australia (Qld), there are many other services available. Some will be useful when seeking a diagnosis and in the period immediately after a diagnosis of dementia has been made. Others will be more useful with the day-to-day management of dementia or as the illness progresses over time.

**Family doctor**

Only a medical practitioner can make a diagnosis of dementia. The family doctor is often the first person that people talk to about their concerns. They may assess for dementia and may refer the person to a specialist. The family doctor will most likely be the key initial contact for a person with dementia and their family members.

Sometimes it can be helpful to take a list of questions to your GP, or know a bit about the condition before you go. National Dementia Helpline advisors can offer you help and guidance or see our website www.alzheimers.org.au for more information.

**Specialists**

The family doctor may refer people with symptoms of dementia to a specialist for particular testing or treatment, particularly at the stage where a diagnosis is yet to be confirmed. Relevant specialists may include:

- **Geriatrician**  
  A doctor who specialises in the care of older people.

- **Psychiatrist**  
  A doctor who specialises in mental health issues.

- **Psychogeriatrician**  
  A doctor who specialises in mental health issues affecting older people.

- **Neurologist**  
  A doctor who specialises in conditions that affect the brain and the nervous system.

- **Neuropsychologist**  
  A psychologist who specialises in conditions that affect the brain and how they affect a person’s day-to-day functioning.
**Aged Care Assessment Teams (ACAT)**

Aged Care Assessment Teams provide an assessment and advisory service to people who are requiring additional support to manage at home. These health professionals provide a thorough assessment of care needs and offer advice for future options. ACAT staff will visit the person in their home and provide guidance about the best care for the person, including those with dementia. An assessment by this service is required to access a number of government subsidised packaged support services, and when residential placement or respite in an Australian Government funded facility is being considered.

There are ACAT teams in both metropolitan and country Queensland. Your doctor can refer the person with dementia to the service, or you can contact them directly. You can obtain the number of the ACAT team which services your area by contacting our advisors on the National Dementia Helpline on 1800 100 500.

**Home support**

There are many services that help people to live more comfortably in their own homes by offering personal support and household assistance. These services are generally subsidised and a negotiated affordable contribution toward the service cost can be arranged. Some of the most commonly used services for people with dementia living at home include:

**The Home and Community Care Program (HACC)**

This program is jointly funded by the Australian and State governments and is often the first program people use on a regular basis when they begin to need help to stay at home. A range of services is available in most areas, including domestic assistance, support with shopping, social support, meals, transport allied health care, minor home maintenance, centre-based day care and in-home respite for carers. Many people are initially assessed to receive meals, transport or home cleaning services and then access other services as they find that they need more assistance to live independently in the community.

**Community Aged Care Packages (CACPs)**

Individualised packages of care that are co-ordinated to meet the needs of older people who are living in the community and have complex care needs. These packages are funded by the Australian Government and they are available to people who have been identified as eligible through the ACAT assessment process.

**Extended Aged Care at Home (EACH) packages**

These packages of care are funded by the Australian Government and are individualised packages of care that are co-ordinated to meet the needs of older people who are living in the community and need management of their services, which can often include nursing care. The care needs are complex and are regarded as “high” by the ACAT team on assessment.
Extended Aged Care at Home - Dementia (EACH-D)

These packages are also funded by the Australian Government and are similar to the EACH packages in the support they provide and in the eligibility requirements. These packages can assist people who need the support generally available through an EACH package but require additional support due to behaviours of concern which are associated with their dementia.

Veterans Home Care Services

Members of the veteran community may also be eligible for specific support to remain living in the community. Contact the Veterans Home Care Intake number on 1300 550 450 for more information.

National Respite for Carers Program

This program is funded through the Australian Government and supports primary carers. Carers may also be able to access additional support which can assist them in maintaining the carer role. This can include ongoing services in specific circumstances such as balancing employment requirements with caring or support to access residential respite, cottage style respite or in-home respite. Commonwealth Respite and Carelink Centres provide information about available services and can also respond to emergency respite needs. They can be contacted on 1800 052 222 (or 1800 059 059 after business hours).

For information about any of the above services you can also contact the National Dementia Helpline on 1800 100 500.
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 the person’s dementia progresses.

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 often help to reduce the impact of the disease.

Unfortunately, many people with dementia and their carers find that family and friends stay away after dementia has been diagnosed. Some people are frightened or embarrassed by dementia, while others 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 to do the kinds 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 have trouble coping with 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 may soon be forgotten, it is still worthwhile and contributes to the person’s sense of wellbeing.

Ask about specific ways you can help. Be aware that many people are 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 feelings and emotions even though they may not understand all that is being said or cannot express things easily. It is important to always maintain the person’s 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.

Ask your doctor

You might like to use the following space to record questions you want to ask your doctor or the National Dementia Helpline.

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Useful Numbers

Emergencies 000
Alzheimer’s Australia (Qld) 1800 100 500
Dementia Behaviour Management Advisory Service (24 hours) 1800 699 799
National Dementia Helpline (8am-5pm weekdays) 1800 100 500

Carer Advisory Service (Carers Queensland) 1800 242 636
Commonwealth Respite and Carelink Centre 1800 052 222
Commonwealth Respite Centre (for emergency respite) 1800 059 059
Centre Link Financial Information Service 13 23 00
Disability Payment, Carer Allowance and Carer Payment 13 27 17
Age Pension 13 23 00

Elder Abuse Prevention Unit 1300 651 192
Enduring Power of Attorney Hotline 1300 651 591
Medicines Line 1300 888 763
National Continence Helpline 1800 330 066
Translating and Interpreter Service 13 14 50
Palliative Care Information and Referral Service 1800 772 273
Public Trustee 07 5588 5333
Queensland Civil and Administrative Tribunal* 1300 780 666
Veterans Home Care Service 1300 550 450
My GP .............................

*formerly Qld Guardianship and Administration Tribunal
You might find this useful to record any names, addresses and telephone numbers that you use regularly.

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