

Assessment and diagnosis

Factsheet 426LP
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This factsheet explains what happens when someone has an assessment to find out if they have dementia. It explains the benefits of getting an assessment and the different steps of the assessment process. It also has information about how a diagnosis might be made, and what happens if it is.

You might find this factsheet useful if you are worried about your own memory, or someone else's. For more advice and support on this, you may find the leaflet **Worried about your memory?** helpful.

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Assessment and diagnosis

The term 'dementia' describes a set of symptoms that occur when the brain is damaged by certain diseases (such as Alzheimer's disease) or a series of small strokes. Dementia can affect people in a variety of ways, depending on the diseases causing dementia, as well as different individual factors such as lifestyle. Common symptoms can include problems with:

- day-to-day memory (becoming more forgetful or feeling confused)
- concentrating, planning or organising
- language (for example, struggling to find the right word)
- judging distances and seeing objects properly (not caused by poor eyesight)
- orientation (for example, being confused about the day or month, or places)
- mood and behaviour (such as feeling persistently anxious and low).

These symptoms may be small changes to start with, but they can become severe enough to affect daily life. For example, they can begin to cause problems with everyday tasks such as using a phone, or taking regular medication.

For more information about dementia, see factsheet 400, **What is dementia?**

If you are worried about your thinking or memory, or you notice any of the symptoms listed above or that you are behaving differently, you should visit your GP. They may suggest that you have an assessment to check if your symptoms can be explained by dementia.

Being assessed for dementia usually takes time and often this is several weeks or months. The process is not a single step but can include various stages and tests, and you will have several appointments. When the assessment is complete, the doctor should have enough information to make a diagnosis – which will tell you what is causing your symptoms. They may give you a diagnosis of dementia and if so, this factsheet tells you what you can do and where you can seek further support after the assessment process ends. See ‘What happens after a diagnosis?’ for more information.

Throughout the assessment process you may feel unsettled or anxious. You can refer to this factsheet over the course of your assessment to understand more about each stage. You can also get support, information and advice at any point throughout the assessment process by calling our National Dementia Helpline on 0300 222 1122.

Why get an assessment?

Dementia is not a normal part of ageing, and so it is important that you discuss any symptoms or changes you have noticed with the GP as soon as you can rather than putting it off. Going through an assessment as early as possible can give you a number of advantages, for example:

- ruling out other medical conditions that may have similar symptoms, such as depression, chest and urinary tract infections, severe constipation, thyroid problems and vitamin deficiencies
- ruling out other possible causes of confusion such as poor sight or hearing, emotional changes and upsets (for example, moving house or bereavement), or the side effects of certain drugs (or drug combinations) you may be taking for other conditions
- having an explanation as to why you’re experiencing your symptoms, so that you can focus on managing them
- getting access to any treatments you may need, as well as any relevant information, advice and support (emotional, practical, legal and financial).

Another benefit of having an assessment is that if you are given a diagnosis of dementia, you will also usually be told what type of dementia it is (although this cannot always be confirmed). Examples of types of dementia include Alzheimer's disease or vascular dementia. Knowing which type of dementia you have can help you to understand your symptoms, predict how the dementia might progress, and know how to manage your symptoms. For example certain drugs would be prescribed to help manage the symptoms of Alzheimer's disease that would not be prescribed for vascular dementia.

What happens during the assessment?

Diagnosing dementia is often difficult, particularly if it is in the early stages. This is because there isn't one simple test for dementia and the early symptoms can be similar to those of lots of other common conditions.

There is more than one way that you might end up being assessed for possible dementia. Most people start by visiting the GP because of their symptoms. The process which follows is described in steps 1–5 in this factsheet.

If you are admitted to hospital, and are over 75 years of age, your assessment may start in hospital. This is because anyone over the age of 75 who is admitted urgently to hospital should now be assessed for confusion and memory problems. If you visit your GP, even if you are visiting for another reason, they may ask you whether you are worried about your memory. This is because GPs are now encouraged to ask this question to certain patients at increased risk of dementia. You could be included in this group if:

- you have Parkinson's disease
- you have had a stroke or a 'mini-stroke'
- you are over 60 years of age and have diabetes or a heart condition.

If any of these apply to you, and you have been experiencing problems with your memory or thinking, you may need to have a further assessment. This could involve being referred to one of the specialists listed in Step 3.

The assessment process can vary. Not all the steps listed in this factsheet will apply to you, and your experiences may be different to those explained throughout. However the assessment and diagnosis process for dementia typically follows steps 1–5 listed in this factsheet.

Step 1: Assessment by a GP

If you (or someone close to you) are worried that your symptoms may be a result of dementia, the first person to consult is the GP. You may see the GP in their surgery, or they may prefer to make a home visit, as it can sometimes be better to examine you when you are in a familiar environment. The GP will carry out the initial assessment in a number of ways, including:

- **Taking a ‘history’** – the GP will spend some time talking to you and someone who knows you well. (The doctor may contact someone close to you by phone if they cannot attend in person.) They will ask about how and when your symptoms started and how they are affecting your life. The GP will look at your and your family’s medical history. They will also review any medicines you are taking.
- **Physical examinations and tests** – the GP may carry out a physical examination, particularly if there is a chance you have had a stroke, or have Parkinson’s disease. They will also take samples (blood and possibly urine) to send off for tests. These may identify other conditions that are causing the symptoms, such as thyroid problems or vitamin deficiencies.
- **Tests of mental abilities** – the GP will ask you a series of questions or give you a short pen-and-paper test. These are designed to test your thinking, memory and orientation.

At the end of their assessment, the GP will explain their findings and discuss what actions need to be taken. It is unlikely that they will feel able to make a diagnosis at this stage. If they are able to make a diagnosis of dementia, they may be able to identify what type of dementia it is – but this is usually only possible if the condition is more advanced, or if it is a more common type of dementia (such as Alzheimer’s disease). It is likely that the GP will refer you for further assessment to get more information to help make a diagnosis.

Step 2: Referral to a specialist

You may be referred to a specialist service for further assessments. This might be a memory assessment service, memory clinic or other specialist service within a community mental health team. These services are set up especially to assess people with memory problems. They have teams of different types of health professionals who can look at your case in more detail.

Normally it will be the GP that refers you to a specialist centre for further assessment, if they think this is necessary. If you (or someone close to you) feel that a referral would be helpful, but the GP has not yet suggested it, you can ask them to refer you. Sometimes people choose not to carry on with any further assessments – for example if they choose not to find out if they have dementia. If this is the case, you can tell the GP that you do not want to be assessed any further. A specialist (such as a consultant) will have more knowledge and experience of assessing dementia than a GP. They will also have more time allocated for appointments and access to more specialised investigations, such as brain scans and in-depth mental testing. Once you have been referred, you should not have to wait longer than 4–6 weeks to see a specialist.

The GP will make the referral to a consultant with special expertise in a particular area of medicine. Who they refer you to may depend on your age and symptoms, and the kinds of consultant available in your area. The main types are explained below.

- **Old age psychiatrists** are psychiatrists who specialise in the mental health of older people, and also dementia. They may sometimes also offer support to younger people with dementia.
- **General adult psychiatrists** specialise in diagnosing and treating a wide range of mental health problems, as well as dementia. If you are under 65 years of age, you may be referred to one of these psychiatrists to help with the diagnosis.
- **Geriatricians** specialise in the care of older people, including physical illnesses and disabilities. You may be referred to one of these specialists to see whether your symptoms are due to a condition other than (or as well as) dementia.
- **Neurologists** specialise in diseases of the brain and nervous system. Some neurologists have particular experience in diagnosing dementia. They tend to see younger people and those with less common types of dementia.

The consultant usually works in a specialist team, alongside a number of doctors at various stages of training in that particular specialty. Although you may not always see the consultant, they are ultimately responsible for your case and will discuss it in detail with the doctor you do see. The consultant also usually works with other health professionals during the assessment process. These can include:

- mental health nurses
- psychologists
- occupational therapists
- social workers
- dementia advisers (professionals who provide information, advice and guidance to people with dementia and their carers).

CT (computerised tomography), CAT (computerised axial tomography) and MRI (magnetic resonance imaging) scans are widely used. They all show structural changes to brain tissue. SPECT (single photon emission computerised tomography) and PET (positron emission tomography) scans are less widely used. They show changes in brain activity.

CT and MRI scans can identify conditions with similar symptoms to dementia such as a brain bleed, tumour or build-up of fluid inside the brain. If there is dementia, these scans may show that the brain has shrunk in certain areas, particularly those involved in storing short-term memories. MRI may show changes caused by damaged or diseased blood vessels in the brain, potentially indicating that a stroke may have occurred at some point, which in turn could lead to vascular dementia. A scan showing no unexpected changes in the brain does not rule out conditions such as Alzheimer's disease. This is because during the early stages of the disease the changes can be difficult to distinguish from those seen in normal ageing.

SPECT and other more specialised scans can show areas where brain activity is reduced. These are mostly used if the diagnosis of dementia type is still unclear after a CT or MRI scan.

Step 3: Assessment by a specialist

Assessment for dementia by a specialist can be a confusing and daunting prospect. Many memory services offer pre-diagnostic counselling. This is a chance for you to talk things over with a health professional before your assessment. You can choose to have somebody you trust such as a partner, friend or family member with you for this. The discussion can be an opportunity to share what you already know about dementia, express your wishes and raise any concerns you have about the assessment process. However, if you do not receive counselling before your assessment, you can still ask questions at any time during the assessment process. Having counselling, or asking questions during the assessment process, can help you to:

- understand the reasons why you have been referred
- learn more about the assessment process
- give consent (or not) to go ahead with the assessment
- prepare for the possibility of receiving a diagnosis.

You may be asked if you want to know your diagnosis at the end of the assessment process. If you don't want to find out your diagnosis, the specialist can discuss this with someone you trust instead of with you directly.

The specialist's assessment may take place at your home or at a hospital. The specialist will carry out their assessment using similar methods to those used by the GP, but in more detail, to obtain as much information as possible. They will gather this information in a number of ways such as those listed below:

- **Taking a history** – as with the GP, the specialist will talk to you and those close to you for up to 90 minutes.
- **Physical examinations and tests** – a physical examination and/or tests will be undertaken, if they have not already been carried out by the GP. In many cases the blood tests will already have been done before referral.
- **Tests of mental abilities** – you will have a more detailed assessment of your memory and other thinking processes. This assessment consists of a range of pen-and-paper tests and questions. These will test things like your memory, orientation, language and visuospatial skills (for example, copying shapes). These tests can be very good at helping to determine the type of problem you may have, particularly in the early stages. The assessment can also be used as a baseline to measure any changes over time, which can help with making a diagnosis. The test is often given by a trained professional such as a mental health nurse or occupational therapist. In some cases you will be assessed by a clinical psychologist or neuropsychologist (professionals whose specialty includes the diagnosis of mental health problems).
- **Scans** – you might be sent for a brain scan. Depending on where you live, this may involve a wait of several weeks. There are several types of brain scan, which are explained in the box below.

Step 4: Outcome of the assessment

Once the assessment process has finished, the specialist will begin to make a diagnosis. To do this, they will bring together all the information they have gathered from your medical history, symptoms, physical exam, tests and any scans you have had.

Once all the information has been collected and analysed, the specialist will make their diagnosis. They may find that your symptoms are caused by dementia. If this is the case it is likely that they will be able to diagnose the type or cause of dementia (for example Alzheimer's disease or vascular dementia).

You will then have a consultation meeting with the specialist to discuss your results. (See 'Step 5: Receiving a diagnosis' on the next page.)

You can change your mind about whether you want to know your diagnosis at any time during the assessment process, and your wishes will be passed on to your consultant.

If the specialist has been able to make a diagnosis, they will write a letter to your GP with the details of the diagnosis. They will also offer you a copy of this letter, and can provide a clearer or more personalised version if required. The letter might also include other information such as a recommended ongoing care plan. This plan will give details of the support or care you might need in the future. It explains options for you to access this support if you need it.

In some cases the consultant may diagnose mild cognitive impairment rather than dementia, especially if they think your symptoms are not causing you severe difficulties with daily living, or if they could be explained by another condition such as depression. If this is the case, the specialist may then discharge you back to your GP. If your symptoms become significantly worse after 6–12 months following this you would be re-referred back to the consultant.

Sometimes a brain scan may not find any evidence to explain your symptoms. If this happens, the doctor may arrange for another scan to look at your brain using a different method. They may also ask you to come back for some more detailed tests.

For more information see factsheet 470, **What is mild cognitive impairment (MCI)?**

Step 5: Receiving a diagnosis

If the assessment shows that you have dementia, you have the right to be told this diagnosis, and so you should be asked if you wish to know the outcome. If you do wish to be told, you will be offered a meeting with the specialist to discuss your diagnosis. You can choose to attend this meeting on your own, but it can be helpful to bring someone you trust, such as a partner, family member or friend, along to this appointment. They may be able to offer you support – for example helping you to remember the details of the meeting.

If the specialist does give you a diagnosis, this should be communicated to you sensitively but honestly. Some doctors might refer to dementia as ‘memory problems’. It is important that you understand the language being used. If they are speaking too fast, or giving you too much information too quickly, you can ask them to slow down or explain things differently. You can also ask them if you are unsure about any part of your diagnosis, or if you would like them to clarify anything.

During this meeting it is likely that the specialist will discuss support and treatment with you. They should let you know what options there are for support and treatment, so that you can come to an agreement with them about which options would be best for you. If you are not clear what the options are or you are not happy with the proposed plan you should tell them. The specialist may go on to talk about how dementia is likely to progress and what to expect in the future. If you are not told this, or if it is unclear, you can ask them.

If you do receive a diagnosis of dementia, you may struggle to take in everything that is said to you, as it can be a lot to deal with all at once and you may be feeling upset or anxious. You may also be given a lot of information which can be quite difficult to understand. Remember that you don't have to read this immediately. You have plenty of time after the meeting to read any information leaflets to help you understand more about what it means to have dementia. The following section has more information on the support and treatments that you may find helpful if you have been given a diagnosis of dementia.

Getting the most from a consultation – tips

- Ask someone who knows you well to attend the consultation with you, if possible, and talk to them about your expectations and worries before seeing the doctor.
- Don't be afraid to ask the specialist to explain anything you don't understand, such as medical terms.
- Write down important points, including any medical terms.
- Don't be afraid to ask the specialist to explain what dementia means.
- Ask the specialist for advice on staying positive and adjusting to living with dementia.

For more information on these topics see booklet 872, **The dementia guide**.

What happens after a diagnosis?

A diagnosis of dementia can be difficult to cope with. Whether you go through a straightforward or drawn-out assessment process, you may feel afraid, hopeless or shocked. It might sound strange, but some people feel relieved that they have an explanation for the symptoms and changes they have been experiencing. However you feel, it's natural and it is okay to give yourself time to process your feelings. Although your assessment has finished, there is support available from a number of different places to help you come to terms with your diagnosis, and to plan for the future.

Some memory services offer sessions running for several weeks after diagnosis. During these you can talk through the next steps in more detail and receive more written information. You can also bring along someone who is important to you, who knows about your diagnosis. These sessions usually give you a chance to discuss different aspects of living with dementia such as:

- medication
- living well
- driving
- benefits
- working
- local support services
- planning for the future.

For some types of dementia medication is available to help manage the symptoms. If you and the specialist agree that medication will be part of your treatment plan, they will explain this and might give it to you to start taking straight away. After that, your GP will take over prescribing your medication. The medication may cause side-effects, such as nausea. It is important that you tell your GP if you experience any side-effects, so that they can try a different kind of medication.

Once you have received your diagnosis (and after any follow-up sessions you have), you probably won't need to go back to the memory service again. Usually, as before the assessment process, your GP will take over the management of your general health. If they think it is necessary, they can refer you back to the memory service in future (for example if you develop unexpected new symptoms).

When you feel ready, it can help to talk to others about how you are feeling about your diagnosis. This could be someone you trust, your GP, a qualified counsellor or psychotherapist, or one of our dementia support workers or dementia advisers. Contact your local Alzheimer's Society office or the National Dementia Helpline for more information about services in your area or search online at [alzheimers.org.uk/dementiaconnect](https://www.alzheimers.org.uk/dementiaconnect)

You might find it reassuring to meet people with similar experiences to you. There are local support groups around the country where you can take part in social activities, and talk to other people with experience of dementia. You can search online for groups and activities in your area at [alzheimers.org.uk/dementiaconnect](https://www.alzheimers.org.uk/dementiaconnect)

You can also find people with experiences of dementia in an online community such as Talking Point. You can chat to people or just read about their experiences at [alzheimers.org.uk/talkingpoint](https://www.alzheimers.org.uk/talkingpoint)

For more information including where to get support and further advice after a diagnosis of dementia, see booklet 872, **The dementia guide** or go to [alzheimers.org.uk/dementiaguide](https://www.alzheimers.org.uk/dementiaguide).

Further reading

Our publications have more information and support on different aspects of dementia and receiving a diagnosis. For more information on different types of dementia, see the following Alzheimer's Society factsheets:

- What is dementia? (400)
- What is Alzheimer's disease? (401)
- What is vascular dementia? (402)
- What is dementia with Lewy bodies (DLB)? (403)
- What is frontotemporal dementia (FTD)? (404)

If you are having memory problems that you think may be associated with dementia, you may find the leaflet, **Worried about your memory?** helpful.

You can also find out more from booklet 872, **The dementia guide** or go to [alzheimers.org.uk/dementiaguide](https://www.alzheimers.org.uk/dementiaguide)

Other useful organisations

Age UK

0800 055 6112 (advice line, 8am–7pm)
contact@ageuk.org.uk
www.ageuk.org.uk

Age Cymru (in Wales)

0800 022 3444 (advice line, 9am–5pm, Monday–Friday)
webenquiries@agecymru.org.uk
www.ageuk.org.uk/cymru

Age NI (in Northern Ireland)

0808 808 7575 (advice and information)
info@ageni.org.uk
www.ageuk.org.uk/northern-ireland

Provides information and advice for older people.

British Psychological Society

0116 254 9568
enquiries@bps.org.uk
www.bps.org.uk

Provides access to a list of clinical and counselling psychologists who offer private therapy services.

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This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, email publications@alzheimers.org.uk

Alzheimer's Society National Dementia Helpline England, Wales and Northern Ireland:

0300 222 1122

9am–8pm Monday–Wednesday

9am–5pm Thursday–Friday

10am–4pm Saturday–Sunday

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Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

