

# What is Alzheimer's disease?



**Alzheimer's  
Research  
UK**

Make breakthroughs possible



This introductory 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, their carers, friends and family.

## Contents

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

The information here does not replace any advice that doctors, pharmacists or nurses may give you. It provides background information that we hope you will find helpful.

This booklet was updated in May 2018 and is due to be reviewed in May 2020. Please contact us if you would like a version with references.

## 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 can affect how people feel, act and function as well as their health. Symptoms usually include the gradual loss of memory and communication skills, and a decline in the ability to think and reason clearly. People may be less able to carry out ordinary daily activities.

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

## What is Alzheimer's?

Alzheimer's disease is the most common cause of dementia, affecting around six in every 10 people with dementia. Alzheimer's may also occur with other types of dementia, such as vascular dementia or dementia with Lewy bodies. You might hear this called 'mixed dementia'.

Alzheimer's becomes more common with advancing age, but it's not a normal part of ageing. The majority of people who develop the disease are over the age of 65.

More rarely, Alzheimer's can affect younger people. It's thought that over 42,000, or around 5% of people with Alzheimer's are under 65. 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.

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

**500,000**

people in the UK

**Around 5% of people with Alzheimer's are under**

**65**

In Alzheimer's disease, changes occur in the brain that go beyond those associated with 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 Alzheimer's, research suggests that both proteins are involved in driving the disease. As Alzheimer's progresses, more and more nerve cells in the brain become damaged. This damage leads to the symptoms of Alzheimer's.

With our help, researchers are learning more about why these proteins build up in the brain and how they damage nerve 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 involvement 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. 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.

### 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.



#### 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

Uncertainty about 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.



## 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'.



## Care

People gradually require more help with daily activities like dressing, eating and using the toilet.



## 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 health, you should talk to your doctor.



If your doctor suspects Alzheimer's or another form 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 you are managing.

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 tests to check your memory, language 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 to test for changes linked to Alzheimer's disease.

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 repeat these assessments in the future to help make the situation clearer.

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

Currently there is no definitive diagnostic test for Alzheimer's disease. 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 progression of the disease, but they may help with the symptoms for a time. It's important to discuss your treatment options with the staff involved in your care.

### Drug treatments

If you are prescribed a drug for dementia, treatment is usually started by a specialist doctor. Specialist doctors who see people with dementia include psychiatrists, geriatricians and neurologists. Once treatment has been started, it may be continued and monitored either by a specialist or by your GP.



### 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 progressing, 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**

---

**rivastigmine**

---

**galantamine**

---

These are available on NHS prescription for people with mild and moderate Alzheimer's but doctors may continue to prescribe one of these drugs for longer if they believe it is still having a beneficial effect.

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. Not everyone will have side-effects.

### Memantine

Memantine is recommended for people with more severe Alzheimer's disease and for people with moderate Alzheimer's if cholinesterase inhibitors don't help or are not suitable. Memantine does not stop the disease from progressing but 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.

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

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





## 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 elements. This includes age, genetics and lifestyle. It's a complicated picture.

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 many years before there are any symptoms, so in the future there may be new ways of preventing and treating the disease.

We know that many people live a healthy and active life but still develop dementia. However, research suggests some 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 heart healthy. It's possible you will be lowering your risk of Alzheimer's too.

### To keep healthy:



be active and exercise regularly



keep cholesterol at a healthy level



don't smoke



maintain a healthy weight



eat a healthy balanced diet



only drink alcohol within recommended limits.



control high blood pressure

Some studies suggest that enjoying an active social life, with lots of interests and hobbies might be beneficial.

## Genetics

Alzheimer's is common, and many people have a relative who has the disease. This doesn't mean they will inherit it. Some research has suggested 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 may be 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. Having these genes does not definitely mean someone will develop the disease, only that their risk is higher than those with a different genetic make-up. However, the discovery of these genes is revealing more about the causes of Alzheimer's.

In some instances early-onset Alzheimer's 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 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 aren't yet getting in the way of normal daily life. You might hear this called mild cognitive impairment or MCI. While people with MCI are at 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 increased risk of developing Alzheimer's and are more likely to develop the disease at an earlier age.

For more information on any of these conditions, 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, others can be arranged through GPs. 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. A diagnosis of Alzheimer's does not mean you automatically have to stop driving, but you will need to notify the Driver and Vehicle Licensing Authority (DVLA) and your insurance company. 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 '**Caring for someone with dementia: organisations that can help**', or visit our website at [www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)

## Research

Alzheimer's Research UK has funded over

**£66.4 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'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.



### Find out more

If you have questions about dementia research or want to find out more about how to get involved in research, contact our **Dementia Research Infoline** on **0300 111 5 111** or email [infoline@alzheimersresearchuk.org](mailto: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



Make breakthroughs possible

**Alzheimer's  
Research  
UK**



## 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](mailto:enquiries@alzheimersresearchuk.org)

Our Privacy Notice can be found at [www.alzheimersresearchuk.org/privacy-policy](http://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](mailto:enquiries@alzheimersresearchuk.org)



#### Dementia Research Infoline

T: 0300 111 5 111  
E: [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org)

[www.alzheimersresearchuk.org](http://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.