



**DementiaUK**  
Helping families face dementia

## Young onset dementia: getting a diagnosis



Dementia is often considered a condition of old age, but it can also occur in younger people. When dementia develops in people under the age of 65, it is known as ‘young onset dementia’.

It is sometimes also referred to as ‘early onset’ or ‘working age’ dementia, but these terms can cause confusion. ‘Early onset’ can be interpreted as the early stages of dementia and ‘working age’ is now less defined as retirement age is more flexible.

Around 70,800 people in the UK are living with young onset dementia.

### Symptoms of young onset dementia

The symptoms of dementia differ from person to person, depending on the type of dementia and which parts of the brain it affects.

Dementia is often associated with memory loss, but people with young onset dementia may not develop memory issues in the early stages. As a result, the signs of dementia may be missed or mistakenly attributed to other conditions.

Early symptoms of young onset dementia may include changes in:

- personality and behaviour
- speech and language
- vision and movement
- social functioning
- relationships with others
- involvement in daily activities
- motivation and mood eg depression, anxiety
- concentration levels
- decision-making and problem-solving

### Causes of young onset dementia

The causes of young onset dementia are not fully understood, but there are some factors that increase the risk of developing it.

These include:

- smoking
- obesity
- diabetes
- high blood pressure
- high cholesterol
- physical inactivity
- untreated depression
- social isolation/loneliness
- a previous severe head injury
- having a learning disability



Most forms of dementia are not inherited, but people who are under 65 are more likely than older people to be diagnosed with a genetically inherited form of dementia, or a rarer type that can be difficult to recognise.

Genetics are thought to be involved in around 10% of young onset dementia cases. If someone has a strong family history of dementia under the age of 65 years, they and their family members may wish to consider genetic testing. This is available on the NHS but is normally only recommended if the person or their close relatives develop symptoms at a very young age (for example in their 30s or 40s).

## Getting a diagnosis of young onset dementia

If someone is concerned about changes they have noticed in themselves or in someone else, it is important to consult a GP as soon as possible to rule out other conditions that have similar symptoms, and to ensure that support can be put in place if dementia is diagnosed.

Sometimes, there may be a delay in being able to see a GP in person, especially as many practices are now using phone or video consultations as standard. In these circumstances, it may be helpful for the person or their family member

to notify their GP in writing (either by letter or email). This should include any concerns they have or symptoms they have noticed, including details such as specific examples and frequency. The GP can then decide if any action needs to be taken, such as offering a face-to-face appointment.

In the initial appointment, the GP should ask the person when their symptoms started, whether they started suddenly or gradually, and how they affect their everyday living.

If possible, it is helpful for the person and/or someone close to them to keep a diary or notes about the symptoms. The Young Dementia Network's personal checklist can be useful for this: visit [youngdementianetwork.org/personal-checklist](http://youngdementianetwork.org/personal-checklist)

It is also a good idea for a family member or friend to accompany the person to the appointment so they can say what changes they have noticed and the effect they are having on the person and the people around them.

The doctor should conduct a

physical examination, organise blood tests and ask questions to identify any physical or psychological conditions that could mimic the signs and symptoms of dementia, for example:

- depression and anxiety
- stress at work
- relationship issues
- an underactive thyroid
- vitamin B12 deficiency
- perimenopause and menopause in women
- delirium caused by a medical condition such as infection
- side effects of some medicines

The GP may also refer the person for a brain scan to look for evidence of other possible problems that could explain their symptoms, such as a stroke or a brain tumour.

If any treatable conditions are identified, the first step will be to treat them.

If the symptoms persist, it is important to go back to the GP to discuss any ongoing concerns so they can be investigated further.

In the initial appointment, the GP may briefly test the person's memory and cognitive abilities,



which might include asking them to:

- state the day, date and year
- name some common objects, for example from pictures, or as answers to questions
- remember and repeat items to test concentration and short-term memory
- complete a drawing

However, because memory loss does not always occur in the early stages of young onset dementia, some people who do have dementia may perform well in the test.

## Further assessments

If other physical or psychological conditions have been ruled out or treated, the GP should then refer the person for a more detailed assessment. This may be carried out by a specialist such as a psychiatrist, neurologist or clinical psychologist.

Some areas of the UK have memory assessment services where professionals have a specialist interest in young onset dementia. However, many areas have no set referral pathways for younger people, so it is not unusual to see a number of different specialists before a diagnosis is

made and getting a diagnosis may take some time.

The assessment process usually involves extensive and detailed assessment of:

- cognition – this involves tests of memory and thinking
- behaviour
- day to day functioning

The person may need scans such as an MRI scan, and possibly a lumbar puncture: a procedure that collects a small amount of fluid from the spinal cord.

### After a diagnosis of young onset dementia

If someone is diagnosed with dementia, they should be told which type of dementia they have, what the symptoms are and how the condition might progress over time.

The specialist should also discuss the possibility of medication and tell the person about or refer them to other services in the local area, such as Social Services, occupational therapy, or support groups.

The person with the diagnosis and their family members should be given the opportunity to ask questions, and to speak separately with the specialist if preferred. They should be provided with written information about the investigations and assessments they have had, and be sent a follow-up letter with information about the diagnosis and further advice.

There is currently no cure for dementia, but there are things that can help including specialist advice, support and interventions. These should be discussed with the person at the time of diagnosis.

### Medication

Some people are prescribed medications for dementia.

These are:

- donepezil
- rivastigmine
- galantamine
- memantine

These medications are not suitable for all types of dementia. They are usually prescribed for Alzheimer's disease (which accounts for around a third of



cases of young onset dementia) but may sometimes be prescribed for people diagnosed with mixed dementia, dementia with Lewy bodies and Parkinson's disease.

They do not cure dementia or stop it progressing, but they may help with the symptoms, including memory, concentration and anxiety. However, some people find that the medications do not work for them or develop side effects that they cannot tolerate.

If someone has vascular dementia (dementia caused by damage to

the blood vessels in the brain, such as by high blood pressure or a stroke) they may be prescribed medication to treat the underlying factors – for example, medication for high blood pressure and high cholesterol.

Medications are usually prescribed by the dementia specialist. They should discuss the benefits of the medication and any potential side effects so the person with the diagnosis can make an informed decision about whether or not to take them.

The person should be monitored and reviewed when they start taking medication to ensure they are tolerating it and to check for side effects. If a medication is not suitable for any reason, they may be able to try another – but they should not stop taking any medication without consulting their specialist or GP.

Once the person with dementia is well established on their medication, their GP is likely to take responsibility for prescribing it.

### Cognitive Stimulation Therapy

Cognitive Stimulation Therapy (CST) is a programme of themed activities and engagement designed to improve the cognition of a person with dementia. The sessions are usually held weekly over a set period of time. There is evidence to suggest that CST could be as beneficial as drug treatments for the symptoms of dementia. The person's GP can tell them if CST is available in their area.

### Sharing the diagnosis

Many people are unaware that it

is possible to be diagnosed with dementia as a younger person, and it can be difficult to explain the impact of young onset dementia to others.

If someone receives a young onset dementia diagnosis, they may find it difficult to talk about, particularly at the start. However, it can be useful for them to tell people close to them so that they understand the changes they may see and can offer support.

### Talking therapies

A diagnosis of dementia, particularly young onset dementia, can be traumatic. Counselling and support may help the person work through their thoughts and feelings. They may be able to access this support through the specialist diagnostic or memory assessment service, or they can speak to their GP who can make a referral.

### Support groups and services

As young onset dementia is a relatively rare condition, many people with the diagnosis do not know anyone else affected by it.



Connecting with and receiving support from others who are in the same situation can make a huge difference.

Groups and support services tailored to younger people can be difficult to locate, and provision is patchy across the UK. For information about what is available in your area, we have compiled a searchable list of face to face and online groups and services across the UK that are tailored to the needs of people with young onset dementia: visit [dementiauk.org/find-support](https://dementiauk.org/find-support)

## Taking part in research

Following a diagnosis of young onset dementia, there may be opportunities for the person to take part in dementia research. Their dementia specialist can offer advice on any appropriate research that they are linked to. You can also find out more from the Young Dementia Network: visit [youngdementianetwork.org/current-research-studies](https://youngdementianetwork.org/current-research-studies) or Join Dementia Research: visit [joindementiaresearch.nihr.ac.uk](https://joindementiaresearch.nihr.ac.uk)

## What to do if someone is reluctant to seek a diagnosis

It is natural for people to be reluctant to see a GP or to be afraid of getting a dementia diagnosis. They might be worried that they will lose their independence, have to give up work or driving, or go into a care home. In some cases, they may not understand why family, friends or colleagues are concerned about them, or deny that there are any problems.

If you are worried about signs of dementia in someone else and they are reluctant to seek help, it may help to explain that:

- their symptoms may be due to another condition that could be treated
- if they do have dementia, a prompt diagnosis often means they can get the right support and any possible interventions sooner
- getting a diagnosis can help them and their family

understand the cause of any symptoms and that they are outside of their control

- having an explanation for their symptoms can relieve stress and worry about what might be happening
- an accurate diagnosis means they and their family can make the most of life and plan for the future

It may be helpful to ask another trusted person – such as a family member, friend or professional – to speak to the person. Sometimes, they may be more open to listening to someone who is slightly removed from the situation.

You may also want to write to the person's GP to outline your concerns. They will not be able to break their patient's confidentiality, but they may decide to call them in for a face-to-face appointment.

## Sources of support

To speak to a dementia specialist Admiral Nurse about young onset dementia symptoms, diagnosis or any other aspect of dementia, please call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video appointment at a time to suit you at [dementiauk.org/get-support/closer-to-home](https://dementiauk.org/get-support/closer-to-home)

### Dementia UK information

**Young onset dementia section**  
[dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

**Practical guide to getting the best out of GP and other health appointments**  
[dementiauk.org/health-appointments](https://dementiauk.org/health-appointments)

**What are the symptoms of dementia?**  
[dementiauk.org/symptoms-of-dementia](https://dementiauk.org/symptoms-of-dementia)

**Emotional impact of the diagnosis**  
[dementiauk.org/emotional-impact](https://dementiauk.org/emotional-impact)

**Young onset dementia: next steps after diagnosis**  
[dementiauk.org/young-onset-dementia/next-steps](https://dementiauk.org/young-onset-dementia/next-steps)

### Other resources

**Dementia Carers Count**  
Support courses for people caring for someone with dementia  
[dementiacarers.org.uk](https://dementiacarers.org.uk)

**Rare Dementia Support**  
Support for people with rare dementias  
[raredementiasupport.org](https://raredementiasupport.org)

**tide – together in dementia everyday**  
Online groups including a monthly young onset dementia carers' group  
[tide.uk.net](https://tide.uk.net)

**Young Dementia Network**  
Personal checklist to record symptoms and diagnosis experience checklists  
[youngdementianetwork.org/resources](https://youngdementianetwork.org/resources)

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [dementiauk.org/donate](https://dementiauk.org/donate) or call **0300 365 5500**.  
**Publication date: Sept 2022**  
**Review date: Sept 2024**  
© Dementia UK 2022



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday-Friday, 9am-9pm  
Saturday and Sunday, 9am-5pm



[dementiauk.org](https://dementiauk.org) • [info@dementiauk.org](mailto:info@dementiauk.org)

Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).