



Alzheimer's
Australia
Living with dementia



**Worried
about your
memory?**

Here's what you can do...





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Introduction

Alzheimer's disease is the major cause of dementia and is associated primarily with loss of memory. But both Alzheimer's disease and the other causes of dementia have symptoms that not only involve memory but also difficulty in recalling words, planning and organising, and mood swings. All these impact on an individual's capacity to carry out the everyday activities of daily life.

This publication focuses on memory. Most of us worry about our memory from time to time – at any age – but certainly more so as we get older. In this information-rich age we hear a lot about memory and quietly wonder whether our memory lapses are something that we should be concerned about...indeed, we may wonder if there is anything we can do about it anyway.

This booklet may help to answer some of the questions that are commonly asked of staff at Alzheimer's Australia. At Alzheimer's Australia we are often asked questions or told stories similar to the following:

'Is my forgetfulness a sign of dementia?'

'I know something, but I just can't recall it.'

'It takes me a long time to remember something.'

'I recently had a worrying experience when I couldn't find my car in the car park.'

'I'm introduced to someone and the next second I can't remember their name – it's embarrassing.'

So, what is 'normal forgetfulness' and what can you do if you are worried about your memory? The answers are rarely simple, but we can endeavour to be better informed about the stages of memory and what happens as we age. Perhaps the critical question you need to consider is whether you feel that you can no longer function with confidence in your daily life.

It may be that you have less need to be worried than you think. But, if after reading this booklet you do feel concerned about your memory, the problems you face organising your life, finding the right word or other cognitive issues, then talking to your doctor is a good starting point.





About the brain

When considering your memory and its capability, it is useful to have a basic understanding of how your brain works, and how this relates to the functioning of your memory. How the brain behaves in health and disease is the great challenge to medicine in the 21st Century. There is no cure for Alzheimer's disease or the other causes of dementia, and it is better to think in terms of reducing risk, because once the damage is done it may be difficult to repair. We now know a lot about the changes that take place in the brain with dementia and also know that they take place over many years before diagnosis.

Research has provided us with the evidence about what constitutes good support and care for people with dementia, the factors that may help to reduce the risk of dementia, and the strategies that may eventually modify progression of the disease and delay onset through medical interventions.

The brain helps us to:

- **plan and organise things**
- **make decisions**
- **understand information**
- **solve complex problems and do calculations**
- **pay attention**
- **behave properly**
- **remember things**
- **speak and communicate**
- **see, hear, taste, smell and feel**
- **read and write**
- **recognise people and objects**
- **find our way**
- **breathe**
- **control our body temperature**

Given that the brain performs so many complex and sophisticated roles it is not surprising that from time to time some aspects of its performance, such as memory, may not be perfect.





How memory works

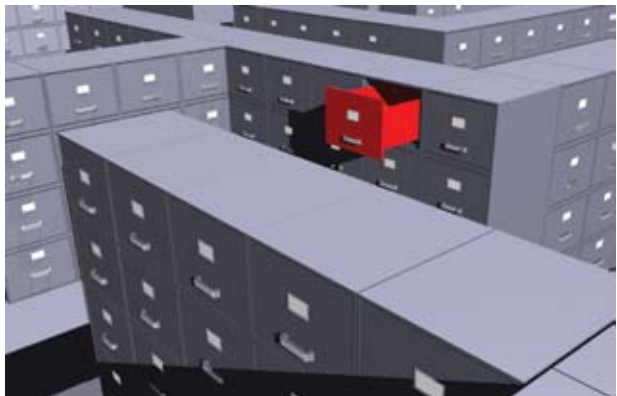
Memory is not a single 'thing' – it involves acquiring, storing and recalling information and images, each of which are complex processes. Memory is who we are – a filing cabinet where all our life experiences are stored.

First, we need to get our thoughts into our filing cabinet as data. We have to acquire memories, and we do this by using a range of techniques that we are all familiar with – we pay attention, we store information that will be useful to us, we absorb memories through experiences and in many other ways¹.

Some information goes into a small temporary store and can be referred to as 'immediate memory'. This is like your in-tray on top of the filing cabinet. Some of this information will be later stored in the filing cabinet as 'enduring memory' and some of it (a lot of it!) you don't bother to keep. Your 'memory in-tray' can only hold a limited amount of information and the next information you put in will wipe out what was there before, compared to your enduring storage, which has no capacity limitations.

Now, if you want to keep some of the information in your 'memory in-tray', like a phone number, you have to move that information into your 'memory filing cabinet'. To do this you have to 'process' the information, and we do this by using various techniques such as repeating the phone number to ourselves, or splitting a phone number into two groups so that we don't have to remember all of the numbers, or picturing what the number looks like, or making up some sort of rhyme about the phone number. Sometimes we collect new memories without realising that we may need them later.

There are many different suspension files or tabs that we use to store information, and some people have better systems than others. It appears that information may be more difficult to retrieve if it hasn't been processed in a meaningful and well-organised way.





So, how do we retrieve and recall memories when we need them? Sometimes we recall them by ‘association’– like when you think of Christmas when you smell plum pudding. There are many other ways of recalling memory, including by recognition, and by free and cued recall, which are referred to in Sargeant and Unkenstein’s book (the full reference is in the footnote below).

The way in which we undertake these tasks, often without an awareness of the process, differs from person to person and so there is no single measure of the effectiveness of our memory. Our memory is influenced by many factors, and there is wide variability between all of us in how we process and store our data.

Memories for procedures such as remembering how to ride a bicycle, the sounds of particular music, familiar or favourite smells, what you see and what you read are stored differently. Short-term memory is more vulnerable to decline with age and dementia, while long-term memory extending back to childhood is more resilient, and may even become clearer with age.

1 This introduction draws on:
Delys Sargeant and Anne Unkenstein, *Remembering Well: How memory works and what to do when it doesn't*, Allen and Unwin, Second edition, 2001 and Alzheimer’s Australia, *Remember This: Ageing and Changing* (education kit, sponsored by Kimberley-Clark Australia).



What happens to memory as we age?

Commonly in older adults:

83% forget names

60% lose things

53% forget things

41% forget directions

34% forget appointments

Physical changes occur in our brains as we age, including some loss of brain cells and the connections between them. Our brains may work more slowly and less efficiently, but the extent of change varies from person to person.

It is normal for some changes to occur in our memory and thinking. For example, you might be a little more forgetful than you used to be, or not as quick in your thinking as you previously were. It might require a little more effort to remember something or to work something out in your mind than it once did.

As we grow older it may be harder to pay attention to several things at the one time, to learn new things, to recall names and nouns and to remember information. Commonly, older adults report that they forget names (83%), lose things (60%), forget things (53%), forget directions (41%) or forget appointments (34%). This is all normal and is called 'age-related cognitive decline'. Some older people will experience a significant amount of decline and others not much at all.

As we get older, we maintain strengths in some aspects of our memory and these parts of our memory continue to improve with age. Our vast array of lifetime memories remains strong and keeps expanding. We often become more strategic with our remembering – in other words, we may learn to use our memory better! We continue to make new associations and think of new ideas. We might take more time to learn new things, but can be more flexible and tolerant.²

Remember: as we get older memory change is the most common complaint most of us make, and most of us do not have dementia.

² Sargeant et al, *ibid.*, p25.





What causes memory problems?

Memory issues become a problem if they significantly disrupt your everyday life.

Many factors may affect memory loss, and many of these are not related to dementia. These include stress, anxiety, pain, grief, some medications and fatigue.

In addition, several medical conditions may affect memory, and these also are not related to dementia. Such conditions include hormone changes, nutritional deficiencies, dehydration, depression, liver or kidney disease and sensory loss.

If you are concerned, it is important that you request a comprehensive medical assessment to identify the causes of your memory loss. Many of these memory-related issues can be fully resolved with treatment that might include lifestyle management, counselling support and/or medication.



When you should worry about your memory

First, ask yourself if any of the suggested causes of memory problems listed in the previous section might be affecting your life.

You may need further support if you are experiencing some of the following problems:

- repeatedly misplacing things
- trouble remembering recent events
- trouble remembering the day and date
- difficulty following a story line
- difficulty adjusting to changes in routine
- difficulty thinking through problems
- difficulty following conversations
- difficulty handling financial matters
- difficulty in remembering familiar routes home or to work
- family and friends are commenting on your poor memory

If you are experiencing some of these problems, and frequently, you would be wise to make an appointment with your doctor.

What you should ask your doctor

Unfortunately, there is not a single medical test that can show whether or not someone has dementia. Diagnosis is based on a clinical judgement and may not necessarily establish whether a person has Alzheimer's disease or some other cause of dementia.

The doctor will form an opinion and diagnosis by talking to you, and perhaps a relative or friend, about the concerns you hold about your memory and thinking.

During your visit you should : ³

- take a list of your concerns with you – as this will provide a useful basis for further discussion and tests
- talk about your concerns openly and honestly, including how long you have been experiencing these problems and whether they have become more of an issue over time
- take a list of the medications that you are taking, including the doses (or bring all of them with you including your tablets, inhalers, creams, herbal medications and vitamins)

Remember that you can:

- ask for a longer appointment
- take a relative or friend with you
- ask questions and request further explanations if you don't understand
- take notes during the visit
- discuss the option of further assessment by a specialist





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You may need a physical and neurological examination to identify the possible causes of any memory problems. Your doctor may refer you to a specialist in the diagnosis of cognitive issues, such as a geriatrician, psychiatrist or a neurologist. Your specialist may request further assessment by a neuropsychologist. Doctors use a number of different tests and assessments to determine whether symptoms fit certain criteria and to rule out other possible causes of the symptoms you may be experiencing.

An assessment for dementia may include several of the following:

- a review of your personal history
- physical examination and laboratory tests, including blood and urine tests
- memory and mental abilities tests
- radiological tests, such as brain imaging

If these assessments are required you may wish to ask your doctor:

- What tests will be conducted?
- Who will be performing these tests, and how long will it take?
- Should I prepare for the tests in any way?
- Will any of the tests involve pain or discomfort?
- Will there be a cost involved?
- What follow-up will be necessary, and who will perform the follow-up?
- How will I be informed of the test results and the diagnosis?
- Who else will be told of my results and diagnosis?
- Will my GP be given information about me? (if you are seeing a specialist)

Most of us want an immediate and definitive diagnosis, but in the case of memory concerns there may be a number of possible explanations. This process can be frustrating, but please be patient and don't expect an immediate answer.



3 For further information see:
Alzheimer's Australia, *Tests Used in Diagnosing Dementia* Update Sheet 8, 2008.
Alzheimer's Australia, *Early Diagnosis of Dementia* Paper 10, March 2007.
Both available at www.alzheimers.org.au



Mild cognitive impairment and dementia



The diagnosis of cognitive conditions is becoming progressively more accurate and sophisticated. What may have previously been diagnosed in decades past as simply 'senile dementia' is now better understood. Nevertheless, it is still sometimes difficult for doctors to discriminate the initial manifestations of Alzheimer's disease and other forms of dementia from the cognitive changes associated with ageing. (Cognition or cognitive functions refers to the brain's ability to reason, plan, reflect, remember, find words, find one's way and perform a variety of other thinking functions). For your reference, some of the distinctions are discussed below.

Mild Cognitive Impairment

The term 'mild cognitive impairment' (MCI) has been proposed to represent the border zone between ageing and dementia.⁴ MCI characterises people who have a higher likelihood of eventually developing dementia but who do not as yet satisfy the diagnostic criteria of dementia. However, not all people with MCI continue to decline in memory function, some remain stable and some even improve.

People with MCI can function reasonably well in everyday activities, but often have difficulty remembering the details of conversations, events and upcoming appointments. About two thirds of people with MCI develop a progressive decline in their thinking abilities over time, and Alzheimer's disease is usually the underlying cause of this.⁵

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 that describes a decline in memory, intellect, social skills and what would be considered normal emotional reactions.

There are many forms of dementia, with Alzheimer's disease being the most common. Other forms of dementia include: vascular dementia; dementia with Lewy bodies; frontotemporal dementia; and many other rare conditions.⁶

⁴ There are many useful references on mild cognitive impairment such as: Burns JM and Morris J C *Mild Cognitive Impairment and Early Alzheimer's Disease: detection and diagnosis* Wiley, England, 2008

⁵ Mayo Clinic Scientists Review 10 Years Research on Mild Cognitive Impairment. www.mayoclinic.org/news2009-rst/5561.html

⁶ Alzheimer's Australia *What is Dementia?* Help Sheet 1.1, 2005. www.alzheimers.org.au



10 signs of dementia



Memory-related changes that disrupt daily life are not a typical part of ageing. If you notice any of the signs listed below you should consult your doctor.⁷

The following '10 Signs of Dementia' were developed by the Alzheimer's Association [USA] and refer to Alzheimer's disease – however, many of these signs also apply to other forms of dementia.

- 1 Memory loss that disrupts daily life**
One of the most common signs of Alzheimer's disease is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events; asking about the same information over and over; relying on memory aids or family members for things they used to handle on their own.
- 2 Challenges in planning or solving problems**
Some people may experience changes in their ability to develop and follow a plan or to work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating, and tend to take much longer to do things they did before.
- 3 Difficulty completing familiar tasks at home, at work or at leisure**
People with Alzheimer's disease often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favourite game.
- 4 Confusion with time or place**
People with Alzheimer's disease can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.
- 5 Trouble understanding visual images and spatial relationships**
For some people, having vision problems is a sign of Alzheimer's disease. They may have difficulty reading, judging distance and determining colour or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realise that they are the person in the mirror.

⁷ Alzheimer's Association (USA) 10 Signs of Dementia
www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp?type=more_information

- 6 New problems with words in speaking or writing**

People with Alzheimer's disease may have trouble following or joining a conversation. They might stop in the middle of the conversation and have no idea how to continue, or they might repeat themselves. They may struggle with vocabulary, have problems finding the right words or call things by the wrong name (e.g. they might call a watch a hand-clock).
- 7 Misplacing things and losing the ability to retrace steps**

A person with Alzheimer's disease might put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This could occur more frequently over time.
- 8 Decreased or poor judgement**

People with Alzheimer's disease may experience changes in judgement or decision-making. For example, they might use poor judgement when dealing with money, such as giving large amounts to telemarketers. They also could pay less attention to their grooming or keeping themselves clean.
- 9 Withdrawal from work or social activities**

A person with Alzheimer's disease may start to withdraw themselves from their hobbies, social activities, work projects or sports. They could experience trouble keeping up with a favourite sports team or remembering how to complete a favourite hobby. They may also avoid being social because of the changes they have experienced or because they feel embarrassed.
- 10 Changes in mood and personality**

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends, or in places where they are out of their comfort zone. They may become more rigid, and some previous character traits could become exaggerated.

Strategies you can adopt if you are concerned about your memory

We are all different and there is no simple solution that applies to all of us. The strategies that you may find helpful will depend on the nature of your memory issues, your lifestyle, your attitudes and beliefs, and the support available to you as well as other factors. We all use memory strategies in some form or another, but if you are experiencing more persistent memory issues you may wish to consider being more systematic with these strategies in your daily life.

Some useful memory strategies that are widely used to improve memory in general include⁸ :

- **Concentrate** – we often under-use our ability to concentrate on something. Develop a habit of paying close attention.
- **Repetition** – repeat to yourself and rehearse what you want to remember.
- **Don't overload** – switching from one subject to another may become more difficult as we get older. Try to work with just one set of information at a time.
- **Reduce the amount of information to be learned** – one technique is to break up a list of tasks (or names) into sub-groups and learn those, rather than attempting to remember all of the items on the list.
- **Make a mental picture** – envisage what you need to remember, such as an identifiable feature near where you parked your car.
- **Use pattern recognition or try to visualise what you are trying to remember** – for example, you might be able to recognise in your mind where various items are located in a supermarket.
- **Make associations** – you might be able to associate a person's name with a rhyme or a colour or a shape.

Use the strategies that work best for you and practice them.



Use strategies
that work best
for you



⁸ McKhann and Albert M, *Keep Your Brain Young: the complete guide to physical and emotional health and longevity* John Wiley & Sons, New Jersey 2002

If your memory concerns are more persistent, you may need to consider using some ‘back-up’ strategies to support your memory.

Some of these include ⁹ :

- **Making lists** – most of us use lists on occasions, but you may now need to make lists a part of your everyday routine.
- **Use a diary** – it can be helpful to use a diary to help recall significant dates, such as family members’ birthdays, times and appointments.
- **Organise important things** – put things (such as car keys) in the same place each time.
- **Maintain routine** – maintaining familiar routines may lessen the load on memory.
- **Plan ahead** – allow more time to get to appointments in unfamiliar places. Plan ahead and write down step-by-step directions.

If you do have early stage dementia, you may need to adopt additional strategies (such as labelling rooms or items) or call on the support of someone to assist you to remember.



⁹ Sargeant et. al., op cit.





Factors associated with a reduced risk of developing dementia include being mentally, physically and socially active; maintaining healthy blood pressure, cholesterol, blood sugar and weight; eating healthily; not smoking; and drinking alcohol in moderation.

How you can protect your memory

In the past the conventional response to this question has been that there's little you can do to protect your memory or reduce your risk of developing dementia.

While there remains much to be learned, there has been an explosion of research evidence in recent years that demonstrates a close relationship between lifestyle and brain health. Many excellent books, based on credible research, are now available¹⁰, and there is a growing understanding that we can influence our own brain health. It is better to start early and maintain sound lifestyle practices; but it is never too late. Research has demonstrated that the dementing disease process starts several years – at least 10 to 15 – before the symptoms of dementia translate into concerns about activities affecting daily living.

In 2005 Alzheimer's Australia convened a research panel to review the research evidence that supported the reduced risk of developing dementia through the adoption of a healthy lifestyle. That report identified factors that we may be able to control in our lives to reduce the risk of cognitive decline and to delay or prevent the onset of dementia. The research literature is developing at such a rate that the evidence is continually being updated.¹¹ Alzheimer's Australia has also developed a dementia risk reduction program called Mind your Mind to raise awareness of these issues. The research shows that while lifestyle is not a guarantee against developing dementia, people who adopt a 'brain-healthy' lifestyle have better brain function on average than those who don't.

¹⁰ See for example:

Valenzuela M, *It's Never Too Late To Change Your Mind: the latest medical thinking on what you can do to avoid dementia* ABC Books, Sydney, 2009.

McKhann and Albert M, *op.cit.*

Doidge N, *The Brain that Changes Itself*, Penguin Books, 2008.

¹¹ Woodward M, Brodaty H, Budge M, Byrne G, Farrow M, Flicker L, Hecker J and Velandai S, *Dementia Risk Reduction: The Evidence* Alzheimer's Australia Paper 13, 2007.

If you are interested to learn more about brain-healthy lifestyles see the companion to this booklet:

Mind your Mind: How to keep your brain healthy and reduce the risk of dementia.

Alzheimer's Australia 2009. Available free in hard copy or online at www.alzheimers.org.au

Alzheimer's Australia has a website where the current evidence relating to the risks of dementia and how to reduce them can be reviewed at www.mindyourmind.org.au

Glossary:

About dementia

Dementia

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning. It is a broad term that describes a loss of memory, intellect, social skills and what would be considered normal emotional reactions. For a long time, the person may look healthy, but on the inside their brain is not working properly. Dementia is not a normal consequence of ageing.

Alzheimer's disease is one of the major causes of dementia, but there are many others.

Alzheimer's disease

Alzheimer's disease is the most common form of dementia accounting for between 50% and 70% of all cases. Alzheimer's disease is a physical condition which attacks the brain, resulting in impaired memory, thinking and behaviour. The basic cause of this progressive, degenerative condition remains unclear.

Vascular dementia

Vascular dementia is the second most common form of dementia, accounting for up to 20% of all cases of dementia. Strokes and mini-strokes can cause vascular dementia, as can poor circulation of blood to the brain. It is common for the brains of persons with dementia to have both Alzheimer and vascular changes.

Other dementias

There are many different forms of dementia. These include:

- frontotemporal dementia which begins in the frontal and/or temporal lobes of the brain
- dementia with Lewy bodies which is a type of dementia closely allied to both Alzheimer's and Parkinson's diseases, characterised anatomically by the presence of Lewy bodies (clumps of particular proteins in the brain)
- alcohol related dementia

- HIV-related dementia
- many other rare forms

Dementia and inheritance

Familial Alzheimer's disease is a rare form that is entirely inherited. It accounts for fewer than 5% of all cases of Alzheimer's disease and is often subject to very early onset, occurring in people in their 30's or 40s. There is a clear family history of the disease. Some other rare forms of dementia are also entirely inherited, including some cases of frontotemporal dementia. The majority of cases of dementia are not directly inherited and likely arise from a combination of genetic and environmental effects.

Prevalence

Dementia is more common in people after the age of 65 years, and the chances of developing dementia increase significantly with age. Younger adults may also develop dementia, but this is uncommon. However, dementia is not a normal part of ageing and most old people do not develop this condition.

The estimated age-specific dementia prevalence rates are:

<i>Age</i>	<i>Female</i>	<i>Male</i>
65-69	1 in 80	1 in 60
75-79	1 in 16	1 in 17
85-89	1 in 4	1 in 5

The estimated number of people with dementia in Australia in 2010 is 257,000. This number is projected to increase to around 1 million by 2050¹² unless preventative strategies or medical breakthroughs have an impact.

12 Access Economics, 'Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050 Alzheimer's Australia, 2009.



About Alzheimer's Australia

Alzheimer's Australia is the national peak body representing people with dementia, their families and carers.

Our vision is a society committed to the prevention of dementia while valuing and supporting people living with dementia.

Alzheimer's Australia provides information, support, advocacy, education services and programs to improve the lives of people living with dementia.

Alzheimer's Australia is an advocate for people with dementia, their families and carers and encourages people with early stage dementia, their families and carers to share their voices and experiences and take part in advocacy opportunities.

To find out how you can help visit
www.alzheimers.org.au



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National Dementia Helpline

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