1 About dementia

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Key points: About dementia

Dementia occurs when the brain is affected by a disease. It is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in the person’s functioning. It is not a normal part of ageing. Dementia affects everyone differently and can result in a wide range of symptoms including problems with memory, thinking, concentration, language or social skills. People may become confused or struggle with how they perceive things. Dementia can also cause changes in mood or emotions and can affect how a person behaves. Because dementia has a slow onset and is a progressive disease, symptoms begin gradually and worsen over time. This means that many people with dementia lead active and fulfilling lives for many years following their diagnosis.

There are many different types of dementia. The most common are Alzheimer’s disease and vascular dementia. These two conditions sometimes occur at the same time. This is known as mixed dementia. Other dementia types include Lewy body disease and frontotemporal dementia.

There are also some rarer conditions that cause dementia. Together, they account for only about five per cent of all people living with dementia. Various factors increase a person’s risk of developing dementia. Ageing, genes, health and lifestyle all play a part. There are a few very rare forms of inherited dementia. However, even if several members of the same family are affected, this does not usually mean the dementia is inherited.

Dementia is most common in people aged 65 and over, but it does also affect younger people. The term ‘younger onset dementia’ is used to describe any form of dementia that develops in people under the age of 65. Some people experience what is known as mild cognitive impairment. This is a condition that results in significant memory loss, but does not result in the loss of other cognitive functions. While people with mild cognitive impairment are more likely to develop dementia than other people in the same age group, mild cognitive impairment does not always lead to dementia or can take many years to do so.
What is dementia?
The word dementia describes a group of symptoms that may include memory loss, difficulties with planning, problem-solving or language, and sometimes changes in mood, personality or behaviour. It is a progressive illness, meaning symptoms gradually worsen over time. The medical term for dementia is Major Neurocognitive Disorder.

Dementia isn’t a natural part of ageing. It occurs when the brain is affected by a disease.

There are many known types of dementia – probably more than 100. The most common type is Alzheimer’s disease. To find out more, see Types of dementia on page 19.

About dementia:

• As of 2016, we estimate there to be more than 353,800 Australians living with dementia.
• The chance of developing dementia increases significantly with age. Three in ten people over the age of 85 and almost one in ten people over the age of 65 have dementia. It is more common among women than men.
• There are approximately 25,100 Australians aged 65 and under currently living with younger onset dementia.

No two people experience dementia in the same way. Many factors can affect a person’s experience including age, the type of dementia, cultural or religious background, and the presence of other health conditions.

What are the symptoms?
While every person’s experience of dementia is different, some common symptoms are listed below.

Memory loss:
• problems recalling things that happened recently (although some people easily remember things from a long time ago)
• repeating yourself (such as asking the same question a number of times)

Difficulty thinking things through and planning:
• issues concentrating, following a series of steps, grasping new ideas or solving problems
• struggling with familiar daily tasks, such as following a recipe or using a debit or credit card

Problems communicating:
• difficulty finding the right words, struggling to follow a conversation or misinterpreting things

Being confused about time or place:
• losing track of the time, date or season
• not knowing where you are, even in a place you know well

Sight and visual difficulties:
• difficulty judging distances
• misinterpreting patterns or reflections in mirrors

Mood changes or difficulties controlling emotions:
• becoming unusually sad, frightened, angry or upset
• losing interest in things and becoming withdrawn
• losing initiative
• lacking self-confidence

Personality or behaviour changes:
• disinhibition
• aggression
• repetitive behaviour

For more information see Help Sheet, About dementia 2: Diagnosing dementia. Available at fightdementia.org.au

Call the National Dementia Helpline on 1800 100 500

For more information visit fightdementia.org.au
Changes over time

Dementia is generally progressive, which means symptoms gradually worsen over time. How quickly it progresses varies greatly from person to person. A lot of people with dementia can maintain their independence for many years.

In the middle and later stages of dementia, people will need more support with activities like cooking, or personal care such as washing and dressing. Dementia does shorten life expectancy, although some people live with it for many years. It is now the second leading cause of death in Australia.

At each stage there will be ways to make life better. To find out more, see Living well on page 53, Services for people with dementia on page 91 and Support for carers on page 101.

What are the causes?

Dementia is caused by physical changes in the brain. As dementia progresses, the structure and chemistry of the brain changes, leading to the damage and gradual death of brain cells.

Damage to different parts of the brain will have different effects. For example, in one area it might affect short-term memory, while in another it might affect a person’s ability to organise things.

To find out more about changes to the brain, see Types of dementia on page 19.

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

Alzheimer’s disease is one type of dementia, but there are many different types. We hear more about Alzheimer’s disease because it is the most common type of dementia.

Dementia can sometimes be hereditary, but this is quite rare. The vast majority of dementia cases are not caused by genetics. Dementia is so common that having several close relatives with the disease is not evidence of a genetic link.

Sometimes, gene variations exist that do not inevitably lead to a person developing dementia, but they can increase the risk of developing it. These are known as susceptibility or risk genes. For more information, speak to your GP or medical specialist.

Importantly, scientific research suggests that living a brain healthy life, particularly during mid-life, may reduce a person’s risk of developing dementia.

Your Brain Matters™ is an Alzheimer’s Australia program that guides people on how to look after their brain health. Being brain healthy is relevant at any age, whether you’re young, old or in between.

For more information visit our website yourbrainmatters.org.au

While a brain healthy lifestyle can reduce a person’s risk of developing dementia, there are no guarantees. Sometimes, people who follow the principles of a brain healthy lifestyle will still develop dementia.

Types of dementia

There are many known types of dementia. Around 95 per cent of people with a diagnosis will have one of the four main types – Alzheimer’s disease being the most common, and vascular dementia (or a combination of these two conditions, known as mixed dementia), Posterior Cortical Atrophy and Lewy body disease or frontotemporal dementia – all described on the following pages.

For more information see Help Sheet, About dementia 1: What is dementia? Available at fightdementia.org.au
Alzheimer’s disease

Inside the brain
Abnormal proteins known as ‘plaques’ and ‘tangles’ build up in the brain, disrupting how nerve cells work and communicate with each other. The affected nerve cells eventually die.

There is also a shortage of some important chemicals in the brain when someone has Alzheimer’s disease. Reduced levels of these chemicals mean messages don’t travel around the brain as well as they should.

Early symptoms
Alzheimer’s disease usually begins gradually with mild memory loss. This is because the first changes are often in the part of the brain that controls memory and learning. A person with Alzheimer’s disease might repeat what they have previously said, or forget where they have put things. They might also have problems with language, such as finding the right word or forgetting people’s names.

Other early symptoms include feeling confused or finding it hard to follow what is being said. Some everyday activities might seem challenging, and some people might become more withdrawn and/or experience mood swings.

For more information see Help Sheet, About dementia 13: Alzheimer’s disease. If you would like to watch a short video about Alzheimer’s disease, visit helpwithdementia.org.au

Vascular dementia

Inside the brain
The word ‘vascular’ relates to blood vessels. Vascular dementia results from problems with the blood supply to the brain. Without enough blood, brain cells can die.

There are several types of vascular dementia. One type is caused by stroke (called stroke-related dementia). Another is caused by poor blood supply to deep parts of the brain often due to narrowing of the arteries supplying blood to the brain (called subcortical vascular dementia).

Strokes happen when a blood clot blocks the flow of blood to part of the brain, or when a blood vessel in the brain bursts. Vascular dementia sometimes follows a large stroke. However, more often it occurs after a number of small strokes (called multi-infarct dementia).

Early symptoms
The symptoms of vascular dementia will depend on which part of the brain has been damaged. Some people might experience physical weakness on one side due to a stroke. Other changes could include difficulty thinking quickly or concentrating, and short periods of confusion. Some people might also become depressed or anxious. Memory loss isn’t always a common early symptom of vascular dementia.

Vascular dementia usually progresses in stages. A person’s abilities will deteriorate following one stroke before stabilising until another stroke occurs. If further strokes do not occur, abilities may not continue to decline, or they might improve. However, these improvements may not last.

On average, people with vascular dementia decline more rapidly than people with Alzheimer’s disease.

For more information see Help Sheet, About dementia 16: Vascular dementia. Available at fightdementia.org.au If you would like to watch a short video about vascular dementia, visit our website helpwithdementia.org.au

Lewy body disease

Inside the brain
This form of dementia gets its name from tiny structures called Lewy bodies that sometimes develop inside brain cells. Similar to the plaques and tangles associated with Alzheimer’s disease, these structures disrupt the way the brain functions, reducing levels of chemical messengers and causing cells to die.

Mixed dementia

Some people may have more than one form of dementia. This is called mixed dementia. It might contain elements of Alzheimer’s disease with vascular dementia, or Alzheimer’s disease with Lewy body disease.

For more information visit fightdementia.org.au
Lewy bodies are also found in people with Parkinson’s disease. In Parkinson’s disease, the deeper parts of the brain responsible for controlling movement are affected initially by the Lewy bodies. Conversely, with Lewy body disease, these structures start in the surface part of the brain, and cause problems with thinking.

It is possible that people with Parkinson’s disease may develop a type of dementia known as Parkinson’s disease dementia, which occurs when a person has been living with Parkinson’s disease for several years.

**Early symptoms**

People who have Lewy body disease might find it hard to remain alert and have problems planning ahead, reasoning and solving problems. These symptoms can vary a lot from one day to the next.

People might also experience problems with how they see things. It might be hard to judge distances or they might mistake one object for another. Some people see things that aren’t really there (visual hallucinations) and disturbed sleep patterns are also common.

However, if someone has Lewy body disease, their memory will often be affected less than someone with Alzheimer’s disease.

Many people that have Lewy body disease also develop symptoms similar to those associated with Parkinson’s disease, including tremors, stiffness and difficulties moving around. These occur as the Lewy bodies spread to the deeper parts of the brain.

For more information see Help Sheet, About dementia 20: Lewy body disease. Available at fightdementia.org.au. If you would like to watch a short video about Lewy body disease, visit our website helpwithdementia.org.au

**Frontotemporal dementia**

**Inside the brain**

The term frontotemporal dementia covers a range of conditions. Although it does affect older people, frontotemporal dementia is more likely to affect people in their 40s, 50s and 60s (younger than most people who get Alzheimer’s disease or vascular dementia).

It is caused by damage to areas of the brain called the frontal and temporal lobes. These areas control behaviour, emotional responses and language skills. Abnormal proteins collect within brain cells in each of these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected.

There are many different forms of frontotemporal dementia. The most common forms include behavioural variant, semantic dementia and progressive non-fluent aphasia. There are also a number of other syndromes that overlap with frontotemporal dementia.

**Early symptoms**

With behavioural variant frontotemporal dementia, changes in personality or behaviour are often noticed first. The person might seem withdrawn or not to care as much about other people. They might make socially inappropriate remarks. They may also become obsessive or impulsive.

When someone has semantic dementia their speech is usually fluent, but they lose their understanding of some words. Language is also affected in progressive non-fluent aphasia. Speech is often slow and requires a lot of effort.

People in the early stages of frontotemporal dementia often don’t experience day-to-day memory loss.

For more information see Help Sheet, About dementia 17: Frontotemporal dementia. Available at fightdementia.org.au. If you would like to watch a short video about frontotemporal dementia, visit our website helpwithdementia.org.au

**Posterior Cortical Atrophy**

**Inside the brain**

Posterior Cortical Atrophy is a progressive condition involving the loss and dysfunction of brain cells particularly at the back (or posterior) of the brain. Consequently, brain tissue in the outer layer shrinks.

In the majority of cases, this loss of brain cells is associated with the same brain changes seen in Alzheimer’s disease, namely ‘plaques’ and ‘tangles’. In other words, Posterior Cortical Atrophy is generally considered to be an unusual variant of Alzheimer’s disease.
Early symptoms

Despite being caused by the same disease process, the effects of Posterior Cortical Atrophy and Alzheimer’s disease on behaviour and thinking can be very different.

Alzheimer’s disease is most commonly associated with deterioration in memory, language, perception and other abilities. People living with Posterior Cortical Atrophy, however, tend to have well preserved memories and language skills, but instead show a progressive decline in visual processing and/or literacy and numeracy skills such as spelling, writing and arithmetic.

For more information on Posterior cortical atrophy see Help Sheet, About dementia 22: Posterior cortical atrophy. Available at fightdementia.org.au

Dementia in younger people (younger onset dementia)

There are currently over 25,000 Australians under the age of 65 living with dementia. The term ‘younger onset dementia’ is used to describe their diagnosis. People under the age of 65 may develop any type of dementia, but the most common form amongst this group is Alzheimer’s disease. Some of the other types of dementia commonly diagnosed in people with younger onset dementia are:

• vascular dementia
• frontotemporal dementia
• Posterior Cortical Atrophy
• alcohol-related dementia
• Parkinson’s disease with dementia
• Lewy body disease
• Huntington’s disease
• multiple sclerosis
• HIV associated dementia
• Creutzfeldt-Jacob disease
• dementia after head injury
• dementia in Down syndrome

In some cases, younger onset dementia has been found to have a genetic link. This is known as Familial Alzheimer’s disease. If a parent has a mutated gene that causes Familial Alzheimer’s disease, each of their children will have a 50% chance of inheriting it. The presence of this gene means the person will eventually develop Alzheimer’s disease, usually in their 40s or 50s. This form of Alzheimer’s disease affects an extremely small number of people – probably no more than 100 across Australia at any one time.

People with younger onset dementia often struggle to get a diagnosis, with the disease frequently misdiagnosed as a psychiatric condition. The person will receive psychiatric treatment until it is discovered they have dementia.

While many of the symptoms between younger and older people with dementia are similar, people with younger onset dementia will often have very different support needs.

They are more likely to be strong and healthy physically, in full time employment, raising a family and perhaps looking after elderly parents. Many will have a mortgage or other financial commitments, and may have planned a future based on retiring at the age of 65. Younger onset dementia can therefore have significant financial and lifestyle implications. In addition, people with the condition may encounter misunderstanding, as many people do not expect to see dementia in younger people.

People with younger onset dementia might also have different interests and expectations of how they can continue to live well with dementia. Accessing some supports and services may prove to be a challenge because of their age.

For information on the support services available to people living with younger onset dementia, see Services for people with younger onset dementia on page 97.

For more information see Help Sheet, About dementia 21: Younger onset dementia. Available at fightdementia.org.au
Rarer causes of dementia

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

These diseases 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

Disease progression

By learning what to expect as dementia progresses, you can develop strategies to help you manage potential future challenges.

Symptoms and disease progression vary between individuals. No two cases are the same.

But despite the variations between different types and symptoms of dementia, most dementias have a gradual onset, are progressive in nature and are irreversible.

The course of dementia is often characterised as occurring in three stages:
- In mild or early-stage dementia there might be problems with memory, but the person can still function with minimal support.
- In moderate or middle-stage dementia difficulties become more obvious and severe, and increasing levels of support are required to help the person maintain their functioning in the home and community.
- Severe or late-stage dementia is characterised by almost total dependence on care and supervision by others.

Mild cognitive impairment

Mild cognitive impairment is generally defined as significant memory loss without the loss of other cognitive functions. People with mild cognitive impairment have more memory problems than would usually be found in people of a similar age, are able to function independently and do not show other signs of dementia.

Typical symptoms associated with mild cognitive impairment include trouble remembering names or the flow of a conversation, and a greater tendency to misplace things. People with mild cognitive impairment can usually accomplish all of their daily tasks, but often compensate for their memory problems by relying on prompts such as reminder notes or calendars.

It is currently estimated that people with mild cognitive impairment are three to five times more likely to develop dementia than other people in the same age group. However, mild cognitive impairment does not always lead to dementia or can take many years to do so.

There is currently no medical treatment for mild cognitive impairment. However, cognitive training such as exercising the mind and memory can help reduce the symptoms, or the risk of developing mild cognitive impairment in the first place. It is important to maintain a healthy diet, take regular physical exercise and maintain good general health, particularly when it comes to controlling blood pressure and cholesterol levels, and stopping smoking.

In most cases a person diagnosed with mild cognitive impairment will not undergo any medical treatment, but will be monitored for changes in their memory. Counselling may assist people with mild cognitive impairment to find ways of adjusting to changes and to learn about ways to compensate for their memory difficulties.

The medical term for mild cognitive impairment is Minor Neurocognitive Disorder.