

Vascular dementia and **stroke**



This guide explains what vascular dementia is and how it is linked to stroke. It also explains what you can do if you are diagnosed with vascular dementia. There is information for family and friends as well.

You do not have to read all of this guide in one go. You might find it helpful to read it and talk through it with someone you trust.

Find more useful information and practical tips at **stroke.org.uk**, or call our Stroke Support Helpline for printed copies.

- Emotional changes after stroke: **stroke.org.uk/emotional-changes**
- Behaviour changes: **stroke.org.uk/behaviour**
- Problems with memory and thinking: **stroke.org.uk/effects-of-stroke/memory-and-thinking**
- Carer's guide to stroke: **stroke.org.uk/caring**

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About dementia

Dementia is a condition that can affect your memory, thinking, communication, mood and behaviour. It happens when parts of your brain become damaged by diseases such as stroke or Alzheimer's disease. Dementia often gets worse over time.

There are different types of dementia. The main types are:

1. **Alzheimer's disease**, the most common type (about 60-70% of cases).
2. **Vascular dementia** (about 15% of cases).
3. **Dementia with Lewy Bodies** (about 10% of cases).
4. **Frontotemporal dementia** (about 2% of cases).
This includes behavioural variant FTD and primary progressive aphasia.

Some people have more than one type of dementia at the same time. This is known as **mixed dementia**. The most common type of mixed dementia is Alzheimer's disease and vascular dementia.

What is vascular dementia?

Vascular dementia happens when the blood supply to parts of your brain is reduced. This can be due to problems with blood flow, or problems with brain blood vessels. Over time, areas of the brain stop working, leading to problems with memory and thinking.

Most other types of dementia, such as Alzheimer's disease, are due to abnormal protein deposits in the brain. This can happen at the same time as vascular dementia.

Vascular dementia affects people in different ways. The symptoms someone has will depend on the areas of the brain that have been damaged.

Some terms you may hear

- **Mild cognitive impairment (MCI):** this can happen after a stroke. This is when someone has memory and thinking problems, but they are not severe enough to interfere with their day-to-day activities.
- **Vascular cognitive impairment (VCI):** this describes any memory and thinking problems associated with stroke or from damaged blood vessels in the brain. It includes vascular dementia and mild cognitive impairment.

Signs of vascular dementia

If you or the people around you notice any of the signs below, you should visit your GP:

- Not being able to remember things.
- Not being able to understand or respond to things very quickly.
- Finding it difficult to concentrate.
- Not being able to find the right word when speaking.
- Struggling to plan ahead for everyday tasks.
- Difficulty learning new tasks or managing more complex tasks, such as finances, using technology or cooking a meal from scratch.
- Seeming down or depressed.

At a later stage, signs may include:

- Becoming confused.
- Behaving differently, such as being aggressive or showing distress.
- Lacking motivation.
- Not being able to control your emotions.
- Finding it difficult to walk and keep your balance.
- Problems with speaking and understanding.
- Having problems controlling your bladder (incontinence).

Both stroke and vascular dementia can cause problems with memory, thinking and mood. Strokes happen suddenly and may cause sudden changes in thinking and memory. In other cases, the symptoms of vascular dementia may come on more slowly and often get worse over time.

How is **vascular dementia** linked to **stroke**?

Stroke

Strokes are a common cause of vascular dementia. When you have a stroke, the blood supply to part of your brain is cut off, killing brain cells. The damage from a stroke can cause problems with memory and thinking (cognitive problems). For many people, these problems improve over time. If the problems do not improve or get worse, this may be a sign of vascular dementia.

Multiple small strokes or 'silent' strokes

Another cause of vascular dementia is when many small strokes happen, creating lots of small areas of damage in your brain. Often, these strokes can be so small that you do not know you are having them. These are known as silent strokes.

Symptoms of vascular dementia can appear suddenly if they are caused by a single stroke. Or if they are caused by silent strokes, they may appear gradually over time. Vascular dementia sometimes develops in 'steps', so that symptoms will stay the same for a while and then suddenly get worse. These steps are usually due to new strokes.

Other causes of vascular dementia

Vascular dementia can also be caused by small vessel disease. This means having damage to the tiny blood vessels deep inside the brain. Small blood vessels become narrowed, which reduces blood flow. This stops blood from getting to parts of your brain. This can cause damage over time which can then lead to vascular dementia. In this situation, the dementia may come on slowly over time.

Many of the things that increase your risk of small vessel disease, such as high blood pressure, diabetes and older age, can also increase your risk of stroke and dementia. But what causes some people to get small vessel disease is not fully understood.

Other blood vessel conditions can cause damage to the brain that can lead to vascular dementia. These include atherosclerosis, where fatty deposits clog and narrow vessels, and cerebral amyloid angiopathy, where a protein builds up and damages vessels, making them more likely to bleed or become narrowed. Both these can make a stroke more likely. A rare genetic vascular disease called CADASIL can also lead to vascular dementia.

Diagnosing **vascular dementia**

If you're noticing signs of vascular dementia, then it's important to see your GP as soon as possible.

Your GP will talk to you and do some tests to see what may be causing your symptoms. It's probably a good idea to take a friend or family member with you if you can, to help you answer your GP's questions. They may have noticed symptoms you're not aware of, or may be able to say how long you've had them.

If they cannot come with you, it may be helpful for them to write down everything they have noticed. You can show this to your GP.

To rule out any other causes of memory problems, your GP is likely to:

- Talk to you about your symptoms.
- Go through your medical history to see if you have any conditions linked to vascular dementia, like heart problems, high blood pressure or diabetes.
- Perform a brief memory test.
- Ask you some questions about your mood.
- With your permission, speak to your friend or family member about any changes they may have noticed.

- Take some blood or a urine sample. This is to check for other problems that could be causing your symptoms, such as an infection, thyroid problems, diabetes or low levels of vitamins.
- Look at the medication you're taking. It's a good idea to bring a list of all the medications, vitamins and supplements you take, including those prescribed by your doctor and the ones you buy yourself.

Your GP may refer you to a stroke clinic, a dementia specialist or a memory clinic for an assessment. This could be led by:

- An old-age psychiatrist (a doctor who specialises in mental health conditions of older people).
- A geriatrician (a doctor who specialises in the health of older people).
- A neurologist (a doctor who specialises in the way the brain works).
- A psychologist (a non-medical clinician who specialises in thinking and feelings).
- A specialist nurse.

Your specialist will carry out further tests:

- They will ask you questions about your memory and thinking and how you're managing with day-to-day activities.
- They may ask you to do some memory and thinking tests. These tests are designed to be challenging. Don't worry if you find them difficult. They help the clinician work out what is wrong, and the particular areas of thinking or memory that are affected.
- They may also arrange for you to have a brain scan, so they can check for damage to your brain, or if they're unsure which type of dementia you may have.
- If possible, they will also ask if they can talk to people close to you about symptoms they have been noticing.

Worried about problems with memory and thinking?

It's important to remember problems with memory and thinking are not always due to dementia. If you have any concerns about your memory, visit your GP.

Are there **treatments** that **can help?**

There are treatments to help with many of the symptoms of dementia and reduce the impact. At the moment, we do not have a treatment that cures vascular dementia.

How vascular dementia symptoms change over time is different for everyone. Symptoms may stay the same for months or even years. They can worsen gradually, or there can be periods where symptoms may suddenly get worse. Although your dementia will not get any better, it may be possible to slow down how quickly it progresses.

Vascular dementia can cause problems like depression, anxiety and falls. The stroke or dementia team can work with you to get help for many of these problems.

There are psychological treatments that may help with anxiety and depression. In some cases, medication may be recommended. You may be offered therapy such as occupational therapy, speech and language therapy and psychological therapies to help you live with dementia. A physiotherapist or falls prevention service can help if you're worried about falling.

You should be supported to reduce your risk of having further strokes or silent strokes. This may include:

- Taking medication to lower your blood pressure and cholesterol.
- Taking medication to stop clots forming.
- Stopping smoking.
- Drinking less alcohol.
- Eating a healthy diet.
- Being more physically active.

Dementia medications

Currently, there are no medications used just for vascular dementia. There are two main types of medication for Alzheimer's disease, which can be offered to someone who has vascular dementia and Alzheimer's disease together (a type of mixed dementia). These are a class of drugs known as cholinesterase inhibitors (AChE inhibitors), and a drug called memantine.

Other types of medication

Sometimes medication may be used to improve your mood if you are feeling very down or depressed. Medication can also help with some of the problems seen in advanced vascular dementia. Your doctor will talk to you about the options available.

Other treatments that may help improve your symptoms

Rehabilitation therapy

Memory and stroke services often have a team of experts that can help with various dementia problems.

1. If your dementia is causing physical problems, such as falls, then you may be able to work with a physiotherapist or occupational therapist.
2. A speech and language therapist may be able to help you with any communication problems you're having.
3. An occupational therapist can work with you to make sure you can be as independent as possible.

Other forms of therapy and support for wellbeing

You should be offered some support to stay independent, help you live well with dementia and develop your memory and concentration. Some therapies and activities may help some people with mild to moderate dementia. These can vary by where you live, but may include:

- **Cognitive stimulation therapy:** group activity sessions, designed to improve your mental abilities.
- **Cognitive rehabilitation:** working with an occupational therapist or psychologist to achieve a goal, such as learning how to use a smartphone.
- **Reminiscence and life story work:** talking about or making a record of things from your past, with support from others and props like photos or familiar objects.

Medications that affect your thinking

Long-term use of some types of medication may cause problems with memory and thinking. They may slow down some of the chemical signals in your brain, so if you have any cognitive problems, it may sometimes make these worse.

The impact on brain chemicals is known as an 'anticholinergic effect'. Several types of medication have an anticholinergic effect. They include some types of strong antihistamines, anti-depressants and muscle relaxants. They are used in treatments for conditions like allergies, depression, insomnia, and bladder and bowel problems.

The effect of each medication varies between individuals and also depends on how long you use them. Your GP, dementia specialist or pharmacist can help you understand the pros and cons of any treatment you need.



Don't stop taking any medication without speaking to your GP or another healthcare professional.

Living with vascular dementia

1. Talk to someone

After your diagnosis, you may feel shock, anger, grief or worry – not just for yourself but for the people around you too. Dealing with these feelings is hard, so it can help to talk to someone about it.

Many people find support groups helpful, because you can talk to people going through the same things. They also help you keep active and connect with others, which can help with your wellbeing and confidence. There are different types of group, from 'dementia cafés' where you can have a cuppa and a chat, to singing and friendship groups. Some organisations in the '**Where to get support and information**' section on **page 30** can tell you about support groups in your area.

If you do not want to join a group, talk to someone close to you instead. It could be a family member, friend or carer – whoever you feel most comfortable confiding in. You can also call our Stroke Support Helpline on **0303 3033 100** if you need someone to talk to.

2. Get the information you need

You may have lots of questions. You might wonder what's going to happen and worry about not being able to do things for yourself. Finding out as much as you can will help ease your fears. There's a lot of information to take in when you're first diagnosed. Do not be afraid to ask questions, even if it's weeks or months later. It's important you understand what's happening and why.

Make a list of questions to take to your next appointment. We've suggested some things you may want to ask below.

Questions to ask your specialist

- Will my symptoms get worse?
- How quickly will it happen?
- Is there anything I can do to slow it down?
- Are there any treatments that can help me with my symptoms?
- Do I need scans or blood tests?
- How often will I have appointments with you?
- What services are available to help me?
- Who can I talk to about care at home?
- Are there local support groups I can contact?
- Is there anything else I should think about?

There are also dementia charities which can offer information, advice and support. Dementia UK offers a free helpline run by dementia specialist nurses on **0800 888 6678**.

3. Plan for the future

Things are going to change as your dementia gets worse. Starting to plan for this now will help you and your family feel more prepared. Here are some of the things you may want to think about.



Your medical care

Your GP surgery should support you and anyone caring for you. They can offer treatments, referrals and advice to help you. Your GP should also see you at least once a year for a review, or sooner if you have any concerns. Dementia UK's website has tips for getting the most out of healthcare appointments.

Your doctor may talk to you about developing a care plan, though arrangements for how this is carried out can vary in different parts of the UK. A care plan is an agreement about the care you want to receive. It gives you a chance to discuss how you want to manage things, now and in the future.

It's important your care plan covers everything you need. Think about what would help you manage your condition better.

Your care plan should be reviewed with you at least once a year, to make sure it still covers everything you need. But you can ask to review it before then if you need to.

Your care plan may include:

- The treatments and medication you've decided to try.
- Any eating or exercise plans you're going to follow.
- Any other goals you want to work towards, such as giving up smoking or losing weight.
- Any support you need and who will provide it.
- An offer to assess the needs of any unpaid carers who support you, such as family members or friends.
- Referrals to other specialists you may need, such as physiotherapists or occupational therapists.

You can ask for a copy of your care plan to keep at home.



Your care at home

You're probably going to need more care as your symptoms get worse. There are different services to help you with this. They may include paid carers who come and help you with day-to-day tasks, meal deliveries, equipment for your home and help for your family.

What's available and who provides it varies depending on where you live. Some services are arranged through the NHS, whereas others may be provided by your local council (or via your Health and Social Care Trust in Northern Ireland).

Your GP surgery should be able to put you in touch with the services you need. They may also have a social prescriber who can direct you towards other support in the community.

Clinical services, support organisations and legal systems can vary in different parts of the UK. See our '**Other sources of support**' section on **page 30** for details of organisations who can advise about what's available where you live.



Check your sight and hearing

- Getting regular eye tests and using any glasses you're prescribed will help you see more clearly. This can make it easier to do everyday things like reading and cooking and reduce the chance of falls.



- Hearing tests can spot any hearing problems you may have. This is important as hearing loss is associated with dementia, depression and social isolation.

Using hearing aids if you need them can help you respond more quickly in conversations and makes it easier to communicate. Hearing aids do not fully correct your hearing, but they do make sounds louder and clearer. They can take a little while to get used to, so ask your audiologist for support if you're finding it hard.



Driving

If you've been diagnosed with dementia, by law you must inform the Driver and Vehicle Licensing Agency (DVLA) if you live in England, Scotland or Wales, or the Driver and Vehicle Agency (DVA) if you live in Northern Ireland. You may have to pay a large fine if you do not. They will ask you to fill in a form with details of your symptoms and any medication you're taking. Your doctor can help you with this. You will also need to give them permission to contact your doctor for more information if they need it.

The DVLA or DVA will decide whether you can continue to drive, based on the information you and your doctor give them. Sometimes, they may ask you to complete a driving assessment at a local centre first.

You will also need to inform your insurance company that you've been diagnosed with dementia. Your policy could become invalid if you do not.



Money and work

It's a good idea to get your finances in order as soon as possible. Make sure you have all the important documents you need, in a place where you can find them easily. This could include details of your bank accounts, your mortgage or rent payments, tax, pension and insurance policies.

Contact your local Citizens Advice, as they may be able to do a benefits check to see if you can get financial support. Or visit **turn2us.org.uk** to use their online benefits checker.

If you're working, speak to your employer. You may not need to give up work, but you will need to talk to them about your symptoms and any support you may need. You can find more information about work after a stroke at **stroke.org.uk/stroke/life-after/work**

Getting advice will help you make decisions. Find out about your rights as an employee, as well as the practical and financial support you may be able to get. Citizens Advice or a work coach at your local JobCentre Plus can help.



Legal matters

There may be a time in the future when your symptoms mean you can no longer make decisions for yourself. It's important to plan for this while you're still able to. There are some things that can help you do this.

- A **lasting power of attorney** is a legal document that allows you to choose someone to make decisions for you, when you're no longer able to make them yourself (sometimes called not having 'capacity'). You can choose someone to look after your property and finances and someone to look after your health and care. Or it can be the same person who looks after both. There are different types of power of attorney, so it's important to get advice before you make one. Your local Citizens Advice or a solicitor can advise you.
- An **advance decision** to refuse treatment, sometimes called a living will, allows you to refuse specific medical treatments. This would happen if you no longer have the ability (capacity) to make decisions about your medical treatment. It's known as an advance directive in Scotland.

In England, Northern Ireland and Wales, advance decisions are legally binding, as long as they meet legal standards. In Scotland, they are not legally binding in the same way but are likely to be treated as if they are by doctors, if they meet legal standards. It's a good idea to get specialist advice about making an advance decision.

- An **advance statement** sets out your wishes for the future. It can include any aspect of your life. For example, where you would like to live if you're not able to live independently, how you would like to be cared for, or choices about your diet. It's not legally binding, but it will help those involved in your care to understand your wishes.
- A **will** allows you to decide what happens to your money and possessions when you die. If you already have a will, you should make sure that it's up-to-date. If you do not have a will, then you should think about making one. You can write a will yourself, but it's advisable to have it checked by a solicitor, to make sure it will be understood the way you want it to be.

Tips for family and friends



It can be difficult to know what to do when someone you love is diagnosed with vascular dementia. Here are some suggestions.



Talk about it in the right way

Coming to terms with dementia is difficult for friends and family members too. But talking about it and planning for the future together can help you both deal with any worries. The more you understand what the person wants, the more confident you will be when it comes to making decisions for them in the future. So start talking about it now and make as many plans as you can.



Find out as much as possible

You may be offering your loved one more support and care as their condition gets worse. Becoming a carer is not something most people feel prepared for. It can help to find out as much as you can at the start.

With their permission, talk to their GP or dementia team and make sure you understand their condition, how it's likely to change and how you can best support them.

Ask your GP surgery and local council about any support you can get as a carer. Speak to your employer to see what support they can offer you, such as flexible working patterns or reduced hours. Find out about benefits you may be entitled to, if you're not working or you care for someone.



Find someone to talk to

Caring for someone can be emotionally and physically demanding. Even if you're not a full-time carer, coping with the fact that someone close to you has dementia is difficult. Talking to other carers or families who are dealing with dementia could be helpful. Organisations in the '**Other sources of support and information**' section can tell you about support available, such as carers' groups in your area.



Don't forget about your own needs

You cannot care for someone else if you're not taking care of yourself. So don't ignore your own needs. Look after your health – try to eat well, stay active and go to the doctor when you need to. Make sure you use all the support available to you. Have a list of jobs to give to other people if they offer to help, for example, going to the supermarket or doing the laundry. Dementia UK's website has more tips on looking after yourself when you care for someone or if you're caring from a distance.

You can also have a carer's assessment to see if you can get some support with your caring role. Support could include providing respite care, where someone else looks after the person to give you a break. Or there may be a day centre they can go to, so you can have a bit of time to yourself. Contact your local council (or health trust in Northern Ireland) if you have not had a carer's assessment.

For more information, visit our carers' guide at **stroke.org.uk/caring**, or call our Stroke Support Helpline for a printed copy.

Where to **get support** and **information**

From the Stroke Association

Stroke Support Helpline

Our Helpline offers information and support for anyone affected by stroke, including family, friends and carers.

Call us on **0303 3033 100**

Textphone **18001 0303 3033 100**

Email **helpline@stroke.org.uk**

Read our information

Log onto **stroke.org.uk**, where you can find easy-to-understand information, videos and an online community to support you. You can also call the Helpline to ask for printed copies of our guides.

Other sources of support and information

Dementia UK

Website: **dementiauk.org**

Dementia Helpline: **0800 888 6678**

Provides a helpline staffed by specialist Admiral Nurses and offers advice to support people with dementia.

Alzheimer's Society

Website: **alzheimers.org.uk**

Dementia Support Line: **0333 150 3456**

Information and support for people with dementia, their carers and families.

Alzheimer Scotland

Website: **alzscot.org**

24-hour Dementia Helpline: **0808 808 3000**

Information and local support for carers and people living with dementia in Scotland.

Carers UK

Website: **carersuk.org**

Helpline: **0808 808 7777**

Advice, information and support for carers, including a directory of local carers' groups.

Citizens Advice

Website: **citizensadvice.org.uk**

Offers advice on finance, benefits and legal matters.

About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.



How did we do?

To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at **feedback@stroke.org.uk**



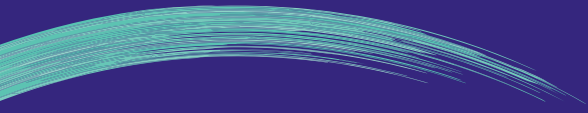
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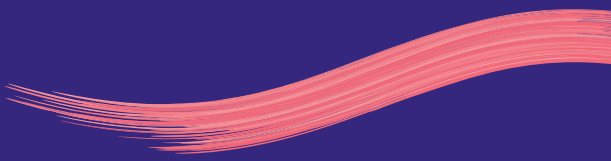


Always get individual advice

This guide contains general information about stroke. But if you have a problem, you should get individual advice from a professional such as a GP or pharmacist. Our Stroke Support Helpline can also help you find support. We work very hard to give you the latest facts, but some things change. We don't control the information provided by other organisations or websites.



Remember, you are not alone.
We are here to support you throughout
your recovery, whenever you need us.



Contact us

Stroke Support Helpline: **0303 3033 100**

Textphone: **18001 0303 3033 100**

Email: **helpline@stroke.org.uk**

Website: **stroke.org.uk**



Finding **strength** through **support**

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