

What is Alzheimer's disease?

Factsheet 401LP
December 2017



Alzheimer's disease is the most common cause of dementia. More than 520,000 people in the UK have dementia caused by Alzheimer's disease and this figure is set to rise. This factsheet is for anyone who wants to know more about Alzheimer's disease. It describes the symptoms, how it is diagnosed, and the things that increase a person's risk of developing it. It also explains the treatments and support that are available.

If you have been diagnosed with Alzheimer's disease, you might find it helpful to read booklet 616, **Alzheimer's disease: Understanding your diagnosis**, or booklet 872, **The dementia guide**. We also produce many other factsheets and resources that cover topics in this factsheet in more detail. You'll find references to these throughout.

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What is Alzheimer's disease?

Dementia is the name for a set of symptoms that includes memory loss and difficulties with thinking, problem-solving or language. Dementia develops when the brain is damaged by diseases, including Alzheimer's disease. Alzheimer's disease is a physical disease that affects the brain. It is named after Alois Alzheimer, the doctor who first described it.

The brain is made up of billions of nerve cells that connect to each other. In Alzheimer's disease, connections between these cells are lost. This is because proteins build up and form abnormal structures called 'plaques' and 'tangles'. Eventually nerve cells die and brain tissue is lost.

The brain also contains important chemicals that help to send signals between cells. People with Alzheimer's have less of some of these 'chemical messengers' in their brain, so the signals are not passed on as well. There are some drug treatments for Alzheimer's disease that can help boost the levels of some chemical messengers in the brain. This can help with some of the symptoms (see 'Treatment and support' on page 12).

Alzheimer's is a progressive disease. This means that gradually, over time, more parts of the brain are damaged. As this happens, more symptoms develop, and they also get worse.

For more information see factsheet 456, **Dementia and the brain**, or watch our Brain tour at alzheimers.org.uk/braintour

520,000

More than 520,000 people in the UK have dementia caused by Alzheimer's disease.

Symptoms

The symptoms of Alzheimer's disease are generally mild to start with, but as more brain cells are damaged over time the symptoms get worse and start to interfere with a person's day-to-day life. This makes them different from the changes that lots of people have as they get older, such as being a bit slower at thinking things through or forgetting something occasionally.

There are some common symptoms of Alzheimer's disease, but no one's experience will be exactly the same as anyone else's.

For most people, the first signs of Alzheimer's are problems with their memory – in particular, difficulties recalling recent events and learning new information. This is because early on in Alzheimer's the damage is usually to a part of the brain called the hippocampus. This has a big role in day-to-day memory. However, the person's memory for events that happened a long time ago is not usually affected in the early stages.

As Alzheimer's disease progresses, memory problems will usually affect someone's daily life more and they may:

- lose items (such as keys and glasses) around the house
- forget a friend's name, or struggle to find the right word in a conversation
- forget about recent conversations or events
- get lost in a familiar place or on a familiar journey
- forget appointments or significant dates.

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As well as memory difficulties, people with Alzheimer's are also likely to have – or go on to develop – other problems. These include problems with thinking, reasoning, language or perception such as:

- speech – they may repeat themselves or struggle to follow a conversation
- seeing things in three dimensions and judging distances (visuospatial skills) – going up or down stairs or parking the car might become much harder
- concentrating, planning or organising – they may struggle with making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal)
- orientation – they may become confused or lose track of the day or date.

A person in the earlier stages of Alzheimer's will often have changes in their mood. They may become anxious, depressed or more easily annoyed. Many people lose interest in talking to people, or in activities and hobbies. These changes can be challenging for both the person with dementia and those close to them to live with. Anyone finding things difficult should ask for support from a GP or other professional.

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Later stages

As Alzheimer's progresses, problems with memory loss, language, reasoning and orientation get much worse. A person with Alzheimer's disease will need more day-to-day support.

Some people start to believe things that are untrue (having delusions) – for example, being convinced that someone is stealing from them. Less often, people see or hear things that are not really there (having hallucinations).

Many people with Alzheimer's also start to behave in ways that aren't normal for them. These might include becoming agitated (for example, being very restless or pacing up and down), calling out, repeating the same question, having disturbed sleep patterns or reacting aggressively. This can be distressing and challenging both for the person and anyone caring for them. The person may need treatment and support for these behaviours which is separate from any treatment specifically for memory problems.

In the later stages of Alzheimer's disease someone may become much less aware of what is happening around them. They may have difficulties eating or walking without help, and become more and more frail. Eventually, the person will need help with all of their daily activities.

How quickly the disease progresses, and the life expectancy of someone with Alzheimer's, vary from person to person. On average, people with Alzheimer's disease live for 8–10 years after the first symptoms. However, this varies a lot, depending especially on how old the person was when they first developed Alzheimer's. For more information see factsheets 458, **The progression of Alzheimer's disease and other dementias**, and 417, **The later stages of dementia**.

Mixed dementia

Around 1 in 10 people with dementia have more than one type at the same time. This is called mixed dementia. The most common form of mixed dementia is Alzheimer's disease with vascular dementia (caused by problems with the blood supply to the brain). The symptoms of this kind of mixed dementia are a mixture of the symptoms of Alzheimer's disease and vascular dementia. For more information about vascular dementia see factsheet 402, **What is vascular dementia?**.

Atypical Alzheimer's disease

In some people with Alzheimer's disease, memory problems are not the first symptoms. This is called atypical Alzheimer's disease. It is still caused by plaques and tangles, but the first part of the brain to be affected is not the hippocampus.

Atypical Alzheimer's disease is not common in people diagnosed when they are over 65. Only around 1 in 20 people over 65 with Alzheimer's disease have this atypical type. However, it's more common in people diagnosed when they are under 65 (early-onset Alzheimer's disease – see 'Who gets Alzheimer's disease?' on page 7). Up to one-third of people diagnosed with Alzheimer's disease under 65 have atypical Alzheimer's.

1 in 3

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The atypical forms of Alzheimer's disease are:

- **Posterior cortical atrophy (PCA)** – this develops when there is damage to areas at the back of the brain. These areas process signals from a person's eyes and help with spatial awareness. This means the early symptoms of PCA are often problems identifying objects or reading, even if the person's eyes are healthy. Someone may also struggle to judge distances when going down stairs, or seem uncoordinated (for example when they're getting dressed).
- **Logopenic aphasia** – this develops when there is damage to the areas in the left side of the brain that produce speech. The person may have problems finding the right word, or take long pauses while they're speaking.
- **Frontal variant Alzheimer's disease** – this develops when there is damage to the lobes at the front of the brain. The symptoms include problems with planning and decision-making. The person may also behave in socially inappropriate ways (such as saying things that other people might find rude) or seem not to care about the feelings of others.

Who gets Alzheimer's disease?

Most people with Alzheimer's disease develop it after the age of 65, but people under this age can also develop it. This is called early-onset Alzheimer's disease, a type of young-onset dementia. In the UK there are over 40,000 people under the age of 65 with dementia. For more information see factsheet 440, **What is young-onset dementia?**.

There are many different factors that affect whether someone gets Alzheimer's disease. Some of these risk factors can be changed, but others cannot. For more information see factsheet 450, **Risk factors for dementia**, or booklet 35, **Dementia: Reducing your risk**.

Risk factors you can't change

Age

Age is the biggest risk factor for Alzheimer's. It mainly affects people over 65. Above this age, a person's risk of developing Alzheimer's disease doubles about every five years. One in six people over 80 have dementia – many of them have Alzheimer's disease.

Gender

There are about twice as many women as men over 65 with Alzheimer's disease. We don't know the exact reasons for this. Possible explanations include:

- women on average live longer than men
- Alzheimer's in women may be linked to loss of the hormone oestrogen after the menopause.

Genetic inheritance

Many people are worried that Alzheimer's disease may be passed down to them from a parent or grandparent. Scientists are researching the genes that contribute to Alzheimer's.

There are a very small number of families where it is clear that Alzheimer's is being passed on through the genes from one generation to the next. This obvious pattern is very rare. In the few families where it is clear, dementia tends to develop well before the age of 65.

For most people with Alzheimer's disease, the role of genes is not as clear. More than 20 genes are known to increase or reduce a person's chances of developing Alzheimer's. Someone with a parent or sibling who was diagnosed with Alzheimer's when over 65 has a slightly higher risk of developing the disease. However, this does not mean that Alzheimer's is inevitable, and everyone can take steps to reducing their own risk by living a healthy lifestyle (see 'Risk factors you can change' on page 9).

The only genetic test approved for Alzheimer's is for the very rare form that develops under 65. For more information see factsheet 405, **Genetics of dementia**.

People with Down's syndrome have a much higher risk of developing Alzheimer's disease, because of a difference in their genetic makeup. For more information see factsheet 430, **Learning disabilities and dementia**.

Risk factors you can change

Lifestyle

People who live a healthy lifestyle, especially from mid-life onwards, are less likely to develop Alzheimer's disease. This includes doing regular physical exercise and keeping to a healthy weight, not smoking, eating a healthy balanced diet and drinking alcohol within the limits recommended by the UK Chief Medical Officers.

Keeping physically, mentally and socially active will help to reduce the risk of developing dementia.

For more information see booklet 35, **Dementia: Reducing your risk**.

Health problems

There are lots of health problems that increase a person's risk of developing Alzheimer's disease and vascular dementia. It's important to keep these under control and get professional support as early as possible. They include:

- medical conditions such as diabetes, stroke and heart problems
- other physical health problems such as high blood pressure, high cholesterol and obesity in mid-life
- depression (although the evidence for this as a risk factor is not as strong).

Getting a diagnosis

If someone is concerned about having Alzheimer's disease (or any other form of dementia) they should see the GP as soon as possible. It's a good idea to take someone else along to any appointments, to give support and listen to what is said.

Getting an early diagnosis of dementia is helpful for lots of reasons:

- the person will have an explanation for their symptoms
- they will be able to get treatment, advice and support
- they can prepare for the future and plan ahead.

There is no single test for Alzheimer's disease. The GP will first need to look into whether the person has other conditions that can have similar symptoms, such as infections, vitamin and thyroid deficiencies (which can be assessed from a blood test), depression and side effects of medication.

The doctor will also talk to the person, and someone who knows them well (where possible), about their medical history and how their symptoms are affecting their life. The GP or a practice nurse may ask the person to do some tests of their mental abilities.

The GP will make a diagnosis at this stage if they're able to. Often, however, they will need to refer the person to a specialist for a diagnosis, which can mean a wait of a few weeks. The specialist could be:

- an old-age psychiatrist (who specialises in the mental health of older people) – often based in a memory service
- a geriatrician (who specialises in the physical health of older people)
- a neurologist (who specialises in conditions of the brain and nervous system)
- a general adult psychiatrist (who specialises in the mental health of working-age adults).

The specialist will assess the person's symptoms, and how they developed, in more detail. With Alzheimer's disease the person's memory will usually have become worse over several months. A family member may be more aware of these changes than the person themselves.

The person will also do a test to assess their memory, thinking and other mental abilities. When someone with Alzheimer's is tested, they will often forget things quite quickly. Often they won't be able to recall them a few minutes later, even when they're prompted.

The person may have a brain scan, which can show whether certain changes have taken place in the brain. There are a number of different types of brain scan. The most widely used are CT (computerised tomography) and MRI (magnetic resonance imaging). A brain scan can show whether the person has another condition that can have similar symptoms to Alzheimer's, such as stroke, tumour or a build-up of fluid inside the brain. If the scan shows the person has dementia, it may also help to show whether this is Alzheimer's disease or another type of dementia. In a person with Alzheimer's disease, a brain scan may show that the hippocampus and the brain tissue around it have shrunk.

The doctor who tells someone they have Alzheimer's disease should do so sensitively and clearly by speaking directly to the person and usually also to a carer, family member or friend close to them. This should include advice for the person with dementia about what happens next. For more information see factsheet 426, **Assessment and diagnosis**.

Treatment and support

There is currently no cure for Alzheimer's disease, but there is a lot of support available to help someone live well with the condition. This includes drug treatments, and care and support without drugs.

The person should have a chance to talk to a professional about their diagnosis who could be a:

- psychiatrist or mental health nurse
- clinical psychologist
- occupational therapist
- GP
- dementia adviser.

Information on the support available, and where to go for further advice, is very important for helping someone to stay physically and mentally well. Professionals such as the GP and staff at the memory service or local Alzheimer's Society can give advice on the best support to help the person and the people caring for them. You can search for services in your area at **alzheimers.org.uk/dementiadirectory**

When the person is talking to professionals they may find it helpful to ask for written information that they can take away and read at their own pace. Our booklet 872, **The dementia guide** is specifically for someone who has recently been diagnosed with dementia.

Drug treatments

There are drug treatments for Alzheimer's disease that can temporarily ease symptoms, or slow down their progression, for some people. These drugs are often marketed under brand names (some of these are in brackets below).

A person in the mild (early) or moderate (middle) stages of Alzheimer's disease or mixed dementia will usually be prescribed a drug such as:

- donepezil (for example, Aricept)
- rivastigmine (for example, Exelon)
- galantamine (for example, Reminyl).

The drug may reduce anxiety, help with memory problems, improve concentration and motivation, and help with aspects of daily living such as cooking, shopping or hobbies. They work by boosting the levels of some chemical messengers in the brain.

A person in the moderate or severe (late) stages of Alzheimer's disease or mixed dementia may be offered a different kind of drug – memantine (for example, Ebixa). This may help with mental abilities (such as orientation) and daily living, and might also reduce behaviours that challenge or are distressing (such as agitation and having delusions). For more information see factsheet 407, **Drug treatments for Alzheimer's disease**.

A wide range of other drugs may be prescribed at different times for a person with dementia. These may include drugs for blood pressure or diabetes, depression or anxiety, sleeping tablets or antipsychotics.

Support without drugs

There are many ways to help someone with dementia stay independent and cope with changes such as memory loss. These include practical things like supporting the person to have a routine or use a weekly pill box. There are other assistive technology products available such as electronic reminders and calendar clocks. For more information see factsheet 526, **Coping with memory loss**. To see a range of products, including equipment and adaptations, go to Alzheimer's Society's online shop at alzheimers.org.uk/shop

If someone is depressed or anxious, they may want to try talking therapies (such as cognitive behavioural therapy). Counselling may help the person adjust to the diagnosis. For more information see factsheet 445, **Talking therapies (including counselling, psychotherapy and CBT)**.

Many people attend sessions to keep mentally active (cognitive stimulation) – memory services and local Alzheimer's Society offices will have more information about what's available in the area. Lots of people also like to do life story work, in which someone shares their life experiences and makes a personal record. This can help with their memory, mood and wellbeing.

Keeping mentally, physically and socially active can have a very positive impact on a person with Alzheimer's disease. They should try to keep up with activities they enjoy and may also want to try new ones. For example:

- taking regular physical exercise such as swimming, walking or tai chi
- exercising their mind with reading or puzzles
- joining a group to sing, dance or make music
- doing arts, crafts or other hobbies
- visiting a local museum or gallery, or going on day trips.

As the person's dementia progresses, they may enjoy more general reminiscence activities such as talking about photographs or familiar objects. Activities may need to be adapted or done with an offer of support to make them enjoyable.

Over time, changes in the person's behaviour such as agitation or aggression become more likely. These behaviours are often a sign that the person is in distress. This could be for different reasons – for example:

- the person is thirsty or hungry, too hot or too cold
- they are in pain or have another medical condition such as constipation or an infection
- their environment is too noisy, bright or cluttered
- they are confused because their glasses or hearing aids are not working or they're not wearing them
- they misunderstood something or someone
- the person is frustrated or doesn't have enough to keep them active.

Understanding the reason behind someone's behaviour will help to support them. This can include making sure they have opportunities for social interaction, life story work, music, exercise or other activities they enjoy or find useful. These should be tried and, if they don't work, the person should be referred to a specialist such as a clinical psychologist before drugs are considered (especially antipsychotics).

Anyone caring for the person is likely to find these behaviours distressing and they should be supported as well as the person with Alzheimer's. As well as talking to their GP, it may be helpful to call the Dementia Helpline on **0300 222 1122** or visit our online community, Dementia Talking Point, at **alzheimers.org.uk/talkingpoint**

For more information see factsheets 525, **Changes in behaviour**, 509, **Aggressive behaviour**, and 523, **Carers – looking after yourself**.

Other useful organisations

Carers UK

0808 808 7777 (advice line) (Mondays and Tuesdays 10am–4pm)

info@carersuk.org

www.carersuk.org

www.carersuk.org/forum (online discussion forum)

Carers UK provides information, advice and support for carers.

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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

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To give feedback on this factsheet, or for a list of sources, email publications@alzheimers.org.uk

Alzheimer's Society Dementia Helpline England, Wales and Northern Ireland:

0300 222 1122

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