

Getting a diagnosis of dementia



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If you are concerned about symptoms of dementia – such as changes in your memory, communication, personality or behaviour – or have worries about these changes in someone close to you, it is important to consult a GP as soon as possible. This means that other conditions with similar symptoms to dementia can be ruled out and, if necessary, further assessments can be carried out so an accurate diagnosis can be made and the right support put in place.

Why is it important to accurately diagnose dementia?

Seeking a diagnosis of dementia can be frightening or overwhelming. Some people feel that they would rather delay finding out or would prefer not to know at all. They may think that they will lose their independence, have to give up work or driving straight away, or have to move into a care home. In some cases, they may not understand that there are concerns about their memory or behaviour and deny there are any issues.

For this reason, many people with signs of dementia put off seeing a GP about their symptoms for some time. However, there are important reasons for taking steps to get a diagnosis as soon as possible:

- In some cases, the symptoms of dementia may be due to another condition that could be treated so the person can resume their normal life – see p6 for information about some of these conditions
- Although there is no cure for dementia at present, medication and other interventions may be used to help manage and reduce the symptoms in some types of dementia, such as Alzheimer’s disease; these are most effective if started as early as possible
- A diagnosis can help the person with dementia and their family to get the best support and put future plans in place. This includes



looking at finances, considering important legal issues and making decisions about the present and the future

- Some people find it a relief to have an explanation for why their memory, behaviour or emotions are changing
- A diagnosis can benefit the wider family (including children) and friends and enable them to understand what is happening and how they can help
- A timely diagnosis can help the person stay well for longer by increasing their awareness of the condition and how they and their family can make adjustments to improve their quality of life

If someone is reluctant to see their GP, you could try to explain these benefits of getting a diagnosis. Sometimes, asking another family member or close friend to talk to the person may help – they may be more willing to take advice from someone who is slightly removed from the situation.

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If the person simply refuses to go to the GP, you can contact the surgery by phone, email or letter to explain the situation. Mention the changes you have noticed, how they are affecting the person, and any ways in which these changes may be putting them at risk. The GP will not be able to break the person's confidentiality, but they should consider the information you have provided and may call the person in for a general check-up.

Signs and symptoms

Some of the possible signs and symptoms of dementia include changes in:

- short-term memory
- thought processes
- concentration level
- communication, comprehension and word finding
- motivation level
- ability to perform everyday tasks
- personality, mood, behaviour or social functioning
- vision
- balance and movement

It is important to note that these signs and symptoms do not mean the person definitely has dementia. Seeing the GP about these concerns will enable further tests to be carried out to identify the cause of these changes.



Preparing for the appointment

The process of getting a diagnosis of dementia starts with seeing the GP. Because dementia is complex, it may be beneficial to request a double appointment to allow enough time to discuss your concerns.

It is helpful to keep a diary of the signs and symptoms you are noticing and share this with the GP before or during the appointment. This could include:

- the signs, symptoms and changes experienced
- the date, time and frequency
- any possible triggers
- their effect on everyday living

It may be difficult for the person experiencing symptoms of dementia to notice the changes in themselves, so you can keep a diary together.

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It is helpful for a family member, or someone else who knows the person well, to go to the appointment with them. They can outline any information they have gathered and support the person to explain what changes they have noticed and the impact they are having.

It is a good idea for the person to have sight and hearing tests at this time, as problems with eyesight and hearing may cause similar symptoms to dementia, such as confusion and difficulty seeing things correctly. These symptoms may also be a sign of some rarer types of dementia that are more common in younger people, such as posterior cortical atrophy (PCA), which causes problems with vision.

What to expect from an initial appointment

At the initial appointment, the GP should ask:

- what the symptoms are
- when they started
- whether they came on suddenly or gradually
- if there is any family history of dementia
- how the symptoms affect everyday living

The GP should conduct a physical examination and arrange blood tests to rule out other underlying conditions that may be treatable, such as:

- depression
- underactive thyroid
- vitamin B12 deficiency
- long Covid



- menopause
- delirium caused by a medical condition like an infection
- work stress
- relationship problems
- side effects of some medicines

The GP may also refer the person for a brain scan to check for other possible causes of their symptoms, such as a stroke or a brain tumour. However, this may be arranged at a later date via the memory assessment service.

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The GP should perform some brief tests of memory and cognitive abilities, for example asking the person:

- what day, date and year it is
- to name some common items, either from pictures or as answers to questions (eg, “What do you use to boil water for a cup of tea?”)
- to remember and repeat a list of items to test concentration and short-term memory
- to complete a drawing such as a clockface

If other physical or mental health conditions are ruled out as possible causes of the changes in memory, behaviour and personality, the GP may then make a referral for further investigation, usually at an NHS memory clinic.

In some cases, the GP may decide the changes do not require a specialist referral. However, it is good practice for them to arrange a review in six months’ time. In this period, keep noting down any changes in symptoms. If the GP does not request a review after six months but you still have concerns, or if the symptoms change noticeably or suddenly, book another appointment.

If you are experiencing difficulty getting a diagnosis, our dementia specialist Admiral Nurses can offer advice – please see Sources of support on p14.

Mild cognitive impairment

Sometimes, people with signs of dementia are diagnosed with mild cognitive impairment (MCI). This itself is not dementia, although many people with MCI will go on to develop dementia. MCI may be diagnosed if the person:



- has cognitive symptoms (eg problems with memory, concentration or language and speech) that have no other obvious cause and are worsening
- scores poorly for their age in tests of mental abilities
- has only minor or no problems with everyday living activities

Often, GPs will diagnose MCI without a specialist referral. In other cases, they may refer the person to a memory assessment service, but they will usually be discharged back to their GP for ongoing support if a diagnosis of MCI, rather than dementia, is made. Please see Sources of support on p14 for information on MCI.

Attending a specialist memory assessment

If someone is referred to a memory service, it may take several weeks or months to be invited for assessment. If you have not heard anything after three months, you can chase this up either via the GP or by contacting the service yourself – the GP practice should be able to give you the contact details. In the meantime, continue to keep a record of symptoms, changes and their effect on daily life.

The initial assessment will be carried out by a healthcare professional such as a:

- specialist nurse
- psychiatrist
- neurologist (a doctor specialising in the brain and nervous system)
- geriatrician (a doctor specialising in older age – this is possible even if the person is younger).

It may be in the person's home, at the clinic, or via video call.

It is helpful if a family member or someone else who knows the person well attends the dementia assessment. They can share the symptom diary and give the specialist a short overview of what they believe the issues are and how they affect the person.

The memory specialist should take a detailed medical and family history from the person with symptoms of dementia. They will then conduct a series of tests called 'cognitive assessment tools'. These look at attention, memory, verbal fluency, language and visual and spatial abilities.

In addition, they will ask questions about the person's abilities to manage everyday tasks such as shopping, completing tasks at work, housework, driving and self-care, such as washing and dressing.

Lastly, the specialist should request a brain scan to look for any abnormalities, if this has not already been done.

It may take several appointments – possibly with different specialists – before a diagnosis of dementia is made, and it is common for the process to take some months.



If the person is diagnosed with dementia, they should be told:

- what type of dementia they have
- what symptoms they can expect, and how they might develop in the future
- possible treatment options
- what will happen next, eg who they will have appointments with and how often – it is likely that the GP will be responsible for ongoing care and support
- information on where to get support

Diagnosing young onset dementia

Over 70,000 people in the UK live with young onset dementia (where symptoms develop before the age of 65) and many struggle to get a diagnosis. This is partly because many healthcare professionals lack detailed knowledge of young onset dementia. Dementia is often seen as a condition of old age, so GPs may overlook the possibility of a younger person being affected.

In addition, memory problems – which are often one of the earliest and most obvious signs of dementia – tend not to be as evident in the early stages of young onset dementia. There are more likely to be changes in personality, behaviour, language, vision and movement, especially in rarer types of dementia, which are more common in younger people. These may be wrongly attributed to another health condition – such as anxiety, depression, vitamin deficiency, relationship issues, or menopause in women.

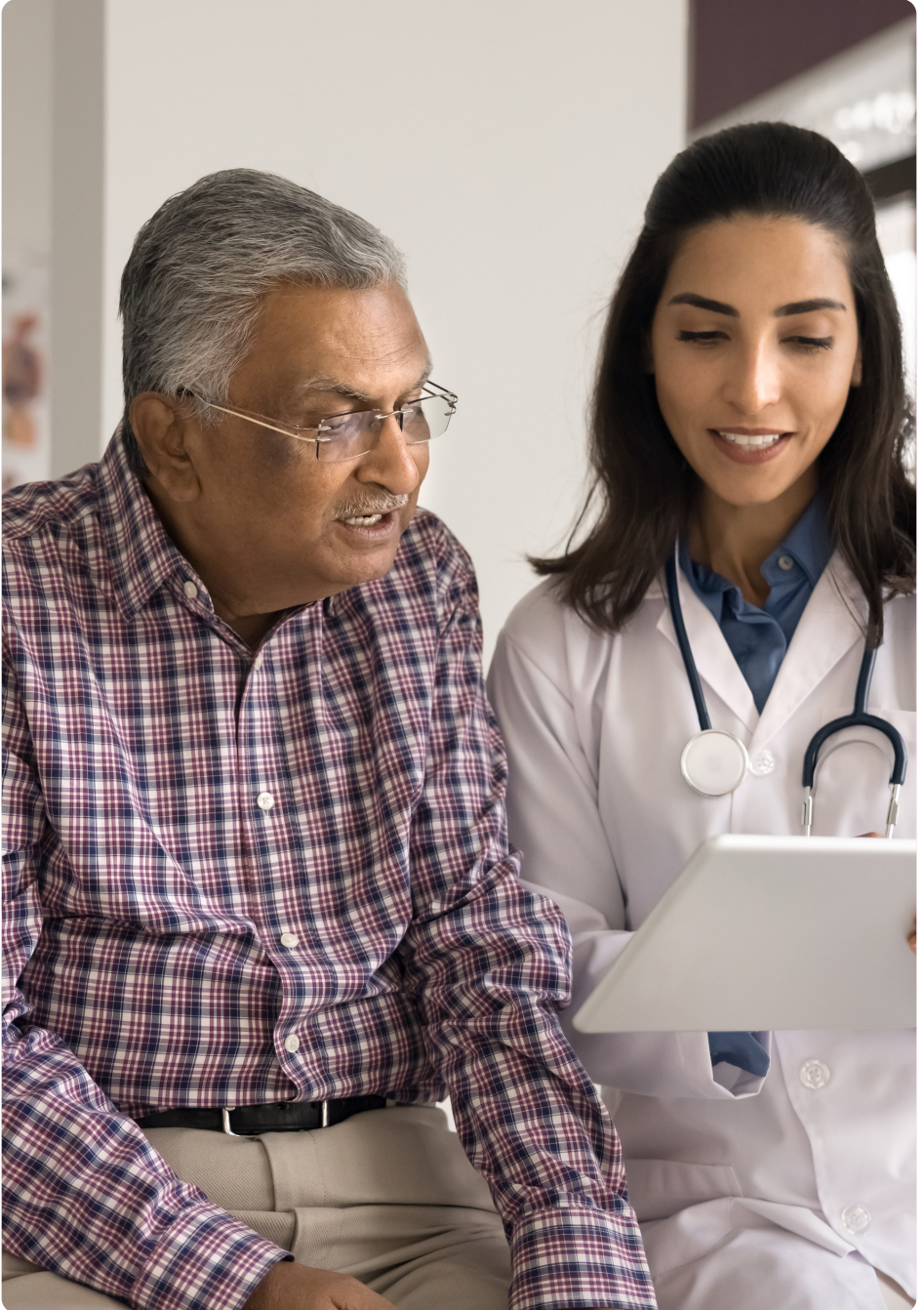
For more information on the different symptoms of young onset dementia and getting a diagnosis, please see Sources of support on p15.

Private assessments

Some people decide to book a private assessment for dementia, either by paying for it themselves or through their private health insurance. However, they should still see their NHS GP as a first step. Once the GP has completed the initial screening, they can refer the person to a private specialist or clinic in the local area.

The assessment procedure will follow the same pathway as the NHS, but it is likely that it will take less time to be given an appointment. Any results will then be sent to the GP.

The person may wish to continue to see a specialist privately for their ongoing care, or the GP can refer them back to NHS services.



Sources of support

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

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

Dementia UK resources

Denial and lack of insight in dementia

[▶ dementiauk.org/understanding-denial](https://dementiauk.org/understanding-denial)

Early stage dementia

[▶ dementiauk.org/early-stage-dementia](https://dementiauk.org/early-stage-dementia)

The emotional impact of a dementia diagnosis

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

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)

Getting the most out of a remote consultation

[▶ dementiauk.org/getting-the-most-out-of-a-remote-consultation](https://dementiauk.org/getting-the-most-out-of-a-remote-consultation)

Mild cognitive impairment

[▶ dementiauk.org/what-is-mild-cognitive-impairment](https://dementiauk.org/what-is-mild-cognitive-impairment)

Symptoms of dementia

➤ dementiauk.org/symptoms-of-dementia

Tests for dementia and Alzheimer's disease

➤ dementiauk.org/tests-for-dementia-and-alzheimers

Types of dementia

➤ dementiauk.org/types-of-dementia

Understanding young onset dementia

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

What is dementia?

➤ dementiauk.org/what-is-dementia

Young onset dementia: different symptoms

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

Young onset dementia: getting a diagnosis

➤ dementiauk.org/young-onset-dementia-getting-a-diagnosis

Young onset dementia: menopause and perimenopause

➤ dementiauk.org/perimenopause-and-menopause

Other resources

The Menopause Charity

➤ themenopausecharity.org

Next Steps: what to do while waiting for a memory assessment

➤ nextsteps.org.uk

Young Dementia Network personal checklist – for recording symptoms of dementia

➤ 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.



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Helping families face dementia



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