ALZHEIMER'S RESEARCH UK FOR A CURE

# YOUNG ONSET DEMENTIA

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# INTRODUCTION

**This booklet provides an introduction to young onset dementia. This 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.

The booklet was updated in March 2026 and is due to be reviewed in March 2028. 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, you can contact our Dementia Research Infoline on **0300 111 5111** or 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:**

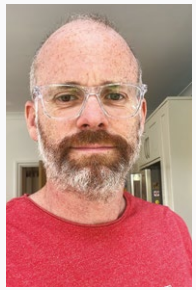
**thinking problems**

**changes in behaviour or mood**

**problems with language, movement or vision**

**confusion.**

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 around seven in every 100 people with dementia in the UK are under 65 years old. This is called young onset, or early-onset, dementia.



“Dementia at any age is difficult for everyone involved, particularly as you can see a loved one’s personality change so dramatically. When this happens earlier in life there are often serious practical repercussions beyond the distress itself, involving children, jobs and income streams.”

**- Michael’s wife Vanessa had young onset Alzheimer’s disease**

# SYMPTOMS OF YOUNG ONSET DEMENTIA

**If you are worried about yourself or someone else who may be showing symptoms of dementia, talk to your doctor. They can do some tests to find out what is causing any symptoms.**

It is possible to have more than one type of dementia. For example, someone may have young onset Alzheimer's disease and vascular dementia. This is known as mixed dementia.

## YOUNG ONSET ALZHEIMER'S DISEASE

Alzheimer's disease is the most common cause of young onset dementia. Around one-in-three people with young onset dementia have Alzheimer's disease. Symptoms of young onset Alzheimer's usually start in people's 40s, 50s or early 60s.

Memory loss is not always one of the first symptoms of young onset Alzheimer's. So, symptoms can be harder to recognise.

For more information, ask for our booklet **'What is Alzheimer's disease?'** using the contact details on the back page.





**Someone with young onset Alzheimer's disease may have symptoms such as:**

**Having trouble finding the right words** (aphasia) and following conversations.

**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.

**Becoming unsteady,** having problems moving around or developing tremors or stiffness.

**Symptoms will get worse over time and become more noticeable. Other symptoms can include:**

**Memory problems** that can get in the way of everyday life. Someone might forget a work meeting or recent event, or repeat questions.

**Becoming confused** more easily, getting lost, or losing track of time.

**Having problems completing daily tasks** that involve planning and problem solving. These may include paying bills, cooking and driving.

**Finding it harder to recognise objects** and judge speed or distance.

# VASCULAR DEMENTIA

Vascular dementia is the second most common cause of young onset dementia. Around one in every five people with young onset dementia has vascular dementia.

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. Over time, this damage spreads and can lead 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 over time.

"At first the changes in everyday life were very small, there was only minor forgetfulness, from misplacing objects to forgetting to make a cup of tea. Gradually the changes in my Dad became more noticeable, his spatial awareness started to go quite quickly. He then became very dependent on my myself, my mum and sister."

**- Ciana's dad, Mike, had young onset Alzheimer's disease**



**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 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.

For more information, ask for our booklet **'What is vascular dementia?'** using the contact details on the back page.

# FRONTOTEMPORAL DEMENTIA (FTD)

Frontotemporal dementia, also known as FTD, can develop in people under the age of 65. FTD accounts for around 12 in every 100 cases of young onset dementia.

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, behaviour and ability to speak and understand others.

There are different types of frontotemporal dementia (FTD). Sometimes doctors use the specific condition names, and other times they may refer to them all together as FTD. Because these types affect different parts of the frontal and temporal lobes, the symptoms someone experiences can vary depending on which areas of the brain are most affected.

For more information ask for our booklets **'What is frontotemporal dementia?'** and **'What is primary progressive aphasia'** using the contact details on the back page.





**Symptoms of FTD can include:**

**Changes to behaviour,** such as being inappropriate, or a change in sense of humour. Someone may also become impulsive or develop obsessions, such as spending lots of money or gambling.

**Changes in emotions and behaviour.** This may include expressing feelings differently or finding it harder to understand how other people feel. Some people may become less motivated, lose interest in things they used to enjoy, or stop looking after themselves as well as before. They may not notice these changes in themselves.

**People may find it more difficult to understand concepts** e.g. that money is used to buy things.

**Someone may have difficulty recognising familiar objects,** e.g. knowing that the remote controls the TV, or the kettle is used to boil water.

**Speech may become slurred or hesitant.** It may be challenging to find and use the correct words, or harder to follow conversations.

**Stiff or slowed bodily movement,** weakness and twitches or cramps. Some people with FTD may have difficulties with swallowing.

# DEMENTIA WITH LEWY BODIES (DLB)

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

In DLB, small round clumps called Lewy bodies build up in the brain. They are linked to damage to brain cells. As more brain cells become damaged, it becomes harder for our brain to carry out normal processes. This 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. That's why symptoms like movement problems and tremors 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, or have periods of being less alert of their surroundings. These periods can be hard to predict and change on an hourly or daily basis.

**Visual hallucinations** – seeing, hearing and believing things that are not really there. These are very realistic for the person experiencing them.

**Movement problems** – such as shakiness and tremors, slowness of movement or stiffness.

**Delusions** – having false beliefs without evidence. People with DLB may believe that others are out to harm them, or that their home is not their own.

**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.

**Walking and balance problems** – such as unsteadiness or being more prone to falling.

**Sleep problems** – people may experience vivid dreams and disrupted sleep where they move around a lot and thrash out their arms and legs. Poor sleep quality is more common in DLB than in other types of dementia.

**Mood changes** – including depression, anxiety and a lack of motivation. Some people may also experience agitation or restlessness.

For more information, ask for our booklet **'What is dementia with Lewy bodies?'** using the contact details on the back page.

# PARKINSON'S DISEASE

Parkinson's disease is most commonly diagnosed around 60 years of age.

Parkinson's disease 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, Parkinson's symptoms begin 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:**

**Hallucinations** – seeing things that are not really there.

**Memory and thinking problems.**

**Disturbed sleep** – including lots of moving around in sleep. Problems with alertness and staying awake.

For more information, contact **Parkinson's UK** on **0808 800 0303** or visit their website **parkinsons.org.uk**

# POSTERIOR CORTICAL ATROPHY

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

It is most commonly caused by the same damage to the brain that is seen in Alzheimer's disease. But in PCA, the damage is to cells at the back of the brain. This part of the brain is called the occipital lobe.

The occipital lobe processes information from our eyes and allows us to make sense of what we are seeing and where things are.

PCA usually begins by affecting a person's vision. It causes symptoms that make moving around and carrying out daily tasks difficult. For more information, ask for our booklet **'What is posterior cortical atrophy?'** using the contact details on the back page.





**Symptoms of PCA that affect someone's vision may include:**

**Not being able to see what is right in front of them,** and bumping into things more frequently. People may also still see an image of an object after looking away, or not be able to see more than one object at a time.

**Changes in ability to judge depth and distance.** For example, a black object or puddle may appear to be a hole in the floor or it may be difficult to find and reach for a door handle.

**Perceiving colours and shapes differently.** For example, items may have an unusual colour or shapes may appear distorted.

**Other symptoms of PCA may include:**

**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 more challenging to read. Words and paragraphs can become jumbled up and harder to understand.

**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.

# DIAGNOSING DEMENTIA

**Diagnosing dementia early is important. It means someone will be able to get the right help, treatments, support 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. It can be helpful to bring somebody that knows you well along to your appointment for support.

**During your appointment, your doctor may:**

- 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 may find it takes longer to get a diagnosis or referral.

This is because young onset dementia is less common, and the symptoms can look different from those usually linked with dementia in older adults.

Sometimes doctors may not immediately recognise these symptoms in younger people, and may think they are due to other common conditions such as stress, depression or menopause. This can mean you need to visit the doctor more than once before getting answers.





If this happens, it can be helpful to ask for a second opinion with a different doctor, as doctors have different areas of experience. You have the right to an accurate diagnosis and to know what type of dementia you have.

This will mean you can get the right treatments and support for you. It's important to keep seeking help if you are worried about your health. 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 help 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.

# 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.**

It is difficult to know whether young onset dementia progresses faster than late onset dementia. There is some evidence that this is the case. But every person's experience of the disease is different, including how fast or slow it progresses.

Difficulties with diagnosis in younger people may mean that they are 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.

"A timely diagnosis has given me and my wife Grainne, the time to discuss the implications, take part in research and make informed choices about what next, together."

**- Julian was diagnosed with Primary Progressive Aphasia in his 50s**

# TREATMENTS FOR YOUNG ONSET DEMENTIA

## Medications for Alzheimer's disease, posterior cortical atrophy and dementia with Lewy bodies

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. They are 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. Memantine can also be prescribed to those with moderate symptoms when cholinesterase inhibitors don't help or are not suitable.

Some people may be offered both a cholinesterase inhibitor and memantine at the same time. These treatments don't slow down the underlying disease, but they can help with some of the symptoms.





Once your treatment has started, it may be continued and monitored by either your doctor or memory clinic.

There are two treatments available privately that can slow down early Alzheimer's. They are not suitable for everyone, and they are not available on the NHS. You can find more information at **alzres.uk/treatment**

Levodopa is a drug prescribed in DLB that can help with movement symptoms. Medications like antidepressants can help with changes in mood.

## Treatments for vascular dementia

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

## Treatments for frontotemporal dementia

Unfortunately, there are no medications currently available to treat frontotemporal dementia. Therapies focus on helping people with the disease manage their symptoms in everyday life, described on page 27.

## Treatments for Parkinson's disease

There is no cure for Parkinson's disease, but there are some treatments that can help with symptoms.

Levodopa is a drug prescribed in Parkinson's disease that can help with movement symptoms. It is usually offered to people whose movement problems affect day-to-day life. People with movement problems that don't affect day-to-day life may be offered a choice of treatments:

- levodopa
- dopamine agonists
- monoamine oxidase-B (MAO-B) inhibitors.

There are other treatments available for people with severe symptoms, such as catechol-O-methyltransferase inhibitors. There are also treatments that don't need to be swallowed for people who find it difficult.

Some people may be suitable for deep brain stimulation (DBS). This involves an operation to place a small device under the skin of the chest. Thin wires run from this device to specific areas of the brain. The device sends small electrical signals through the wires, which can help reduce certain symptoms.

Medications like antidepressants can help with other symptoms like changes in mood.

Your doctor will be able to tell you more about treatment options. You can also contact **Parkinson's UK** on **0808 800 0303** or **hello@parkinsons.org.uk**





## Non-drug therapies for young onset dementia

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 and engage people affected, with an emphasis on enjoyment and 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'**.

# WHAT CAUSES YOUNG ONSET DEMENTIA?

**Most cases of young onset dementia are caused by a mixture of age, genes, lifestyle and environment. Researchers are still working to find out why some people develop symptoms at a younger age than others.**

Because dementia is so common, it's not unusual for people to have multiple family members with the condition. But this does not mean that they will definitely get it too. Most cases of dementia are not directly inherited. However, young onset dementia is more likely to have a genetic cause than late onset Alzheimer's.

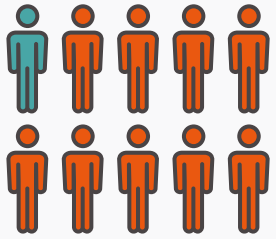
Directly inherited young onset dementia is caused by a faulty gene. In families with these genes, there is a clear pattern of someone in every generation of a bloodline developing the same condition, such as young onset Alzheimer's or frontotemporal dementia, at around the same age.

If someone has a strong family history of Alzheimer's where the disease has developed at a younger age, a doctor can refer them for genetic counselling. You can find out more in our booklet **'Genes and dementia'**. You can also find out more about what causes each type of dementia in our dedicated booklets.

Many people live a healthy and active life but still develop dementia. That's because there are no surefire ways of preventing it. However, research does suggest more than almost half of all dementia cases worldwide could be prevented or delayed by helping people address lifestyle factors.

Maintaining a healthy lifestyle in your 40s and 50s seems to be particularly important for helping to lower your risk of dementia. However, taking steps to look after our health is important at any age. By keeping your heart and brain healthy, you will be lowering your risk of Alzheimer's, or at the very least delaying its onset.

For more information about reducing your risk of developing dementia, ask for our **'Reducing your risk of dementia'** information. Contact details can be found on the back of this booklet. You can also explore your brain healthy habits and discover more tips to look after your brain at **thinkbrainhealth.org.uk**



**ONE IN 10 CASES OF YOUNG ONSET DEMENTIA MAY BE DIRECTLY INHERITED** from a parent with the condition.





## For good brain health and heart health, and to help lower your risk of dementia:

Keep physically active.

Stay socially and mentally active.

Don't smoke.

Keep cholesterol and blood pressure under control.

Eat a healthy balanced diet.

Maintain a healthy weight.

Have your hearing checked regularly.

Only drink alcohol within the recommended limits.

If you have diabetes, ensure your condition is well managed.

# HELP AND SUPPORT

**There are organisations that offer advice, information, care, and practical and emotional support for everyone affected by dementia and their loved ones. Over time, dementia symptoms will get worse, and someone will require more support. The speed of change in symptoms can vary widely from person-to-person.**

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 Research Infoline

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**

## Dementia UK

Dementia UK's specialist Admiral Nurses offer practical advice and support to people affected by dementia and their families. The free Helpline can be contacted on **0800 888 6678** or at **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.





## Young Dementia Network

Young Dementia Network is an online influencing community for everyone living with, working with or interested in young onset dementia. Free to join, the Network brings people together to increase knowledge, understanding and awareness of young onset dementia.

It campaigns for improved support by calling for the needs of younger people with dementia to be met in national and local dementia plans and policies. Find out more at **youngdementianetwork.org**

# RESEARCH

**Alzheimer's Research UK has funded over £237 million of pioneering research into different kinds of dementia, including young onset dementia.**

Several studies are looking at the genetics of young onset dementia. Another is working with people with young onset dementia to follow their health over several years. Our studies are 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**

With your support, we will fund many more studies into young onset dementia. We promise we will not stop until dementia can no longer destroy lives.

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

## STAY UP-TO-DATE WITH THE LATEST DEMENTIA RESEARCH

Call **0300 111 5555** or scan the QR code.





# HOW TO GET INVOLVED

**Research is the only way we'll find new ways to prevent, diagnose and treat dementia and scientists need your help. Without people volunteering to take part in research, finding a cure would be impossible.**

People with dementia, their carers, and people without dementia are all needed to take part.

Anyone over the age of 18 can register to Join Dementia Research, which is run by the NHS. This will match you to research studies you are suitable for. Then you get to choose which ones to take part in.

People have many different reasons for wanting to volunteer for dementia research, and it's their support that will drive forward our progress and change the lives of everyone affected by dementia.

**Join them today.**

Find out more and register to take part by calling the Dementia Research Infoline on **0300 111 5111** or visiting **joindementiaresearch.nihr.ac.uk**

Join dementia research

## Alzheimer's Research UK is the UK's leading dementia research charity.

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### CONTACT US

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3 Riverside, Granta Park, Cambridge CB21 6AD

### VISIT

alzheimersresearchuk.org/dementia-information

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