



# Precious Time

Caring and coping with  
Alzheimer's disease



**Medications checklist**

Medication	Amount	Time(s) to give	Special instructions (eg with/without food etc)

**Important numbers**

Ambulance: 000

GP: \_\_\_\_\_

Specialist: \_\_\_\_\_

Hospital: \_\_\_\_\_

Other members of the healthcare team: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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## Foreword



A diagnosis of Alzheimer's disease (AD) is traumatic for the person and for their family and friends. However, it is now possible to approach the management of the disease in a more positive way.

This is because we now better understand that early diagnosis of AD and access to appropriate support and AD medications can improve the wellbeing of the person and their family and carers.

While AD medications will not benefit all and are only of benefit for a time, they have changed the psychology of the management of the disease from one in which the medical profession can do little, to a

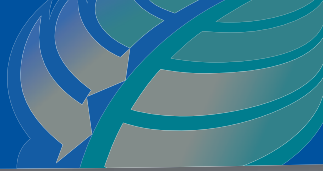
situation where offering a medical intervention provides some relief from the symptoms of the disease.

It is important to recognise that every individual is different, and that their personal and physical characteristics will cause them to respond in very different ways to support and medications. Notwithstanding the terrible nature of dementia, Alzheimer's Australia believes it is important to promote positive solutions for the management and care of people with AD, including the use of medications.

I encourage readers of this booklet to ring Alzheimer's Australia on 1800 100 500 to seek information about the support available or to visit their website [www.alzheimers.org.au](http://www.alzheimers.org.au) to access information about AD and the many other causes of dementia.

**Dr Robert Yeoh**

Immediate Past President  
Alzheimer's Australia



## Section 1: Information about AD

### What is AD?

AD is a physical disease that affects the brain. The disease attacks the brain cells, and causes messages in the brain to be disrupted. The cells eventually die, leading to problems with some of the brain's functions such as memory, thinking and behaviour.

AD is the most common form of dementia, which is the term used to describe problems with memory and thinking. AD is a progressive disease, which means that the symptoms generally worsen over time. There is currently no cure for AD.

### Who gets AD?

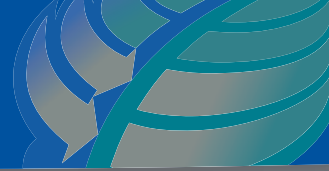
AD can affect adults at any age, but it is much more common in people aged over 65.

### What causes AD?

AD is caused by chemical changes that damage the brain cells. However, it is not known why some people get AD and others do not. Scientists think that environment and disturbances in a person's brain chemistry may play roles in the development of AD, but the exact causes are unknown in most cases. The exception is familial AD, a rare form of the disease that runs in families and is caused by a known genetic mutation.

### What are the symptoms of AD?

In the early stages of the disease, the symptoms are often very subtle and not always noticeable. People with AD often have difficulty remembering things, and trouble thinking of the right word for everyday objects. They may also find it difficult to remember recent events.



Other symptoms may include:

- Difficulty performing familiar tasks
- Confusion
- Vagueness in everyday conversation
- Lack of interest in things that were previously enjoyable
- Change in personality
- Poor judgment
- Misplacing things
- Forgetting well-known people or places.

Symptoms can vary from day to day, or even within one day. Symptoms are often worse during times of stress, fatigue or poor health.

## How is AD diagnosed?

There is no single test to diagnose AD, and sometimes it can be quite difficult to distinguish AD from other causes of dementia. It is important to rule out other causes of the symptoms which may be treatable. The diagnosis is usually based on a thorough examination by a doctor.

The doctors who may diagnose and help manage AD include the:

- General practitioner (GP)
- Neurologist, who specialises in diseases and disorders of the nervous system
- Geriatrician, who specialises in the treatment of older people
- Psychiatrist, who specialises in emotional and behavioural problems
- Psychogeriatrician, who specialises in emotional and behavioural problems in older people
- General physician, who specialises in general medicine.

The examination may include:

- *Detailed medical history*: to investigate whether there has been a slow or sudden onset of symptoms, and establish how quickly the disease has been progressing
- *Physical and neurological examination*: to assess all senses and movements
- *Neuropsychological examination (mental status check)*: to identify where the problem areas are in terms of memory, thinking, judgment and problem solving
- *Laboratory tests*: eg blood and urine tests. A computerised tomography (CT) scan or magnetic resonance imaging (MRI) scan may also be performed
- *Psychiatric assessment*: to investigate whether the symptoms are being caused by another condition such as depression.

## How does AD progress?

The progression of AD occurs at different rates in different people, and can depend on the parts of the brain that are most affected. Eventually, the disease will affect most brain functions and the person with AD will need assistance with all activities.

## Treatments for AD

### Medications

While there is no cure for AD, some medications can help to temporarily improve mental function in some people. Other medications can treat associated symptoms such as depression, anxiety and sleeplessness.

A group of drugs called acetylcholinesterase inhibitors may help the brain to function by preventing the breakdown of a chemical called acetylcholine. This chemical is important in transmitting messages between some brain cells, especially the cells involved in memory. Reminyl® (galantamine) is a type of acetylcholinesterase inhibitor; others include Aricept (donepezil) and Exelon (rivastigmine). Clinical trials involving people with AD have shown that these drugs have a

modest effect on brain function for some people with mild to moderate AD. The most common side effects of these drugs are nausea and diarrhoea, and these occur in about 10% of people.

Another drug called Ebixa (memantine) has been shown to have a positive effect on brain function in people with moderate to severe AD. Ebixa belongs to a group of medicines called NMDA-receptor antagonists. It is thought to work by protecting NMDA receptors in the brain against high levels of a chemical called glutamate, which may be involved in brain damage when present in excessive amounts. Ebixa has been shown to improve thinking and the ability to remember things in some people with moderate to severe AD.

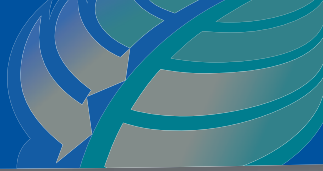
Because drugs can interact with each other, it is important to tell the doctor about any other drugs that are being taken.

The doctor will be able to provide more information about any drugs that they are recommending. Such information is likely to include:

- Why the drug is being prescribed
- The benefits of the drug
- Any known side effects
- Whether the drug should be taken at any particular time of day, with or without food
  - How long the drug takes to work
  - How much the drug will cost
  - What to do if side effects develop.



*Because drugs can interact with each other, it is important to tell the doctor about any other drugs that are being taken*



Alzheimer's Australia produces regular update sheets about drug treatments for dementia: see section 4 of this booklet for contact details.

## Additional treatment strategies

Treatment of AD does not just involve medications — other forms of therapy are important and can help the person with AD to stay as healthy as possible in mind and body.

Other treatments may include:

- Physiotherapy for strength and flexibility
- Dietary advice about balanced, nutritious meals
- Psychological counselling to help with behavioural changes and feelings of depression or anxiety
- Peer group support for the person with AD and their carers
- Therapeutic massage for relaxation and to relieve tight, sore muscles
- Activity and exercise programs.

## Complementary medicines

There has been a lot of interest in other therapies for the treatment of AD, and several claims have been made regarding the benefits of these 'alternative' or 'complementary' medicines. However, many supplements have not been studied extensively in clinical trials and in those that have, results show that they make little if any difference to the symptoms of AD.

Some therapies that have been studied include ginkgo biloba, vitamin E, vitamin B12, and folic acid.

Overall, further research is needed before deciding whether these agents are effective for the treatment of AD. It is important to inform the doctor before taking any alternative therapies or supplements, because side effects and interactions with other drugs can occur.

## Section 2: Coping with AD

### Telling the person with AD about their diagnosis

Generally, it is recommended that the person with AD be told about their condition. It helps them to understand why they have been having symptoms, and helps them to plan for the future. Generally, a person's doctor will tell them about the diagnosis of AD. The doctor may talk about why the symptoms are occurring, treatment options, and the support services available. It is useful or even desirable to involve a member of the family in sharing the diagnosis.

### Coming to terms with the diagnosis of AD

Many people with AD may already know something is wrong, and may be relieved because they now know what is causing their symptoms. However, being told the diagnosis can also be stressful, so the person with AD will need the support of family and friends at this time. The person may worry about whom to tell, how to tell them, and the reactions of people when they know about the diagnosis. Sensitivity and respect for the person with AD are essential.

Alzheimer's Australia is able to provide information to people with AD, their families and carers. They have a wide range of services available, eg written fact sheets about AD, confidential counselling and support services. Alzheimer's Australia runs Living with Memory Loss group programs for people in the early stages of dementia and a family member or friend. The free program runs for 6–8 weeks and gives people and their carers an opportunity to ask questions, talk confidentially with others in a similar situation, discuss experiences and express feelings in a safe environment. Alzheimer's Australia also provides the National Dementia Helpline: 1800 100 500. Contact details are provided in section 4 of this booklet.

### Where to go from here? Next steps

Early planning can help the person with AD to deal with their condition, and can allow them to be involved in arrangements for the future.

### Financial and legal decisions

Where possible, the person with AD should be involved in discussions about money and legal issues. Legal and financial planning after diagnosis may include making or updating wills, and setting up an enduring power of attorney, an enduring power of attorney covering health matters, and an advance directive expressing the person's wishes about medical treatment. Nominee arrangements should also be put in place with Centrelink so that the carer can act on the person's behalf.

An enduring power of attorney is a legal arrangement that allows another person to look after the financial affairs of someone who is no longer able to do so themselves. A medical enduring power of attorney is a legal arrangement that allows another person to make medical and lifestyle decisions for someone who is no longer able to do so themselves. The arrangements for planning ahead vary in each state and territory. Visit [www.alzheimers.org.au/legal](http://www.alzheimers.org.au/legal) to find legal planning resources in each state and territory. A solicitor, local community legal centre, the state law society or Alzheimer's Australia can help.

*Early planning can help the person with AD to deal with their condition, and can allow them to be involved in arrangements for the future.*



### Employment decisions

If the person with AD is still working, they will need to consider how their work will be affected by the diagnosis. It is important to make plans as early as possible, and to be realistic about which activities are possible. The person with AD may wish to talk to their employer about their condition, and discuss ways in which they can still participate at work, eg changing work hours or responsibilities. AD is a disease, and the person is entitled to special consideration in the workplace.

At some point, the person with AD will probably decide to leave work. Before doing this, they should find out about the status of any benefits, superannuation, unused leave and other entitlements. Alzheimer's Australia, trade unions or professional organisations, legal advisors or counsellors can help.

## Tips for staying well

There are several things that the person with AD can do to stay as independent as possible:

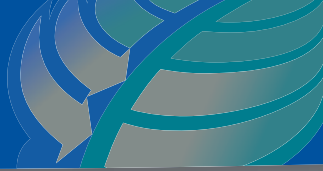
### Staying healthy

The person with AD can:

- Take regular exercise
- Eat a balanced diet
- Get plenty of rest
- Set aside time for relaxation
- Limit their alcohol intake
- Take medications as prescribed by their doctor (a pillbox may help — the chemist can organise each week's pills in a special box)
- Have regular health checks with the doctor
- Stay active by doing things that are enjoyable.

### Keeping active

Staying active and involved in things that are enjoyable is important for the person with AD. If some activities are becoming difficult, they may be able to be modified so that they are easier to do, eg doing activities with someone else, not worrying about keeping score during sport, breaking an activity down into smaller parts. Talking to friends and family may help the person with AD to work out ways that they can keep doing the things they enjoy. It is important for the person with AD to stay active.



## Getting through each day

The person with AD may find it takes longer to do things or they may have trouble completing tasks. It is therefore important not to rush activities, and to allow time to do them. It is also important that the person with AD carries identification with them at all times (their name, address, phone number and contact details for their carer).

*Staying active and involved in things that are enjoyable is important*



## Managing feelings

The person with AD may experience a range of different feelings and emotions. Talking to a trusted friend, family member or health professional can help, and joining a support group can also be helpful.

## Managing memory loss

To deal with memory problems, the person with AD may:

- Keep a notebook of things to remember, eg doctor's appointments, names of family and friends, identification details, daily activities or tasks that need to be completed
- Have the same routine each day or week so that there is less dependence on memory
- Have a list of phone numbers next to the telephone, including emergency numbers
- Have a noticeboard at home to record important information and things to remember
- Put labels on drawers and cupboards to identify what is inside
- Have photos displayed of family and friends; these can be labelled with names to help the person with AD to remember who they are
- Have a safe place for keys, medications and money
- Have a calendar and mark off each day
- Ask visitors to ring just before they come around so they are expected.

## Section 3: Caring for a person with AD

### Being a carer

Caring for someone with AD can be an emotional experience. Carers may experience a range of feelings, from relief at finally having an explanation for a person's behaviour, to anger and frustration. You are not alone in your situation — over 210,000 Australians have dementia, which means that many thousands of other people are involved in providing care and support.

It is important to remember that, as a carer, there are many positive things you can do to help the person with AD. This section provides some information about caring, and details about support services and other sources of information.

### The caring team

Caring for someone with AD is a shared responsibility between the carer and healthcare professionals. The team may include one or more doctors, a social worker, physiotherapist, psychologist, mental health nurse, home health aide and dietitian. All have important roles to play, and by working together, carers and healthcare professionals can develop a treatment plan that best serves the needs of everyone involved.

You should take the time to develop a list of questions to ask doctors and other health professionals about the treatment and management of AD. Because AD is a long-term condition, it is extremely important that you and the person with AD find healthcare professionals that you can understand, trust and work with comfortably. Ideally, the doctor should know about the special needs and stresses of AD, and be available and accessible to talk to you.



### Preparing for a medical examination

Talk to a doctor as soon as you suspect someone may have AD. Let the doctor know about:

- Changes in mental ability, attitude, personality or patterns of behaviour
- The timing of changes (eg rapid or gradual onset of symptoms)
- All medicines the person is taking, including prescriptions, over-the-counter medicines, nutritional supplements, alternative or complementary therapies.

It is also important for doctors to know about a person's family history and background, including previous or current:

- Alcoholism
- Chronic drug/medication abuse
- Depression
- Mental illness
- Nutritional deficiencies/eating disorders.

If the person with AD is reluctant to visit the doctor, talk with other carers who may have experienced the same thing. You can also get help from Alzheimer's Australia's Helpline (see section 4) and from the Aged Care Assessment Team (ACAT) in your area.

### Assistance with treatment planning

By keeping a diary or observation log, you can help health professionals to keep track of how the person with AD is progressing, and provide valuable information that can assist in treatment planning.

You can help to monitor:

- Changes in, or patterns of, cognitive and behavioural symptoms
- Reactions and responses to medications
- Shifts in ability to perform activities of daily living.



In addition to medical management, a comprehensive treatment plan will include strategies for dealing with deteriorating psychological and social skills that occur as AD progresses.

### Communication with family and friends

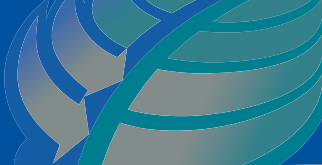
Part of your role as a carer may be letting family and friends know about the diagnosis of AD. Breaking this kind of news is never easy: should you make phone calls, send emails or convene a family meeting? Making decisions about who needs to know, and when, may be difficult. A social worker, counsellor, psychologist or family doctor can assist you in working out how to break the news and can also help your family to deal with the news. Sharing this booklet with family and friends, as well as other information about AD, can help others to learn more and understand what is happening to their loved one. See section 4 for more information and support services.

### Health insurance and subsidies

Private health insurance may help to offset the cost of some medicines. Contact your health insurance provider to see what cover they provide for AD treatment. The Federal and state governments also subsidise several types of respite services so that you can have breaks from caring duties should they be needed.



*Sharing this booklet with family and friends, as well as other information about AD, can help others to learn more*



### Behavioural and psychological changes

Changes in behaviour are very common in people with AD. This occurs because the disease affects the parts of the brain that are responsible for memory, mood and behaviour. In addition, the person with AD may feel frustrated, angry or depressed at not being able to do things they previously could do.

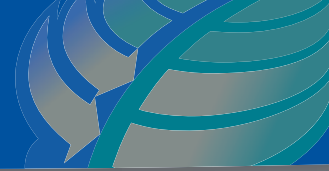
As a carer, it is important that you discuss any changes in behaviour with the person's doctor, and they will be able to advise you on what to do about these changes. This section also offers some suggestions for coping with changing behaviours.

### Coping with changing behaviour

It is important to remember that the new behaviour is not deliberate, even if directed at you. People with AD may be angry towards you because you are the closest person to them, but their behaviour can be out of their control and may be quite frightening, particularly for them.

You can help by:

- Consulting with a doctor or other health professional
- Providing reassurance
- Maintaining a calm environment and familiar routines
- Avoiding punishment (the person may not remember the event and cannot learn from it)
- Calling the Alzheimer's Australia Helpline on 1800 100 500 to talk to a trained counsellor if you are concerned about the behaviour of a person with AD
- Taking regular breaks from caring: make sure you have a support network of your own so that you are not the only one caring for the person with AD.



## Aggressive behaviour

People with AD can sometimes become physically and/or verbally aggressive. This is usually an expression of the fear or frustration they are feeling. It may also be due to health-related problems such as fatigue, lack of sleep, physical discomfort, adverse effects of medication or hallucinations. Other illnesses, urinary tract infections and constipation may also contribute.

To prevent or minimise aggressive behaviours:

- Consult with a doctor, who can help find out if there is a physical cause of pain or discomfort
- Try to reduce the amount of stress placed on the person with AD
- Avoid confrontation
- Spend time calmly explaining what is happening in simple language.

To deal with an outburst of aggression:

- Give the person space to calm down, and make sure they are safe
- Stay calm, and speak calmly to the person
- Try distracting the person by asking them if they would like to take a walk, look at a magazine, have a cup of tea etc.

If you feel threatened, you may need to go to another room until the person has calmed down.

In cases where non-drug strategies have failed, drugs called antipsychotics may have a modest effect on some of the behavioural problems associated with AD, especially those involving aggression. Risperdal® (risperidone) is a type of antipsychotic drug that is approved for use in people with dementia who have behavioural problems.

## Depression

Depression is very common in people with dementia. This may be due to fatigue, feelings of isolation, physical illness or side effects of medication. Depression can make the symptoms of AD seem worse, and can make caring more challenging.

The signs of depression include:

- Lack of energy
- Loss of interest and pleasure in previously enjoyed activities
- Loss of appetite
- More emotional, angry or agitated behaviour
- Feeling worthless and sad
- Poor sleep
- More confusion.

What you can do:

- Discuss it with the person's doctor: antidepressant medication may be recommended, and can be helpful in improving some of the symptoms of depression
- Maintain a regular daily routine so that the person with AD is familiar and comfortable with their routine
- Don't expect too much of the person with AD: be realistic about what they can and can't do
- If the person is bothered by lots of noise and activity around them, try to limit their exposure to these situations
- Be aware of the activities that the person used to enjoy and try to continue them
- Be positive and encouraging.

## Agitated or repetitive behaviour

Sometimes people with dementia develop agitated or repetitive behaviours, such as pacing, constant talking, repeating words or phrases, repetitive questioning and fiddling. These behaviours can be particularly annoying for carers, and can also be distressing for the person with AD. This type of behaviour can be caused by health problems (eg urinary tract infection, constipation, other illness) or fear and frustration at not being able to function in the same way. It can also be a symptom of depression.

What you can do:

- Consult with the doctor, who can examine the person and see if there is an underlying cause of the agitation (eg a physical problem or side effects of medication)
- Try to reduce the amount of stress placed on the person with AD
- Spend time calmly explaining what is happening in simple language
- Avoid confrontation: if the person is agitated, try to distract them by suggesting another activity
- To deal with repetitive questioning, don't remind the person that they have already asked the question: some people find answering the questions helps, while others find that ignoring them works. But try to see if the person also needs reassurance about a particular issue, which they may be having trouble expressing verbally
- Minimise repetitive movements by giving the person something else to do with their hands, such as holding a soft ball or folding clothes etc
- Talk to trained counsellors at Alzheimer's Australia by calling 1800 100 500.

## Lack of inhibition

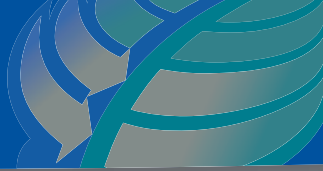
Sometimes a person with AD may display disinhibited behaviour, which means that they may say or do things that are seen as rude, tactless, inappropriate or offensive. This can be very upsetting, particularly when the person was previously caring and sensitive. However, it is a symptom of their illness, and is not directed deliberately at you.

Examples of disinhibited behaviour include:

- Tactless or rude remarks about another person's appearance or actions
- Bold behaviour, eg inappropriate flirting or sexual remarks
- Exposure, eg removing clothes at inappropriate times.

What you can do:

- Consult with the doctor, who can examine the person and see if there is an underlying cause
- Try not to overreact to the behaviour, even though it may be embarrassing for you



- Be gentle and patient, while reminding the person that the behaviour is not appropriate
- Provide reassurance through physical contact (eg hugging) and by speaking calmly
- Try to distract the person by suggesting a new activity
- Talk to trained counsellors at Alzheimer's Australia by calling 1800 100 500.

## Hallucinations and/or delusions

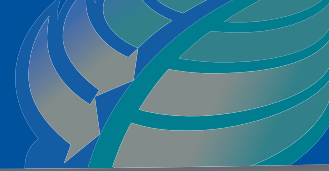
Some people with AD experience hallucinations, which means that they see, hear or smell things that are not there. Hearing voices is a common hallucination. Sometimes the person also experiences delusions, where they think others are watching them and plotting against them, or they have ideas that are not based on reality.

*Try to reduce the amount of stress placed on the person with AD*



What you can do:

- Consult with the doctor, who can examine the person and see if there is an underlying cause, eg other psychiatric problems. In some cases, they may recommend a trial of drug treatment
- Don't argue with the person, but acknowledge that they are frightened or worried
- Don't get annoyed at the person for losing or hiding things
- Learn the person's hiding places and check these for missing items
- Distract the person by suggesting a change in activity, eg listening to music, exercise, looking at photos etc
- Maintain a consistent routine and environment, including consistent and familiar carers
- Keep a diary to see if these behaviours occur at particular times or with particular people
- Talk to trained counsellors at Alzheimer's Australia by calling 1800 100 500.



## Everyday matters

Developing a daily routine is an important part of caring for a person with AD. This familiarity can help them to feel safe and in control of their situation, and can minimise some of the behaviours described above.

## Safety around the home

- Use nightlights in hallways and bathrooms
- Arrange furniture so it is easy to get around
- Make sure rugs are secure and don't slide
- Remove any old medications and hazardous materials
- Consider removing hot water bottles and electric blankets
- Use electric appliances that have automatic shut-offs (eg kettles and heaters)
- Use a thermostat to control water temperature if possible
- Make sure smoke detectors are working

## Good nutrition

Maintaining good nutrition can be challenging for the person with AD because they may forget to eat or not recognise foods that they are given. They may also have difficulty with chewing or swallowing, crave sweet things, have mouth discomfort or a poor appetite.

To help maintain good nutrition for the person with AD:

- Serve finger foods if the person is having difficulty using cutlery
- Place food on plain plates (as opposed to patterned china) so it can be easily seen
- Avoid serving lots of different foods together
- Eat with the person so that they can copy you
- If you are not with the person when they are eating, leave food that is easy to eat and doesn't need to be kept cold. Leave it out where it can be easily seen
- Talk to a dietitian about preparing nutritious foods. Your doctor can help you to find a dietitian to work with.

## Sexual intimacy

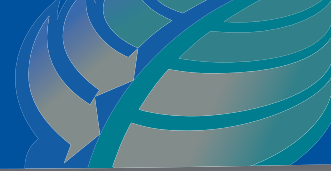
Many people with AD lose interest in a sexual relationship, but some have an increased interest in sex. Some people may also display inappropriate sexual behaviour (due to disinhibition). It is important to remember that these changes are part of the disease process, and should not be taken personally. Support from friends and family can help you to cope with these issues, and talking to a counsellor or support group may be beneficial. Alzheimer's Australia provides a confidential counselling service: call 1800 100 500.

## Continence

Incontinence — the loss of control over bladder and/or bowel function — may occur in someone with AD due to illness or because of a change in the person's ability to recognise when they need to go to the toilet. Also the person with AD may not recognise the toilet or be able to find it or know to wait until it is appropriate to go to the toilet. If incontinence occurs, it is important to consult with the person's doctor so that they can see if there is a medical cause for the incontinence (eg enlarged prostate, hormonal changes, infection, medication). If not, the likely cause is dementia. Incontinence and its impact may be minimised by:

- Ensuring the person is drinking adequate fluids
- Reducing caffeine intake
- Monitoring when the person uses the toilet each day, then reminding them to go at these times
- Reminding the person to use the toilet before and after meals, and before going to bed
- Using appropriate incontinence products.

Contact the National Continence Helpline on 1800 330 066 or the National Dementia Helpline on 1800 100 500 for advice about ways to promote continence and manage incontinence.



## Personal hygiene

As AD progresses, the person will need help to maintain personal hygiene, eg regular dental and oral hygiene, shaving, bathing and toileting.

Because these activities involve personal privacy and modesty, they can be stressful for the person with AD and for the carer. The person with AD may feel threatened or vulnerable during bathing and toileting or may simply not remember what to do. They may even be resistant. You can help by:

- Giving simple instructions in a soothing voice
- Reducing the noise level by running water slowly
- Putting a non-skid mat in the bathtub, using warm instead of hot water and installing bars to hold onto in the shower and bath
- Creating a regular schedule for personal hygiene activities
- Getting everything organised in advance: collect the soap, toothpaste, washcloths, sponges, towels and clean clothes before heading for the bathroom.

To preserve the person's privacy, you can use a towel to screen the person's body during bathing and providing a robe to put on afterwards.

## Dressing

Some people with AD have trouble dressing. This may occur because they forget how to do it, or they may have problems with balance or walking, making it difficult to perform the tasks required to get dressed. You can help by providing gentle assistance with choosing clothes, laying them out on the bed in the order in which they should be put on, and sensitively reminding the person about the need to change clothes regularly.



## Sleeping

Sleeping problems are common in people with AD. They may sleep during the day and not at night, have trouble telling the difference between night and day, or be less active than they used to be and so don't need as much sleep. Sleep problems are also common in people who have other diseases such as diabetes, heart conditions, depression and arthritis, so these may be contributing to the problem. Maintaining a consistent routine can help to remind the person with AD when it's time to sleep. In addition, getting plenty of exercise, reducing the amount of sleep during the day, and reducing caffeine intake can be helpful.

## Wandering

Wandering is quite common in people with dementia. It may occur due to loss of memory (the person sets off to go somewhere and then forgets where they are going); it may happen after changing environments (moving to a new home or care centre); or it can occur because of anxiety, restlessness or confusion. To deal with wandering, make sure the person with AD always carries identification in case they get lost, eg an identity bracelet. You may also consider:

- Putting certain objects that remind the person about going out out of sight, eg keys, handbags, coats etc
- Keeping a diary to see if the wandering occurs at certain times, and distracting the person with activities at these times
- Securing the garden so that the person can safely walk around in their own environment
- Tell neighbours and local shopkeepers about the problem, so they can keep an eye on the person or call you if they see them
- Registering with a program like Safe Return Home, which is available in Victoria and Tasmania. For more information, contact Alzheimer's Australia on 1800 100 500.

## Travelling

Many people with AD travel overseas or interstate in the company of a carer, especially during the early stages of the disease. This can be challenging for the carer, and should be planned carefully. The person with AD should always wear an identification bracelet, and keep contact information in a wallet or purse. It may be wise to let the airline know that you are travelling with someone who has AD so they can arrange seating that is easily accessible and close to toilets.

However, there are times when travelling is not recommended, such as when the person:

- Shows delusional, paranoid, aggressive or disinhibited behaviours
- Is often disoriented or agitated in familiar settings
- Has regular problems with incontinence
- Becomes anxious, upset or withdrawn in crowded or noisy settings
- Displays agitated or wandering behaviours.

## Driving

The person with AD will have to stop driving at some point, but deciding when this should happen is a difficult issue. While it is important for people with AD to maintain as much independence as possible, safety concerns about driving are of prime concern. It is generally believed that a diagnosis of dementia should be a clear warning sign that the person *may not* be competent to drive, but the timing of *when* the person should stop driving is hard to determine. You should discuss this issue with the doctor. Alzheimer's Australia also has a useful driving checklist to help monitor any changes in driving ability.

## Caring for the person who lives alone

Looking after the person with AD who lives alone is a challenge for carers. They may have trouble:

- Remembering to take medication
- Remembering to change clothes or bathe regularly
- Using gas and electrical appliances

- Making judgments about whom to let into their home
- Contacting other people when they need help.

A visit by the ACAT can help people with AD and their carers to work out what assistance is needed, and how to get it. As a carer, you can also:

- Make sure the home of the person with AD is safe and well lit
- Place easy-to-read contact information by the telephone
- Have the chemist place all pills in a pillbox
- Place reminders around the home about medication, food etc
- Call the person to remind them to eat or take their medication
- Arrange Meals-on-Wheels if necessary
- Alert neighbours so that they can help to keep an eye on the person
- Involve others in caring, so that you are not the only one helping and monitoring the person.

*The person with AD will have to stop driving at some point, but deciding when this should happen is a difficult issue*



## Taking care of the carer: looking after yourself

Caring for someone with AD is a demanding role, and it is important that you take care of yourself as well. One of the most important things to remember is that you are not alone. Alzheimer's Australia can provide support, information and counselling, and a helpline is available 24 hours a day: 1800 100 500. They also coordinate carer support groups around Australia, and attendance is free.

### Your feelings

You are likely to experience a range of feelings while caring for the person with AD. You may feel:

- *Grief* at the loss of your past relationship with the person with AD; the loss of your own previous lifestyle; and the loss of future plans
- *Anger and frustration* at having to be the carer; at other people for not helping; at the person with AD
- *Guilt* because you may be embarrassed about the person's behaviour; that the person with AD may need to go into residential care; that you do not understand the behaviour of the person with AD
- *Stress* because of the pressures associated with caring for someone with AD, or because of added financial pressure or changes to your relationship.

It is important to know that these and a range of other feelings are normal and common. Remember that you are not alone in caring for someone with AD. Support groups for carers can help you to talk through the issues you face, and find out how others deal with similar problems.

There is also a carers association in every state and territory of Australia. Call the Commonwealth Carer Resource Centre on 1800 242 636 for the association nearest you. They have many things that can assist you in your caring role, and can send you a carer's resource kit, which contains information and resources for carers.

## Taking a break

It is essential that you take regular breaks from caring. Breaks are important so that you can rest, get some exercise, go on holiday or go out with friends. Breaks give you something to look forward to, and give you an opportunity to be with other people. These breaks also give the person with AD an opportunity to get used to other people caring for them.

Respite care (care provided while you take a break) is available in many forms: emergency care, occasional care and regular care inside and outside the home. Many programs are funded by the Federal and state governments. Church groups, community centres and local councils may also offer respite care services.

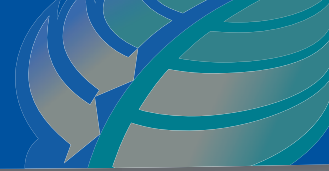
Commonwealth Carer Respite Centres can let you know what is available for you in your local area: call 1800 059 059 for more information.

## Stress relief

It may be hard to know when you're suffering from stress, and people manage stress in different ways. The most common warning signs of stress include:

- Insomnia (inability to sleep)
- Tiredness/exhaustion
- Headaches
- Loss of appetite
- Inability to relax
- Trouble concentrating
- Irritability, anger
- More emotional/teary
- Trouble making decisions
- Frustration
- Digestive problems.



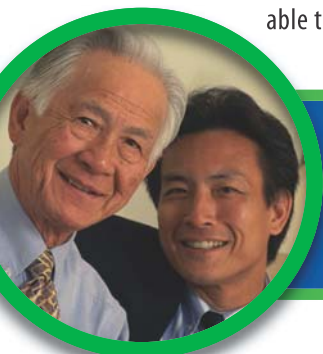


To minimise the stress involved in caring for a person with AD, consider:

- Paying attention to your own feelings and emotions, and talking things over with family, friends, other carers or a counsellor
- Looking after your own lifestyle by getting regular exercise, maintaining a good diet, having social contacts and interests that do not involve the person with AD
- Learning to recognise the warning signs of stress, and getting help/taking a break before they progress
- Learning stress-relieving or relaxation techniques, eg yoga, meditation
- Taking regular breaks from being a carer
- Asking for help when you feel overwhelmed
- Developing your own support network that may include joining a carers support group
- Trying to share the caring role
- Learning as much as possible about AD so that you are prepared for changes
- Maintaining a regular schedule for yourself and the person with AD.

## Sharing the caring role

Caring for someone with AD can be physically and emotionally demanding, so it is important to share the caring role with others. You may be able to involve other family members or friends, and use respite care services on a regular basis. You should not feel guilty about sharing this role — maintaining your own health and wellbeing is vital, and will mean that you are better able to care for the person with AD.



*Caring for someone with AD can be physically and emotionally demanding, so it is important to share the caring role with others*

## Section 4: Resources and support

### Alzheimer's Australia

Alzheimer's Australia provides a range of resources and support services for people with AD, carers and families, including:

- Information fact sheets for patients and carers
- Support groups for patients and carers
- Private and confidential counselling services
- A library of books and videos
- The National Dementia Helpline: 1800 100 500.

Alzheimer's Australia in each state and territory can provide further information about services around the country. Contact the National Dementia Helpline on 1800 100 500 for further details.

### National office

Alzheimer's Australia

PO Box 4019

Hawker ACT 2614

National Dementia Helpline: 1800 100 500 (freecall)

Interpreter service: 13 14 50

Website: [www.alzheimers.org.au](http://www.alzheimers.org.au)

### National Dementia Behaviour Advisory Service

NDBAS is part of Alzheimer's Australia. The service provides information for people who are concerned about the behaviour of a person with AD.

A free 24-hour helpline is available: 1300 366 448.





### Carers Australia

Carers Australia provides information about support services for carers. The Commonwealth Carer Resource Centres are part of the carers association in each state and territory, and provide carers with information on the range of community services and government assistance available to support them in their caring role. Carer support kits are available in 10 languages, and can be ordered by contacting the Commonwealth Carers Resource Centre on 1800 242 636.

#### Contact details

PO Box 73

Deakin West ACT 2600

Helpline: 1800 242 636 (freecall)

Telephone: (02) 6122 9900

Facsimile: (02) 6122 9999

Website: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

### Commonwealth Carer Respite Centres

Commonwealth Carer Respite Centres can let you know what respite care options are available for you in your local area. Call 1800 059 059.

## Section 5: Glossary

### acetylcholine

A chemical that helps conduct messages throughout the brain.

### acetylcholinesterase inhibitors

Drugs that are used to treat AD. They are thought to help the brain to function by preventing the breakdown of the chemical acetylcholine.

### Alzheimer's disease (AD)

AD is a physical disease that affects the brain. The disease attacks the brain cells, and causes messages in the brain to be disrupted. The cells eventually die, leading to problems with some of the brain's functions such as memory, thinking and behaviour.

### amino acids

The subunits of proteins that are necessary for human growth, development and functioning.

### aphasia

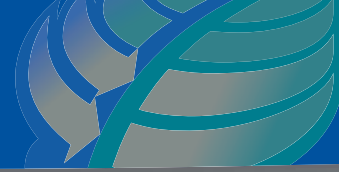
Difficulty with verbal expression and/or comprehension.

### cognitive abilities

Abilities involving thinking, learning, comprehension, remembering, reasoning and discernment.

### cognitive symptoms

Symptoms such as confusion, memory loss, inability to recognise people, places or things.



### computed tomography (CT) scan

An imaging scan that provides information about brain structure.

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### dementia

A general term to describe the loss of cognitive, emotional and intellectual functions. Characterised by disorientation, impaired memory, poor judgment and reduced intellect. AD is a common form of dementia.

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### hallucinations

False perceptions. Person sees, hears, smells or feels things that aren't really there.

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### incontinence

Loss of bladder and/or bowel control.

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### magnetic resonance imaging (MRI) scan

An imaging scan that provides information about brain structure.

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### palliative care

Healthcare that relieves or lessens the symptoms of a disease for which there is no cure.

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### positron emission tomography (PET) scan

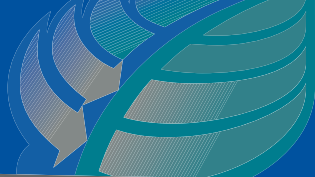
Imaging scan that measures brain activity; can be used to help assess the functional ability of the brain.

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This booklet is intended as a guide only. Please see your doctor for further information about Alzheimer's disease. The publisher and sponsor thank Alzheimer's Australia for their contribution to this publication.

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Living with dementia

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