WHAT IS ALZHEIMER’S DISEASE?
INTRODUCTION

Information in this booklet is for anyone who wants to know more about Alzheimer’s disease, including people living with Alzheimer’s disease, their carers, families and friends. This booklet gives an overview of the causes, symptoms, diagnosis and treatments.

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, you should speak with your doctor as soon as possible.

This booklet was updated in April 2024 and is due to be reviewed in April 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.

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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 a word used to describe a group of symptoms, it is not a disease itself. This group of symptoms include:

- memory loss
- confusion
- mood and behavioural changes
- vision, language and communication problems.

Dementia is caused by different diseases that affect the brain. Alzheimer’s disease is the most common cause of dementia. These diseases damage brain cells, causing dementia symptoms to get worse over time. People living with dementia will need more support and help with everyday life as time goes on.

There are almost one million people living with dementia in the UK, and this is estimated to increase to over 1.7 million by 2040.

IN THE UK, OUT OF EVERY 10 PEOPLE WITH DEMENTIA, SIX HAVE ALZHEIMER’S.
WHAT IS ALZHEIMER’S DISEASE?

As we age, our brains naturally shrink a little and our thought processes slow down. However, in Alzheimer’s disease, changes occur in the brain that are different to the changes seen in normal ageing.

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, and this is called ‘late onset’ Alzheimer’s.

Sometimes, Alzheimer’s can affect younger people too. At least three in every 100 people with Alzheimer’s in the UK are under 65. These uncommon cases of the disease are called ‘young onset’ Alzheimer’s disease.

If you would like more information about young onset Alzheimer’s, please request our booklet ‘Young onset dementia’ using the details on the back of this booklet.

In Alzheimer’s disease, two proteins, called amyloid and tau, build up. Amyloid builds up in the space between different cells in the brain, and tau is present inside nerve cells themselves, as seen in the diagram on the right.

Although we don’t yet have a complete understanding of what triggers these proteins to build up, research suggests that these proteins damage more and more brain cells over time. This damage affects how our brain works and leads to dementia symptoms. If you would like more detailed information about these proteins, please contact us using the information on the back page.

Some people can have more than one cause of their dementia. For example, someone might have Alzheimer’s as well as vascular dementia or dementia with Lewy bodies. This is often called ‘mixed dementia’.
SYMPTOMS

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

In the early stages, it can be difficult to tell the difference between memory problems caused by Alzheimer’s, and mild forgetfulness that happens as we get older. If symptoms start to get in the way of everyday life or are getting worse, it is important to see a GP as soon as possible.

Early symptoms of Alzheimer’s may include:

- **Memory loss.** Regularly forgetting recent events, names, faces and recently learned information.
- **Repetition.** Becoming increasingly repetitive, e.g. repeating the same question or repeating behaviours and routines.
- **Misplacing things.** Regularly misplacing items or putting them in odd places.
- **Confusion.** Not being 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, understanding the meaning of words or following conversations.
- **Mood and behaviour.** Some people become low in mood, anxious or agitated. Others may lose self-confidence, show less interest in what’s happening around them and in doing activities they would usually enjoy.

Alzheimer’s is a progressive disease, which means symptoms will get worse over time. The speed of change varies between people. People with Alzheimer’s will need more support doing everyday tasks and an increasing amount of care as time goes on.

As Alzheimer’s progresses, symptoms may impact:

- **Memory and thinking.** People will find that their ability to remember, think and make decisions disrupts daily life. People may have difficulty recognising household objects or familiar faces.
- **Communication.** Speaking with and understanding people becomes more difficult. People may also develop problems with reading, writing and numbers.
- **Day-to-day tasks.** Familiar tasks such as using a phone or using the kettle become harder.
- **Sleeping.** Some people develop changes to their normal sleep patterns, such as waking frequently during the night or sleeping more during the day.
- **Behaviour.** Some people become restless, aggressive or anxious. Some may also experience paranoia and be fearful or suspicious of others.
- **Movement.** People may have problems walking, be unsteady on their feet and find swallowing food more difficult.
- **Senses.** People may experience hallucinations, where they see or hear things that aren’t there.
- **Care.** People gradually require more help with daily activities like dressing, eating and using the toilet.
DIAGNOSIS

It can be hard to come to terms with any symptoms or behaviour changes that you or your loved ones notice. Some people may be reluctant to get a diagnosis. It can be useful to keep a diary of any symptoms you notice or experience, to help monitor changes over time. This can help to guide discussions with a GP.

If you are worried that you are experiencing symptoms of Alzheimer’s disease you should talk to your GP.

First the doctor will:
• Discuss your symptoms and the impact they are having on your daily life.
• If possible, ask someone who knows you well if they have noticed any changes.
• Check on your physical health.
• Run a blood test to rule out other causes of your symptoms such as vitamin deficiencies or thyroid problems. They may also ask you for a urine sample.
• Ask you to complete some quick memory and thinking tests.

If your doctor suspects Alzheimer’s or another disease that causes dementia, they may refer you to a memory clinic or another specialist clinic. Here, a doctor or nurse will run through some further questions and tests with you.

These may include:
• More questions about your concerns, symptoms and how they affect you.
• A physical check-up.
• A brain scan and lumbar puncture.
• Completing some in-depth tests to check your memory, thinking and problem-solving skills.

Sometimes, a lumbar puncture, where a sample of fluid is taken from the base of the spine, is used as part of a diagnosis. This fluid is tested for abnormal levels of the proteins amyloid and tau, found in people with Alzheimer’s disease.

Together, these tests will help a doctor find out about the likely cause of your memory and thinking problems. 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. Currently, there is no way to diagnose any type of dementia with complete accuracy.
If you are assessed for dementia, you can choose not to know the diagnosis. You can choose for someone else to be told about your diagnosis instead.

Sometimes, if someone’s symptoms are mild, they may be diagnosed with something called mild cognitive impairment (MCI). For more information about mild cognitive impairment, ask for our ‘What is Mild Cognitive Impairment?’ information. Our contact details can be found on the back of this booklet.

If symptoms are mild, a doctor may also want to wait 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 the assessments.

Your doctor may also discuss opportunities for you to get involved in dementia research. There is more information about this on page 30.

For more information on what to do if you are experiencing symptoms, and how to get a diagnosis of dementia, please request our booklet ‘Getting a dementia diagnosis’ using the contact details on the back of this booklet.
TREATMENTS

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

DRUG TREATMENTS

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

If you are prescribed a drug to manage symptoms of Alzheimer’s disease, treatment is usually started by your GP or specialist doctor after your diagnosis has been made. Your GP will then monitor any prescribed treatments.

Cholinesterase inhibitors

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

There are three cholinesterase inhibitors to treat mild to moderate Alzheimer’s:

• donepezil (Aricept)
• rivastigmine (Exelon)
• and galantamine (Reminyl).

People with Alzheimer’s disease often have a decreased level of a chemical called acetylcholine in their brain. These drugs work by increasing the amount of acetylcholine, which 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.

Cholinesterase inhibitors are normally given as tablets or capsules, but they are available in 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. You can discuss the most appropriate one for you with your doctor.

Some people with Alzheimer’s find their symptoms improve by taking a cholinesterase inhibitor. They may see an improvement in thinking, memory, communication, or general day-to-day activities. Others may not notice an effect. Doctors will continue to prescribe one of these drugs as symptoms get worse, so long as it is safe and suitable to do so.

Some people taking these drugs may experience side-effects. The most common are:

• feeling or being sick
• being unable to sleep
• stomach upset and diarrhoea
• muscle cramps
• and tiredness.

These effects are often mild and usually don’t last long. Most people do not get these side effects.
Memantine

Memantine, also known as Ebixa or Axura, is recommended for people with moderate or severe Alzheimer’s disease. It may be used for people with moderate Alzheimer’s if cholinesterase inhibitors don’t help or are not suitable. People with moderate or severe Alzheimer’s are sometimes prescribed a cholinesterase inhibitor and memantine together.

Memantine helps nerve cells in the brain communicate with each other. In people with Alzheimer’s disease, there is often an imbalance of a chemical called glutamate in the brain. Memantine helps regulate glutamate in the brain. This helps brain cells to work better and to reduce the symptoms of Alzheimer’s disease for a while.

Memantine comes in tablets, capsules, or as a liquid. Your doctor will discuss the most suitable form with you. Like cholinesterase inhibitors, memantine is not a cure. It does not slow down the progression of the disease. However, it can help with some symptoms like memory, thinking and carrying out daily tasks. Some people taking memantine may not notice any effect at all.

People may experience side-effects when taking memantine. The most common are:

- headaches
- dizziness
- drowsiness
- and constipation.

These are usually mild and short-term effects.

Medications for mood and behaviour changes

People with Alzheimer’s disease may experience low mood and depression. Research has shown that antidepressants may only work for people whose depression was already being treated before they developed dementia.

Sometimes in the later stages of the illness people may experience agitation or aggression. This often happens once it becomes more difficult for someone to communicate. In the most severe cases, antipsychotic drugs such as risperidone (Risperdal) may be offered to 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.
COMPLEMENTARY TREATMENTS

Cognitive stimulation

Cognitive stimulation activities are designed to stimulate thinking skills and reduce symptoms of low mood and anxiety. 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 Alzheimer’s should be given the opportunity to participate in cognitive stimulation programmes, if available in your area. You can discuss your options with your doctor or care provider.

Talking therapies

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. Talk to your doctor to find out if this is a treatment that you would be able to access.

Promoting wellbeing

For people with agitation and aggression in Alzheimer’s, it is important to look for reasons why someone may be behaving this way. For example, they could be confused by 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 for those experiencing symptoms of agitation of aggression. This will depend on a person’s preference as well as the availability of treatments.

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NEW ALZHEIMER’S TREATMENTS

In research trials, new drugs called lecanemab and donanemab have been found to slow down the worsening of early stage Alzheimer’s disease by a small amount.

In the UK, the regulatory authorities are looking into allowing these drugs to be prescribed to people in England, Scotland and Wales (Northern Ireland is covered by a separate regulator). So far they have only shown benefit in people with very early stage Alzheimer’s disease. Either a lumbar puncture or specialist scan called a PET scan is used to confirm who is suitable for the treatment.

To find the most up to date information about lecanemab, donanemab and other treatments for Alzheimer’s disease, visit our website or contact us using the details below.
RISK FACTORS

A risk factor is something that increases your likelihood of developing a disease.

Our risk of developing Alzheimer’s is made up of a complex mixture of factors including our age, the genes we inherit from our parents, our lifestyle, and our environment. Some of these things we cannot control, like our age and our genes. The biggest risk factor for developing late onset Alzheimer’s is age. The older you are, the more likely you are to develop it.

RISK FACTORS WE CAN CHANGE

Many people live a healthy and active life but still develop dementia, because there are no surefire ways of preventing it. However, research does suggest more than one in three cases of dementia could be avoided by helping people address lifestyle factors.

Maintaining a healthy lifestyle in your forties and fifties seems to be particularly important for helping to lower your risk of dementia. However, taking steps to look after your brain is important at any age. By keeping your heart and brain healthy, you will be lowering your risk of Alzheimer’s, or at the very least delaying its onset.

For good brain health and heart health, and to help lower your risk of Alzheimer’s disease:

- If you have diabetes, ensure your condition is well managed
- Keep physically active
- Don’t smoke
- Maintain a healthy weight
- Keep cholesterol and blood pressure under control
- Only drink alcohol within the recommended limits
- Have your hearing checked regularly
- Eat a healthy balanced diet
- Stay socially and mentally active
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. This is called mild cognitive impairment (MCI). While people with MCI are at an increased risk of developing Alzheimer's, many people do not go on to develop the disease. Some people with MCI even regain normal memory function, depending on what is causing their symptoms.

For more information on mild cognitive impairment, order our booklet ‘What is mild cognitive impairment?’ using the contact details on the back page.
GENES AND ALZHEIMER’S

There are around 600,000 people living with Alzheimer’s in the UK, so many of us are likely to have at least one relative with the disease. This doesn’t mean that we will inherit it.

If someone has a parent or grandparent with Alzheimer’s who developed the disease after the age of 65, then their own risk of developing Alzheimer’s may be slightly higher than someone with no family history. This is because they are more likely to have risk genes.

Risk genes have been identified by researchers and are associated with a higher risk of late onset Alzheimer’s in some people. Having these risk genes does not mean someone will definitely develop the disease. Only that their chances are higher than people who do not have these risk genes present in their family. There is currently no genetic testing available on the NHS to find out if we carry risk genes or not.

In some rare cases, young onset Alzheimer’s, where people develop symptoms before the age of 65, can run in families and may be caused by faulty genes.

People with these faulty genes are extremely likely to develop the disease during their lifetime. In these cases, there is a clear pattern of many members of the same side of the family being affected, often in their 30s, 40s or 50s. Around one in 100 cases of dementia are caused by these inherited faulty genes.

There are genetic tests available on the NHS to investigate these cases of Alzheimer’s disease. If you are worried these cases are present in your family, you should talk to your GP.

Research also shows that 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. This is because the genetic differences in people with Down syndrome cause the faulty proteins amyloid and tau to build up in the brain.

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

There is a range of support organisations that offer practical and emotional support for people with dementia and those helping to care for them.

If you have questions about symptoms, diagnosis, or treatments for dementia you can contact the Alzheimer’s Research UK Dementia Research Infoline on 0300 111 5111 or infoline@alzheimersresearchuk.org

The Admiral Nurse Dementia Helpline is provided by Dementia UK. The helpline is run by dementia nurses who can give practical and medical advice, support and care tips. Call 0800 888 6678 or email helpline@dementiauk.org

Alzheimer’s Society provides dementia care information, emotional support, and local support groups. Call 0300 150 3456 or email dementia.connect@alzheimers.org

Alzheimer Scotland offers support services, information and advice to people in Scotland. Call 0808 808 3000 or email info@alzscot.org

For more details of other helpful dementia organisations, ask us for our booklet ‘Support for people affected by dementia: organisations that can help’. Contact and order details can be found on the back of this booklet.

You can also speak to your nurse, GP or doctors’ surgery for advice and signposting to local services
RESEARCH

So far, Alzheimer’s Research UK have funded almost £65 million of pioneering research to help advance our understanding of Alzheimer’s disease.

One big research initiative this has helped fund is the Drug Discovery Alliance between the Universities of Oxford, Cambridge and University College London. This alliance is trying to bridge the gap between understanding the complex biology of Alzheimer’s disease and developing new drugs to treat Alzheimer’s.

We have also funded over 621 other research projects into Alzheimer’s disease. You can read more about recent projects we’ve funded into Alzheimer’s disease on the research section of our website alzheimersresearchuk.org/research.

With your support, we will fund many more studies into Alzheimer’s disease. We promise we will not stop until dementia can no longer destroy lives.

We are Alzheimer’s Research UK.
We exist for a cure.

TAKING PART IN RESEARCH

Our scientists are working hard to change the lives of people affected by dementia. But they need your help.

People with dementia, their carers, and people without dementia are all needed to take part in vital dementia research studies. If you’re interested in taking part, you can register at joindementiaresearch.nihr.ac.uk or by calling 0300 111 5111.

SHARE YOUR STORIES
If you have been diagnosed with Alzheimer’s disease and would like to share your story to inspire others, or to help shape our work please get in touch via stories@alzheimersresearchuk.org
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

CONTACT US
0300 111 5111
infoline@alzheimersresearchuk.org
Alzheimer’s Research UK
3 Riverside, Granta Park, Cambridge CB21 6AD

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