



Section 1

About dementia

The Dementia Guide is for anyone who has been impacted by any form of dementia. The information in this guide is divided into sections. Each section relates to a particular stage of your dementia journey.

It is important to remember that everyone living with dementia is unique. The content in this guide is general in nature and we recommend you seek professional advice in relation to any specific concerns or issues you may have.

While we strive to keep content accurate and up-to-date, information can change over time. For updates, please visit dementia.org.au or call the **National Dementia Helpline** on **1800 100 500**.

Web: dementia.org.au/the-dementia-guide



“

Study is very good because by keeping your brain active, you're slowing the progress of your dementia. If you want to study, you have to look at what you can actually do and tailor it to your abilities. ”

Juanita, a Dementia Advocate who lives with dementia

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About dementia

Section contents

What is dementia?	12
Who gets dementia?	14
What causes dementia?	15
How does dementia affect younger people?..	21
How does dementia progress?.....	22



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What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia may affect thinking, communication, memory, behaviour and the ability to perform everyday tasks. It will impact on the person's family, social and working life.

Dementia is not a normal part of ageing.

Everyone experiences dementia differently. Symptoms will depend on the cause of dementia and the parts of the brain affected.

Common symptoms include:

- memory loss
- challenges in planning or solving problems
- difficulty completing everyday tasks
- confusion about time or place
- trouble understanding visual images and spatial relationships

- difficulty speaking or writing
- misplacing things and losing the ability to retrace steps
- decreased or poor judgement
- withdrawal from work or social activities
- changes in mood and personality.

Dementia is generally progressive. Symptoms often begin slowly and become gradually worse over time.

It is important to remember that no two people experience dementia in the same way. People often lead active and fulfilling lives for many years after their diagnosis.

Who gets dementia?

Dementia can happen to anybody.

The risk of dementia increases with age



Over the age of 65,
dementia affects
almost one person
in ten.



Over the age of 85,
dementia affects
three people in ten.

People under the age of 65 can experience dementia, although it is less common.

Researchers in dementia now believe it depends on a combination of age, genes, health and lifestyle. Dementia can sometimes be hereditary, but this is quite rare.

What causes dementia?

There are many known types of dementia. Most people are diagnosed with one of four types.

Alzheimer's disease

Alzheimer's disease is the most common cause of dementia. This disease disrupts the brain's neurons due to a build-up of abnormal proteins, called 'plaques and tangles'. It affects how they work and communicate with each other. A decrease of important chemicals stops messages travelling normally through the brain.

You might experience:

- difficulties with short-term memory, especially recalling more recent events
- language and comprehension difficulties, such as problems finding the right word
- increasing disorientation in time, place and person
- problems becoming motivated and initiating tasks.

Vascular dementia

Vascular dementia occurs when there is reduced blood supply to the brain, causing cells to die. This can be the result of a stroke, narrowing of the arteries supplying blood to the brain, or bleeding in the brain.

You might experience:

- stepped progression of symptoms with periods of relative stability
- slowed motor speed
- impaired attention and short-term memory
- difficulty making decisions in response to a situation
- depression and apathy.

Lewy body disease

Lewy body disease causes gradual brain damage. Tiny structures, called Lewy bodies, develop inside brain cells. These structures disrupt the way the brain functions and can cause cells to die. This causes gradual brain damage, resulting in changes in movement, thinking and behaviour.

You might experience:

- fluctuating and sudden bouts of reduced alertness, confusion, or both
- slowed movement, rigidity, a shuffling walk, increased falls and tremors
- loss of facial expression
- difficulty with visual and spatial perception
- hallucinations
- poor abstract reasoning and judgement
- difficulty planning, reasoning, problem-solving and making decisions
- vivid dreaming with your body moving as you dream.

Lewy bodies are also found in people with Parkinson's disease. A person who has lived with Parkinson's disease for several years can develop Parkinson's disease dementia.

Frontotemporal dementia

Frontotemporal dementia causes progressive damage to the frontal, temporal, or both lobes of the brain. Three main subtypes of frontotemporal dementia exist, a behavioural variant, and two language variants. The form of frontotemporal dementia diagnosed will depend on which areas of the brain are damaged.

If the damage is predominantly in the frontal lobes (behavioural-variant frontotemporal dementia), you may experience:

- changes in personality, emotion and behaviour
- apathy or lack of motivation
- distractibility and impulsiveness.

If the damage is in the temporal lobes, you may experience:

- difficulty in understanding words and concepts, difficulty recognising familiar people, or both (semantic dementia)
- difficulty with speech and expressive language (progressive nonfluent aphasia).

Other causes of dementia

A wide range of other conditions can also lead to dementia. These are rare, only accounting for about five per cent of all people with dementia.

Other diseases or causes include:

- Parkinson's disease
- corticobasal degeneration
- Creutzfeldt-Jakob disease
- HIV-related cognitive impairment
- Huntington's disease
- alcohol-related brain damage and Korsakoff's syndrome
- multiple sclerosis

- Niemann-Pick disease type C
- normal pressure hydrocephalus
- progressive supranuclear palsy
- chronic traumatic encephalopathy (from repeated head injuries)
- Down syndrome.

Mild cognitive impairment

Some people experience changes in memory and other cognitive (thinking) functions greater than that usually experienced with ageing, but without other signs of dementia. This is called mild cognitive impairment.

You might experience:

- some loss of memory
- decline in cognitive abilities (thinking skills).

There is an increased risk of developing dementia, caused by Alzheimer's disease or other neurological conditions. This may take many years, if it happens at all. A doctor or specialist may want to review symptoms over time to monitor for any potential changes in symptoms and brain health. Many people with mild cognitive impairment never get worse, and a few even improve over time.

How does dementia affect younger people?

The term younger onset dementia describes any form of dementia diagnosed in people under the age of 65. Younger people may develop any type of dementia, but Alzheimer's disease is the most common type.

Familial Alzheimer's disease

In some cases, dementia has a genetic link. This is called Familial Alzheimer's disease. It is more common in people under the age of 65. It affects an extremely small number of people, less than 100 people across Australia.

Many of the symptoms experienced by younger and older people with dementia are similar. However, people with younger onset dementia can need different support as their life circumstances are different.

You may be strong and healthy, in full-time employment and raising a family. You may have a mortgage or other financial commitments, with plans to work until the age of 65.

Younger people can find that they are misunderstood in the community. Often, people do not expect younger people to live with dementia.

How does dementia progress?

People with dementia differ in the symptoms they have and the speed with which their abilities deteriorate. Abilities may change from day to day, or even within the same day.

Progression may happen rapidly in a period of a few months or slowly over several years. While the progression of dementia can vary, the disease usually has three stages. Understanding these stages can help you plan for potential challenges.

1

Mild or early-stage dementia

You might have some problems with thinking skills, such as memory loss, but need minimal support.

2

Moderate or middle-stage dementia

You need support to help you function at home and in the community. Difficulties are now more obvious and have a greater impact on your abilities and dependency.

3

Severe or late-stage dementia

You are likely to be fully dependent on the care and supervision of others.

Unfortunately, dementia isn't reversible.

However, you may be able to maintain your independence and live well for many years. At each stage, there will be ways to make life better.