

Early-onset Alzheimer's disease

Affecting people under 65



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**

This leaflet aims to give an introduction to early-onset Alzheimer's disease, a form of young-onset dementia. It's for anyone who might be worried about themselves or somebody else.

It was updated in March 2018 and will be reviewed in March 2020. Please get in touch if you'd like a version with references or in a different format.



The word dementia is used to describe a group of symptoms – often including memory loss, confusion or mood changes that are severe enough to affect day-to-day life. There are many causes of dementia, with Alzheimer's disease the most common.

What is early-onset Alzheimer's?

Although often thought of as a disease of older people, around 5% of people with Alzheimer's disease are under 65. This is called early-onset or young-onset Alzheimer's. It usually affects people in their 40s, 50s and early 60s.

Alzheimer's is the most common cause of early-onset dementia. However, there are other causes in younger people such as frontotemporal dementia and vascular dementia. Contact us for more information on these forms of dementia.

If you are worried about yourself or someone else who is showing symptoms of dementia, talk to your doctor. They will be able to rule out other health issues such as depression or anxiety that may cause similar symptoms in younger people. They will also be able to refer you to a specialist for other tests if necessary.

Symptoms

While some symptoms can be similar to those of late-onset Alzheimer's, the disease can also reveal itself in more unusual ways in younger people. This can make it more difficult for people, families and doctors to recognise.



Symptoms can include:



Memory

Memory problems that interfere with everyday life. This may include forgetting messages or recent events that would normally be remembered, or repeating questions.



Confusion

People may become confused in unfamiliar situations and lose a sense of place and time.



Changes in personality and behaviour

These may be subtle at first. People may become low in mood, irritable, lose their confidence or show less interest in activities they used to enjoy.



Language

Difficulty finding the right words and communicating. This may sometimes be called aphasia.



Visual problems

People can have difficulty recognising words and objects and judging speed or distance. When visual problems are a major symptom, the disease may be called posterior cortical atrophy.

Alzheimer's is a progressive disease, which means that symptoms get worse over time. For more information, ask us for our booklet '**What is Alzheimer's disease?**' or talk to your doctor.

Frequently asked questions

Can I inherit early-onset Alzheimer's?

In most cases the answer is no. Inherited or 'familial' forms of Alzheimer's are very rare.

Several genes have been found that play a role in the development of familial Alzheimer's. Mistakes in these genes (called mutations) can cause the build-up of a toxic protein called amyloid in the brain. If someone has a strong family history of Alzheimer's at a young age, a doctor may suggest genetic testing to close relatives and refer them on for genetic counselling. For more information, ask for our booklet '**Genes and dementia**'.

In the vast majority of cases, the cause is still unclear. It is likely to be a combination of our lifestyle and genetic make-up.

Will early-onset Alzheimer's progress faster?

It is difficult to know. There is some evidence that early-onset Alzheimer's may progress faster and more aggressively, but experts are unsure whether this is conclusive. Every person's experience and response to the disease is different. Difficulties with diagnosis may mean that people are diagnosed later, making their progression seem faster. Research into better methods of detection will help to improve early diagnosis.



Treatments

There are treatments available that may help relieve some symptoms of early-onset Alzheimer's.

If you are prescribed a drug for dementia, treatment is usually started by a specialist doctor, such as a psychiatrist or neurologist. Once treatment has been started, it may be continued and monitored either by a specialist or by your GP.

People with early-onset Alzheimer's disease could benefit from taking one of these cholinesterase inhibitors:

donepezil (Aricept)

rivastigmine (Exelon)

galantamine (Reminyl)

These drugs are licensed and recommended specifically for people with mild to moderate Alzheimer's. Doctors may continue to prescribe one of them for longer if they believe it is still having a beneficial effect.

Memantine (Ebixa or Axura) is recommended as an option for people with severe Alzheimer's disease, and for those with moderate Alzheimer's if cholinesterase inhibitors don't help or are not suitable. These treatments can't cure the disease, but they can help with some of the symptoms.

There are several types of cognitive therapy that may benefit people with early-onset Alzheimer's. For more information about all the treatment options talk to your doctor or request our free booklet '**Treatments for dementia**'.



Risk factors

A risk factor is something that increases your likelihood of developing a disease.

The biggest risk factor for Alzheimer's disease is usually age, while genetics, lifestyle and medical history also play a part. When people develop the disease earlier in life, the causes are less clear.

Some of the risk factors for Alzheimer's disease are the same as for cardiovascular disease (like heart disease and stroke). By leading a healthy lifestyle you will be helping to keep your heart healthy, and you may be lowering your risk of Alzheimer's too.

To keep healthy:



don't smoke



keep active and exercise regularly



eat a balanced diet and maintain a healthy weight



only drink alcohol within Chief Medical Officers' guidelines



keep cholesterol and blood pressure under control.

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

Diagnosing dementia

Diagnosing dementia early is important.

You will be able to get the right help, treatments and support and plan for the future. You may also be able to take part in research studies.

If you go to your doctor with memory problems:



They will ask about your symptoms and medical history and may give you a physical check-up.



They may ask you to do some memory and thinking tests.



Other tests, like brain scans or blood tests, may help the doctor to find the cause of your symptoms.

If your doctor suspects dementia, they may refer you to a memory clinic or a specialist for further tests. If you are diagnosed with dementia your doctor can advise you on the help, support and treatments available. You can choose not to know your diagnosis and who else can be told.

Help and support

The impact of early-onset Alzheimer's can be significant – people are often working and may have young families. There are organisations that offer advice, information, care, and practical and emotional support.

YoungDementia UK can advise on specialised, person-centred enabling services for people with young-onset dementia and their families. Call **01865 794311** or email **support@youngdementiauk.org**

For a full list of organisations, visit **www.alzheimersresearchuk.org** or ask for our booklet '**Caring for someone with dementia: organisations that can help**'. You can also ask your doctor.



Find out more

If you have questions about dementia research or want to find out more about how to get involved in studies, 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.



Send me more information

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

I would like to know more about

Alzheimer's disease (SCIHIALZ)

Treatments for dementia (SCIHITMT)

Genes and dementia (SCIHIGENE)

Caring for someone with 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):

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Research

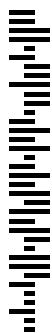
Alzheimer's Research UK
has funded over

£12.4 million

of pioneering research into
early-onset Alzheimer's.

Several studies are looking at the genetics of early-onset Alzheimer's. Another is working with people with early-onset Alzheimer's to follow their health over several years. Our studies are helping to increase understanding of the condition, improve diagnosis and develop potential new treatments.

We believe that dementia can only be defeated through research. Thanks to the generosity of our supporters we will continue to fund pioneering studies into early-onset Alzheimer's.



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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

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