

Vascular dementia and <u>stroke</u>

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

Find more useful information and practical tips at **stroke.org.uk**, or call our 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-andthinking
- 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 50-75% of cases).
- 2. Vascular dementia (about 20% of cases).
- 3. Dementia with Lewy Bodies (about 10-15% of cases).
- 4. Frontotemporal dementia (about 2% of cases).

You can have more than one type 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.
- Small vessel disease (SVD): damage to the blood vessels deep inside the brain, often caused by conditions like diabetes and high blood pressure.
- Vascular cognitive impairment (VCI): this describes all 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 understand or respond to things very quickly.
- Not being able to remember things.
- Finding it difficult to concentrate.
- Not being able to find the right word when you're speaking.
- Struggling to plan ahead for everyday tasks.
- Difficulty managing more complex tasks such as finances.
- Difficulty in learning new tasks.
- Seeming down or depressed.

At a later stage, signs may include:

- Becoming confused.
- Behaving differently, such as being aggressive or behaving inappropriately.
- Lacking motivation.
- Not being able to control your emotions.
- Finding it difficult to walk and keep your balance.
- Having problems controlling your bladder.

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. The symptoms of vascular dementia may come on more slowly and often get worse over time.

How is vascular dementia linked to stroke?

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 don't 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.

Small vessel disease

Vascular dementia can also be caused by small vessel disease. This is when the small blood vessels deep within your brain become narrow and clogged up. This stops blood from getting to parts of your brain. This can cause damage over time which can then lead to vascular dementia.

Many of the things that increase your risk of small vessel disease, such as high blood pressure and diabetes, also increase your risk of stroke and dementia.

What should I do if I think I have vascular dementia?

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

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

If they are not able to attend, it may be helpful for them to write down everything they have noticed so 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 that are 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 relative about any changes they may have noticed.

- Take some blood or ask for a urine sample, so that they can 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 is 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 to check your memory and thinking.
- They may ask you to perform pencil and paperbased 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 you can't pass or fail these tests.
- They may also arrange for you to have a brain scan, so that they can see how much damage has been caused to your brain.
- If possible, they will also ask to talk to people close to you about symptoms they have been noticing.

Worried about problems with memory and thinking? It's important to remember that 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. 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.

Although there is no proven treatment for vascular dementia, it may be possible to prevent mild problems developing into dementia.

Vascular dementia can cause problems like depression, anxiety and falls. The stroke or dementia team can work with you to find ways around many of these problems.

You might be offered medication for anxiety, or therapy such as occupational therapy, speech and language therapy and psychological therapies to help you live with dementia. You can try to reduce your risk of having further strokes or silent strokes. To do this, you may need to:

- Take medication to lower your blood pressure and cholesterol.
- Take medication to stop clots forming.
- Stop smoking.
- Drink less alcohol.
- Eat a healthy diet.
- Be more 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. 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 GP will talk to you about the options available.

Other treatments that can 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 that you're having.
- **3.** An occupational therapist will also be able to work with you to make sure that you can be as independent as possible, particularly at home.

Other forms of therapy and support for wellbeing

You should be offered some support to stay independent and develop your memory and concentration. Some therapies, including cognitive stimulation therapy, cognitive rehabilitation and occupational therapy, may be offered to some people with mild to moderate dementia. Some people might find group reminiscence work helpful.

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 depression, allergies, 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 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.

What should I do if I'm diagnosed with vascular dementia?

1. Talk to someone

Being told that you've got vascular dementia can be devastating. Suddenly your future is not what you thought it would be. People feel lots of different emotions when faced with news like this. You may feel shock, anger, grief or worry, and 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 about your problems with people who are going through the same thing. Some of the organisations we've listed in the '**Where to get help and information**' section will be able to tell you about support groups in your area. If you don't 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.

2. Get the information you need

You're going to have lots of questions. You may 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 to ease your fears. There's a lot of information to take in when you're first diagnosed, so don't be afraid to go back and ask questions, even if it's weeks or months later. It's important that you understand what's happening and why.

Sit down and write a list of all the questions you have and take it to your next appointment. We've suggested some things 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 that I can contact?
- Is there anything else I should think about?

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 to feel more prepared. Here are some of the things you may want to think about.



Your medical care

Your GP should support you (and your carer) and 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.

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 that your care plan covers everything you need, so think about what would help you to manage your condition better.

You and your GP surgery should review your care plan 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'll provide it.
- An offer to assess the needs of any informal carers supporting you.
- Referrals to other specialists you may need, such as physiotherapists or occupational therapists.

If you would like a copy of your care plan to keep at home, you can ask for this.



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 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 a Health and Social Care Trust in Northern Ireland).

Your GP should be able to put you in touch with the services you need, or contact one of the organisations we've listed under '**Where to get help and information**' to find out what support you can get.

Your GP surgery may also have a social prescriber who can direct you towards other support in the community.

Clinical services, support organisations and laws can vary in different parts of the UK. See our '**Other sources of help**' section for details of organisations who can advise about where you live.



Check your sight and hearing

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



 Hearing tests can spot any hearing problem you may have. Using hearing aids if you need them can help you respond more quickly in conversations and makes it easier to communicate. Hearing aids don't 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 don't. They will ask you to fill in a form, giving them 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 make a decision about 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, as your policy could become invalid if you don't.



Work and money

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 be details of your bank accounts, your mortgage or rent payments, tax, pension and insurance policies.

Contact your local Citizens Advice, as they will be able to do a benefits check to see if you may be able to get financial support from the government. Visit **turn2us.org.uk** to use their online benefits checker.

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



Legal matters

There may be a time in the future when your symptoms mean you're no longer able to make decisions for yourself. It's important to plan for this while you're still able to, so you can ensure that your future is how you want it to be. 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. 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, and there are variations across different UK nations, 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 and Wales, advance decisions are legally binding, as long as they meet legal standards. In Scotland and Northern Ireland, 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 is a good idea to get specialist advice about making an advance decision.
- An advance statement sets out all of your wishes for the future. It can include any aspect of your life, such as where you would like to live when you're not able to live on your own, how you would like to be cared for, or choices about your diet. It is not legally binding, but it will help the people 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 don't already have a will, then you should think about writing one. You can write a will yourself, but it's sensible 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 the worry and fear that you're likely to have. The more you understand what your friend or family member 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.



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Find out as much as possible

Your friend or family member is going to need more care as their condition gets worse, which may fall to you. Becoming a carer is not something most people feel prepared for. So you need 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 your friend or family member's condition and how it's likely to change. Ask your GP and local council about the support you can get. If you work, speak to your employer to see what help they can offer you. Find out about the benefits you may be able to receive if you're not working or if you have to stop.



Find someone to talk to

Caring for someone else can be emotionally as well as 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 that are dealing with dementia could be helpful. Find out about carers' or other support groups that you could go along to. Organisations we've listed in the '**Other sources of help and information**' section should be able to tell you about groups in your area.

Don't forget about your own needs

You can't care for someone else if you're not taking care of yourself. So don't ignore your own needs. Look after your health – eat well, stay active and go to the doctor when you need to. Make sure you use all the support that's available to you. Have a list of jobs that you can give to other people when they offer to help, for example, going to the supermarket or doing some washing.

If you care for someone, you are entitled to have your own carer's assessment to make sure that your local council is supporting you, as well as your friend or family member. This could include providing respite care, where someone else comes and looks after your friend or family member to give you a break. Or there may be a day centre they can go to, so that you can have a bit of time to yourself. Contact your local council (or health trust in Northern Ireland) if you haven't had a carer's assessment.

You can find more ideas about supporting someone in our guide for carers. Read online or download from **stroke.org.uk/caring**, or call our Helpline to request a print copy.

Where to get help and information

From the Stroke Association

Helpline

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

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100**. Email **helpline@stroke.org.uk**

Read our information

Log onto **stroke.org.uk**, where you can find easyto-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 help and information

Dementia UK

Website: **dementiauk.org** Dementia Helpline: **0800 888 6678** Charity which provides Admiral Nurses and advice to support people with dementia.

Alzheimer's Society (England, Northern Ireland and Wales)

Website: alzheimers.org.uk

Dementia Connect 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 people living in Scotland.

Dementia NI

Website: **dementiani.org** Helpline: **028 9693 1555** Offers support groups across Northern Ireland and advice on living well with dementia.

Carers UK

Website: **carersuk.org** Adviceline: **0808 808 7777** Advice and individual support for carers.

Call the Stroke Helpline on 0303 3033 100

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**



Accessible formats

Visit our website if you need this information in audio, large print or braille.



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 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. When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

Contact us

We're here for you. Contact us for expert information and support by phone, email and online. Stroke Helpline: **0303 3033 100** From a textphone: **18001 0303 3033 100** Email: **helpline@stroke.org.uk** Website: **stroke.org.uk**

Rebuilding lives after stroke



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