



DementiaUK
Helping families face dementia

What is dementia?



Dementia is an umbrella term for a range of progressive conditions that affect the brain. The brain is made up of nerve cells (neurones) that communicate with each other by sending messages.

Dementia damages these nerve cells so messages cannot be sent effectively, which prevents the brain from functioning normally.

There are over 200 subtypes and causes of dementia. The four most common are:

- Alzheimer's disease
- vascular dementia
- frontotemporal dementia
- Lewy body dementia

It is possible to have more than one type of dementia at the same time – this is known as mixed dementia. The most common is a combination of Alzheimer's disease and vascular dementia.

Dementia can affect a person at any age but it is more commonly diagnosed in people over the age of 65 years, with the risk increasing the older a person gets. However, around 70,800 people in the UK live with young onset dementia,

where symptoms develop before the age of 65. Please see Sources of support on p11 for our information on young onset dementia.

A very small number of cases of dementia are due to genetic mutations, such as some forms of frontotemporal dementia, Huntington's disease and rare varieties of Alzheimer's disease. However, for most people, dementia is not inherited.

Symptoms of dementia

Every person will experience dementia in their own unique way but the main symptoms include:

Memory problems

People with dementia might:

- have problems retaining new information
- get lost in familiar places
- struggle to remember names of people and objects
- become increasingly forgetful
- misplace things regularly



**Cognitive ability
(processing information)**

People with dementia may:

- have difficulties with concentration and short-term memory
- have problems understanding time and place, eg getting up in the middle of the night to go to work, even if they are retired
- struggle with choosing items when shopping and and paying
- have difficulty with reasoning
- have problems making decisions

Some people with dementia feel a sense of restlessness and prefer to keep moving than sit still; others may slow down and lack the

motivation to take part in activities they used to enjoy.

Communication

People with dementia may:

- repeat themselves often
- have difficulty finding the right words
- struggle with reading, writing and numeracy
- lose interest in seeing others socially

Following and engaging in conversation can be difficult, so a formerly outgoing person might become more introverted. Their self-confidence might also be affected.

Mood and behaviour

People with dementia might develop changes in personality, behaviour and mood, and may experience anxiety and depression as a result of the changes they are going through and their effect on their life.

Types of dementia

Alzheimer's disease

Alzheimer's disease is the most common type of dementia in the UK. It is caused by a build-up of proteins in the brain, resulting in 'plaques' and 'tangles' which damage the brain cells' ability to transmit messages.

In the early stages, the symptoms of Alzheimer's disease include:

- forgetting recent events and conversations
- misplacing items or putting them in the wrong place
- forgetting the names of people, places or objects
- struggling to find the right words
- repeating themselves
- mood changes

- becoming withdrawn
- feeling unsettled by unfamiliar situations or changes in routine

As Alzheimer's disease progresses, you may notice:

- increasing confusion
- hallucinations and delusions
- disturbed sleep
- increasing speech and language difficulties
- difficulty with spatial awareness, eg judging speeds and distances

Eventually, the person may experience:

- distressed or aggressive behaviour
- problems swallowing and eating
- incontinence
- loss of speech
- mobility problems
- frailty

Medication is available which may help to improve symptoms and slow progression, but it does not prevent or cure Alzheimer's disease and is not suitable for everyone with the diagnosis.



Please see Sources of support on p10 for more information on Alzheimer's disease.

Vascular dementia

Vascular dementia is the second most common type of dementia. It is caused by problems in the blood supply to the brain cells, commonly due to strokes or a series of 'mini strokes', known as transient ischaemic attacks (TIAs), which cause areas of localised cell damage in the brain.

Changes in a person's condition as a result of TIAs or a larger stroke are often sudden; their condition may then stabilise, before worsening again. While the person may have periods where their symptoms

seem stable, the damage to the brain means they will not function in quite the way they did before.

The symptoms of vascular dementia depend on which area of the brain is affected. Some of the most common include:

- concentration problems
- poor short-term memory
- difficulty with everyday skills
- slowed thought processes
- changes in behaviour and personality
- difficulty solving problems and making decisions and plans
- rapidly changing mood

Please see Sources of support on p11 for more information on vascular dementia.

Frontotemporal dementia

Frontotemporal dementia is an umbrella term for a group of dementias that mainly affect personality, behaviour, language and speech. Memory is usually less affected in the early stages.

Frontotemporal dementia is most common in people aged 45 to 65 years. The areas of the brain most affected are the:

- **frontal lobes:** these are involved in personality, decision-making, social functioning, problem-solving, insight, empathy, motivation and planning. Dementia that predominantly affects the frontal lobes may be known as **frontal dementia, behavioural variant frontotemporal dementia** or **Pick's disease**
- **temporal lobes:** these relate to speech, word-finding, comprehension and language ability. Dementia that predominantly affects the temporal lobes may be known as

semantic dementia or **primary progressive aphasia (PPA)**

Often, the early signs of frontotemporal dementias are missed or mistaken for another condition by the person, their family and health professionals. This may result in a delay in diagnosis – sometimes of several years.

Please see Sources of support on p11 for more information on frontotemporal dementia.

Lewy body dementia

Lewy body dementia is caused by abnormal clumps of proteins, known as Lewy bodies, within the brain. It particularly affects movement and thinking, and can cause hallucinations, fluctuations in alertness and sleep disturbances.

There are two subtypes of Lewy body dementia; the difference between them is when certain symptoms first appear.

In **dementia with Lewy bodies**, the first symptoms include changes in thinking, visual perception and sleep. Difficulties with movement (motor symptoms) may develop at the same time or later.

In **Parkinson's disease dementia**, mobility problems – known as Parkinsonism symptoms – typically develop before changes to memory, concentration or thinking. Not everyone with Parkinson's disease will develop dementia, but the risk increases over time.

Symptoms include:

- falls
- tremors (similar to Parkinson's disease)
- difficulty swallowing

- shuffling when walking
- disrupted sleep due to intense dreams/nightmares
- visual and auditory hallucinations

Memory is often less affected than with other types of dementia, but a person might experience sudden bouts of confusion which can change on an hourly basis.

Please see Sources of support on p11 for more information on Lewy body dementia.



Other forms of dementia

There are many other forms of dementia, or conditions that may lead to dementia, including alcohol-related brain damage (Wernicke's encephalopathy, Korsakoff's syndrome and alcoholic dementia), posterior cortical atrophy and Huntington's disease. You can find links to information on these in Sources of support on p10-11.

Getting a diagnosis

If someone is showing symptoms of dementia it is important to visit a GP as soon as possible. Some conditions have similar symptoms to dementia and may be treatable, so the GP should investigate these first. They include:

- infections
- thyroid problems
- delirium (intense confusion, often caused by an infection or other illness)
- circulation problems
- vitamin B12 deficiency
- sleep apnoea

- stress, anxiety and/or depression

First, the person's GP will take a full medical and family history and do a basic physical examination, including the person's heart rate and blood pressure. They should order blood and/or urine tests and may request other tests such as an ECG (a tracing of heart activity), X-rays and/or a brain scan to look for any underlying physical conditions.

They should also conduct a brief test of memory and cognition, including asking the person to name objects; remember and recall information (such as an address); and complete a simple drawing, eg putting numbers on a clockface.

If other causes of the person's symptoms are ruled out, the GP should refer the person to a memory service/clinic/specialist for further assessment.

If the person is diagnosed with dementia, they may be referred for additional assessments and support, for example from health and social care professionals and voluntary organisations. They



should be told about any specialist advice and support services in their area.

You can also contact our dementia specialist Admiral Nurses for support and advice. Please see Sources of support on p10-11 for their contact details and further information on diagnosing dementia and next steps.

Some people with minor problems with memory and cognition are diagnosed with mild cognitive impairment (MCI) – where the changes are significant enough to be noticed by the person and those around them, but do not interfere

seriously with everyday life. MCI itself is not a form of dementia, but a person with MCI is more likely to be diagnosed with dementia in the future.

Can dementia be prevented?

There is currently no known way to prevent dementia, but you may be able to delay it or reduce the risk by making some changes to your lifestyle, eg:

- eating a balanced, healthy diet
- aiming to maintain a healthy weight – the NHS body mass index (BMI) calculator is a guide:

[nhs.uk/live-well/healthy-weight/bmi-calculator](https://www.nhs.uk/live-well/healthy-weight/bmi-calculator)

- keeping hydrated
- not smoking – you can read NHS stop smoking advice at [nhs.uk/conditions/stop-smoking-treatments](https://www.nhs.uk/conditions/stop-smoking-treatments)
- keeping alcohol intake within recommended guidelines – visit [drinkaware.co.uk](https://www.drinkaware.co.uk) for information
- having regular check-ups with your GP, including blood pressure and cholesterol levels
- staying physically active
- if you have type 2 diabetes, following any advice you have been given to manage this effectively and ensure your blood sugar levels stay under control
- taking part in mentally stimulating activities that use different parts of the brain, such as walking, gardening, singing, art, music, sport, reading, puzzles, or learning a language

Sources of support

To speak to a specialist dementia nurse about any aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video appointment with an Admiral Nurse, please visit [dementiauk.org/book-an-appointment](https://www.dementiauk.org/book-an-appointment)

Dementia UK resources

Alcohol-related brain damage
[dementiauk.org/alcohol-related-brain-damage](https://www.dementiauk.org/alcohol-related-brain-damage)

Alzheimer's disease
[dementiauk.org/alzheimers-disease](https://www.dementiauk.org/alzheimers-disease)

Emotional impact of a dementia diagnosis

dementiauk.org/emotional-impact

Frontotemporal dementia

dementiauk.org/frontotemporal-dementia

Getting a diagnosis of dementia

dementiauk.org/getting-a-diagnosis-of-dementia

Getting a diagnosis of young onset dementia

dementiauk.org/young-onset-dementia-getting-a-diagnosis

Huntington's disease

dementiauk.org/huntingtons-disease

Lewy body dementia

dementiauk.org/dementia-with-lewy-bodies

Posterior cortical atrophy

dementiauk.org/posterior-cortical-atrophy

Next steps after a dementia diagnosis

dementiauk.org/after-a-diagnosis

Next steps after a young onset dementia diagnosis

dementiauk.org/young-onset-dementia-next-steps

Parkinson's disease

dementiauk.org/parkinsons-disease

Tests for dementia

dementiauk.org/tests-for-dementia-and-alzheimers

Vascular dementia

dementiauk.org/vascular-dementia

Young onset dementia section

dementiauk.org/young-onset-dementia

Other resources

Huntington's

Disease Association

hda.org.uk

Lewy Body Society

lewybody.org

Parkinson's UK

parkinsons.org.uk

Rare Dementia Support

raredementiasupport.org

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

Publication date: March 2023

Review date: March 2025

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.

Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.
Helpline: **0800 888 6678** or helpline@dementiauk.org
Virtual clinics: dementiauk.org/book-an-appointment



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