

ALL ABOUT DEMENTIA





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INTRODUCTION

This information is for anyone who wants to know more about dementia and the diseases that cause it. This includes people living with dementia, their carers, friends and family.

This booklet introduces the four most common types of dementia - Alzheimer's disease, dementia with Lewy bodies, vascular dementia and frontotemporal dementia.

It covers:

- what they are
- typical symptoms
- causes
- diagnosis.

There is also information about how you can help lower your risk of developing dementia, and what support is available to people with dementia and their families.

The information here does not replace any advice that doctors, pharmacists or nurses may give you. If you are worried about your health, including memory and thinking problems, speak with your doctor as soon as possible.

This booklet was updated in November 2022 and is due to be reviewed in November 2024. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers. Please get in touch using the contact details below if you'd like a version with references or in a different format.

ANY QUESTIONS

If you have questions about dementia or dementia research, or any feedback on this booklet, you can contact the Dementia Research Infoline on **0300 111 5111**. You can also email infoline@alzheimersresearchuk.org or write to us using the address on the back page.

WHAT IS DEMENTIA?

Dementia is not a disease itself. It is a word used to describe a group of symptoms that occur when brain cells stop working properly. This happens to specific areas of the brain that control how you think, remember and communicate.

Common dementia symptoms include the gradual loss of memory, a decline in communication skills and difficulty with thinking and problem solving. Dementia is caused by diseases that affect the brain.

Alzheimer's disease is the most common cause of dementia, accounting for about two in every three cases in people over 65. After Alzheimer's disease, the most common types of dementia are vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Other causes include Parkinson's disease dementia, posterior cortical atrophy and primary progressive aphasia.

It is possible to have more than one of the diseases that cause dementia at the same time. This is called 'mixed dementia'. The most common mixed dementias are Alzheimer's with vascular dementia, or with dementia with Lewy bodies.

There are many other rarer types of dementia, such as Creutzfeldt-Jakob disease (CJD), HIV/AIDS and alcohol-related dementia. You can find out more about these on our website or by calling us.

Dementia affects almost one million people in the UK. Most people with dementia are over 65 years old, but more than 42,000 people under 65 have dementia too. When dementia affects people under the age of 65 it is often called young onset dementia, or early onset dementia. The most common causes are young onset Alzheimer's disease and frontotemporal dementia. A range of other rarer conditions may also cause young onset dementia.

DEMENTIA AFFECTS AROUND ONE MILLION PEOPLE IN THE UK. IT'S CAUSED BY DISEASES LIKE ALZHEIMER'S, WHICH DAMAGE BRAIN CELLS AND STOP THEM FROM WORKING.



I KEEP FORGETTING THINGS. HAVE I GOT DEMENTIA?

Most of us forget things every day, like people's names or where we put our keys, but this is not necessarily a sign of Alzheimer's disease or another type of dementia. For a person with dementia, memory loss is more serious than forgetting things occasionally and begins to affect everyday life.

There are many reasons why people become forgetful. Some medications can affect our memory, as can underlying infections such as urinary infections. Depression, anxiety, vitamin deficiency and thyroid problems can also cause forgetfulness and problems with concentration.

Your doctor can run tests to detect and treat some of these problems and so it is important to contact them if you have any concerns about your memory.

MILD COGNITIVE IMPAIRMENT

Many people have a natural decline in memory and thinking as they get older. In some people this is a sign of a condition called mild cognitive impairment (MCI), where problems with memory are worse than expected for their age. However, these problems do not tend to get in the way of a person's day-to-day life.

MCI can be caused by a range of underlying conditions and may or may not get worse over time. MCI does not always lead to dementia. But it could indicate the early stages of a disease like Alzheimer's. For more information, you can request our booklet 'What is mild cognitive impairment?'

If you are worried about your memory, if it is getting worse, or interfering with everyday life, you should talk to your doctor.

Dementia often develops slowly and is not always obvious in the early stages. Symptoms similar to dementia can be seen in other illnesses. Sometimes it can be difficult to tell the difference between dementia and the usual mild forgetfulness seen in normal ageing.

IF YOU ARE WORRIED ABOUT SYMPTOMS YOU SHOULD TALK TO YOUR DOCTOR AS SOON AS POSSIBLE, GETTING A DIAGNOSIS IS IMPORTANT.

DEMENTIA SYMPTOMS

You should see your doctor if you or your family and friends are worried about any changes in:



Memory



Personality and mood



Ability to carry out daily tasks



Concentration and thinking skills



Behaviour



Balance and movement problems

Your doctor will be able to assess your symptoms and, if necessary, refer you to a specialist. Diagnosing dementia early is important to allow you to get the right help and treatments and to plan for the future.

Everyone with dementia will experience symptoms in their own way, and every person's progression is unique. While the different diseases that cause dementia can have different symptoms to each other early on, sometimes these can overlap, making it hard to tell them apart and get an accurate diagnosis. Where possible, diagnosing which disease is causing a person's dementia symptoms as early as possible is important as it changes the treatment options available.

ALZHEIMER'S DISEASE

Alzheimer's disease is the most common type of dementia, accounting for two in every three cases. Symptoms are often subtle to begin with and can be mistaken for other conditions like depression and anxiety.

Typical symptoms of Alzheimer's include:

- **Regularly forgetting recent events**, names and faces.
- **Becoming increasingly repetitive**, e.g. repeating questions after a very short interval.
- **Regularly misplacing items** or putting them in odd places.
- **Getting confused** about the date or time of day.
- **Being unsure of where you are** or getting lost more often.
- **Having problems finding the right words.**
- **Changes in mood or behaviour** such as loss of interest in daily activity, becoming easily upset and annoyed or losing confidence.

VASCULAR DEMENTIA

Vascular dementia can have many different symptoms depending on the area of the brain affected. Sometimes the early symptoms of vascular dementia may be similar to those of Alzheimer's disease, but they can also affect someone more physically and include problems with walking, movement and speech. The first symptoms of vascular dementia typically appear gradually but, in some cases can develop suddenly depending on the cause.

Symptoms of vascular dementia can include:

- **Memory problems** that affect your everyday life.
- **Slower thinking**, taking more time to process information, follow instructions or to plan ahead.
- **Speech difficulties**, struggling to find the right words, slurring speech or difficulty following conversations.
- **Personality changes** – People may become low in mood, have reduced motivation or lose interest in what's happening around them.
- **Movement problems and instability**, difficulty or unsteadiness walking or changes in the way a person walks.
- **Problems with bladder control.**



DEMENTIA WITH LEWY BODIES

Dementia with Lewy bodies (also known as DLB or Lewy body dementia) is thought to affect about 125,000 people in the UK.

Symptoms of DLB can include:

- **Changes in attention, alertness and level of confusion.** These variations can be very noticeable from day to day or even hour to hour.
- **Parkinson's type symptoms**, like slowing or difficulty walking, stiffness in the arms and legs and sometimes shaking or trembling.
- **Visual hallucinations.** These can often involve seeing people or animals that are not really there.
- **Movements and talking during sleep**, including acting out dreams.
- **Fainting and falls** due to difficulties with balance.
- **Problems detecting smells.**
- **Symptoms similar to Alzheimer's**, including memory loss and disorientation.

FRONTOTEMPORAL DEMENTIA

The term frontotemporal dementia (FTD) is used to describe a number of different diseases. These include behavioural variant FTD and primary progressive aphasia, which affects speech and language. FTD is quite rare and most commonly affects people aged 45-64.

Symptoms of FTD can include:

- **Changes in emotions.** This may include a change in how people express their feelings towards others or a lack of understanding of other people's feelings.
- **Lack of interest.** People may become withdrawn or lose interest in looking after themselves, perhaps not maintaining their normal level of personal hygiene.
- **Inappropriate behaviour.** This might include making inappropriate jokes or being insensitive. Humour or sexual behaviour may change. Some people become impulsive or easily distracted.
- **Overeating** or changes in what people choose to eat.
- **People may develop unusual beliefs,** interests or obsessions.
- **Difficulty with simple plans and decisions.**
- **Not being aware of changes** to their own personality or behaviour.
- **Decline in language and communication abilities.** For example, problems speaking or understanding words, repeating common words and phrases, or forgetting the meaning of words.
- **Difficulty recognising people** or knowing what everyday objects are for.
- **Movement problems,** including stiff or twitching muscles, muscle weakness and difficulty swallowing.

CHANGES TO BEHAVIOUR, EMOTIONS AND COMMUNICATION ARE COMMON SYMPTOMS OF FRONTOTEMPORAL DEMENTIA.

HOW DEMENTIA PROGRESSES

The diseases that cause dementia mentioned in this booklet are all neurodegenerative diseases. This means that the symptoms get worse over time.

Everybody is unique and is affected in their own way. The speed of change varies from person to person and between different diseases, but in most dementias, symptoms progress slowly over several years.

As dementia progresses:

- **Memory and thinking skills.** People find that their ability to remember, think and make decisions worsens.
- **Communication and understanding** words often becomes more difficult.
- **Behaviour and personality.** A person's behaviour may change, and some people can become withdrawn or depressed. Anxiety is also common.
- **Recognition.** People may have difficulty recognising household objects or familiar faces.
- **Restlessness.** Problems with sleeping and restlessness at night may occur.
- **Anger.** Anger or agitation can be common in the later stages of dementia.
- **Unsteadiness.** It is common for people to be unsteady on their feet and fall more often.
- **Extra help.** Gradually people require more help with daily activities like dressing, going to the toilet and eating.

Across the UK there are local services and support groups for people living with dementia and their carers. You can contact the organisations on page 16 to find out about support in your area.

DIAGNOSING DEMENTIA

Your doctor is the first person to contact if you are concerned about dementia symptoms. If the doctor suspects dementia, you might be referred to a memory clinic or specialist doctor. These specialists include psychiatrists, geriatricians, neurologists, clinical psychologists and memory nurses.

When you see a doctor or nurse, they will ask you about your symptoms and how they are affecting you. They may also speak with your partner or someone close to you about your symptoms. You will be asked some questions relating to your memory and may have a physical check-up.

There are a range of memory tests available, and you might have one or more of these during your assessment. As dementia gets worse over time, the tests may be repeated every six to 12 months to see if there have been any changes. Other tests can help to diagnose the type of dementia someone may have.

These can include:

- a brain scan such as an MRI, CT and PET scan.
- a lumbar puncture (spinal tap). In a lumbar puncture, a needle is used to take a sample of fluid from the bottom of someone's spine.

All of these tests will help a specialist doctor find out the likely cause of a person's memory problems.

If you are assessed for the possibility of having Alzheimer's or another type of dementia, you can choose not to know the diagnosis. You can also decide who else can be told about your diagnosis if you choose not to know.

If you, or someone close to you, are given a diagnosis of dementia, you may have many questions about what to do next. You can ask your doctor about local services that can help you and your family. You may be entitled to benefits and other types of support.

WHAT TREATMENTS AND MEDICATIONS ARE AVAILABLE?

There are medications that can help people with some types of dementia, like Alzheimer's disease or dementia with Lewy bodies. There are also different types of treatments and therapies that can help people cope better with their dementia symptoms.

If you or a loved one has been diagnosed with dementia, the treatment you receive will depend on the specific type of dementia that has been diagnosed. If you are unsure what type of dementia you have, you can ask your doctor. Following a diagnosis, you can talk with your doctor about the treatments available and what would be suitable. Together, you can decide which ones might be best for you. You might also like a family member or carer to be involved in these decisions.

You can request our booklet '**Treatments for dementia**' which gives a detailed explanation of medications and treatments used for different types of dementia. Call us on **0300 111 5111**, use the information the page to order one, or download a copy from our website alzheimersresearchuk.org

Unfortunately, current treatments cannot stop the diseases that cause dementia from progressing, so people will continue to get worse over time. This is because medications available now cannot fix damage to brain cells that has already happened or stop further damage from happening. This is why ongoing research and the projects we fund are so important. Research is the only path to slow dementia down and to one day find a cure.

WHAT CAUSES ALZHEIMER'S AND OTHER DEMENTIAS?

The causes of dementia are not yet fully understood but research is making progress. Understanding the causes of dementia is essential for developing new treatments.

ALZHEIMER'S DISEASE

Scientists know that in Alzheimer's disease, two proteins build up abnormally in the brain. They are called amyloid and tau which form clumps called 'plaques' and 'tangles'. These interfere with the way brain cells work and communicate with each other. The plaques are usually first seen in the area of the brain that makes new memories. A lot of research is focused on finding ways to stop the build-up of these proteins and protect brain cells from harm.

In people who develop Alzheimer's disease over the age of 65, what causes these proteins to build up is thought to be a complex mixture of our age, genetics and lifestyles. Researchers are working hard to understand more about how these factors interact in the development of Alzheimer's.

DEMENTIA WITH LEWY BODIES

In dementia with Lewy bodies there are small clumps of protein that build up inside brain cells. One of these proteins is called alpha-synuclein and the clumps it forms are called Lewy bodies. People with Parkinson's disease also have a build-up of Lewy bodies in brain cells that control our movement. Some people with Parkinson's disease will also go on to develop dementia symptoms too.

The protein clumps damage the way brain cells work and communicate with each other. The brain cells affected by Lewy bodies control thinking, memory and movement. Researchers are working hard to understand how the protein builds up and discover ways to stop it causing dementia.

VASCULAR DEMENTIA

Vascular dementia is caused by reduced blood flow to the brain. Blood carries essential oxygen and nutrients to the brain, and without them brain cells die. The network of blood vessels that carries blood around the body is called the vascular system.

There are different types of vascular dementia that relate to the blood vessel damage causing the disease.

These are:

- **Stroke-related dementia** - is a type of vascular dementia that happens after a stroke, when blood supply to a part of the brain is suddenly cut off. This may cause difficulties with moving, co-ordination, speech, and sight. A stroke can also cause memory loss and problems with attention.
- **Multi-infarct dementia** - is caused by a series of small strokes in the brain, which can happen without a person noticing. Doctors may refer to these as transient ischemic attacks (TIAs).
- **Subcortical vascular dementia** is caused by changes to very small blood vessels in the brain and is often referred to as small vessel disease. Over time, parts of the brain that are important for attention, memory and language become more and more damaged.

FRONTOTEMPORAL DEMENTIA

In frontotemporal dementia (FTD) there are a variety of abnormal proteins that build up in the brain including tau, TDP-43 and FUS. The brain cells affected are in areas called the frontal and temporal lobes. These areas control our personality, emotions and behaviour, as well as our speech and understanding of language. The way that this build-up causes the symptoms of FTD is not yet fully understood and research is ongoing.



DOES DEMENTIA RUN IN FAMILIES?

Our genes naturally vary from person to person. Often this variation has no effect on us, but sometimes our DNA can contain differences that slightly alter the protein made by a particular gene, causing it to work differently.

This can lead to changes in processes in our cells, which may increase (or sometimes decrease) our likelihood of developing a disease. These are known as risk genes.

We inherit risk genes from our parents, but having a certain risk gene does not mean that we will definitely get dementia. This is because a person's risk of developing dementia is a combination of their genes, lifestyle, environment, and age. We cannot change our age or genes, but some research has found that even if you carry a risk gene, there are still things you can do to reduce your risk.

In very rare cases, a person may inherit a gene that does not work properly from one of their parents. This faulty gene, sometimes called a mutated gene, can cause a person to develop a disease no matter what other risk factors they have. Rare types of Alzheimer's disease, and some cases of frontotemporal dementia, can be caused by faulty genes and are passed down from an affected parent. Someone who carries one of these rare mutations is extremely likely to develop the disease during their lifetime. Around 1 in 100 cases of dementia are caused by inherited faulty genes.

If you would like to find out more about genetics and risk, you can request our booklet '**Genes and dementia**'.

AROUND 1 IN 100 CASES OF DEMENTIA ARE CAUSED BY INHERITED FAULTY GENES.

ALL ABOUT RISK

Alzheimer's and other types of dementia are complex diseases. A mixture of our age, genes and lifestyle contribute to our risk of developing dementia.

A risk factor is anything that can increase your likelihood of developing dementia. We can change some of the risk factors, like our diet and the amount we exercise. Other risk factors we cannot change, like our age and our genes. The chances of developing most types of dementia increase with age. This means as we get older, we are more likely to develop the condition. One or two in every 100 people aged 65 to 69 years have dementia, but this figure rises to one in five for those aged 85 to 89.

However, developing dementia is not an inevitable or normal part of getting older. We cannot change our age and there is currently no way we can completely prevent dementia, but there are some simple things we can all do that might help lower our risk of developing diseases like Alzheimer's and vascular dementia.

Some studies suggest that enjoying an active social life, with lots of interests and hobbies, might be beneficial. Other researchers have found that spending more time in education is associated with a lower dementia risk.

There is currently not enough evidence to suggest that food supplements like omega-3 fish oil or vitamins could reduce the risk of dementia. NSAIDs (non-steroidal anti-inflammatory drugs like aspirin or ibuprofen), HRT (hormone replacement therapy) and statins have not yet been found to protect against dementia, but research is continuing in this area. You should talk to your doctor before taking any supplements or drugs that claim to prevent dementia, as most are unproven and can have serious side-effects.

You might read or hear about other risk factors for dementia. Despite occasional publicity, there is no reliable evidence that flu vaccines, exposure to aluminium and living close to power lines are risk factors for dementia. There is also no firm evidence that turmeric, ginkgo biloba, ginseng or coffee can protect against dementia.

For further information contact us for our free **'Reducing your risk of dementia'** booklet.

You can reduce your risk of dementia and keep your brain healthy by:



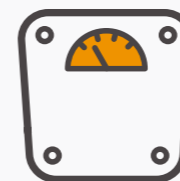
Controlling your blood glucose if you have diabetes



Being physically active



Don't smoke



Maintaining a healthy weight



Managing high blood pressure and high cholesterol



Only drinking alcohol within the recommended limits



Having your hearing checked regularly



Eating a healthy balanced diet



Being socially and mentally active

SUPPORT FOR PEOPLE AFFECTED BY DEMENTIA

Dementia has a huge impact on someone's life, as well as on their family and carers. Accessing services and support can make a positive difference to those affected by dementia.

Some services will be provided by local authorities and others can be arranged through your doctor, or you can contact local authority social services directly. The number will be in the phone book and on your local council website.

Everyone with dementia is entitled to an assessment that establishes their support needs and suggests how those needs can be met.

The following organisations provide information, support and care services to people affected by dementia as well as their families and carers. For more information contact us for our booklet, '**Support for people affected by dementia: organisations that can help**'.

The **Admiral Nurse Dementia Helpline** is supported by the charity Dementia UK. It offers practical and medical advice and emotional support to people affected by dementia on **0800 888 6678**.

The **Age UK** advice line **0800 678 1602** can give you information about help available through social services, as well as advice about other issues faced by older people.

Alzheimer Scotland provides the National Dementia Helpline **0808 808 3000** in Scotland as well as local services all over Scotland for people with dementia and their families.

Alzheimer's Society Dementia Connect service for England, Wales and Northern Ireland. They provide information, support, guidance and signposting to local support services. You can contact them on **0300 150 3456**.

The **Carers Trust** works to improve support, services and recognition for anyone living with the challenges of unpaid caring for a family member. Contact them on **0300 772 9600**.

Carers UK offers advice and information to carers through booklets, factsheets and their website. Their Adviceline can be contacted on **0808 808 7777**.

The **Lewy Body Society** provides support and advice to people with dementia with Lewy bodies, their families and carers. You can contact them on **01942 914 000**.

Parkinson's UK provides support and advice to people with Parkinson's disease, and dementia with Lewy bodies. They also have specialist nurses who can provide medical information. You can contact a helpline advisor on **0808 138 6593**.

Rare Dementia Support runs specialist support services for people living with, or affected by, five rare dementias:

- frontotemporal dementia (FTD)
- posterior cortical atrophy (PCA)
- primary progressive aphasia (PPA)
- familial Alzheimer's disease (FAD)
- familial frontotemporal dementia (fFTD).

They run regular support group meetings and offer newsletters, telephone support and access to information and advice. Call **0203 325 0828** for support. You can also email contact@raredementiasupport.org

TAKING PART IN RESEARCH

Volunteers, both with and without dementia, can take part in research studies or clinical trials that play an essential role in helping scientists to understand dementia and test potential new treatments.

Join Dementia Research is a UK-wide service that allows you to register to take part in dementia research studies. The service will match you to research studies that you are suitable for. If you would like to register to take part visit joindementiaresearch.nihr.ac.uk or call the Dementia Research Infoline on **0300 111 5111**.

You can also ask your doctor about any local research studies you can get involved with.



FIND OUT MORE

If you have questions about dementia, dementia research or how to take part in studies contact the Dementia Research Infoline on **0300 111 5111** or email infoline@alzheimersresearchuk.org. You can also write to us at the address on the back of this booklet.

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages. Interpreter services are available.

RESEARCH

Alzheimer's Research UK has funded over **£171 million** of pioneering research into the causes, diagnosis, prevention and treatment of dementia.

As the UK's leading dementia research charity we've invested in more than 1,000 projects since 1998. Your support has allowed us to fund thousands of dementia researchers based across the UK and the world.

We believe that medical research will deliver life changing preventions and treatments, and better ways to detect and diagnose the diseases that cause dementia.

With continued support, we will fund many more studies into dementia. We promise we will not stop until dementia can no longer destroy lives.

**We are Alzheimer's Research UK.
We exist for a cure.**

Alzheimer's Research UK is the UK's leading dementia research charity. We provide free dementia health information, like this booklet and others.

If you would like to view, download or order any of our other booklets please use the details below. If you'd like to help us review and improve our booklets, visit alzres.uk/reviewer

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alzheimersresearchuk.org/dementia-information

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