

# What is Alzheimer's disease?



**Alzheimer's  
Research  
UK**

**The Power  
to Defeat  
Dementia**



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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.

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

This booklet was written in April 2014 and is due to be reviewed in April 2016. Please contact us if you would like a version with references.

Dementia is used to describe a group of conditions that share common symptoms and behaviours.

### What is dementia? What is Alzheimer's?

Symptoms of dementia usually include the gradual loss of memory and communication skills, and a decline in the ability to think and reason clearly. The term dementia is used if the symptoms are severe enough to have an effect on a person's ability to carry out ordinary daily activities.

Alzheimer's is the most common cause of dementia, affecting around 500,000 people in the UK.

Alzheimer's often occurs with other types of dementia, such as vascular dementia or dementia with Lewy bodies. You might hear this called 'mixed dementia'.



The most common form of Alzheimer's is called late-onset Alzheimer's and affects people over the age of 65. It's thought that around 4% of people with the disease are under 65. These rare cases of Alzheimer's are called early-onset Alzheimer's. If you would like more information about early-onset Alzheimer's, please contact us.

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### Symptoms

Alzheimer's often develops slowly over several years. It is not always obvious to begin with and symptoms can overlap with other illnesses. Sometimes it can be difficult to distinguish Alzheimer's from mild forgetfulness which can be seen in normal ageing.

Everyone with Alzheimer's will experience symptoms in their own way. Early signs usually include difficulties forming new memories, but people may also experience language or spatial awareness difficulties.

#### Typical early symptoms of Alzheimer's may include:



##### Memory

Regularly forgetting recent events, names and faces.



##### Repetition

Becoming increasingly repetitive, e.g. repeating questions after a very short interval.



##### Misplacing things

Regularly misplacing items or putting them in odd places.



##### Confusion

Uncertainty about the time of day.



##### Disorientation

Disorientation, especially away from normal surroundings. Getting lost.



##### Language

Problems finding the right words.



##### Mood and behaviour

Some people become disinterested in what's happening around them, become irritable, or lose confidence.

### As the disease develops

Alzheimer's gets worse over time, but the speed of change varies between people. As Alzheimer's progresses:

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#### Memory and thinking skills

People will find that their ability to remember, think and make decisions worsens.

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#### Communication

Communication and language become more difficult.

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#### Behaviour

A person's behaviour may change and some people can become sad or depressed. Anger and agitation become more common and people may develop anxieties or phobias.

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#### Hallucinations

People may experience hallucinations, where they may see things or people that aren't there.

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#### Restlessness

Problems with sleeping and restlessness at night often occur.

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#### Unsteadiness

People may become increasingly unsteady on their feet and fall more often.

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#### Daily activities

People gradually require more help with daily activities like dressing, toileting and eating.

### 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 or someone else's, you should talk to your GP.



If your GP suspects dementia, they may refer you to a memory clinic or another specialist clinic.

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

- Asking you some questions about your symptoms and medical history.
- Asking about your mood.
- Speaking with your partner or someone close to you about your symptoms.
- Having a physical check-up.
- Completing some standard pen-and-paper tests to check your memory, language and problem-solving skills.





These tests may be repeated, perhaps every six to 12 months, to see if there are any changes. Sometimes, if symptoms are mild, looking for change with time is the best way to be sure if anything is wrong.

You may also be asked to undergo other tests, including brain scans and blood tests. Together all of these things will help a doctor find out about any problems in memory or thinking and the likely cause.

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.

If you are given a diagnosis of Alzheimer's, you may be offered various types of support. You may also be prescribed drugs or other treatments to help with symptoms or improve your quality of life.

### Treatments

There are several treatments available to help with the symptoms of Alzheimer's.

#### Non-drug treatments

Cognitive stimulation activities are designed to stimulate thinking skills and engage people who have Alzheimer's. They are often group-based and include games, with an emphasis on enjoyment.

The benefits of cognitive stimulation for people with Alzheimer's could 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.



## Drug treatments - 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 which 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:**

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**donepezil (Aricept)**

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**rivastigmine (Exelon)**

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**galantamine (Reminyl)**

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These are available on NHS prescription for people with mild and moderate stage Alzheimer's.

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

Some people have side effects from these drugs. The most common are feeling sick, vomiting, diarrhoea, being unable to sleep, muscle cramp and tiredness. These effects are often mild and usually don't last long. Not everyone will have side effects.

## Treatments

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### Drug treatment – Memantine

Memantine (Ebixa or Axura) is recommended for people with 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. Some people experience side effects when taking memantine. The most common side effects are headaches, dizziness, drowsiness and constipation. These are usually short-term effects.

### Treatments for depression, agitation, anxiety and aggression

People with depression or anxiety in Alzheimer's may be offered social support or psychological treatments, such as cognitive behavioural therapy (CBT), to help with symptoms. CBT provides an opportunity for people to talk about their concerns with a specialist, and aims to help people develop different ways of thinking and behaving. People with more severe symptoms may also be offered an antidepressant drug, although these are not always suitable for someone with Alzheimer's. Your doctor will carefully consider what may be appropriate.

To help relieve symptoms of agitation and aggression a doctor should review someone's physical and mental health and environment. This helps to identify any causes or triggers which could be removed. Approaches such as aromatherapy or music therapy may also be considered. This is likely to depend on your preference as well as the availability of treatments.

In some circumstances antipsychotic drugs such as risperidone (Risperdal) may be used to relieve very severe symptoms. These drugs are not suitable for everyone and your doctor will carefully consider what is appropriate. These drugs can have serious side effects and their use should be carefully monitored.

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



### 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 positive difference to someone with dementia and their family. Some services are provided by local authorities, others can be arranged through GPs.

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)**



## Causes

In Alzheimer's, there are changes in the brain beyond those associated with normal ageing. Among the most prominent are the build-up of two proteins, called amyloid and tau. Research suggests that both of these are involved in the disease process, but the exact sequence of events is still not understood. As the disease progresses, more and more nerve cells in the brain become damaged. This damage leads to the symptoms of Alzheimer's.

We still need to learn 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.

## 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. While we can't change our age or our genes, research is underway to learn more about ways we might help prevent Alzheimer's or lower our risk.

## 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:

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**be active and exercise regularly**

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**don't smoke**

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**eat a healthy balanced diet**

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**control high blood pressure**

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**keep cholesterol at a healthy level**

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**maintain a healthy weight**

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**only drink alcohol within recommended limits.**

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





## Genetics

Alzheimer's is a common disease. This means it's quite likely you will have a relative who has it. This doesn't mean you will inherit it. Some research has suggested that if you have a parent or grandparent with Alzheimer's and they developed Alzheimer's over the age of 65, then your risk of developing Alzheimer's may be slightly higher than someone with no family history.

Research has identified some genes that may be associated with a higher risk of late-onset Alzheimer's in some people. This is helping us to understand more about the causes of Alzheimer's.

In some instances early-onset Alzheimer's can run in families. 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.

## Risk factors

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### Other risk factors

People who have developed mild memory problems, which don't interfere with normal daily activities, are at increased risk of developing Alzheimer's. You might hear this called mild cognitive impairment or MCI. However, many people with MCI do not develop Alzheimer's 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.



## Research

Alzheimer's Research UK has funded over

**£40 million**

of pioneering research across the UK 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.

We believe that Alzheimer's can only be defeated through research. Thanks to the generosity of our supporters, we continue to support scientists who will take us one step closer to a cure.



### 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.



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## Send me more information

For free information, simply complete this slip. You can drop it straight in a post box or put it in an envelope labelled with the freepost address overleaf. Alternatively, phone us on **0300 111 5555**.

### I would like to know more about

Early-onset Alzheimer's

Treatments for dementia

Genes and dementia

Caring for someone with dementia:  
organisations that can help

The latest dementia research

Title

Name

Address

We would like to keep you informed about our research and our progress in defeating dementia. However, if you do not wish to receive any further communications from us, please tick here:

# We are the UK's leading research charity aiming to defeat dementia.

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

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## Dementia Research Infoline

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



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