



Australian Government
Department of Health and Ageing

Living with Dementia



A booklet for people with dementia

DEMENTIA

*prevention and early intervention
care and support
information, awareness and education
research*

Helping Australians with dementia and their carers



Living with Dementia

A booklet for people with dementia

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About this book

If you have been diagnosed with dementia this book may help you. It contains ideas about ways you may help yourself and gives you information about services that can offer you support.

Many people with dementia have contributed their ideas and advice to the book.

This book covers:

- types of dementia
- causes
- who you can talk to
- helping your memory
- how you can tell other people about dementia
- feelings
- planning for the future.

It also lists some books, videos and DVDs that you and your family might find helpful.

A companion book to this one is available for families and carers of people with dementia. *The Caring Experience* contains a lot of valuable information about dementia. You might like to tell your family about this book, which is available by contacting the **Commonwealth Carer Resource Centre** on **1800 242 636**.

What is dementia?

Dementia is a general term to describe problems with memory and thinking. It is a neurological condition. In other words, physical changes in the brain cause the symptoms you are experiencing.

The early symptoms of dementia include difficulties with:

- remembering, particularly recent events
- making decisions
- expressing thoughts
- understanding what others are saying
- finding your way around
- performing more complex tasks
- managing finances.



“When other people presented a number of ideas, priorities or suggestions to me at one time I had difficulties in trying to organise in my mind as to just what these thoughts from other people really were.

“Perhaps an example of this is when others presented me with a series of things to do, or a number of items to purchase at the supermarket, my inability to respond, as I used to quite normally, increased in me my feelings of loss of confidence, embarrassment and confusion.

“‘Whatever is causing me to be like this?’ I asked myself.”

What causes it?

There are many different types of dementia and they all have different causes. Some of the most common forms of dementia are:

- Alzheimer’s disease
- vascular dementia
- dementia with Lewy bodies
- Fronto Temporal Lobar Degeneration (FTLD).

We do not know why some people are affected by dementia and others are not. However we do know that Alzheimer’s disease is caused by a build up of protein in the brain.

Introduction to memory loss and dementia

This build up blocks the brain cells and affects the ability to learn and remember.

Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain and is the second most common cause of dementia. There are a number of different types of vascular dementia.

Dementia with Lewy bodies is caused by the degeneration and death of nerve cells in the brain.

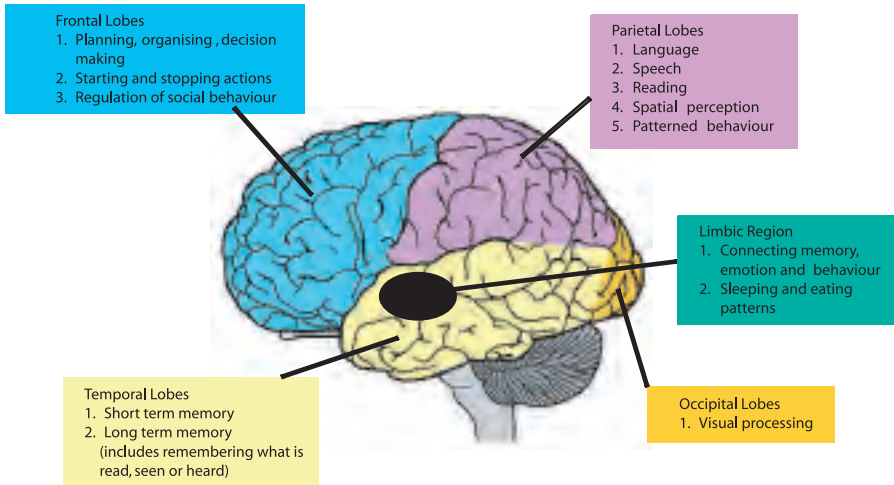
The name comes from the presence of abnormal structures, called Lewy bodies, which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells.

Fronto Temporal Lobar Degeneration (FTLD) is the name given to a group of dementias when there is degeneration in one or both of the frontal or temporal lobes of the brain.

“When the doctor said I had dementia I was shattered. I was really shaky.”

What changes are happening to my brain?

Different parts of the brain have different functions. Dementia damages one or more areas of the brain, and the way in which you will be affected will depend on which part has been damaged.



This diagram shows the different parts of the brain and the areas that they are responsible for.

For instance, if there is damage to the temporal lobes of the brain you may have some problems remembering what is read, seen or heard. Damage to the parietal lobes may mean that you have trouble understanding what others are saying, or have difficulty finding the right words.

What is the difference between Alzheimer's disease and dementia?

Alzheimer's disease is the most common form of dementia. Between 50% and 70% of people diagnosed with dementia have Alzheimer's disease.

How many people have dementia?

Dementia can happen to anyone, but it is much more common in people who are over the age of 65.

Approximately 200,000 people in Australia are currently living with dementia. The numbers are increasing due to Australia's ageing population. By the year 2050, it is estimated that there will be more than 730,000 people with dementia.

“I couldn't work out what was wrong with me. I was losing things all the time and I didn't know the reason. When they said I had dementia, that lifted a weight off me because I had something, I had something to grab hold of.”

Is there treatment available?

At present there is no cure for most forms of dementia. However, some medications and alternative treatments have been found to slow down the progression of symptoms for some people. Your doctor or specialist can advise you about these treatments.

Will my children or grandchildren inherit dementia?

This will depend on the cause of the dementia, so it is important to have a firm medical diagnosis. However, most cases of dementia are not inherited.

What can I do to help my memory?

It is important to know that:

- The changes you are experiencing are caused by a condition of the brain.
- You may have good days and bad days.
- Each person is affected differently and symptoms will vary.
- You are not alone – there are people who understand what you are going through and can help.

Alzheimer's Australia provides a range of services to support people with any type of dementia, and their families, throughout the course of the illness. Alzheimer's Australia can help you with:

- information about dementia
- support groups for people who have been diagnosed with dementia
- private and confidential counselling
- other programs and services in your local area.

Contact the **National Dementia Helpline** on **1800 100 500** or visit **www.alzheimers.org.au**



“I notice that some people lose patience if I ask for something more than once. But it’s just that I didn’t remember what they said the first time.”

Ideas

- Establish a memory centre, an area in your home where phone, notebook, pen, diary or calendar, whiteboard or pinboard are all together.
- Try to establish a regular routine that can help reduce your reliance on memory.
- Try to get in the habit of writing things down.
- Try not to overdo it, or pack too much into one day as short-term memory deteriorates as fatigue increases.
- Take your time and tell others to give you time.
- Alzheimer’s Australia has developed a Help Card for people with dementia who might need help and understanding at certain times such as in shops or on public transport. The card is distributed free of charge and can be obtained by calling the **National Dementia Helpline** on **1800 100 500**.

“I don’t feel ill, I don’t feel worried, I don’t feel there’s anything wrong with me really. It’s my wife who feels it. I feel sorry for her because we know what she’s going to be in for further down the track.”

Will I be able to continue driving?

A diagnosis of dementia can affect your driving ability in a number of ways including:

- finding your way around
- remembering which way to turn
- judging distance from other cars and objects
- judging speed of other cars
- understanding signs
- reaction times.

In most states and territories, drivers must tell their licensing authority of any condition that might affect their ability to drive. Dementia is one of the medical conditions that need to be disclosed because it may affect a person’s driving ability.

The licensing authority will generally advise the driver to see a doctor who will assess whether it is safe to keep driving for a period of time.

Living with dementia

Some people decide to voluntarily give up their licence. You might like to consider having a family member or friend drive with you at least monthly to monitor your driving skills and safety.

It can be hard to give up driving. Your car may be an important part of your independence, and without it your life will change. You may feel angry, frustrated or upset about this change. Talk about these feelings with a trusted friend or family member, or an Alzheimer's Australia counsellor.

Many people find that there are benefits in no longer driving. The alternatives, such as walking or getting a lift with family or friends, can be less stressful than driving, cost less and allow you to enjoy the scenery along the way.

“I wish I could still drive, but I know it’s just too risky.”





Why do I feel this way?

Experiencing changes caused by dementia may lead to a range of different emotions. Feelings of shock, sadness, embarrassment and anger are very common and it may help to share them with others. Talking about these feelings with a trusted family member, friend or Alzheimer's Australia counsellor may help.

You might like to join a support group and meet other people living with dementia to share experiences and ideas for managing with the condition.

Here are some of the feelings you might experience. You may or may not experience any of them. There are also some suggestions that others with dementia have found helpful.

Some people treat me like a child and others continually ask me how I am, as if they're expecting me to be sick.

I worry more than usual

You may be worried about what will happen to you and how quickly things will get worse. There are no definite answers to these questions, but talking about them with those you care about can help.

An idea

- Take one day at a time, rather than worrying about what may, or may not, occur in the future. Doing something that you enjoy will help reduce your level of worry.

Sometimes I think I'm going crazy

You are not going crazy, but the illness might make you feel like you are losing control at times.

Ideas

- Tell people around you about how you are feeling.
- Sharing your feelings with other people who have dementia may also help.

“I might be fine one minute and the next minute I’m forgetting things again, so you never know what you’ll get with me.”

I sometimes feel sad

Your life is changing. It is natural to feel sad. This is a very common feeling for people with dementia. If the sadness persists for a long time without easing, you may be suffering from depression. It is important to talk to a doctor or counsellor about this. Sometimes medication can help.

“I was so frightened by what was happening to me and so unsure of my future. The fear and anxiety soon turned to depression. I was crying all the time. It got so bad I just had to get help.”

Ideas

- Try talking to people around you.
- Having a good laugh or cry can help release feelings of sadness.
- You may feel better if you spend time with your friends or family or take part in an activity you enjoy.
- Try to focus on the skills and abilities you still have.

Living with dementia

When things go wrong I'm really embarrassed

Forgetting a familiar face or not being able to find the right word to express yourself can be embarrassing. Explaining to people that you are having memory difficulties because of an illness might help. People can be very understanding.

“It helps when people lighten up and share a joke, especially when things are really tough.”

I get so frustrated

Not being able to do things you once did or searching for something you've misplaced is frustrating. This is one of the most common feelings expressed by people with dementia.

Ideas

- Talk to the people around you about why you are frustrated.
- Focus on things you can do rather than getting frustrated about the changes you are experiencing.

“I walk around with a diary in one hand and a sense of humour in the other. These are my two helpers in living with dementia.”



What can I do to keep positive?

There are many things you can do to look after yourself and stay positive about your life:

- Focus on what you are still able to do.
- Stay connected to family and friends.
- Continue to participate in activities that are meaningful to you.
- Eat properly and exercise.
- Take medications as prescribed.

“I find so much more enjoyment in the simple things in life like walking around the park or doing the gardening. I never had the time to enjoy them before.”

The benefits of physical and mental exercise if you have been diagnosed with dementia

Both physical and mental exercise have been found to have a number of benefits for people with dementia; they can assist with mobility problems, communication and social participation, and reduce stress and depression, which are sometimes experienced by people with dementia.

Physical and mental exercise incorporated into your lifestyle in the early stages of dementia is more likely to be maintained as

Living with dementia

the condition progresses, extending the benefits to health and well-being for as long as possible.

As the condition progresses, it is important that the physical and mental activities chosen are enjoyable and that frustration or stress is avoided by choosing activities that are within your abilities and interests.

“Sometimes I just need a little more time to do things; rushing just doesn’t work for me any more.”

Simple activities involving physical or mental stimulation include:

- crosswords
- dancing
- walking
- playing musical instruments.

Of course, a doctor should be consulted before starting any program of physical exercise, particularly where there are other illnesses or disabilities to consider.

“I walk a lot. Walking helps me to remember things I have forgotten. It also helps to sit for a while and listen to the birds singing.”

I live alone. How can I get help?

Many people with dementia continue to live successfully on their own for some time.

As well as family and friends, many community services can help you stay at home while you want to. These services can help in a variety of ways including preparing and delivering meals, cleaning and house maintenance, transport and social visits.

Alzheimer's Australia can give you information about the services available in your area. Ring the **National Dementia Helpline** on **1800 100 500**.



Living with dementia

Commonwealth Carelink Centres around Australia provide information about the range of community care programs and services to help people stay in their own homes.

Call **1800 052 222**.

If you are concerned about how you will manage as the illness progresses talk to Alzheimer's Australia about alternative living arrangements or care options for the future.

Ideas

- Have two or three sets of house keys to leave with family members, friends or a trusted neighbour.
- Use electrical appliances that have automatic cut off switches.
- Ask for help when you need it, and accept it when it is offered.
- Take your time.
- If something is too difficult, take a break.

“At my support group we laugh a lot and we play a lot. We have fits of laughter. We have too long a road to travel with dementia to spend it crying.”

How do I tell my family and friends about dementia?

There are a number of questions you may need to consider when making a decision to tell people about your diagnosis.

- Who do I tell?
- How and when should I bring it up?
- How will people respond to me after I tell them?

These are all difficult questions and there are no right or wrong answers. It can help to talk to someone outside the family such as your doctor or a counsellor. Alzheimer's Australia offers confidential counselling and support for people with dementia as well as for their family and friends.

Although the news may be difficult, sometimes people feel a bit of relief just to have the problem out in the open. Discussing the diagnosis also means that you and your family and friends may be able to find out about services that can help you manage with dementia.

“My friends have tended to push me away when they found out I had an illness – I think perhaps they’re worried that they’ll catch it. It’s caused by fear of dementia and that is caused by not knowing about it.

“I told my family and close friends that I had been diagnosed with dementia, but I just tell other people that I have problems with my memory.”



What should my family do?

The diagnosis has probably been a shock for your family and friends. Like you, they may be experiencing a wide range of feelings including disbelief, anger or sadness.

Let them know that they can contact Alzheimer's Australia to talk it over and obtain information about dementia written especially for families. Call the **National Dementia Helpline** on **1800 100 500** or visit **Alzheimer's Australia** at **www.alzheimers.org.au**

Alzheimer's Australia Education Services in each state and territory offer information sessions and a variety of more detailed courses for families and friends of people with dementia.

The Australian Government has produced a book written for families and carers of people with dementia, called *The Caring Experience*. Anyone can obtain a free copy by contacting the **Commonwealth Carer Resource Centre** on **1800 242 636**.

Commonwealth and state and territory governments allocate funds to organisations to provide services to help you.

Various government, local council, church and community organisations provide services to families and carers. This varies between states, territories and local areas.

A number of information services have been set up to help families find out what services are available and how to contact them.

Commonwealth Carer Resource Centres

Commonwealth Carer Resource Centres are operated by Carers Associations in each state and territory and provide a range of free information and services including:

- practical written information
- counselling, through the National Carer Counselling program
- referrals to community and government services
- emotional support
- educational and training opportunities.

For information and support call the **Commonwealth Carer Resource Centre** on **1800 242 636**

Commonwealth Carelink Centres

Commonwealth Carelink Centres act as a single point of contact to provide information and guidance about community care services available in the local community.

Commonwealth Carelink Centres can give you free information about:

- the types of services available in your local area
- how to contact these services
- eligibility criteria
- general cost information about receiving services.

My family and friends

Anyone can use a **Commonwealth Carelink Centre** either by visiting personally or by telephoning **1800 052 222**.

Aged Care and Community Care Information Line

The Aged and Community Care Information Line is a single hotline number that provides you with information about Australian Government funded residential aged care and community care.

The information line can also refer you to services in your region and one of 54 Commonwealth Carelink Centres around Australia. Contact the **Aged Care and Community Care Information Line** on **1800 500 853**.



How can I take care of my finances?

It's a good idea to make decisions about your future as early as possible. This means that you can be sure that your preferences will be followed and it will assist your family to help you in the way that you have chosen.

Make sure that all your important documents are the way you want them to be.

Consider signing an enduring power of attorney. This is a legal arrangement that enables you to nominate someone to look after your financial affairs if you become unable to do so.

“No one knows what the future holds, but it helps to know that your affairs are all in order if the worst does happen.”



Planning for the future

What legal matters should I attend to?

You may wish to review your will.

You can appoint one or more people you trust to make important personal and lifestyle decisions on your behalf when you need assistance. These decisions may include choice of accommodation, recreational activities and holidays. In some states and territories this can include health and medical decisions. An advance directive may allow you to define the medical treatment you wish to have, or refuse, should it become difficult for you to make these decisions later on.

Questions for you

Important legal documents for you to consider:

- will
- enduring power of attorney
- enduring power of medical guardianship
- advance directive.

Different names may be used in some states and territories.

For further information about financial and legal matters contact:

- a solicitor
- community legal service
- the Public Advocate or Public Guardian in your state or territory
- the National Dementia Helpline.

What about care arrangements in the future?

At some point, you may need extra assistance in your home, or alternative living arrangements. Consider what services are available, and where and with whom you might want to live. Talk about it with your family and friends.

Alzheimer's Australia can give you information about extra assistance or alternative living arrangements. **Commonwealth Carelink Centres** provide information about the range of community care programs and services available to help people stay in their own homes.

National Dementia Helpline 1800 100 500

Commonwealth Carelink Centres 1800 052 222

A question for you

Does someone you trust know where these documents are kept?

- Wills
- House and land titles
- Mortgage documents
- Birth and marriage certificates
- Insurance policies
- Superannuation documents
- Centrelink and Department of Veterans' Affairs documents
- Share certificates
- Enduring power of attorney form

Planning for the future

“I looked after my husband with Alzheimer’s disease and now I’ve got it. So I know all about it and the most important thing is to talk about it to your loved ones without any shame – it’s not something you’ve done, it’s something that has crept up on you. If you do that, most people will try and help you or stand by you.”



Living with Memory Loss program

The Living with Memory Loss program is available in each state and territory. It consists of information and support groups for people living with early stage dementia and their family and friends.

A group program consisting of 6–8 sessions is usually held one day a week for a two-hour session. Ongoing support groups often meet monthly for some time after the program.

In each case, there are two small groups – one for people living with memory loss and the other for family members and carers. People with memory loss may attend alone if desired. The groups meet separately for part or all of the time and come together for a cuppa.

There are many benefits from taking part in a Living with Memory Loss program. Most people enjoy the chance to share information, have questions answered, talk confidentially with others in a similar situation, discuss experiences and express feelings in a safe environment.

The program has a positive focus on maintaining and enhancing skills and abilities and exploring ways of managing now and in the future.

For more information about the Living with Memory Loss program call the National Dementia Helpline on 1800 100 500 or visit the website at www.alzheimers.org.au and go to the *I have dementia* section.



Books, videos and DVDs

More and more people with dementia are sharing their experiences of being diagnosed with dementia and of living with memory loss. Alzheimer's Australia can help you find books or videos that may be of interest to you. **Call the National Dementia Helpline on 1800 100 500.**

Books

Who will I be when I die? by Christine Boden

Christine was diagnosed with Alzheimer's disease at 46 and re-diagnosed with frontal lobe dementia when she was 49. This is the first book written by an Australian with dementia and offers a unique insight into her battle with dementia.

Dancing with dementia by Christine Bryden

Formerly Christine Boden (see *Who will I be when I die?*) this author's new book is a thoughtful exploration of how dementia challenges our ideas of personal identity and of the process of self-discovery it can bring about.

Living in the labyrinth by Diana McGowin

This autobiographical book tells of the author's struggle with the effects of Alzheimer's disease and offers the reader insight into the world of dementia.

Show me the way to go home by Larry Rose

Larry Rose records his experiences with Alzheimer's disease with humour and unquenchable spirit.

Losing my mind: An intimate look at life with Alzheimer's

by Thomas DeBaggio

Not only does the author have the ability to chart the mechanics and musings of his failing mind, he also turns an autobiography, a medical history and a book of meditations into a testament to the splendour of memory and a triumphant celebration of the human spirit.

Videos and DVDs***Understanding dementia***

This is an introductory video/DVD in which medical professionals explain the causes and symptoms of dementia and people who are living with different stages of dementia show how it affects their lives. Strategies are given to help manage the changes that dementia brings and to ensure that those affected continue to enjoy quality of life.

Living with memory loss

This video takes you into the world of early stage dementia and the role that sharing experiences can play in forging a meaningful direction in life after diagnosis of dementia.

Understanding memory changes: Normal ageing or dementia?

Produced by Alzheimer's Australia Vic., this 30-minute production is based on an interview with Anne Unkenstein (co-author of *Remembering Well*) in 2002. Topics include how memory works, early changes with dementia, and strategies for dealing with memory loss and challenges for the family.

Useful contacts



Understanding the brain & behaviour

Presented by Dr Helen Creasey, geriatrician and neurologist, this valuable resource gives a clear explanation of sections of the brain and includes colour coded 3D graphics as well as personal vignettes of people living with dementia to demonstrate behavioural changes.

The Forgetting

This documentary weaves together the intense real-world experiences of people with Alzheimer's disease and caregivers, the history and biology of Alzheimer's and the ongoing struggle to end the disease.

Useful websites

Alzheimer's Australia	www.alzheimers.org.au
Department of Health and Ageing	www.health.gov.au
Centrelink	www.centrelink.gov.au
Department of Veterans' Affairs	www.dva.gov.au

Useful contacts

My contacts

My emergency contacts and information _____

My doctor: _____

Family contact: _____

I am allergic to: _____

General contacts

National Dementia Helpline **1800 100 500**

A companion booklet to
Dementia – The caring experience

Important contacts

National Dementia Helpline	1800 100 500
Commonwealth Carelink Centres	1800 052 222
Commonwealth Carer Resource Centres	1800 242 636
Commonwealth Carer Respite Centres	1800 059 059
