

# What is Alzheimer's disease?



**Alzheimer's  
Research  
UK**

**The Power  
to Defeat  
Dementia**



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	10
What is Alzheimer’s?	04	Causes	14
Symptoms	06	Risk factors	15
Diagnosis	08	Support	16
		Research	19

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 2016 and is due to be reviewed in May 2018. 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 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 disease is the most common cause of dementia, affecting around six in every 10 people with dementia. The disease is named after the German doctor who first described it in 1906.

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 an inevitable part of getting older. The majority of people who develop the disease are over the age of 65; this is called late-onset or sporadic Alzheimer's.

More rarely, Alzheimer's can affect younger people. It's thought that around 4% 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.

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**500,000**  
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## Symptoms

Alzheimer's often develops slowly over several years. It is not always obvious to begin with and symptoms can be subtle and overlap with other illnesses such as depression. In the early stages, it can sometimes be difficult to distinguish Alzheimer's from mild forgetfulness that can be seen in normal ageing.

Everyone with Alzheimer's will experience symptoms in their own way, but certain changes are characteristic of the disease.

### 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 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 or show less interest in what's happening around them.

## As the disease develops

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



#### 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.



#### Hallucinations

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



#### Unsteadiness

People may become increasingly unsteady on their feet and are at greater risk of falling.



#### 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 GP.



If your GP 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 standard 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.

If symptoms are mild or the cause is uncertain, looking for change over time can help to make the situation clearer. For this reason, a doctor may repeat these assessments, perhaps every six to 12 months, to see if there are any changes.

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 (Aricept)**

**rivastigmine (Exelon)**

**galantamine (Reminyl)**

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 (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. 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.

## 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.

## Treatments for depression, agitation, anxiety and aggression

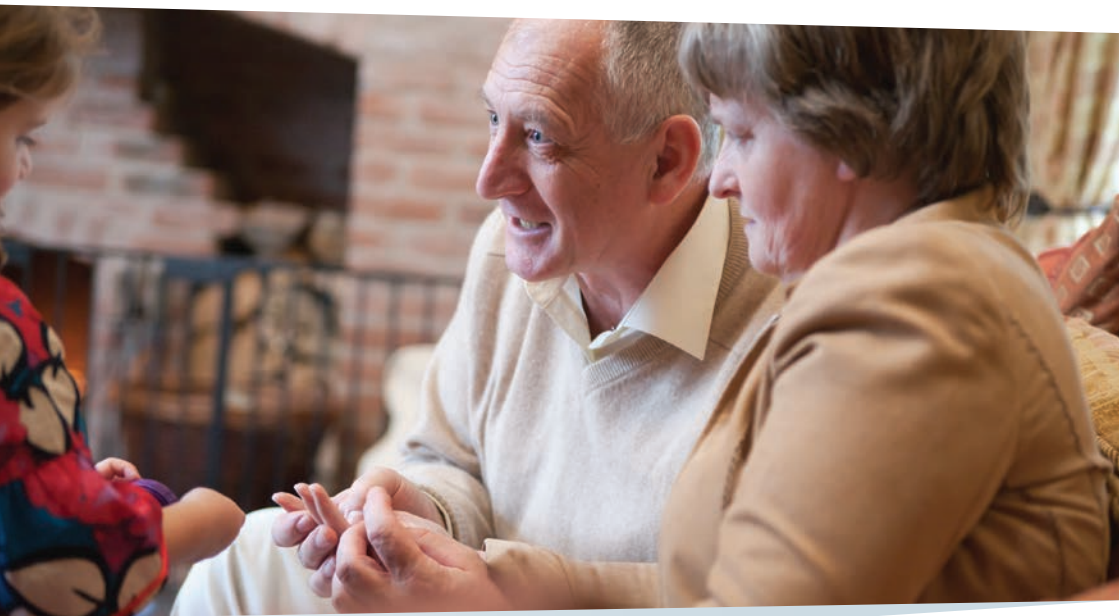
People with depression or anxiety in Alzheimer's may be offered social support or different types of talking therapies depending on their needs and personal situation. Talking therapies, such as cognitive behavioural therapy (CBT), can help with symptoms. CBT provides an opportunity for people to talk about their concerns with a specialist and develop different ways of coping, thinking and behaving.

People with more severe symptoms may also benefit from 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, such as pain or another health problem, which could be removed or reduced. Approaches such as aromatherapy or music therapy may also be considered. This will 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, 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.

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



## 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, and is revealing more about the sequence of events. As the disease 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.

## 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:

**be active and exercise regularly**

**don't smoke**

**eat a healthy balanced diet**

**control high blood pressure**

**keep cholesterol at a healthy level**

**maintain a healthy weight**

**only drink alcohol within recommended limits.**

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, so 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 the disease 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 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. However, their discovery is revealing 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.



## Other risk factors

Some people develop mild memory problems that are worse than those to be expected at their age, but that aren't yet interfering with normal daily activities. 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 **£47 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 breakthrough.



#### 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.

Freepost Plus RTSJ-ZCSB-RGCK  
Alzheimer’s Research UK  
The Boulevard  
Orbital Park  
Ashford  
TN24 0GA



## 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 (SCIHIEO)

Treatments for dementia (SCIHITFD)

Genes and dementia (SCIHIGENE)

Caring for someone with dementia:  
organisations that can help (SCIHICARE)

The latest dementia research (SMTTHINK)

Name

Address

We'd really like to keep you updated with the latest research developments, how your support is making a difference, and fundraising activities that you can get involved in. Your details are always held securely, but if you'd rather not hear from us please tick the relevant box:

No information by post  No information by phone

If you're happy for us to contact you by email, please enter your email address here:

If you're happy for us to contact you by SMS, please enter your mobile number here:

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# 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

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)

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