

What is Alzheimer's disease?



**Alzheimer's
Research
UK**

Make breakthroughs possible



This booklet aims to provide an overview of Alzheimer's disease. It is for anyone who wants to know more about the disease, including people living with Alzheimer's, as well as their carers, friends and family.

Contents

Introduction	03	Treatments	12
What is dementia?	04	Risk factors	18
What is Alzheimer's?	05	Support	22
Symptoms	07	Research	23
Diagnosis	10		

The information in this booklet does not replace the advice that doctors, pharmacists or nurses may provide, but gives you information that we hope you will find useful.

Versions

This booklet was updated in May 2020 and is due to be reviewed in May 2022. If you would like a version of this information including references, please get in touch.

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 can be caused by one of several different diseases that affect the brain. It involves a decline in people's thinking skills. This can affect our memory, ability to reason and solve problems, ability to communicate, and other types of thinking. People living with dementia have difficulty carrying out daily activities like preparing food, paying bills or going to the supermarket.

Currently around 850,000 people in the UK are affected by dementia.

Alzheimer's is the most common cause of dementia, affecting around

500,000

people in the UK



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. Some people can have more than one type of dementia, for example, they might have Alzheimer's as well as vascular dementia or dementia with Lewy bodies. This is often called 'mixed dementia'.

Alzheimer's is not a normal part of ageing, but the chances of developing the disease do increase the older we get. The majority of people who develop the disease are over the age of 65. Sometimes, Alzheimer's can affect younger people. It is thought that around 5% of people with Alzheimer's are under 65, about 42,000 people. These rare cases of the disease are called early-onset Alzheimer's. If you would like more information about early-onset Alzheimer's, please contact us.

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.

These changes include the build-up of two proteins, called amyloid and tau. Although researchers don't yet have a complete understanding of what triggers this, both proteins are involved in the development of Alzheimer's. As the disease progresses, the protein build-up damages more and more brain cells. This damage affects how our brains work and leads to the symptoms of Alzheimer's.

With the help of our researchers, we are learning more about why these proteins build up in the brain and how they damage brain cells. Research is underway to understand more about what happens in the brain during Alzheimer's and find new ways to treat the disease.

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.

Typical early symptoms of Alzheimer's may include:



Memory

Regularly forgetting recent events, names and faces.



Disorientation

People may be unsure of their whereabouts or get lost, particularly in unfamiliar places.



Repetition

Becoming increasingly repetitive, e.g. repeating questions after a very short interval or repeating behaviours and routines.



Language

Problems finding the right words.



Misplacing things

Regularly misplacing items or putting them in odd places.



Mood and behaviour

Some people become low in mood, anxious or irritable. Others may lose self-confidence or show less interest in what's happening around them.



Confusion

Not sure of the date or time of day.



As the disease develops

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 worsens.



Communication

Communication and language become more difficult.



Recognition

People may have difficulty recognising household objects or familiar faces.



Day-to-day tasks

These become harder, for example using a TV remote control, phone or kitchen appliance. People may also have difficulty locating objects in front of them.



Sleeping

Changes in sleep patterns often occur.



Behaviour

Some people become sad, depressed or frustrated about the challenges they face. Anxieties are also common, and people may seek extra reassurance or become fearful or suspicious.



Physical changes

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.



Hallucinations and delusions

People may experience hallucinations, where they see or hear things that are not there. Others may believe things to be true that haven't actually happened, known as 'delusions'.



Diagnosis

Diagnosing Alzheimer's 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 memory or health, you should talk to your doctor.



If your doctor suspects Alzheimer's or another type of dementia, they may refer you to a memory clinic or another specialist clinic.



Here, a doctor or nurse will run through some questions and tests with you. These are likely to include:

- Questions about your concerns, your symptoms and how they affect you day to day.
- Questions about your general health and medical history.
- Speaking with your partner or someone close to you about your symptoms.
- A physical check-up.
- Completing some pen-and-paper tasks to check your memory, thinking and problem-solving skills.

You may be offered other tests, including brain scans and blood tests. 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 the proteins, amyloid and tau, linked to Alzheimer's disease.

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 test for any further changes over time. For this reason, they may repeat these assessments in the future to see if symptoms have got worse, to help them make a more accurate diagnosis.

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

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



Treatments

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

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. Specialist doctors who see people with dementia include psychiatrists, geriatricians and neurologists. 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 cholinesterase inhibitor. These drugs work by increasing 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 at a slightly higher level than they would do without the drug.

There are three cholinesterase inhibitors 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 carrying out 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 do not last long. Not everyone will have 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 do not help or are not suitable.

Memantine 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 more effectively 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. 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 are headaches, dizziness, drowsiness and constipation. These side-effects usually do not last long.

Your doctor will advise on the best treatment and may prescribe both a cholinesterase inhibitor and memantine. This is sometimes called combination therapy.

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.

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

Non-drug treatments

Cognitive stimulation activities are designed to stimulate thinking skills and engage people who have Alzheimer's. 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.



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

To help relieve symptoms of agitation and aggression, a doctor should review someone's physical and mental health, and their environment. This helps to identify any causes or triggers, such as pain, another health problem, or something in their surroundings that distresses or angers 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 to relieve symptoms, especially if someone is 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

Complementary therapies

Antipsychotics (if appropriate)

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 and lifestyle.

The biggest risk factor for late onset-Alzheimer's, where people develop the disease over 65, 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 these changes earlier on, so there may be new ways to prevent and treat the disease in the future.

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



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 regular exercise you will be helping to keep your brain healthy. It is likely you will be lowering your risk of Alzheimer's too.

To keep healthy:



be active and exercise regularly



keep cholesterol at a healthy level



do not smoke



maintain a healthy weight



eat a healthy balanced diet



only drink alcohol within recommended limits.



control high blood pressure

Some research suggests that enjoying an active social life, with lots of interests and hobbies, might be beneficial. Staying mentally and socially active has been linked 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 signing group or social club can help you to feel happier, stay mentally active and feel more positive in life.

Genetics

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

Research has found that 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 is slightly 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. The discovery of these genes is revealing more about the causes of Alzheimer's. Having these genes does not definitely mean someone will develop the disease, only that their chances are higher than people who do not have them.

Sometimes early-onset Alzheimer's, where people develop the disease 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 the genetics of Alzheimer's, ask us for our **'Genes and dementia'** leaflet.

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's 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.



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.

Accessing services and support can make a real and positive difference to someone with dementia and their family. Some services are provided by local authorities and others can be arranged through your doctor. 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**', or visit our website at www.alzheimersresearchuk.org

Research

Alzheimer's Research UK has funded over **£75.8 million** of pioneering research into Alzheimer's disease.



Through the research we fund into the causes of Alzheimer's, our scientists are building a detailed picture of what happens in the brain in the disease. This is essential for improving diagnosis and developing new treatments to stop it.

Backed by our passionate scientists and supporters, we are 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 we fund you can visit www.alzheimersresearchuk.org/research/research-projects/



Find out more

If you have questions about dementia, dementia research or want to get involved, contact our **Dementia Research Infoline** on **0300 111 5 111** or email infoline@alzheimersresearchuk.org 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.

Freeport RTYR-ZUUZ-AULL
Partridges
3 Eagle Avenue
Magnetic Park
Desborough
NN14 2WD



Send me more information

For free information, simply complete this slip and drop it straight in a post box. Alternatively, phone us on **0300 111 5555**.

I would like to know more about

Early-onset Alzheimer's (SCIHIEO)

Treatments for dementia (SCIHITMT)

Genes and dementia (SCIHIGENE)

Support for people affected by dementia:
organisations that can help (SCIHICARE)

The latest dementia research (SMTTHINK)

Name

Address

Email

We'd like you to be the first to know about the latest research and how your support makes a difference, as well as ways you can get involved and help fund our life-changing work. We'll keep your information safe and never sell or swap it with anyone.

Let us know how we can contact you (tick below):

Post Email Telephone Text message

You can change how we talk to you at any time, by calling **0300 111 5555** or emailing enquiries@alzheimersresearchuk.org

Our Privacy Notice can be found at www.alzheimersresearchuk.org/privacy-policy and explains how we will use and store your information.

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

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



Contact us

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



Supporter care

T: 0300 111 5555
E: enquiries@alzheimersresearchuk.org



Dementia Research Infoline

T: 0300 111 5 111
E: infoline@alzheimersresearchuk.org

www.alzheimersresearchuk.org



**Alzheimer's
Research
UK**

Make breakthroughs possible

Registered charity number 1077089 and SC042474



This booklet was printed with support from The Perfume Shop, who had no input into the content of the booklet.