

Early-onset Alzheimer's disease

Affecting people under 65



**Alzheimer's
Research
UK**

Make breakthroughs possible

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

It was updated in March 2020 and will be reviewed in March 2022. 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 types 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 problems 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, they can also appear 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 is called aphasia.



Visual problems

People can have difficulty recognising objects and judging speed or distance. When visual problems are a leading symptom, the cause may be posterior cortical atrophy, a rare type of Alzheimer's disease.

Alzheimer's is a progressive disease, so the 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.

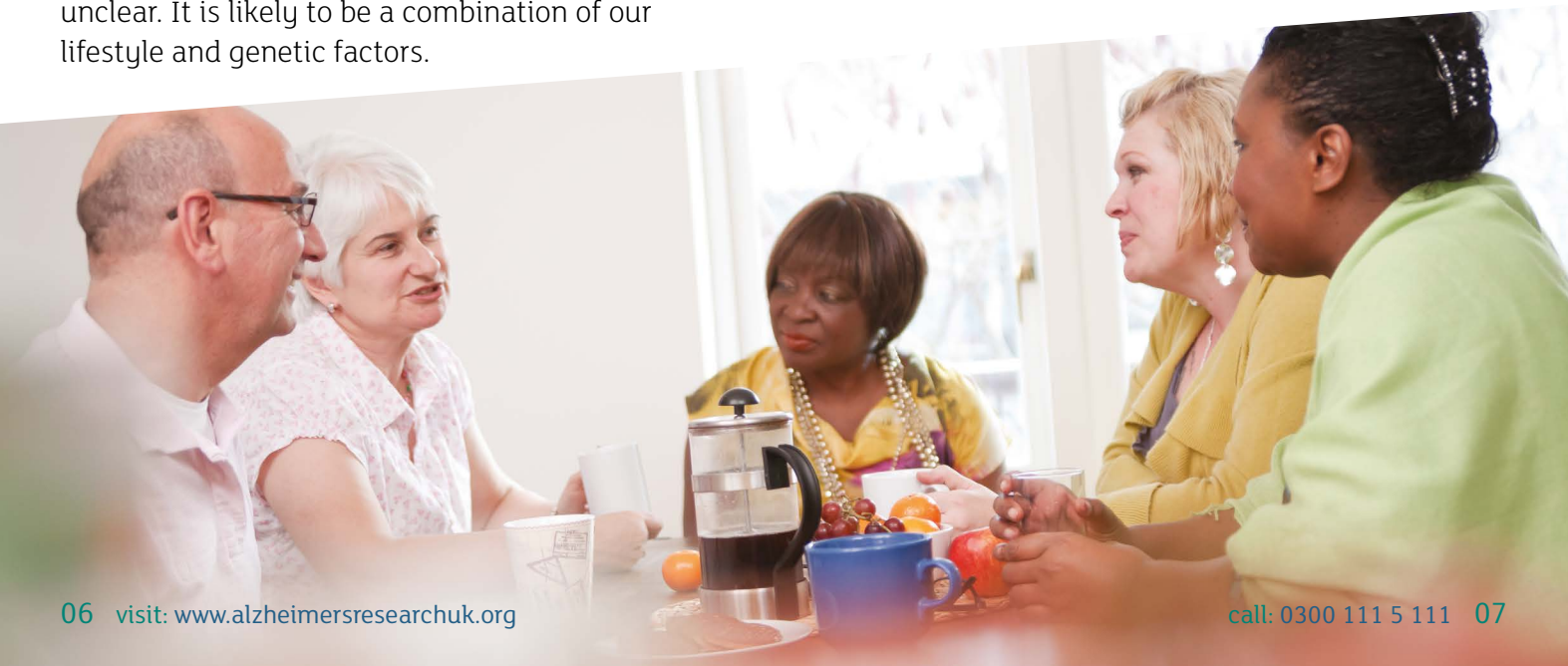
If someone has a strong family history of Alzheimer's at a young age, a doctor may suggest genetic testing to close relatives and refer them on for genetic counselling. For more information, ask for our booklet '**Genes and dementia**'.

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

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 in younger people may mean that they are diagnosed later, making their progression seem faster. Research into better methods of detection will help to improve early diagnosis.



Risk factors

A risk factor is something that increases your chances 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 heart disease and stroke. By leading a healthy lifestyle, you will be helping to keep your heart healthy, and it's likely you'll be lowering your risk of Alzheimer's too.

To keep healthy:



don't smoke



drink fewer than 14 units of alcohol per week



keep active and exercise regularly



eat a healthy balanced diet and maintain a healthy weight



keep cholesterol and blood pressure under control.

Some studies suggest that 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 tell you about the help, support and treatments available. You can choose not to know your diagnosis and who else can be told.

Treatments

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

These include the following drugs, known as cholinesterase inhibitors:

donepezil

rivastigmine

galantamine

These drugs are licensed and recommended for people with mild to moderate Alzheimer's. Doctors may continue to prescribe one of these drugs for longer if they believe it is still helping with symptoms.

Another drug called memantine may be given to people with severe Alzheimer's disease, and to those with moderate Alzheimer's if cholinesterase inhibitors don't help or are not suitable.

People with moderate or severe Alzheimer's disease are sometimes offered combination therapy, where a cholinesterase inhibitor is given in addition to memantine.

The memory clinic may suggest to your doctor that you take one of these drugs. Once your doctor has started your treatment, it may be continued and monitored either by them or by the memory clinic.

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**'.



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 services for people with young-onset dementia and their families. If you would like to contact them for support via email or telephone, fill in the form on their website here www.youngdementiauk.org/need-advice

For a full list of organisations, visit www.alzheimersresearchuk.org or ask for our booklet '**Support for people affected by dementia: organisations that can help**'.

You can also ask your doctor.



Find out more

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

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

Our Privacy Notice can be found at www.alzheimersresearchuk.org/privacy-notice and explains how we will use and store your information.



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Research

Alzheimer's Research UK has funded over

£13.9 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 disease, improve diagnosis and develop potential new treatments.

Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, and investing in research to make breakthroughs possible.

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

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Registered charity number 1077089 and SC042474