

Diagnosing dementia

A practical guide to assessment



Alzheimer's
Society

It will take a society to beat dementia



We are reviewing this publication. If you would like to give us any feedback, you can email us at **publications@alzheimers.org.uk** or call us on **020 7423 7455**.

About this handbook

This handbook is about how dementia is diagnosed. It explains the benefits of getting tested and finding out the cause for someone with symptoms. It outlines the different types of assessment a person will have in order to find out whether they have dementia. It also describes how a diagnosis might be given and what happens next.

The thought of being told you have dementia is frightening. It can be difficult to talk to other people about your symptoms and how you're feeling. But doing this will help to get answers and any support you need.

This handbook is for you if you are worried about your own memory, or someone else's.



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Do I need an assessment?

People often start to forget things more as they get older. Most often this is a normal sign of ageing. But for someone with dementia, changes will be different, more serious and will affect their life more.

Dementia is a group of symptoms. It's caused by different diseases that damage the brain. The symptoms get worse over time and include:

- **memory loss** – such as quickly forgetting things that recently happened
- **confusion and needing help with daily tasks** – such as shopping or paying bills
- **problems with language and understanding** – including often being unable to find the right word, or having trouble following a conversation
- **changes in behaviour** – such as becoming unusually anxious or irritable.

The changes may be small to start with, but they will become more noticeable. For example, they can begin to cause problems with familiar tasks, such as using a phone or public transport.



Comparing normal signs of getting older and dementia

Dementia is not a normal part of getting older. The table on pages 8–10 shows differences between changes that are likely to be part of getting older and those that could be signs of Alzheimer’s disease or vascular dementia – the two most common types of dementia. Less common types such as frontotemporal dementia (FTD) and dementia with Lewy bodies (DLB) can include other symptoms (see ‘Types of diseases that cause dementia’ on pages 20–21).

The table on pages 8–10 lists common examples, but everyone’s experience of dementia is different and you know yourself best. Any changes that aren’t normal for you should be taken seriously. The changes may not seem big, but if you are struggling with things you used to find easier, it’s best to speak to your GP.

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It’s easier to manage once you know for sure what you’re dealing with.

A person living with dementia

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Possible signs of ageing



Possible signs of Alzheimer's disease or vascular dementia

Forgetting something you were told a while ago.

Forgetting something you were only recently told. You may ask for the same information repeatedly – for example, 'Are the doors locked?'

Misplacing things from time to time – for example, your phone, glasses or the TV remote – but retracing steps to find them.

Putting objects in unusual places – for example, putting your house keys in the bathroom cabinet.

Taking longer to work out new tasks, such as how to set up and use a new appliance or device.

Being unable to learn new tasks, like setting up and using a new appliance or device.

Being a bit slower when planning, but being able to think things through.

Getting very confused when planning or thinking things through.





Possible signs of ageing



Possible signs of Alzheimer's disease or vascular dementia

Occasionally making decisions without fully thinking them through.

Not making informed, careful decisions when dealing with money or looking at risks.

Occasionally struggling to find the right word, but remembering it eventually.

Having frequent problems finding the right word, or regularly referring to objects as 'that thing'.

Losing track of the conversation if you're distracted or if many people are speaking at once.

Regularly being unable to follow what someone is saying even without distractions.

Getting confused about the day or the week but figuring it out later.

Losing track of the time and date, or the passage of time.





Possible signs of ageing



Possible signs of Alzheimer's disease or vascular dementia

Getting lost in a place you don't know well, but being able to figure out where you need to be.

Getting lost in a place that is familiar or that should be easy to find your way around – for example, a supermarket.

Having misty or cloudy vision, caused by cataracts or other changes in the eyes.

Having problems making sense of what you see – for example, difficulty judging distances on stairs, or mistaking reflections or patterns for other objects.

Sometimes feeling reluctant to join in at work, family and social meetings.

Becoming withdrawn and losing interest in work, friends or hobbies.

Being irritated when a routine is disrupted, but being able to cope with the change.

Getting easily upset at home, at work, with friends or in places that usually feel comfortable or familiar.



The changes described in the table can also be caused by other health conditions. For example, a person with depression can have problems making decisions, get confused easily and appear withdrawn. See page 13 for examples of treatable conditions that can cause symptoms similar to dementia.

In the same way, a person with mild cognitive impairment (MCI) or functional cognitive disorder (FCD) may experience some of these changes, but both these conditions are different from dementia (see page 51 for more information).

For this reason, it's important not to use this table to try to diagnose dementia in yourself or someone else. You should speak to a qualified health professional to find out what is causing your symptoms.

If you have any concerns about changes you've noticed, you should contact your GP surgery. You might be worried about your memory or have noticed one or more of the symptoms listed in the table. Or perhaps you're finding something more difficult than it used to be. The health professional at the GP surgery may suggest that you have an assessment to check if your symptoms can be explained by dementia.

1



Why get an assessment?

You may have been living with memory problems or other symptoms for some time. Your problems probably developed very gradually, so can be harder to recognise. Often, close friends and relatives see changes in us before we do.

If you've only recently become aware of changes, it might feel as though your symptoms aren't 'bad enough' yet. You might dread what the diagnosis will be, or think being diagnosed won't help your problems. But your problems are worth investigating – you deserve to know what is behind them and health professionals are there to support you. Deciding to speak to your GP is a positive and important step.

In an Alzheimer's Society survey, three out of five people with dementia wish they had got a diagnosis sooner. There are important reasons for this, which may help you if you are wondering whether to talk to the GP. Remember that:

- **signs of dementia are not a normal part of getting older.** Dementia is caused by diseases in the brain. If you're worried about changes in your usual abilities that are affecting your everyday life, you should not accept this as a normal sign of ageing.
- **everyone's experience of dementia is different.** There are many different symptoms of dementia. The condition affects everyone individually, and symptoms change over time.



- **younger people can also have dementia.** A lot of people think of dementia as something that only elderly people have. But it also affects people in mid-life. Around one in 20 people with dementia are younger than 65, so it's important that people of any age seek help if they are struggling.

There are many reasons for symptoms that look like dementia. These include conditions that can be treated, such as:

- depression or anxiety
- medication side effects
- hearing or sight problems
- chest or urinary tract infections
- severe constipation
- thyroid problems
- sleep problems
- stress
- iron and vitamin deficiencies.

There are also other conditions that affect memory and thinking that are different to dementia, and can get better with the right support. See 'Results of the assessment' on pages 49–55 for information about these conditions.

Often, it's a combination of things that cause symptoms. Seeing the GP can help you get the treatment you need to feel better.





Rarer causes of dementia

Dementia Hero Awards



Being diagnosed with dementia at an early stage gives you a chance to adjust and get things you need, such as:

- **access to support.** There is no cure for the diseases causing dementia yet, but there is lots of support that can help you live as well as possible. Going through the diagnosis process should let you know what type of dementia you have. As well as helping you plan for the future (such as setting up power of attorney) and access therapies and support groups, this may also mean you get access to medicines that can help you manage your symptoms.
- **the offer of benefits and protections.** Being diagnosed with dementia means you are protected from discrimination (being treated unfairly) at work by law. It can also give you access to financial benefits.
- **information that will help people understand what you're going through.** Dementia can cause changes in your mood and behaviour. If you have been feeling low, getting irritated easily or acting differently, a diagnosis can help people understand what you have been dealing with. They may be better able to support you.

You may worry that people will see you differently if they know you have dementia. This can be particularly hard in communities where conditions like dementia are not well understood or accepted. Remember that it is your decision who you tell about any diagnosis you have, and when and how you tell them.





How is dementia diagnosed?

For many people, getting a diagnosis can be quite simple and take just a few weeks. For others, it can take much longer, particularly for the less common types of dementia – sometimes more than a year.

There isn't yet a simple test for dementia. You will have several tests to give health professionals enough information to tell you what is causing your symptoms. The process may feel overwhelming. It can help to focus on one appointment at a time, rather than worrying about the diagnosis at the end.

2



Some people do not start their assessment process by deciding to see their GP. Often, hospitals routinely check for confusion and memory problems in people over 75 who have been admitted to hospital urgently. If they think a person may have dementia, the hospital doctor will refer them for a more detailed assessment. Similarly, care home staff may be the first to recognise that a care home resident has memory problems and may refer the resident to the GP.



For most people, the diagnosis process usually follows these steps:

Step 1

At an appointment, your GP or another health professional at the surgery will ask about any health problems you have had in the past. They will also check for other conditions and problems with memory or thinking things through. If they think it's possible you have dementia, they will refer you to a local memory service, which has medical staff who specialise in dementia (see 'Talking to my GP' on pages 23–33).

Step 2

A specialist will check your memory and see how you answer different types of questions. You don't need to prepare for this. You may have a scan to check for changes in your brain (see 'Assessment by a specialist' on pages 35–47).

Step 3

The specialist will tell you what they think is causing your symptoms, based on what you have told them and the results from your tests. You will then be able to access the support that is right for you (see 'Results of the assessment' on pages 49–55).

This booklet contains detailed information about each of these steps. The assessment process can vary and will not be the same for everyone.

2



Types of diseases that cause dementia

Different diseases that affect the brain cause dementia. Health professionals will try to be specific about the type of dementia they diagnose someone with. Around 19 out of 20 people with dementia have one of four main types. The two most common of these are:

- **Alzheimer's disease** – this is the most common type of dementia. It is caused when proteins that are not formed properly build up inside the brain. These proteins join together into structures called 'plaques' and 'tangles', which stop the brain working properly.
- **Vascular dementia** – this is the second most common type of dementia. It's the result of the brain not receiving enough blood.

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Vascular dementia wasn't something I was aware of – it was new to me.

Person diagnosed with vascular dementia

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Less common types of dementia often have different early symptoms to those in the table on pages 8–10. A smaller proportion of people with dementia have one of the following types:

- **Dementia with Lewy bodies (DLB)** – Lewy bodies are tiny clumps of protein that develop in the brain and stop it working properly. Someone with the early stages of DLB may find it hard to stay alert or have problems with how they see things. This includes seeing things that are not there (hallucinations), mistaking patterns or reflections for other objects, and having problems judging distances.
- **Frontotemporal dementia (FTD)** – damage from proteins that are not formed properly stops the front and side parts of the brain from working as they should. This leads to symptoms that can include changes in personality, such as becoming withdrawn or inappropriate. Or the person may lose the meaning of words, or have difficulty or become slower at getting words out.

The symptoms someone has can help health professionals make an accurate diagnosis of the type of dementia. Knowing this can help the person access the right support.

Some people have more than one type of dementia. This is known as ‘mixed dementia’. The most common combination is Alzheimer’s disease and vascular dementia.





Talking to my GP

If you (or someone close to you) are worried that your symptoms may be dementia, the first thing to do is to contact your GP surgery. They will try to see if something else is causing your symptoms, or refer you for further tests for dementia with a specialist.

You may be seen by a GP, who is a doctor, or a nurse who works at the surgery. Both are qualified in checking for signs of dementia and other conditions. It can be hard talking about your problems with a health professional, especially if you don't know them very well. But doing this will mean you get the right support.

If you have an increased risk of dementia, your GP may ask about your memory even if you are visiting for another reason. If you have an annual review for a long-term health condition, this can be a good chance to raise any concerns.

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Try and keep a diary of the sensations or signs being experienced, and what things were happening at the time, as they might help when telling the details to the consultants/doctors.

Carer of a person living with dementia

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What happens at the GP appointment?

You are likely to see the health professional in their surgery. In some cases, they may make a home visit to examine you when you are in a familiar place. The GP, or another health professional from the GP surgery, will carry out the initial assessment in a number of ways, including:

- **Taking a ‘history’** – the GP will talk to you and someone who knows you well. They may contact someone close to you by phone if this person cannot get to the GP surgery. They should ask about:
 - how and when your symptoms started and how they are affecting your life
 - your medical history and that of your close family
 - any medicines you are taking.
- **Physical examinations** – 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 may look at how you move, your coordination, and any obvious problems with your hearing and sight.

3



- **Tests** – the GP should request a sample of your blood (and sometimes urine) to send off for testing. This is to check for other conditions that could be causing your symptoms, such as thyroid problems or vitamin deficiencies. If necessary, you may also have an electrocardiogram (ECG) to check how your heart is working. In an ECG, small sticky patches called electrodes are put on your skin. These are connected by wires to a machine that records your heartbeat.
- **Checking your mental abilities** – the GP will ask you a series of questions to understand more about your memory, how you think things through, and your awareness about time and place. This is called a ‘cognitive assessment’. If your appointment is in person, they may ask you to write answers to some questions on a piece of paper.

At the end of the assessment, the GP will explain their findings and discuss what actions need to be taken. If they think you might have dementia, they will probably need more information before they can confirm this.





Preparing for the GP appointment

If you have time to think about the appointment in advance, the following tips can help you prepare.

Before the appointment

- ✓ **Ask someone close to you if they can come to the appointment with you.** They can support you and help you remember what was said at the appointment. It also helps the GP to talk to someone close to you, as they may have noticed changes that you haven't.
- ✓ **Write down what you want to say before you go and take your notes with you.** This will help you remember what you wanted to talk about. Keeping a diary of the problems you've been having will help your GP understand how your symptoms are affecting you. You can also fill out the 'My checklist for possible dementia symptoms' form on pages 66–67. This can help you explain the symptoms you are having and how they are affecting you.
- ✓ **Make a list of all the medicines you take.** Your GP will ask about this. Remember to include over-the-counter medications and other remedies that haven't been prescribed by your doctor, such as herbal medicines and vitamins.



- ✓ **Ask for a longer appointment** if you have lots to talk about or feel you may take a long time to get your words out. You will need to do this when you are booking the appointment.
- ✓ **Ask to see a GP you know well.** If there is a GP in your practice who you feel comfortable talking to, ask to speak to them.
- ✓ **Ask for a translator, if needed.** It's important that you and your GP can understand what each other are saying well.
- ✓ **Consider asking for an in-person appointment.** Many GP appointments now happen virtually – over the phone or video call. It may be easier for the GP to understand how your problems are affecting you if you see them in person.
- ✓ **If you are seeing the GP in person, ask for an appointment at a quieter time of day.** This can help if you find the noise of the waiting room hard to cope with.
- ✓ **Give yourself enough time to get to your appointment,** so that you don't feel rushed or stressed.
- ✓ **Think about what you want your GP to do.** This may be further tests, a referral to a local memory service or arranging more support at home.



During the appointment

- ✓ **Be honest.** You may find it hard to open up about mistakes you have been making with your memory, or behaviour changes you are unhappy with. But your GP is used to talking about these problems with people and will respect and support you as a patient. Their main concern is to find out the cause of your problems.
- ✓ **Let your GP know what's normal for you, and how that has changed.** Tell them what you used to find easy, but you now struggle with. You should mention when you first noticed changes, and if they're getting worse.
- ✓ **Use words and descriptions that feel right to you.** Don't be afraid to use phrases that show how bad things are for you, such as 'I'm not coping with...' or 'I'm concerned about...'
- ✓ **Show your GP any information that helps you explain your concerns.** This could be from the table on pages 8–10, your diary of symptoms, or you can use the checklist on pages 66–67.
- ✓ **Make a note of anything important the GP says.** You might want to write down any medical terms that are used, or what the next steps will be.
- ✓ **Ask if you're unsure.** If there is anything you do not understand, ask the GP to explain in simpler terms.



Will I be referred to a specialist?

If, after being checked, you have been treated for other health conditions, you may start to feel better. If your symptoms cannot be explained by another condition, or you have not improved with treatment, your GP may refer you to a specialist service for further tests. This might be a memory clinic (perhaps in a memory assessment service) or other specialist service within a community mental health team.

The specialist is likely to be an expert in dementia and have more experience diagnosing the condition than GPs do. They can arrange brain scans and have teams of different types of health professionals who can assess you in more detail.

The GP may not refer you to a dementia specialist if they think something else may be causing your symptoms, such as another health condition. If so, they should talk to you about how they will diagnose and treat the other condition.

3



If your GP tells you that your symptoms are a normal sign of ageing, you may wish to:

- ask them how your symptoms are different to what's expected in someone with dementia
- fill out the 'My checklist for possible dementia symptoms' form on pages 66–67, and show it to your GP. This can help you explain your symptoms and how they are affecting you
- show them information from pages 8–10 about normal ageing and dementia
- ask them what to do if your symptoms get worse, or if you have new symptoms
- ask to be referred to the specialist, so you can be sure of the diagnosis.

If the GP doesn't refer you to a specialist, but you feel this is necessary, you can ask them to arrange a second opinion. This can be from a specialist or another GP. However, the GP does not have to do this if they do not think it is needed. If you have not been referred for a second opinion and feel this has made your health worse, you may wish to complain.

Disagreeing with your doctor isn't easy, but you know yourself best. Feel confident in explaining your situation. The doctor has a duty to provide the most appropriate support for you, and you can help them to find out what is causing your symptoms and get the right support.



Sometimes, people choose not to carry on with any further assessments – for example, if they don't want to find out whether they have dementia. If this is the case, you can tell the GP that you do not want to be assessed any further.



How to register with a GP

Registering with a GP is free in the UK. In England and Wales, you do not need proof of address or immigration status, ID or an NHS number to register.

If a person cannot make decisions about their care, registration with a GP can be done by:

- a relative
- the main carer
- a lasting power of attorney
- a person appointed by a court (often known as a deputy or controller) under the Mental Capacity Act 2005.

See the NHS website for more information on GP registration and services.





Assessment by a specialist

It can help to know more about who you will see and what will happen during the assessment process. This can help you to feel more prepared and confident about what will happen next.

Waiting for your appointment

You may have to wait a few weeks or several months before you are able to see a specialist for further tests. How quickly you are seen depends on where you live and how serious your symptoms are. For many people, the waiting is the hardest part of the diagnosis process. You can ask the health professionals questions at any time during the assessment process. There are also several things you can do to live well while you wait for your assessment:

- **Take care of yourself.** Waiting for a specialist assessment is an emotional time, which can affect your wellbeing and relationships. It's easy to feel like life is on hold until you get your diagnosis, but it's important to keep doing the things you enjoy and looking after your physical and mental health. Getting regular exercise and eating a balanced diet can help. The Next Steps website by the Dementia Change Action Network has lots of helpful information on how to look after yourself while waiting for a memory assessment (see 'Other useful organisations' on pages 64–65).



- **Read our tips on coping with memory problems** in our booklet 1540 **The memory handbook**. You can start trying out the useful strategies even if you don't have a dementia diagnosis.
- **Talk to others in a similar situation.** You are not alone – there are many people going through similar things or feeling the same way. Join our online community Dementia Support Forum to connect with others who are waiting for a diagnosis. Visit **forum.alzheimers.org.uk**
- **Stay organised with your appointments.** This can help you feel more in control of the process. Our booklet 923 **My appointments** gives you an easy way to record dates and notes of all your appointments.
- **Get personalised support.** If you have any questions about the diagnosis process, or need support, our dementia advisers are here to help. Call our Dementia Support Line on **0333 150 3456**.

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Having a diagnosis won't make the dementia any worse.

Carer for a person living with dementia

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Call our Dementia Support Line on **0333 150 3456**

- **If you've been referred to a memory service, ask whether it offers pre-diagnostic counselling.**
This is a chance for you to talk with a health professional before your assessment about your wishes and concerns. You can choose to have somebody you trust with you for this. Counselling can help you to understand why you have been referred and what will happen next, as well as help you to prepare for the possibility of being diagnosed with dementia.
- **Think about if you want to know your diagnosis.**
When you are seen by a specialist, you may be asked if you want to know your diagnosis at the end of the assessment process. Start thinking from now what your wishes might be. If you don't want to find out your diagnosis, the specialist can discuss this with someone you trust instead of with you directly.



Who will I see?

The specialist that your GP surgery refers you to will depend on your age and symptoms, and the services available in your local area. You may see one of the following consultants (specialist doctors):

- **Old age psychiatrists** 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.
- **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. Although you may not always see the consultant, they are ultimately responsible for your care and will discuss it in detail with the health professional you do see. Other professionals you may see during your assessment 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).

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I feel it is better to have information early to make sensible proactive decisions for the future rather than panic and be reactive further down the line.

Carer for a person living with dementia

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Where will my appointment be?

Memory assessments can be carried out in different places. Since the impact of coronavirus, more virtual appointment options are available. If you are offered a choice of where to have your appointment, think about which option would suit your needs best – the GP or memory clinic can help you decide.

- **In-person clinic appointment** – having your assessment face to face in a memory clinic was the most common form of appointment before coronavirus. It allows the health professional to speak to you in person and do any physical checks. They may ask you and anyone with you to wear a face covering. The specialist may be wearing one too.
- **In-person appointment in your home** – if you are not able to go to a clinic, a health professional may be able to come to your own home to carry out the memory assessment.
- **Virtual appointment by phone or video call** – the specialist calls to speak to you. This means you do not have to worry about travelling to the appointment, but you may still have to attend a clinic in person to have physical tests. Think about how you find communicating virtually or by phone – especially if you have particular difficulties with this.

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You could ask if there are different waiting times for each option. Or you may prefer to wait longer for an in-person appointment if it means having to attend fewer appointments overall.

The Next Steps website has information on the different ways you may have your assessment, and the things you may want to consider for each option (see 'Other useful organisations' on pages 64–65).



The assessment process and scans

Going to a specialist appointment can feel scary and confusing if you have possible symptoms of dementia. However, a specialist's assessment will be similar to those you have already done at your GP surgery – just more detailed to give them as much information as possible. This includes:

- **Taking a history** – as with your first assessment, the specialist will talk to you and those close to you. They may ask you questions that feel quite personal, about your life, relationships, home environment and mental health. But the specialist needs as much information about you as possible to understand what could be causing your symptoms.
- **Physical examinations and tests** – if you have not already had them at the GP surgery, you will have a physical examination and/or tests. See 'What happens at the GP appointment' on pages 25–26 for what this may involve.
- **Understanding your mental abilities** – you will have a more detailed assessment to see how you answer different types of questions, for example:
 - using your memory to recall a list of items
 - factual information, for example, about the time and place
 - interpreting shapes
 - solving problems.

4



If you are having an appointment by video call, you can write answers on a piece of paper and hold this up to the screen to show the specialist. You do not need to prepare for any tests. It's understandable to want to do 'well' in the test, but it's very important that your health professional understands how your mind is working. Feeling as relaxed as possible will help you to complete the test as well as you can.

These tests cannot be used on their own to diagnose dementia. However, they can help the specialist work out the type of problem you may have, particularly in the early stages of your symptoms. The assessment can also be used to compare with later tests you may do, to see if anything has changed.

4



If you have communication needs

Let the health professional know if you have difficulty reading or writing, or need support because of the language or format of the test. This could be if you have trouble hearing what the health professional is saying, or if you are not confident in speaking and understanding English. They can try to make adjustments or make sure that the reasons you may struggle with the test format are taken into consideration.



Scans

Some people may have a scan to check for changes in the brain. Not everyone needs a scan, especially if it is already clear what is causing your symptoms. Brain scans do not hurt, and you will not need time to recover. The health professional will explain what these different scans involve.

CT (computerised tomography) and MRI (magnetic resonance imaging) are the most common scans used to check for changes in the brain.

- **CT scans** can check for signs of stroke or a brain tumour. But they cannot provide detailed information about the structure of the brain.
- **MRI scans** can help confirm the type of disease causing a person's dementia. They can do this by:
 - showing if blood vessels are damaged, which happens in vascular dementia
 - showing which parts of the brain are shrinking (getting smaller). This helps find out which type of dementia a person has, as different diseases that cause dementia affect different parts of the brain.

The MRI machine can be very loud so you may be offered earplugs. You will also have to stay as still as you can. If you are uncomfortable with loud noises, or have trouble staying still, you should discuss this with your doctor before your appointment.





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It can take a long time to get an appointment for a brain scan, so the specialist may give you a temporary diagnosis while you wait. For more information, see ‘Results of the assessment’ on pages 49–55.

Your scan may not show any unusual changes in your brain. This could mean that you don’t have dementia, but does not rule it out completely. If your dementia is in an early stage, it may not be seen on the scan.



Other specialist scans

If the result of your MRI or CT scan is not clear, you may have another type of scan called a SPECT scan or a PET scan. These can show if there are problems with the blood flow in the brain.

If the specialist thinks you could have dementia with Lewy bodies or Parkinson’s disease dementia, you may have a scan of the brain called a DAT scan.

These scans involve the injection of liquid and special scanning equipment that can look at how the brain is working, rather than what it looks like.

4





Factsheet 401 What is Alzheimer's disease?
September 2022

What is Alzheimer's disease?



Results of the assessment

Once the assessment process has finished, the specialist will bring together all the information gathered from your medical history, symptoms, physical exam, tests and any scans you have had. With this information, they should be able to give you a diagnosis to explain your symptoms. You can change your mind about whether you want to know your diagnosis at any time during the assessment process.

If you are told you have dementia, this can bring about a range of emotions. See ‘What happens after a diagnosis of dementia?’ on pages 57–63 for information on coping with a dementia diagnosis and what happens next.

The health professional will aim to tell you the type of disease causing your dementia – for example, Alzheimer’s disease or vascular dementia. This can give you a better idea of how your condition will progress, and what treatment options are right for you.

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You may be given a diagnosis of ‘unspecified dementia’. This means that the specialist thinks you have dementia, but they do not yet know which type of disease you have. This may happen if you are still waiting for a brain scan appointment to confirm your condition. It can be very difficult not knowing the type of dementia you have, but you will still be able to access support and services to help you live well.



Other outcomes after an assessment at a memory service include:

- **Mild cognitive impairment (MCI)** – this condition causes minor problems with memory or thinking. Unlike dementia, the symptoms are not severe enough to cause problems with a person's daily life. Most people with MCI can manage their symptoms and do not go on to develop dementia. For more information, see factsheet 470 **What is mild cognitive impairment (MCI)?**
- **Alcohol-related brain damage (ARBD)** – this is a brain disorder with similar symptoms to dementia. It is caused by a person regularly drinking too much alcohol, or binge drinking, over several years. For more information, see alzheimers.org.uk/arbdc
- **Functional cognitive disorder (FCD)** – This causes problems with thinking and memory. Unlike dementia, FCD symptoms are unlikely to keep getting worse over time. They can even get better with the right support. For more information about FCD, visit www.neurosymptoms.org
- **Unexplained** – sometimes, the results may not clearly show what is causing your symptoms. If this happens, the doctor may arrange for a different type of scan to look at your brain in another way. See 'Scans' on page 45. They may also ask you to come back for some more detailed tests.



Some people may not be diagnosed with dementia or mild cognitive impairment, but have a higher risk of developing these conditions later. If this is the case for you, a specialist may follow up with you in the future to check on your symptoms.

If the specialist has been able to make a diagnosis, they will write a letter to your GP surgery 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.

“

It was a breath of fresh air. My wife and I said, ‘Thank goodness for that.’ At least we knew what the problem was and could accept it and build the future.

Person living with 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 more about 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**.



Receiving a dementia diagnosis

You have the right to be told you have dementia, rather than this being kept from you. If you want to know your diagnosis, you will be offered a meeting with the specialist to discuss this. You can go to this meeting on your own, but it can be helpful to bring someone you trust with you. They can offer you support – for example, helping you to remember the details of the meeting.

You should be told the details of your diagnosis 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 or complicated information, you can ask them to slow down or explain things differently. If you are unsure about any part of your diagnosis, you can ask them to explain again or make it clearer to you.

The doctor should let you know what options there are for support and treatment, so that you can agree which would be best for you. As well as medicines, there are many activities and therapies that can help you stay well for as long as possible. If you are not clear what the options are or you are not happy with what is suggested, you should tell them.



The specialist should 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. It can be a lot to deal with all at once, and you may be feeling upset or anxious. You may also be given information to take away that 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 leaflets or booklets that you've been given or that you find online (our website at alzheimers.org.uk has lots of information) 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.

“

You can also access help from user groups, specialist groups, and other people in your situation that's for the carer and the person who has dementia. There is help out there and treatment is progressing, if you hide away you could get missed.

Carer of a person living with dementia

”





What happens after a diagnosis of dementia?

Being diagnosed with dementia can be difficult to cope with. It's common to feel hopeless, shocked or afraid of what comes next. You will have had to go through a lot of tests and waiting to get your diagnosis, so you may feel relieved that you now have an explanation for your symptoms. However you feel, it's natural and it is okay to give yourself time to process your feelings.

Now that you have a diagnosis, you can start to learn how to live with dementia. You are not alone. In the UK, there are currently one million people living with dementia. There is help available for you and the people who support you. Many people with dementia are able to continue with the things they enjoy, and keeping well and healthy will help you do this for longer.

It's important to stay positive. Focus on what you can and want to do. Try not to become cut off from other people – be open about how they can help you. Keeping busy and doing what you enjoy should help you to feel better and more confident.

6

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**Dementia is nothing to be ashamed of –
I didn't buy it!**

Person living with dementia

”



Support from memory services

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 information relevant to you. 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
- keeping healthy and living well
- driving
- benefits
- working
- local support services
- planning for the future.

After any follow-up sessions you have, you probably won't need to go back to the memory service again. Dementia advisers and Admiral Nurses who specialise in dementia are available to support you after your diagnosis, and your GP surgery will continue to look after your general health. If they think it is necessary, they can refer you back to specialist services in the future (for example, if you develop new and challenging symptoms).

The memory service may be able to help with other symptoms or a change in your diagnosis. They can also help if your symptoms become worse after a fall or stroke.



Medication

For some types of dementia, medication can help manage your 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. It is important that you tell your GP if you experience any side effects from the medication, so that they find what works best for you. These medications do not slow the progress of the brain disease causing your dementia, but can help you manage symptoms.

Research

Many memory services are involved with research into better treatments for the causes of dementia. Taking part in research may involve sharing some of your routine NHS data, answering a questionnaire or giving a blood sample. Some people may be able to join a clinical trial. These are special studies of whether new treatments work. To find out whether there are research opportunities near you, ask your memory clinic. You can also visit **alzheimers.org.uk/research** for more information about supporting research.





Other information and support

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 us on **0333 150 3456** for more information about services in your area. You can also search online at **alzheimers.org.uk/get-support**

It can be 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/dementiadirectory**

You can also find people with experiences of dementia in an online community such as the Dementia Support Forum. You can chat to people or just read about their experiences at **forum.alzheimers.org.uk**

We produce a wide range of information about all aspects of dementia. For comprehensive support and further advice after a recent diagnosis of dementia, see booklet 872 **The dementia guide** or go to **alzheimers.org.uk/dementiaguide**



For details of all our booklets and factsheets as well as online information and how to read and order these:



visit our website at
alzheimers.org.uk/publications



call **0300 303 5933**



email **orders@alzheimers.org.uk**



Other useful organisations

Age UK

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

Age Cymru

0300 303 4498 (advice line, 9am–4pm Monday–Friday)
advice@agecymru.org.uk
www.ageuk.org.uk/cymru

Age NI

0808 808 7575 (advice line, 9am–5pm Monday–Friday)
advice@ageni.org
www.ageuk.org.uk/northern-ireland

Age UK, Age Cymru and Age NI aim to improve later life for everyone through information and advice, services, campaigns, products, training and research.

British Psychological Society (BPS)

0116 254 9568 (9am–5pm Monday–Friday)

info@bps.org.uk

www.bps.org.uk

The BPS provides access to a list of clinical and counselling psychologists who offer private therapy services.

Next Steps

www.nextsteps.org.uk

Next Steps helps you to find the right support while waiting for your memory assessment.

My checklist for possible dementia symptoms

This checklist will help you have a conversation with a doctor or other health professional. Use it to note any difficulties you've had.



Memory and mental ability problems

Tick if affected by

Tick if impacting daily life

How long it's been happening

Memory loss – difficulty learning new information or forgetting recent events or people's names			
Struggling to find the right word			
Difficulty judging distances or mistaking reflections or patterns for other objects			
Struggling to make decisions, or making careless or risky decisions			
Losing track of time and dates			
Asking the same question over again, or repeating phrases			
Putting objects in unusual places			



Problems with daily living activities

Struggling with tasks like paying bills, planning ahead, shopping			
Difficulty getting enough sleep			
Getting lost in familiar places			



Mood and behaviour problems

Tick if
affected
by

Tick if
impacting
daily life

How long
it's been
happening

Becoming easily upset, irritable, or aggressive			
Symptoms of depression, like feeling sad or hopeless			
Symptoms of anxiety, like feeling very worried or uneasy			
Withdrawal or losing interest in things I previously enjoyed			
Acting inappropriately or out of character			
Feeling restless and walking about			



Notes on other symptoms or concerns



Hearing problems

Date of last hearing test:



Sight problems

Date of last sight test:

Last reviewed: April 2022
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Reviewed by: Dr Jill Rasmussen, Clinical Representative for Dementia, Royal College of General Practitioners (RCGP); Professor Dame Louise Robinson, Regius Professor of Ageing, Newcastle University; Dr Ross Dunne, Consultant Old Age Psychiatrist, Greater Manchester Mental Health NHS Foundation Trust

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



Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Getting a diagnosis**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**



Patient Information Forum



**Alzheimer's
Society**

It will take a society to beat dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimers.org.uk
alzheimers.org.uk

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