

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.

It is estimated that over 70,000 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

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- 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.

If there is the option of a phone/video or face-to-face GP appointment, consider which would best suit the person's needs. While you may need to wait longer for a face-to-face appointment, initial assessments for dementia often involve some simple cognitive tests that are best carried out in person. Communication may also be easier face-to-face.

You or the person may wish to book a double appointment to allow enough time to explain your concerns fully, with less pressure. It is a good idea for a family member or friend to accompany the person



to the appointment so they can explain what changes they have noticed and the effect they are having on the person and the people around them.

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 record of their symptoms. The Young Dementia Network's personal checklist can be useful for this: visit [▶ youngdementianetwork.org/personal-checklist](https://youngdementianetwork.org/personal-checklist)

The GP should ask the person about any family history of dementia – while genetically inherited forms of dementia are rare, they are more common in younger people.

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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

They may also 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.

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.

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 with a memory clinic or 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 an 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 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 of dementia 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. Our leaflets on next steps after a diagnosis of young onset dementia; driving and dementia; and employment explain some of the things you may need to think about after a diagnosis – please see Sources of support on p14-15.

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, Lewy body



dementia and Parkinson’s disease. They do not cure dementia or stop it progressing, but they may help with the symptoms, including problems with 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 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.

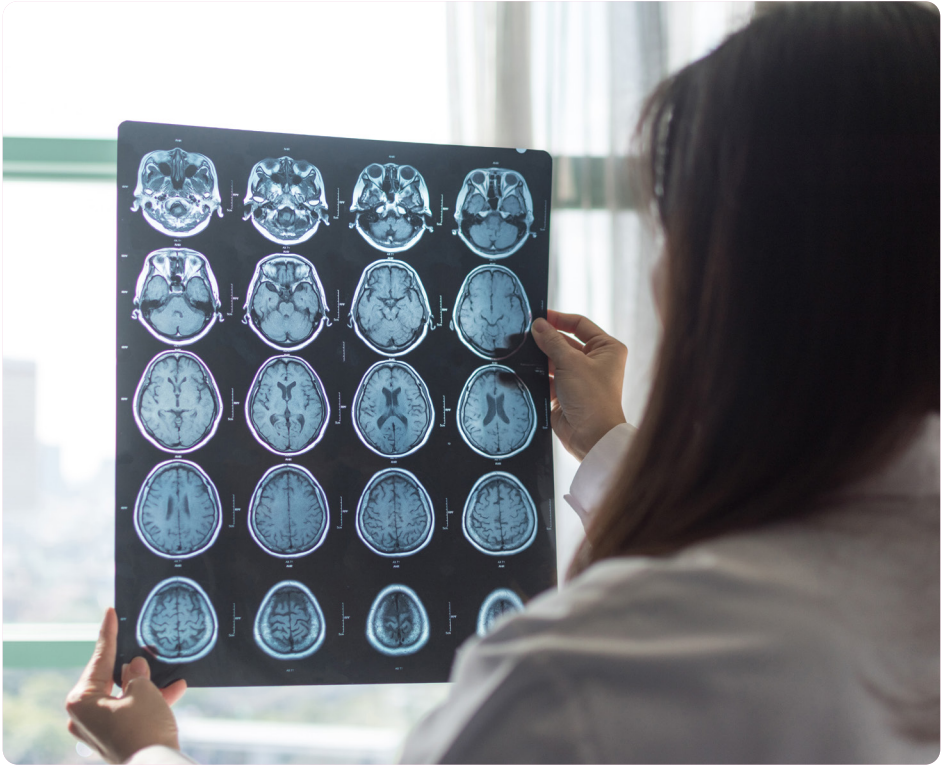
Talking therapies

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 ask their GP to make a referral or refer themselves – please see Sources of support on p15.

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. To see if there are any groups and services in your area, please visit our



searchable database at [▶ 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. As well as furthering our knowledge and understanding of dementia, this could help the person themselves learn more about their condition and how to manage it.

You can also find out more about current research opportunities through 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)

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.

It is a good idea for the person with dementia to inform their employer and their children's school (if applicable) about their diagnosis, so the relevant support can be put in place. In some jobs – for example, healthcare, the armed forces and jobs that involve driving or using machinery – there is a legal obligation to tell the employer about a dementia diagnosis.

It is also compulsory for a person who drives to notify the DVLA (DVA in Northern Ireland) and vehicle insurer about their diagnosis – please see p14 for our information on driving and dementia.

What to do if someone is reluctant to seek a diagnosis

It is natural for people to be reluctant to see a GP about possible symptoms of dementia. They might be worried that if they are diagnosed, they will lose their independence, have to give up work or driving, or go into a care home. They may fear that they will be judged or discriminated against. 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

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to an Admiral Nurse on our free Helpline, call **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 call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK information

Young onset dementia section

[▶ dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

Driving and dementia

[▶ dementiauk.org/driving](https://dementiauk.org/driving)

Employment and young onset dementia

[▶ dementiauk.org/employment](https://dementiauk.org/employment)

Emotional impact of a dementia diagnosis

[▶ dementiauk.org/emotional-impact](https://dementiauk.org/emotional-impact)

Find young onset dementia support groups and services

[▶ dementiauk.org/find-support](https://dementiauk.org/find-support)

Getting the best out of GP and other health appointments

[▶ dementiauk.org/getting-the-best-out-of-gp-and-other-health-appointments](https://dementiauk.org/getting-the-best-out-of-gp-and-other-health-appointments)

Symptoms of dementia

[▶ dementiauk.org/symptoms-of-dementia](https://dementiauk.org/symptoms-of-dementia)

Types of dementia

[▶ dementiauk.org/types-of-dementia](https://dementiauk.org/types-of-dementia)

Young onset dementia: different symptoms

➤ dementiauk.org/young-onset-dementia-different-symptoms

Young onset dementia: next steps after diagnosis

➤ dementiauk.org/young-onset-dementia-next-steps

Understanding young onset dementia

➤ dementiauk.org/what-is-young-onset-dementia

Other resources

DEEP

Network of dementia groups across the UK

➤ dementiavoices.org.uk

Dementia Carers Count

Support courses for people caring for someone with dementia

➤ dementiacarers.org.uk

NHS talking therapies services

➤ nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service

Rare Dementia Support

➤ raredementiasupport.org

tide – together in dementia everyday

Online groups including a young onset dementia carers' group

➤ tide.uk.net

Young Dementia Network

An online community of people living with dementia, their families and friends, and professionals

➤ youngdementianetwork.org

Young Dementia Network: personal checklist

To record symptoms

➤ youngdementianetwork.org/personal-checklist

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:
[👉 dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit [👉 dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code

Thank you.



DementiaUK
Helping families face dementia



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Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
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