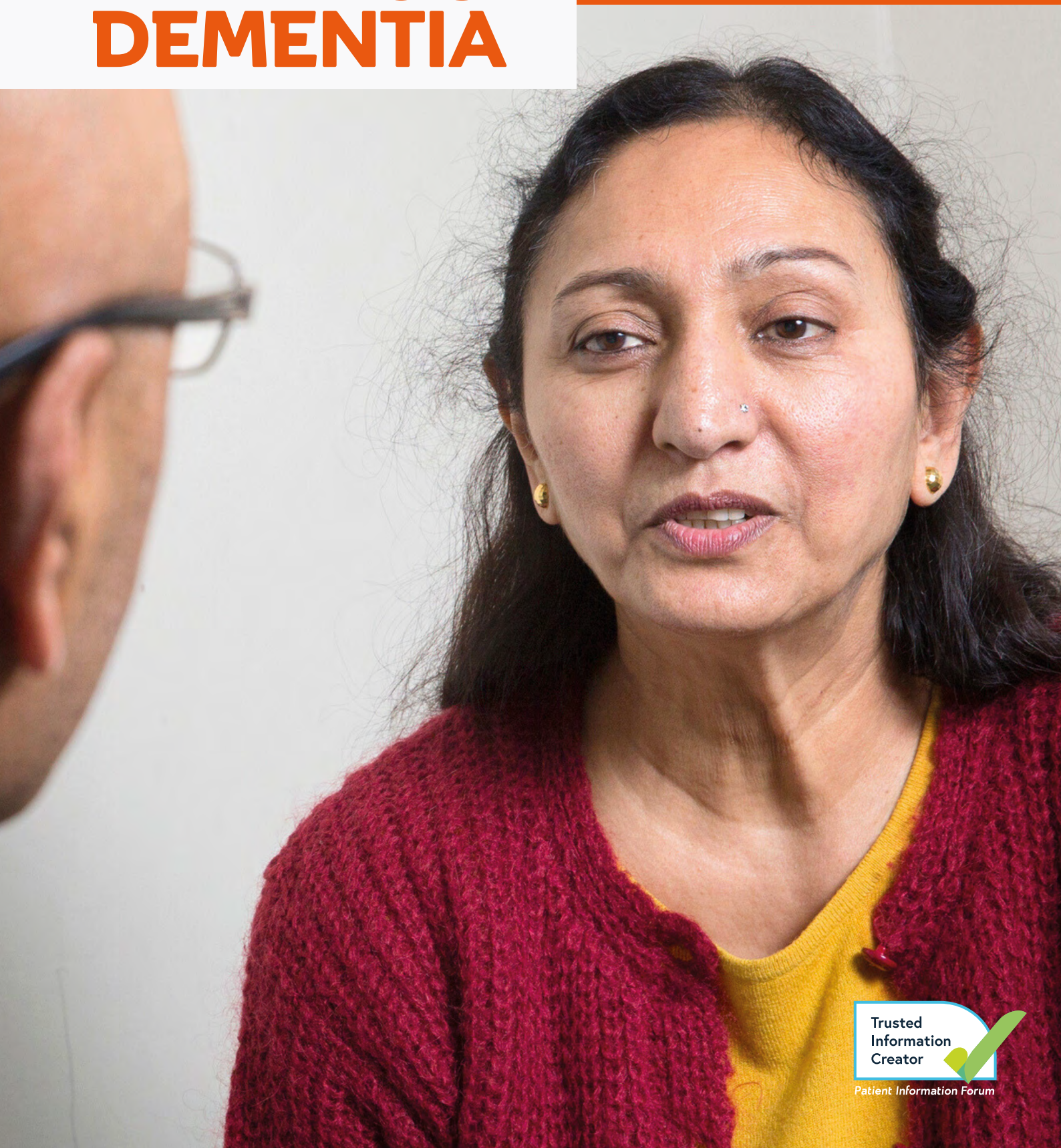


# ALL ABOUT DEMENTIA



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Patient Information Forum

# 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, vascular dementia, dementia with Lewy bodies, 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 2024 and is due to be reviewed in November 2026. 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](mailto:infoline@alzheimersresearchuk.org) or write to us using the address on the back page.

## CONTENTS

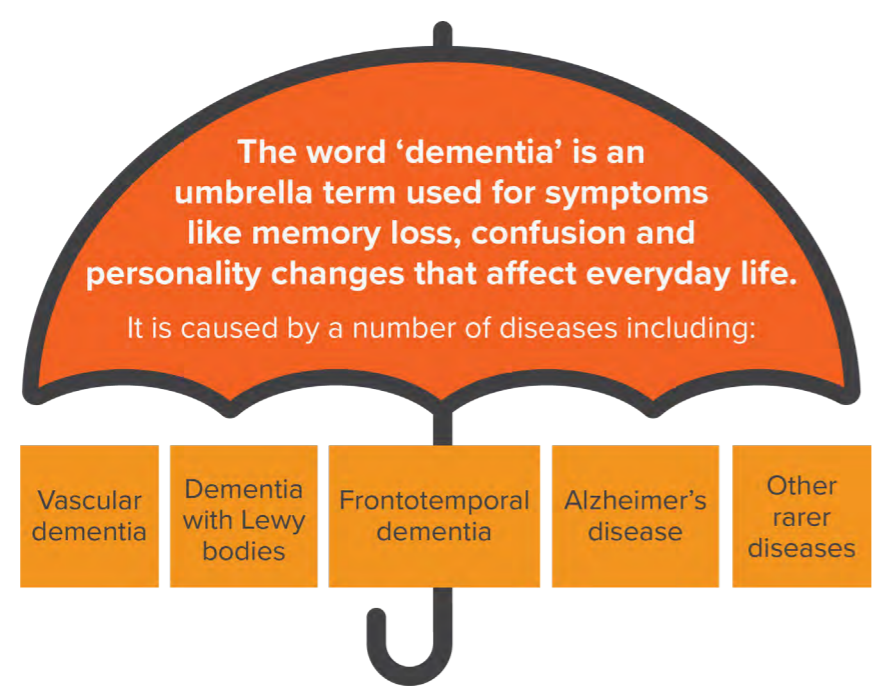
- |   |  |
|---|--|
| <b>03</b> Introduction                                      | <b>14</b> Diagnosing dementia                      |
| <b>04</b> What is dementia?                                 | <b>15</b> What treatments and drugs are available? |
| <b>05</b> I keep forgetting things. Have I got Alzheimer's? | <b>17</b> Does dementia run in families?           |
| <b>06</b> Symptoms  | <b>18</b> All about risk                           |
| <b>07</b> Mild cognitive impairment                         | <b>20</b> Support for people affected by dementia  |
| <b>08</b> Types of dementia                                 | <b>22</b> How to get involved in research          |
| <b>12</b> How dementia progresses                           | <b>23</b> Research                                 |

# 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. Dementia is caused by different diseases that affect the brain.**

Common dementia symptoms include memory problems, a decline in communication skills and difficulty with problem solving. Dementia symptoms get worse overtime.

Dementia affects around one million people in the UK. Most people with dementia are over 65 years old, but it is estimated that around 70,000 with dementia in the UK are under 65. When dementia affects people under 65 it is called young onset dementia.



Alzheimer's disease is the most common cause of dementia, accounting for 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.

There are types of dementia related to other medical conditions like Creutzfeldt-Jakob disease (CJD) and HIV/AIDS. Contact us for information about these or visit our website.

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 Alzheimer's with dementia with Lewy bodies.



**DEMENTIA AFFECTS AROUND ONE MILLION PEOPLE IN THE UK.**

# I KEEP FORGETTING THINGS. HAVE I GOT DEMENTIA?

**Most of us forget a few things every day, like people's names or where we put our keys. This is not necessarily a sign of dementia. For a person with dementia, memory loss and thinking problems are more serious than forgetting things occasionally and problems start to get in the way of everyday life.**

There are many reasons why people become forgetful, it is not always dementia. Common medications and health conditions can affect our memory, as can things like a urinary infection. Your doctor will run tests and treat these problems, and so it is important to contact them if you have any concerns about symptoms you may have.

## DEMENTIA SYMPTOMS

Dementia often develops slowly and is not always obvious in the early stages, but symptoms get worse overtime. 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

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 early on, sometimes these can overlap. This can make it harder to tell them apart and get an accurate diagnosis. Diagnosing the disease which is causing a person's dementia symptoms as early as possible is important as it means you get the right support, treatment and can plan for the future.

Your doctor will be able to assess your symptoms and if needed, refer you to a specialist. If possible, it is helpful if you can bring someone who knows you well to your appointments. They can give information about any changes and symptoms they have noticed.

## MILD COGNITIVE IMPAIRMENT

Many people experience a natural decline in memory and thinking as they get older. Early and mild symptoms might be a sign of a condition called mild cognitive impairment (MCI). This is where problems with memory and thinking are worse than expected for someone's age, but do not tend to get in the way of everyday 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 might be the early stages of a disease like Alzheimer's. If you are worried about your memory, if it is getting worse, or interfering with everyday life, talk to your doctor. For more information, you can request our booklet 'What is mild cognitive impairment?'

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



## ALZHEIMER'S DISEASE

Alzheimer's disease is the most common type of dementia, accounting for two in every three cases.

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.
- **Losing things** 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** including a loss of interest in daily activity, becoming easily upset and annoyed.

In Alzheimer's disease, two proteins called amyloid and tau build up abnormally in the brain. They form clumps called 'plaques' and 'tangles' which interfere with the way brain cells work and communicate with each other. For the majority of cases what causes Alzheimer's disease to develop is a mixture of factors that interact over our lifetime. This includes our age, genes, medical history, lifestyle and environment.



## VASCULAR DEMENTIA

Vascular dementia can affect different areas of the brain, so can have many different symptoms. The early symptoms of vascular dementia may be similar to those of Alzheimer's disease but can also affect someone more physically and include problems with walking, moving and speech.

The first symptoms of vascular dementia usually appear gradually but can develop suddenly in some people, for example after a stroke.

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**, becoming low in mood, reduced motivation or loss of 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.**

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 become damaged and die. The network of blood vessels that carries blood around the body is called the vascular system.

There are different underlying causes of vascular dementia including:

- **Stroke-related dementia** - a type of vascular dementia that develops after a stroke, when blood supply to a part of the brain is suddenly cut off.
- **Multi-infarct dementia** - is caused by a series of small strokes 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.

## DEMENTIA WITH LEWY BODIES

Dementia with Lewy bodies (also known as DLB) is the third most common type of dementia. Around 100,000 people in the UK have DLB.

Symptoms of DLB can include:

- **Memory and thinking problems.**
- **Changes in attention**, alertness and level of confusion. These can be very noticeable from day to day or even hour to hour.
- **Parkinson's type symptoms**, like slowing or difficulty walking, stiffness and 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.
- **Falls** due to difficulties with balance.

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; they disrupt the way brain cells work and communicate with each other which leads to symptoms.

The build-up of Lewy bodies is also found in Parkinson's and leads to symptoms like movement problems and tremors. People who have Parkinson's disease are more likely to go on to develop dementia. This is known as Parkinson's disease dementia (PDD).

As the symptoms are so similar, dementia with Lewy bodies and Parkinson's disease dementia are sometimes grouped together using an umbrella term: Lewy body dementia or LBD.

In most cases a mixture of risk factors leads to the build-up of Lewy bodies including age, genetics, lifestyle and environment.

## 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.** Like a change in expressing feelings or a lack of understanding of other's feelings.
- **Lack of interest**, becoming withdrawn or losing interest in looking after themselves, like not wanting to wash.
- **Changes to behaviour**, like making inappropriate jokes or being insensitive. Some people become impulsive or easily distracted.
- **Developing unusual beliefs**, interests or obsessions.
- **Changes to speech**, language and communication abilities. For example, difficulty speaking or understanding words, or forgetting the meaning of words.
- **Movement problems**, including stiff or twitching muscles, muscle weakness and difficulty swallowing.

In frontotemporal dementia (FTD) there are a variety of abnormal proteins that build up in the brain including tau, TDP-43, and a group of proteins called FET proteins. These disrupt and damage the brain cells in the frontal and temporal lobe areas of the brain. These areas control our personality, emotions and behaviour, as well as our speech and understanding of language.

Some people with FTD may have a strong family history of the condition, and in these cases the disease may be directly inherited. You can find out more about directly inherited dementia in our booklet '**Genes and dementia**', which you can order using the detail on the back of this booklet.

# 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 as the disease spreads and affects more of the brain.

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 types of dementia 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** 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 20 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. They will run some tests to rule out other conditions, check your overall health, ask about your symptoms and do some quick memory and thinking tests.

If they suspect dementia, it's likely you'll be referred to a memory clinic or specialist doctor. Here they will perform more in-depth tests to see what type of dementia you may have. This includes:



**In-depth memory and thinking tests.**



**A brain scan** such as an MRI, CT and PET scan.



**A lumbar puncture**, where a needle is used to take a sample of fluid from the bottom of someone's spine.

The results of all these tests help to find out the likely cause of a person's memory problems. Sometimes, it can be challenging to get an accurate diagnosis. You may need to visit your doctor more than once. Some doctors have different specialities and requesting a second opinion with a different doctor can be helpful.

If you are assessed to have 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.



**IF YOU ARE WORRIED ABOUT YOUR HEALTH, YOU HAVE THE RIGHT TO AN ACCURATE DIAGNOSIS.**

## WHAT TREATMENTS AND MEDICATIONS ARE AVAILABLE?

**People with Alzheimer's disease and dementia with Lewy bodies can be prescribed treatments to help manage their symptoms and alleviate the impact dementia can have on daily life. These treatments do not slow down the progression of the underlying disease, so people continue to get worse over time.**

There are new treatments emerging that are designed to tackle the underlying diseases, to slow down the progression of dementia. Research has shown that these are most effective when given in the very early stages. In 2024, two new Alzheimer's medications, called lecanemab and donanemab, were approved for private use in Great Britain. They were not made available on the NHS.

For people with vascular dementia, treatments focus on managing any underlying conditions that may lead to or contribute to the development of the condition. This includes diabetes, high blood pressure, high cholesterol and stroke.

Unfortunately, there are currently no drug treatments for FTD, but researchers are working hard to develop and test effective treatments for the condition.

Other medications and therapies may be prescribed to ease anxiety and agitation in people with dementia. For people with speech or swallowing difficulties, a speech therapist can help. And for people who have movement symptoms, a referral to a physiotherapist or occupational therapist can help. Complementary therapies – like cognitive therapy, music therapy and aromatherapy can be beneficial for people with dementia and can help to increase wellbeing.

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 back page to order one, or download a copy from our website [alzres.uk/treatment](http://alzres.uk/treatment)



## DOES DEMENTIA RUN IN FAMILIES?

Every cell in our bodies contains thousands of genes. Each gene is a portion of DNA 'code' which holds the information our cells need to make a specific protein. These proteins make up our tissues and organs, and many have specific functions, like carrying messages between our nerve cells.

The DNA code in our genes naturally varies from person to person. Often this variation has no effect on us, but sometimes the DNA code 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.

Inheriting 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 one 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 ONE IN 100 CASES OF DEMENTIA ARE CAUSED BY INHERITED FAULTY GENES.**

# ALL ABOUT RISK

Alzheimer's and other types of dementia are complex diseases. In the majority of cases a mixture of our age, genes, medical history, lifestyle and environment contribute to our risk of developing dementia.

A risk factor is anything that can increase your likelihood of developing dementia. Some risk factors for dementia 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 and there are risk factors we have some control over. While there is currently no way to completely prevent dementia, there are some steps we can all take that will help lower our risk of developing 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:



## KEEPING ACTIVE

Aim for at least 150 minutes of physical activity each week.



## NOT SMOKING

If you smoke, quitting is one of the best things you can do for your brain health.



## CUTTING DOWN ON ALCOHOL

Drink less than 14 units of alcohol per week.



## LOOKING AFTER YOUR MENTAL HEALTH

Speak to your GP or somebody you trust if you have concerns.



## EATING A BALANCED DIET

Try to follow a balanced diet. Only eat high fat and sugary foods as an occasional treat.



## PREVENTING OR MANAGING DIABETES

By eating healthily and managing your weight, you can reduce your risk and manage symptoms of diabetes.



## MANAGING YOUR BLOOD PRESSURE

Get your blood pressure checked regularly. Try to keep your systolic blood pressure at 130 mm Hg or less from age 40 years.



## MANAGING CHOLESTEROL LEVELS

Try to keep your cholesterol level below 200 mg/dL. Many of the other steps listed here may help you do this.



## TAKING CARE OF YOUR HEARING

Get your hearing checked regularly, and wear a hearing aid if you've been given one. Wear ear defenders in noisy environments.



## LOOKING AFTER YOUR EYES

Have your eyes tested regularly, and use prescribed treatments to correct vision problems.



## KEEPING SOCIALLY CONNECTED

Take part in regular social activities like dance classes and game nights.



## STAYING SHARP

Keep challenging your brain throughout your life.



## PROTECTING YOUR HEAD

Wear a helmet during sports or when riding a bike.



# 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.**

Everyone with dementia and their carer is entitled to an assessment that establishes their support needs and suggests how those needs can be met. Some services will be provided by local authorities and others can be arranged through the doctor, or you can contact local authority social services directly.

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** offers practical and medical advice and emotional support to people affected by dementia on **0800 888 6678** or **helpline@dementiauk.org**

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

**Alzheimer's Society** Dementia Connect service for England, Wales and Northern Ireland provides information, support, guidance and signposting to local support services. You can contact them on **0300 150 3456** or **DementiaSupportLine@alzheimers.org.uk**

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

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** or **info@lewybody.org**

**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** or **hello@parkinsons.org.uk**

**Rare Dementia Support** runs specialist support services for people living with, or affected by, under-recognised dementias:

- Lewy body dementia (LBD)
- 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**

**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** or **info@carers.org**

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

## TAKING PART IN RESEARCH

Research is the only way we'll find new ways to prevent, diagnose and treat dementia. Scientists need your help. People with dementia, their carers, and people without dementia are all needed to take part in vital research studies.

Join Dementia Research is a service that allows you to register to take part in dementia research studies. You'll be matched with studies you are suitable for, then you can choose which ones to take part in. If you would like to register to take part visit [joindementiaresearch.nihr.ac.uk](http://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](mailto: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 **£220 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 or your loved one have been diagnosed with dementia in the last two years and would like to share your experience to help shape our work visit [alzres.uk/MCV](https://alzres.uk/MCV)**

## **CONTACT US**

**0300 111 5111**

**[infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)**

**Alzheimer's Research UK  
3 Riverside, Granta Park, Cambridge CB21 6AD**

## **VISIT**

**[alzheimersresearchuk.org/dementia-information](https://alzheimersresearchuk.org/dementia-information)**

## **ORDER**

**[alzheimersresearchuk.org/supporter-orders](https://alzheimersresearchuk.org/supporter-orders)**

**Or scan the QR code**



## **LET'S KEEP TALKING ABOUT DEMENTIA**

**Scan the QR code to be the first to know about the latest research**



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