



Alzheimer's
Research
UK

What is Alzheimer's disease?



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Introduction

This booklet aims to provide an overview of Alzheimer's disease. It's for anyone who is worried about themselves or somebody else, or for people who want to know more about Alzheimer's disease and how it is diagnosed.

The information here does not replace 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.

The booklet was updated in May 2022 and is due to be reviewed in May 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.

If you have questions about dementia or dementia research you can contact the **Dementia Research Infoline** call **0300 111 5111** email infoline@alzheimersresearchuk.org
Or write to us using the address on the back page.

What is dementia?

The word dementia is used to describe a group of symptoms – these include memory loss, confusion, mood changes and communication difficulties.

Dementia is not a disease in itself, but it is caused by different diseases that affect the brain. These diseases damage brain cells over time causing symptoms of dementia.

People living with dementia may have difficulty and need help carrying out daily activities like preparing food, paying bills, or going to the supermarket.

There are almost

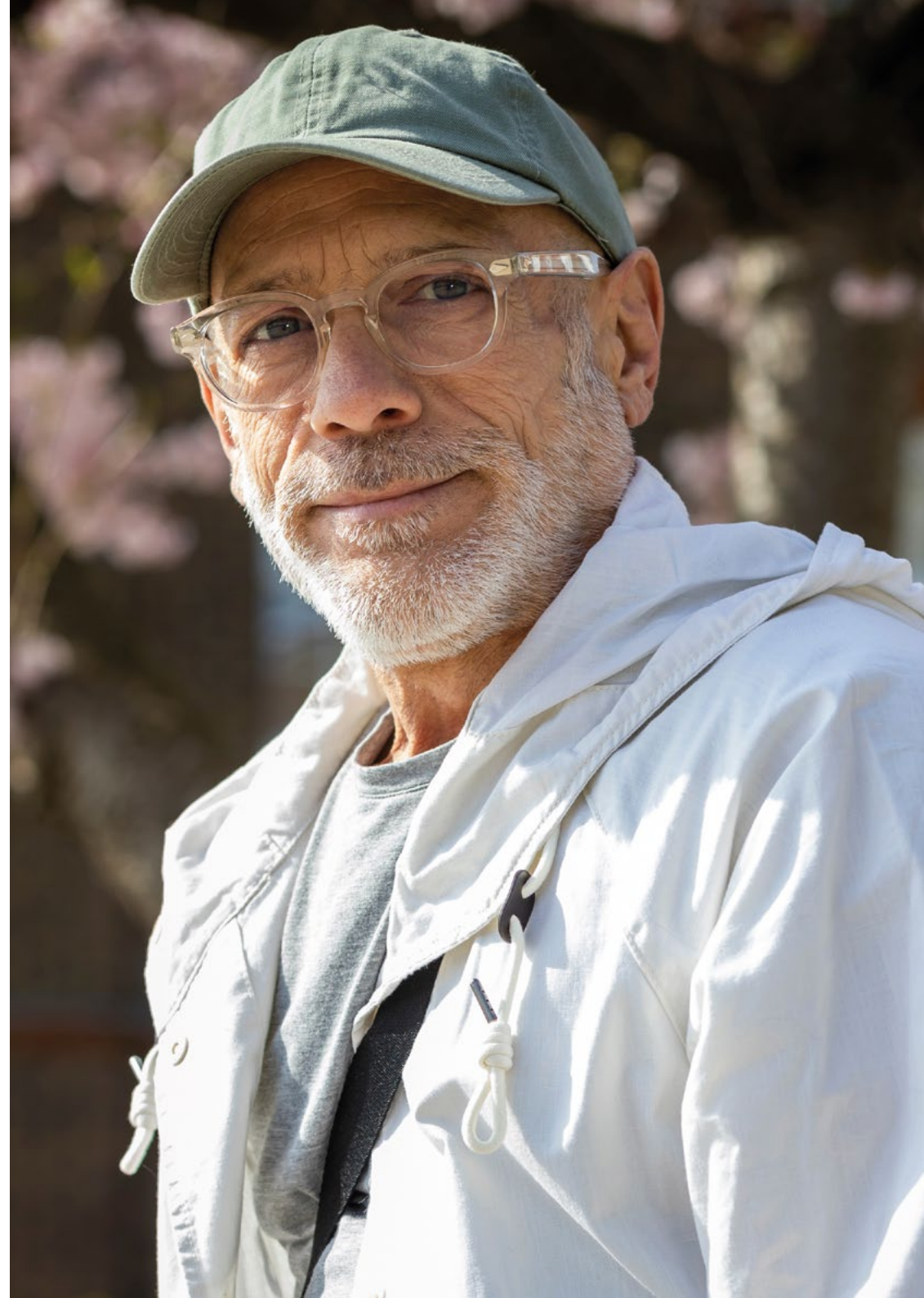
1,000,000

people living with dementia in the UK.

This is set to increase to over

1,600,000

by 2050.



What is Alzheimer's?

Alzheimer's disease is the most common cause of dementia, affecting around six in every 10 people with dementia in the UK.

As we age, our brains naturally shrink a little and our thought processes slow down. However, in Alzheimer's disease, changes that occur in the brain are different to the changes seen in normal ageing. In Alzheimer's disease, two proteins, called amyloid and tau, build-up. We don't yet have a complete understanding of what triggers this, or how it causes the symptoms of dementia.



However, research suggests that the build-up of these proteins damages more and more brain cells over time. This damages affects how our brains work and leads to the symptoms of Alzheimer's.

Some people can have more than one type of dementia. For example, someone might have Alzheimer's as well as vascular dementia or dementia with Lewy bodies. This is often called 'mixed dementia'. The older someone is, the more likely it is that they have more than one disease contributing to their dementia.

Alzheimer's is not a normal part of ageing, but the chance of developing the disease increases as we get older. Most people who have Alzheimer's are over the age of 65, this is called late onset Alzheimer's. Sometimes, Alzheimer's can affect younger people too. It's thought that over 42,000, or at least five in every 100 people with Alzheimer's are under 65. These rare cases of the disease are called young onset Alzheimer's disease, and are more likely to have a genetic cause.

Risk factors

A risk factor is something that increases your chances of developing a disease. Someone's risk of developing Alzheimer's is made up of a number of different things including our age, genetics, lifestyle, and environment.

The biggest risk factor for developing late onset Alzheimer's is age – the older you are, the more likely you are to develop it. However, the brain changes that lead to Alzheimer's start 15-20 years before there are any symptoms.

Current research is finding ways to identify and diagnose these changes earlier on, so there may be new ways to prevent and treat the disease in much earlier stages in the future.

We know that many people live a healthy and active life but still develop dementia. However, research suggests around one in three cases of dementia could be avoided by helping people address lifestyle factors.



1 in 3
cases of dementia could be avoided by leading a healthier lifestyle.



Genetics

Because Alzheimer's is common, many people have a relative who has the disease, but this doesn't mean they will definitely inherit it.

However, if someone has a parent or grandparent with Alzheimer's who developed the disease over the age of 65, then their own risk of developing Alzheimer's may be higher than someone with no family history. Research has identified several genes that are associated with a higher risk of late onset Alzheimer's in some people. Having these risk genes does not definitely mean someone will develop the disease, only that their chances are higher than people who do not have them.

Sometimes, young onset Alzheimer's, where people develop symptoms before the age of 65, can run in families and may be caused by faulty genes. In these cases, many members of the same side of the family are affected, often in their 30s, 40s or 50s. These types of directly inherited Alzheimer's are very rare.

If you want to know more about genetics and Alzheimer's, ask us for our '**Genes and dementia**' leaflet. You can contact us using the details on the back of this booklet.



Lifestyle

Some of the risk factors for Alzheimer's are the same as for cardiovascular disease (like heart disease and stroke). By leading a healthy lifestyle and taking exercising regularly you will be helping to keep your heart and brain healthy. It's likely you will be lowering your risk of Alzheimer's too, or at the very least delaying its onset.

Some studies suggest that enjoying an active social life, with lots of interests and hobbies, might be beneficial. Research has linked staying mentally and socially active to a lower risk of dementia. It's not clear which activities are most beneficial, but doing things you enjoy like reading, doing puzzles, or joining a singing group, or social club can help you to feel happier, stay mentally active and feel more positive in life.

You can speak to your doctor to find out more about steps you can take to look after your health and to reduce your risk of dementia.

For a healthy brain:



Don't
smoke



Control
high blood
pressure



Only drink
alcohol within
recommended
limits



Maintain
a healthy
weight



Keep
cholesterol
at a healthy
level



Be active
and exercise
regularly



Eat a healthy
balanced diet



Have your hearing
checked regularly

For more information about this, you can request our booklet '**Reducing your risk of dementia**' using the details on the back of this booklet.



Other risk factors

Some people develop mild memory problems that are worse than expected for their age, but do not get in the way of normal daily life.

You might hear this called mild cognitive impairment (MCI). While people with MCI are at an increased risk of developing Alzheimer's, many people with MCI do not develop the disease and some even regain normal memory function.

People with Down syndrome are at an increased risk of developing Alzheimer's and are more likely to develop the disease at an earlier age.

For more information about these conditions, you can talk to your doctor or contact the **Dementia Research Infoline** on **0300 111 5111** or **infoline@alzheimersresearchuk.org**

Symptoms

Alzheimer's often develops slowly over several years, so symptoms are not always obvious at first.

A loss of interest and enjoyment in day-to-day activities can often be one of the first changes, but this can be subtle and may be mistaken for other conditions such as depression. In the early stages of the disease, it can also be difficult to distinguish memory problems associated with Alzheimer's from mild forgetfulness that can be seen in normal ageing.

Early symptoms of Alzheimer's may include:

- **Memory.** Regularly forgetting recent events, names, and faces.
- **Repetition.** Becoming increasingly repetitive, e.g. repeating the same question over and over or repeating behaviours and routines.
- **Misplacing things.** Regularly misplacing items or putting them in odd places.
- **Confusion.** Not sure of the date or time of day.
- **Disorientation.** People may be unsure of their whereabouts or get lost, particularly in unfamiliar places.
- **Language.** Problems finding the right words.
- **Mood and behaviour.** Some people become low in mood, anxious or irritable. Others may lose self-confidence, show less interest in what's happening around them or just start to do.

As the disease progresses

Alzheimer's develops over time, but the speed of change varies between people.

As Alzheimer's progresses, symptoms may include:

- **Memory and thinking skills.** People will find that their ability to remember, think and make decisions gets worse.
- **Communication.** Speaking and understanding people becomes more difficult.
- **Recognition.** People may have difficulty recognising household objects or familiar faces.
- **Day-to-day tasks.** Such as using a TV remote control, phone or using the kettle become harder.
- **Hallucinations and delusions.** People may experience hallucinations, where they see or hear things that aren't there. Others may believe things to be true that haven't actually happened, known as 'delusions'.
- **Behaviour.** Some people become sad, depressed, or frustrated about the challenges they face. Anxiety is also common, and people may become fearful or suspicious.
- **Physical change.** People may have problems walking, be unsteady on their feet, find swallowing food more difficult or have seizures.
- **Care.** People gradually require more help with daily activities like dressing, eating, and using the toilet.



- **Sleeping.** Changes to sleep patterns often occur, such as waking frequently during the night.
- **Sundowning.** People with Alzheimer's can experience increased confusion and anxiety during the evening and at night. This is called sundowning.

Alzheimer's is a progressive disease. This means symptoms will get worse over time. People with Alzheimer's will need more support doing everyday tasks and an increasing amount of care as time goes on.

Diagnosis

Diagnosing Alzheimer's disease as early as possible is important. It means you can get the right support and treatments. It also means you can plan for the future. If you are worried about your thinking, memory, or health, you should talk to your doctor.



The doctor will:

- Check on your physical health and medical history.
- Ask you about your symptoms and concerns.
- Run a blood test to rule out other causes for your symptoms.
- Ask you to complete some quick memory and thinking tests.
- If possible, ask someone who knows you well about your symptoms and how they affect you.
- If your doctor suspects Alzheimer's or another cause of dementia, they may then refer you to a memory clinic or another specialist clinic.



A memory clinic or specialist will include:

- Questions about your concerns, your symptoms and how they affect you day to day.
- A physical check-up.
- A brain scan and maybe a lumbar puncture.
- Completing some in-depth tests to check your memory, thinking and problem-solving skills.



- Occasionally a lumbar puncture is used, where a sample of fluid is taken from the base of the spine. This tests for abnormal levels of proteins linked to Alzheimer's disease, called amyloid and tau. This is usually only done in research clinics.

Together, all of these things will help a doctor find out about any problems in memory or thinking and the likely cause.

If symptoms are mild or the cause is uncertain, the doctor may want to look for any further changes over time. For this reason, they may ask you to come back in six months or a year to repeat these assessments.

Currently, there is no way to diagnose any type of dementia with 100% accuracy. Your doctor will make the best judgement about the most likely cause of your symptoms based on the information they collect from these assessments and tests.

If you are assessed for Alzheimer's, you can choose not to know the diagnosis. You can choose someone else who will be told about your diagnosis instead.

For more information on what to do if you are experiencing symptoms and how to get a diagnosis of dementia, please request our free booklet '**Problems with your memory?**' using the contact details on the back of this booklet.

Treatments

The treatments currently available in the UK for Alzheimer's do not slow or stop the disease from getting worse, but they may help manage the symptoms for a time. It's important to discuss your treatment options with the people involved in your care.

Non-drug treatments

Cognitive stimulation activities are designed to stimulate thinking skills. They are often group-based, with an emphasis on enjoyment. The activities might include games, group discussions or practical tasks such as baking. The benefits of cognitive stimulation for people with Alzheimer's may include improvement in memory, thinking skills and quality of life.

People with mild to moderate dementia, including Alzheimer's, should be given the opportunity to participate in cognitive stimulation programmes, if available. You can discuss your options with your doctor or care provider.

For more information on treatments for Alzheimer's, please contact us and ask for our booklet '**Treatments for dementia**'.



Drug treatments

If you are prescribed a drug for Alzheimer's disease, treatment is usually started by your own doctor following guidance from a specialist doctor after you have been to a memory clinic. Alternatively, your own doctor may start your treatment and it may be continued and monitored either by a specialist or by your doctor.

Doctors often refer to people as having mild, moderate or severe Alzheimer's disease. This reflects how much the symptoms affect the person's day to day life. Different drug treatments are recommended at different stages of the disease.

Cholinesterase inhibitors

People with mild to moderate Alzheimer's disease could benefit from taking a drug called a cholinesterase inhibitor.

These increase the amount of a chemical called acetylcholine that helps messages to travel around the brain. Cholinesterase inhibitors do not prevent the disease from getting worse but may help people to function better every day than they would do without the drug.

There are three cholinesterase inhibitors prescribed to treat Alzheimer's:

- donepezil (Aricept)
- rivastigmine (Exelon)
- galantamine (Reminyl).

These are given to people with mild or moderate Alzheimer's, and doctors will continue to prescribe one of these drugs as symptoms progress, so long as it is safe and suitable to do so.

Some people with Alzheimer's find their condition improves by taking a cholinesterase inhibitor. They may see an improvement in thinking, memory, communication, or day-to-day activities. Others may not notice an effect.

The drugs may have side-effects in some people. The most common are feeling or being sick, being unable to sleep, having diarrhoea, muscle cramps or tiredness. These effects are often mild and usually don't last long. Most people do not get these side effects.

Memantine

Memantine (Ebixa or Axura) is recommended for people with moderate or severe Alzheimer's disease, and for people with moderate Alzheimer's if cholinesterase inhibitors don't help or are not suitable.

Memantine also helps nerve cells in the brain communicate with each other. It does this by regulating a chemical called glutamate in the brain. In Alzheimer's disease this can allow brain cells to work better for longer, and it can help to reduce the symptoms of Alzheimer's disease for a while.

Like cholinesterase inhibitors, memantine is not a cure or does not slow down the progression of the disease. However, it can help with some symptoms. Some people taking memantine may not notice any effect at all. Others may find that their condition stays the same when they would have expected it to decline.

People may experience side-effects when taking memantine. The most common side-effects are headaches, dizziness, drowsiness, and constipation. These are usually short-term effects.

Cholinesterase inhibitors and memantine are normally given as tablets or capsules, but they are available in a liquid form too. Donepezil is also available as a tablet that dissolves on the tongue, and Rivastigmine is available in patches, where the drug is absorbed through the skin.

Your doctor will discuss the most suitable form for you. People with moderate or severe Alzheimer's disease are sometimes offered combination therapy, where a cholinesterase inhibitor and memantine are given together.

Treatment options for mood and behaviour changes

Depression and anxiety

People with depression or anxiety in Alzheimer's may be offered social support or different types of talking therapies, depending on their needs and personal situation.

Talking therapies, such as cognitive behavioural therapy (CBT) and counselling, can help with symptoms. They provide an opportunity for people to talk about their concerns with a specialist and develop different ways of coping, thinking, and behaving. Some people may also benefit from an antidepressant drug, although these are not always suitable for someone with Alzheimer's. A doctor should carefully consider what may be appropriate.

Treatment options for depression and anxiety:

- Social support.
- Talking therapy.
- Antidepressants (if appropriate).

Agitation and aggression

These sometimes occur in the later stages of the illness, often once it is becoming more difficult for someone to communicate in words. It is important to look for reasons why someone may be behaving this way. For example, they could be misunderstanding a situation, be anxious or in pain, or be disturbed by noise or something else happening around them.

Addressing these issues might reduce the person's agitation or aggression. Complementary therapies, such as aromatherapy, dance or music therapy, may also be considered. This will depend on a person's preference as well as the availability of treatments.

In some cases, antipsychotic drugs such as risperidone (Risperdal) may be used for someone with dementia who is persistently agitated or aggressive, especially if they are very distressed or at risk of hurting themselves or others. These drugs are not suitable for everyone and may have serious side-effects.

Treatment options for agitation and aggression:

- Identifying and addressing trigger and causes (always).
- Complementary therapies.
- Antipsychotics (in the most severe cases).



Support

Alzheimer's has a huge impact on someone's life, as well as on their family and carers. There is practical and emotional support available to help everyone affected.

Local authorities provide some practical support services. Access to specialist healthcare can be arranged through your doctor if needed. The type of services available may vary depending on where you live, but can include home, day, and respite care.

You may need to think about legal and financial matters and seek advice on the best approach for you. If you wish, you can arrange for a loved one to make financial, legal and health decisions on your behalf, this is called **Lasting Power of Attorney (LPA)**.

If you drive and are diagnosed with Alzheimer's you must notify the **Driver and Vehicle Licensing Authority (DVLA)** and your insurance company. You may not have to stop driving straight away, and you can discuss this further with your doctor.

Many organisations provide information, support and care services to people affected by dementia, as well as families and carers. For more information, request our booklet **'Support for people affected by dementia: Organisations that can help'** using the details on the back page or visit our website at www.alzheimersresearchuk.org



Taking part in research

People with and without dementia, and dementia carers are needed for research studies.

If you're interested in taking part in research and would like to find out more, you can contact **Alzheimer's Research UK's Dementia Research Infoline** on **0300 111 5111** or **infoline@alzheimersresearchuk.org**

You can register to the Join Dementia Research service, which is run by the NHS. This will match you to research studies you are suitable for, so you can see what type of research you could take part in. You can find out more and register here **www.joindementiaresearch.nihr.ac.uk** you can also register over the telephone on **0300 111 5111**.



Research

Alzheimer's Research UK has funded over **£57.3 million** of pioneering research into Alzheimer's disease.

Through our funding, researchers at the University of Cambridge will investigate how proteins in Alzheimer's disease interact with our immune response to cause harmful inflammation in the brain. By understanding more about this interaction, the team will identify potential new drug targets that could control inflammation and prevent the damage to the brain in Alzheimer's.

Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make breakthroughs possible.

To find out about the research projects we fund you can visit **www.alzheimersresearchuk.org/research/research-projects/**

Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

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 details below.

Contact us

0300 111 5111

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Make
breakthroughs
possible



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