

YOUNG ONSET DEMENTIA



Trusted
Information
Creator



Patient Information Approved

**Young
Dementia
Network**
Hosted by
Dementia UK



CONTENTS

- | | |
|---|---|
| 04 What is young onset dementia? | 22 Posterior cortical atrophy |
| 06 Diagnosing dementia | 24 Parkinson's disease |
| 10 Young onset Alzheimer's disease | 26 Treatments for young onset dementia |
| 14 Vascular dementia | 28 Help and support |
| 16 Frontotemporal dementia (FTD) | 30 Taking part in research |
| 20 Dementia with Lewy bodies (DLB) | 31 Research |

INTRODUCTION

This booklet provides an introduction to young onset dementia, which is when a person's symptoms start before they turn 65. It's for anyone who is worried about themselves or somebody else, and for people who want to know more about different types of young onset dementia and how they are diagnosed.

The information here does not replace advice that doctors, pharmacists, or nurses may give you. If you are worried about your health, including memory, thinking, behavioural and communication problems, speak with your doctor as soon as possible.

This booklet was updated in March 2024 and is due to be reviewed in March 2026. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers, and the Young Dementia Network. Please get in touch using the contact details below if you'd like a version with references or in a different format.

ANY QUESTIONS

If you have questions about dementia or dementia research, or any feedback on this booklet, you can contact the Dementia Research Infoline on **0300 111 5111**. You can also email infoline@alzheimersresearchuk.org or write to us using the address on the back page.

WHAT IS YOUNG ONSET DEMENTIA?

The word dementia is used to describe a group of symptoms that are severe enough to affect day-to-day life. Symptoms can include:

- **thinking problems**
- **confusion**
- **problems with language, movement or vision**
- **and mood changes.**

Dementia is caused by diseases that affect how our brain cells work. It is often thought of as a condition that affects older people, but when symptoms develop in people under the age of 65 this is called young onset dementia.

This booklet will give details about the following causes of dementia that can affect people under the age of 65:

- Alzheimer's disease
- vascular dementia
- frontotemporal dementia
- dementia with Lewy bodies
- posterior cortical atrophy
- and Parkinson's disease.

There are similarities between the diseases that cause young onset dementia and dementia in later life (late onset dementia). However, some diseases such as frontotemporal dementia (FTD) are more common in younger people.

If you are worried about yourself or someone else who may be showing symptoms of dementia, talk to your doctor. They should assess your symptoms and medical history, and perform some tests.



DIAGNOSING DEMENTIA

Diagnosing dementia early is important. You will be able to get the right help, treatments and plan for the future. You will also be able to take part in research studies if you'd like to.

You should speak to your doctor about your concerns as soon as possible. In some cases, it can be helpful to bring somebody that knows you well along to your appointment for support.

The doctor will:

- ask about your symptoms and medical history and may give you a physical check-up.
- ask you to do some memory and thinking tests.
- run blood tests, which may help the doctor to rule out other common causes for your symptoms like thyroid disorders or vitamin deficiencies.
- make a referral to a memory clinic or specialist doctor such as a neurologist for further tests.

A memory clinic or specialist may carry out:

- a brain scan to look for changes in the structure of your brain or to rule out other causes of your symptoms.
- in depth memory and thinking tests.

- a lumbar puncture which can help to detect “markers” of some of the diseases that cause dementia in a sample of your spinal fluid.
- genetic counselling if there is a strong family history of young onset dementia.

People who experience dementia symptoms at a younger age can often struggle to get a diagnosis or referrals, and the process can take longer than it does for someone over the age of 65. This is in part because young onset dementia is less common and often causes symptoms that may not typically be associated with dementia.

Some doctors may not recognise dementia symptoms in younger people and put the concerns down to other common conditions like stress, depression or menopause. You may need to visit your doctor more than once. Some doctors have different specialities and requesting a second opinion with a different doctor can be helpful.

If you are worried about your health, you have the right to an accurate diagnosis.

KEEPING A DIARY OF YOUR SYMPTOMS AND TAKING IT TO YOUR APPOINTMENTS CAN HELP YOUR DOCTOR TO UNDERSTAND YOUR CONCERNS.

The **Young Dementia Network** produce a 'personal checklist' and other resources that can aid discussions with your doctor about symptoms: youngdementianetwork.org/resources

You can also contact **Dementia UK's Admiral Nurses**, who are dementia specialist nurses on **0800 888 6678** or helpline@dementiauk.org

Alternatively, you can book a free video appointment with an Admiral Nurse at dementiauk.org/book They can provide support and advice on all aspects of dementia, including support around getting a diagnosis.

For more information on getting a diagnosis, you can order or download a copy of our booklet '**Getting a dementia diagnosis**' using the details on the back page.

WILL YOUNG ONSET DEMENTIA PROGRESS FASTER?

Diseases like Alzheimer's are progressive. This means the symptoms get worse over time and people will require more support with their everyday lives. There is some evidence to suggest that young onset dementia progresses faster than late onset dementia. But every person's experience is different.

Difficulties with diagnosing young onset dementia mean that people are often diagnosed later, making their progression appear faster. Research into better and earlier ways to detect diseases that cause dementia is essential to improve early diagnosis and get people the support that they need.



YOUNG ONSET ALZHEIMER'S DISEASE

Alzheimer's disease is the most common cause of young onset dementia, accounting for around one in three of all young onset dementia cases. Young onset Alzheimer's usually affects people in their 40s, 50s and early 60s.

Although often thought of as a disease that affects older people, it is estimated that at least five in every 100 people with Alzheimer's disease in the UK are under 65. This figure may be higher as it can be more difficult to get an accurate diagnosis at a younger age.

While the symptoms of young onset Alzheimer's disease are similar to those of late onset Alzheimer's, more unusual symptoms can develop too. These might be harder to recognise. Symptoms will get worse overtime and become more noticeable.

IT IS ESTIMATED THAT AT LEAST FIVE IN EVERY 100 PEOPLE WITH ALZHEIMER'S DISEASE IN THE UK ARE UNDER 65.

Symptoms can include:

- **Memory problems that interfere with everyday life.** This may include forgetting a work meeting or recent events, or repeating questions.
- **Confusion and disorientation.** People may become confused more easily, get lost or lose track of time.
- **Changes in personality and behaviour that may be subtle at first.** People may become low in mood, more irritable, lose their confidence or show less interest in activities they used to enjoy.
- **Language difficulties.** Trouble finding the right words (aphasia) and following conversations.
- **Problems with movement.** People may become unsteady, have problems moving around, develop tremors or experience stiffness.
- **Visual problems.** Difficulty recognising objects and judging speed or distance.
- **Planning and problem solving.** Daily tasks like paying bills, cooking and driving may become difficult to do.

Causes of young onset Alzheimer's disease

For the majority of people affected, the cause of young onset Alzheimer's disease is a combination of lifestyle, genetic and environmental factors. Research is ongoing to understand why some people are affected at a younger age than others.

Most cases of Alzheimer's are not directly inherited. However young onset Alzheimer's disease is more likely to be passed down in families compared to late onset Alzheimer's.

Directly inherited Alzheimer's occurs when a parent with the disease passes a faulty gene on to their children. In these cases there is a strong family history, where at least one person from every generation has had the disease. A person who has a parent with a faulty gene has a 1 in 2 chance of inheriting it themselves, and if they inherit it they will go on to develop the disease.

It is thought that around one in 10 cases of young onset Alzheimer's may be directly inherited. This is sometimes referred to as familial Alzheimer's disease (FAD).

So far, three genes have been linked to FAD. Mistakes in genes called mutations cause the build up of a protein called amyloid in the brain. This build up of amyloid is a key feature of Alzheimer's disease. If someone has a strong family history of young onset Alzheimer's a doctor can refer them for genetic counselling.

For more information, ask for our free booklet **'Genes and dementia'**, contact and order details can be found on the back of this booklet.



VASCULAR DEMENTIA

Vascular dementia is the second most common cause of young onset dementia, accounting for around one in every five cases.

Vascular dementia occurs when blood vessels in the brain are damaged. This affects how our brain cells work and causes them to become damaged too, leading to dementia symptoms.

Vascular dementia can cause some similar symptoms to Alzheimer's disease, but speech and movement problems can be more common too. Symptoms can come on suddenly after a stroke or develop more slowly overtime.

Symptoms may include:

- **Thinking problems.** People may find it harder to carry out tasks and follow instructions that they used to find simple.
- **Speech and language difficulties.** Struggling to find and use the right words and slurred speech.
- **Changes in personality, mood and behaviour.** People can experience low mood, agitation and anger.
- **Movement and stability problems.** People can become unsteady on their feet, or experience changes to the way they walk.

Causes of vascular dementia

Blood vessel damage in the brain can occur after a stroke, or due to small vessel disease. Small vessel disease is caused by long-term damage of the smaller vessels in the brain, often due to underlying medical conditions like high blood pressure and type 2 diabetes.

There are other risk factors including age, genetics and lifestyle factors that increase someone's risk of developing vascular dementia. This is because they increase the likelihood that blood vessels will become damaged.

CADASIL is one rare, inherited type of vascular disease caused by a faulty gene that can be passed from a parent to their child. A person who has a parent with the mutated gene has a one in two chance of inheriting the gene themselves. It causes the blood vessel walls to thicken which blocks blood flow to some areas of the brain.

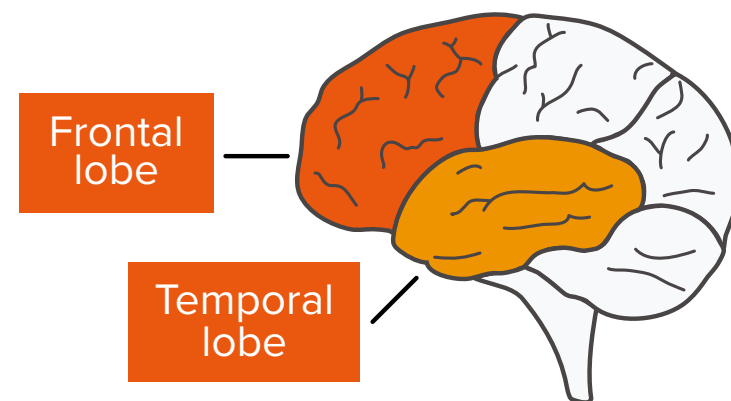
For more information on vascular dementia, please request our free information booklet, **'What is vascular dementia?'** or speak to your doctor.

FRONTOTEMPORAL DEMENTIA (FTD)

Frontotemporal dementia, also known as FTD, often occurs in people under the age of 65. FTD accounts for around 12 in every 100 cases of young onset dementia. FTD symptoms often begin between the ages of 40 and 60.

In FTD there is damage to cells in areas of the brain called the frontal and temporal lobes. These areas of our brains control our personality, emotions and behaviour, as well as speech and understanding of words.

There are different types of FTD. Sometimes the separate conditions are known by their specific names, and other times doctors may refer to them collectively as FTD. Symptoms can vary depending on which parts of the brain are affected.



Symptoms of FTD can include:

- **Changes to behaviour and emotions.** Being inappropriate or experiencing a change in sense of humour. There may be a change in how people express their feelings or understand other people's feelings. People may not notice these changes in themselves.
- **Concepts and understanding.** People may find it more difficult to understand concepts like that money is used to buy things, or that the remote controls the TV.
- **Communication problems.** Speech may become slurred or hesitant. It may be challenging to find and use the correct words and people may find it hard to follow and engage with conversations. Complex sentences can become hard to follow, which can impact reading and writing skills.
- **Movement problems.** Stiff or slowed bodily movement, weakness and twitches or cramps. Some people with FTD may have difficulties with swallowing.

For more information on the different types of FTD, please request our booklet '**What is frontotemporal dementia?**' We also have separate booklet about a type of FTD called primary progressive aphasia which you can request.



Causes of FTD

In FTD, there is a build-up of proteins in the frontal and temporal lobes of the brain. These are tau, TDP-43 and a group called FET proteins. These proteins clump together and damage the brain cells, eventually causing them to die.

In most cases, the cause of FTD is unclear. It is likely to be a combination of our lifestyle, environment, and genetic factors. In young onset FTD, about 1 in 10 cases are caused by a directly inherited gene. The gene is passed down from an affected parent to their child. There is a 1 in 2 chance that an affected parent will pass the gene on to their child. This type of FTD is called familial FTD and there is a strong pattern of inheritance in every generation.

If you're worried about familial FTD, speak to your doctor who can refer you for specialist testing called genetic counselling.

DEMENTIA WITH LEWY BODIES (DLB)

Around 1 in 10 cases of young onset dementia is caused by dementia with Lewy bodies, or DLB.

In DLB, small round clumps of protein called alpha-synuclein build up in the brain, these clumps are called Lewy bodies. This build-up is accompanied by damage to nerve cells. This damage affects the way that our brain cells communicate which leads to the symptoms of dementia.

DLB is closely related to Parkinson's disease. The build-up of Lewy bodies is also found in Parkinson's and leads to symptoms like movement problems and tremors. These symptoms can also occur in DLB.

Symptoms of DLB may include:

- **Confusion and changes to levels of alertness.** People may have problems carrying out daily activities. People often experience periods of being less alert to things going on around them. Levels of alertness can vary from day to day or even within the same day.
- **Movement problems.** Including shakiness and tremors, slowness of movement or stiffness.
- **Hallucinations and delusions.** Seeing, hearing and believing things that are not really there. These are very realistic for the person experiencing them.

- **Changes to thinking and memory.** People can find it difficult to find their way around places that used to be familiar. Memory loss can be less common in DLB compared to other types of dementia.
- **Mood changes.** Including depression and anxiety.
- **Sleep problems.** People may experience vivid dreams and disrupted sleep where they move around a lot and thrash out their arms and legs.

Causes of DLB

We don't yet know what causes the alpha-synuclein to build up in the brains of people with DLB or the specific role that it plays in the condition. However, whilst age is the biggest risk factor for the development of DLB, conditions like high blood pressure and obesity increase the risk.

Some research has found several genes linked to a higher risk of DLB, including a known risk gene for Alzheimer's disease. People with a family history of DLB or Parkinson's disease have a higher risk too.

For more information on dementia with Lewy bodies, please ask for our free booklet '**What is dementia with Lewy bodies?**' or talk to your doctor.

POSTERIOR CORTICAL ATROPHY

Posterior cortical atrophy (PCA) is a rare form of dementia usually affecting people between 50 and 65.

PCA is caused by damage to brain cells at the back of the brain. This is the part of our brain that processes information from our eyes and allows us to make sense of what we are seeing and where things are. It usually begins by affecting a person's vision, causing various symptoms that make moving around and carrying out daily tasks difficult.

People living with PCA have symptoms that vary from person to person and can change over time. Most people will have problems with their vision first, and as symptoms worsen people may have problems with dressing, handwriting, coordination and using numbers and language too.

Symptoms of PCA may include:

- **Vision problems.** People may bump into things as they might be unable to see what is right in front of them, things may appear to be distorted or moving around. It can be challenging to judge depths and distances and they may still see the image of an object even after looking away.
- **Coordination problems.** People may find it more challenging to complete tasks such as getting dressed. Everyday objects such as kitchen utensils or a remote control can be difficult to use.

- **Literacy, numeracy and reading skills can become more challenging.** For example, people may find it difficult to work out simple calculations and find spelling and writing hard. Certain fonts can become challenging to read, words or lines of words can become jumbled up and harder to understand.

Causes of PCA

Alzheimer's disease is the most common cause of brain cell damage in PCA, but it can also be caused by other types of dementia such as vascular dementia and dementia with Lewy bodies.

PCA is a rare type of dementia and one that doctors may have little experience of and this can make getting a diagnosis difficult.

The **Rare Dementia Support** PCA group provides opportunities for people with PCA to meet each other and share their experiences. You can contact them by phone on **0203 325 0828** or email contact@raredementiaupport.org

For more information on posterior cortical atrophy, please request our health information booklet '**What is posterior cortical atrophy?**' or speak to your doctor.



PARKINSON'S DISEASE

Parkinson's disease is most commonly diagnosed around age 60. It affects brain cells that produce a chemical called dopamine.

The brain uses dopamine to send messages which control the body's movement. When the brain cannot produce enough dopamine to control movement properly, symptoms of Parkinson's start to appear. As more brain cells are affected, problems with movement will get worse.

Over half of people with Parkinson's go on to develop dementia, usually about 10 years after their diagnosis. This is called Parkinson's disease dementia (PDD).

The main symptoms of PDD are similar to those seen in DLB, and include:

- **Memory and thinking problems.**
- **Problems with alertness and staying awake.**
- **Disturbed sleep.** Including lots of moving around in sleep.
- **Hallucinations.** Seeing things that are not really there.

Causes of Parkinson's disease

In the vast majority of cases, the cause is still unclear. It is likely to be a combination of our lifestyle, environment and genetic factors. Cases of people passing Parkinson's disease to their children are very rare.

However, some genes have been identified in a small number of people that increase their risk of developing the disease. People who receive a diagnosis of Parkinson's disease earlier in life are more likely to have a genetic link.

For more information and support regarding Parkinson's disease, please contact **Parkinson's UK** at **0808 800 0303** or email hello@parkinsonsuk.org

OVER HALF OF PEOPLE WITH PARKINSON'S GO ON TO DEVELOP DEMENTIA, USUALLY ABOUT 10 YEARS AFTER THEIR DIAGNOSIS.

TREATMENTS FOR YOUNG ONSET DEMENTIA

There are drug treatments available on prescription that can help relieve some symptoms of **young onset Alzheimer's** and **dementia with Lewy bodies** when symptoms are mild or moderate.

These include the following drugs, known as cholinesterase inhibitors:

- donepezil
- rivastigmine
- galantamine

Another drug called memantine may be given to people with these conditions who have moderate to severe symptoms, and to those with moderate symptoms when cholinesterase inhibitors don't help or are not suitable.

People with Alzheimer's or DLB are sometimes offered combination therapy, where a cholinesterase inhibitor is given in addition to memantine. These treatments don't slow down the underlying disease, but they can help with some of the symptoms.

Levodopa is a drug prescribed in Parkinson's disease and DLB that can help with movement symptoms. Medications like antidepressants can help with changes in mood.

Unfortunately, there are no medications currently available to treat frontotemporal dementia, so the focus is on helping people with the disease manage their symptoms in everyday life.

There are currently no specific treatments for vascular dementia. However, a doctor may prescribe or monitor medicines taken to treat underlying conditions like high blood pressure, that can damage blood vessels and contribute to vascular dementia and stroke.

There are several types of cognitive therapy that may benefit people with young onset dementia. For example, cognitive stimulation activities are designed to stimulate thinking skills. They are designed to be enjoyable and are often group activities. The benefits of cognitive stimulation for people with dementia can include improvement in mood, thinking skills and quality of life.

People with young onset dementia 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) and counselling can help with common symptoms of depression and anxiety. They provide an opportunity for people to talk about their concerns with a specialist and develop different ways of coping, thinking and behaving.

For more information about your treatment options talk to your doctor or request our free booklet '**Treatments for dementia**' or visit alzres.uk/treatment

HELP AND SUPPORT

The impact of young onset dementia can be significant – people are often working, have financial commitments like a mortgage, and may have children still living at home.

Everyone with dementia and their carer is entitled to an assessment that establishes their support needs and suggests how those needs can be met.

Dementia is a progressive disease. Over time symptoms get worse, and someone will require more support to look after themselves and with day-to-day activities. The speed of change in symptoms can vary widely from person to person.



There are organisations that offer advice, information, care, and practical and emotional support for everyone affected by dementia and their loved ones.

Dementia UK's dementia specialist **Admiral Nurses** offer practical advice and support to people affected by dementia and their families. They can be contacted on **0800 888 6678** or **helpline@dementiauk.org**

If you prefer, you can book a phone or video appointment at a time to suit you at **dementiauk.org/book**. To find out about face-to-face Admiral Nurse services in your area, please contact the Helpline.

The **Young Dementia Network** is an online collaborative community of people affected by young onset dementia and those working in the field. Free to join, the network works to increase knowledge, understanding and awareness of young onset dementia. It campaigns for improvements to services for younger people with dementia to be explicitly included in national dementia plans and policies. Find out more at **youngdementianetwork.org**

If you have questions about young onset dementia, symptoms, diagnosis, treatment, or about taking part in research you can contact the **Dementia Research Infoline** **0300 111 5111** or **infoline@alzheimersresearchuk.org**

TAKING PART IN RESEARCH

Volunteers aged 18 and over, both with or without dementia, can take part in research studies or clinical trials that play an essential role in helping scientists to understand dementia and test potential new treatments.

If you're interested in taking part in research and would like to find out more, register to the Join Dementia Research service, which is run by the NHS. This will match you to research studies you are suitable for, so you can see what type of research you could take part in.

You can find out more and register here joindementiaresearch.nihr.ac.uk You can also register over the telephone on **0300 111 5111**.



SHARE YOUR STORIES

If you have been diagnosed with young onset dementia and would like to share your story to inspire others and to help shape our work please get in touch via stories@alzheimersresearchuk.org

RESEARCH

Alzheimer's Research UK has funded over £194 million of pioneering research into different kinds of dementia, including young onset dementia.

Several studies are looking at the genetics of young onset dementia. One study is working with people with young onset dementia, including FTD and Alzheimer's to follow their health over several years. Our research is helping to increase understanding of the diseases that cause young onset dementia, improve diagnosis and develop potential new treatments.

You can find out more about these projects and our other funded research by visiting alzheimersresearchuk.org/research

We are Alzheimer's Research UK.
We exist for a cure.

Alzheimer's Research UK is the UK's leading dementia research charity. We provide free dementia health information, like this booklet and others.

If you or your loved one have been diagnosed with dementia in the last two years and would like to share your experience to help shape our work visit alzres.uk/MCV

ORDER

alzheimersresearchuk.org/supporter-orders
or scan the QR code



CONTACT US

0300 111 5111
info@alzheimersresearchuk.org

Alzheimer's Research UK
3 Riverside, Granta Park, Cambridge CB21 6AD

VISIT

alzheimersresearchuk.org/dementia-information

STAY UP TO DATE

with our work and dementia research
Scan the QR code or call **0300 111 5555**



This booklet was printed with support from The Perfume Shop who had no input into the content.

**ALZHEIMER'S
RESEARCH UK**

**FOR A
CURE**

THE PERFUME SHOP