stroke.org.uk



A complete guide to

Vascular desalation



If you are worried about vascular dementia or know someone who is, this guide can help you understand what you need to do.

It will tell you what vascular dementia is and how it is linked to stroke. It also explains what you should do if you or someone you know is diagnosed with vascular dementia.

It's aimed at people who have had a stroke or who think they may have vascular dementia, but there is information for family and friends as well.

We have information on all aspects of stroke.

If you have a question that is not answered in this guide visit **stroke.org.uk** or call our Stroke Helpline on **0303 3033 100**.



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What is vascular dementia?

Dementia is a condition that can affect your memory, thinking, communication, mood and behaviour. It happens when parts of your brain become damaged. There are different types of dementia and it's possible to have more than one.

Vascular dementia is a common type of dementia. It happens when the blood supply to parts of your brain is cut off, so it doesn't get the oxygen and nutrients that it needs. This causes brain cells to die.

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

Signs of vascular dementia

If you or the people around you notice any of these things then you should go to see your GP:

- not being able to understand or respond to things very quickly
- becoming confused
- not being able to remember things
- finding it difficult to concentrate
- not being able to find the right word when you're speaking
- seeming down or depressed
- behaving differently, especially if you're being aggressive or behaving inappropriately
- not being able to control your emotions
- finding it difficult to walk and keep your balance
- having problems controlling your bladder
- seeing or hearing things that aren't
- believing things that aren't true.

How is it linked to stroke?

When you have a stroke, the blood supply to parts if your brain is cut off and the cells in these areas die. This can lead to vascular dementia.

This can happen after a single stroke, but it's more likely to be caused by lots of small strokes, which create 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.

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 (known as vascular cognitive impairment) 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.

Symptoms of vascular dementia can sometimes be confused with the effects of stroke, as many of them are the same. The difference is that vascular dementia gets worse over time. If you're unsure, go to see your GP.

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

If you're noticing signs of vascular dementia, then you need to **go and 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 haven't or be more aware of how long you've had them.

To help them rule out any other causes 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
- 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 or low levels of vitamins or hormones
- look at the medication you're taking to see if that could be causing any of your symptoms

If your GP isn't able to find any other causes, they will refer you to a **dementia specialist**. This could be a:

- psychiatrist (a doctor who specialises in mental health conditions)
- geriatrician (a doctor who specialises in the health of older people)
- neurologist (a doctor who specialises in the way the brain works).

These doctors are often based within a **memory clinic**, so it's possible that you may be referred to one of these. Memory clinics are services that have been set up all over the UK to help people with dementia.

Your specialist will carry out further tests. They will ask you questions to see how your memory and thinking may have been affected. 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.



Will it get better?

Unfortunately, there is **no way to cure vascular dementia**. It is a progressive condition, which means it gets worse over time.

How quickly it progresses is different for everyone. Your symptoms may stay the same for months, or even years, but then they will suddenly get worse. Although your dementia will not get any better, it may be possible to slow down how quickly it progresses.



Are there treatments that can help?

Unfortunately there isn't any way to treat vascular dementia. However, if it's caught early enough you may be able to slow down how quickly it progresses. This means reducing your risk of having further strokes, which could cause more damage to your brain.

To do this you may need to:

- take medication to lower your blood pressure or cholesterol
- take medication to thin your blood and stop it from clotting as easily
- stop smoking
- eat a healthy diet
- · drink less alcohol
- do more exercise
- lose weight.

Your doctor should talk to you about all the things you need to do to reduce your risk of further strokes.

Acetylcholinesterase or AChE

inhibitors are drugs that are used to treat Alzheimer's disease – the most common type of dementia. But there has not been enough evidence so far to suggest that they could help to improve vascular dementia. They also have side effects. More research needs to be done before doctors can recommend them as a treatment for vascular dementia.

Whilst there aren't any treatments for vascular dementia itself, there may be things that can help to improve your symptoms. These could include:

Medication

Sometimes medication may be able to improve your mood if you are feeling very down or depressed. Some drugs have also been shown to improve confusion, although they don't seem to work as well for vascular dementia compared to other types of dementia. Medication can also help with some behaviour problems. However, there are risks to taking these drugs, so it's important you talk through all the advantages and disadvantages with your family and doctor before you decide to try them.

Rehabilitation therapy

If your dementia is causing physical problems, then you may be able to work with a physiotherapist to try to improve them. Or a speech and language therapist may be able to help you with any communication problems that you're having. An occupational therapist will also be able to work with you to make sure that you can be as independent as possible.

Other forms of therapy

There are other therapies that can help with the effects of dementia. Cognitive stimulation therapy, for example, uses group activities to help people improve their memory, concentration and ability to solve problems. Reality orientation therapy helps people to feel less disorientated and confused. These therapies are not suitable for everyone and may not be available in all areas, so it's best to talk to your doctor about what your options are.

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

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 round 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 on page 13 will be able to tell you about support groups in your area. These kinds of groups aren't for everyone though. So if you don't want to go to a support group, talk to someone close to you instead. It could be a **family member**, **friend or carer** – whoever you feel most comfortable confiding in.

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

- At what stage is my dementia?
- 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?
- 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?

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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 doctor should talk to you about developing a **care plan**. This is an agreement between you and your doctors 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. Use the time you have with your doctor to ask questions and talk about any worries or concerns you have.

When you've agreed it, you should be given a copy of your care plan. It should explain:

- 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
- who you should contact if you're unwell and your doctor's surgery is closed
- when your plan will be reviewed.

You and your doctor 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 at home

You're probably going to need more care as your symptoms get worse. There are lots of services to help you with this. They include carers to come and help you with day-to-day tasks, delivered meals, equipment for your home and help for your family.

What's available and who provides it varies from area to area. Some services are arranged through the NHS, whereas others may be provided by your local council. Your GP should be able to put you in touch with the services you need, or you can contact one of the organisations on page 13 to find out what support you can get.



Driving

If you've been diagnosed with dementia, you will have to 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. It's likely that you will have to stop driving at some point, but you may not have to do it straight away.

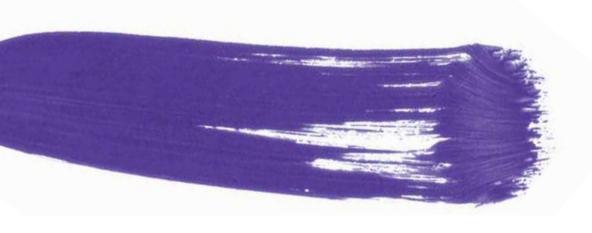
You will also need to **inform your insurance company** that you've been diagnosed with dementia, as your policy could become invalid if you don't.

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 Citizen's Advice Bureau, as they will be able to do a **benefits check** to see if you may be able to get financial support from the government.

If you are still working you'll need to speak to your employer. You may not need to give up work straight away, but you will need to talk to them about your symptoms and any support you may need to help you with them. Getting advice will help you make the decisions you need to. So find out about your rights as an employee as well as the practical and financial support you may be able to get. Your local Citizen's Advice Bureau or the disability employment adviser 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 whilst 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 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, so it's important to get advice before you make one. Your local Citizen's Advice Bureau or a solicitor can advise you.
- an advance decision or directive allows you to refuse, in advance, any medical treatments that you don't want to have in the future. It is a legal document and your doctors and family have to follow what it says. It's very important to talk to your doctor before you make 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 a legal document, so although the people making decisions for you should take it into account, they do not have to follow it if they don't think it's in your best interests to do so.
- 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.

It's very important to get the right advice before making any of these decisions. Your local Citizen's Advice Bureau or one of the organisations we've listed on page 13 will be able to help.

Where can I get help and support?

If you're worried that you may have dementia, then you need to **speak to your GP**. They will be able to talk to you about your symptoms and refer you to a specialist for more advice if needed.

If you have vascular dementia and you want to know more about your condition or the support you can get, your GP is also a good place to start.

How we can help

Our **Stroke Helpline** can give you information and support on any issue you or your family may be facing after stroke. Whatever the problem, we're here to help.

We have **coordinators** in some areas of the UK, who can meet with you and your family and give you information, practical advice and emotional support. We also run **stroke groups** across the UK. Even if we don't run one in your area, we can tell you about others that do.

Or you can talk to other people affected by stroke on our online forum TalkStroke or on our Facebook page. Visit stroke. org.uk/talkstroke or facebook.com/TheStrokeAssociation

To find out how we can help, just get in touch:

- call our Stroke Helpline on 0303 3033 100
- email info@stroke.org.uk
- visit **stroke.org.uk**
- write to us at Stroke Information Service, Life After Stroke Centre, Church Lane, Bromsgrove, Worcestershire B61 8RA.



Other organisations that can help

Below are some other organisations in the UK that may be able to help. Contact our Stroke Helpline if you'd like to know about others in your area.

Dementia UK is a charity for everyone affected by dementia. They provide support through Admiral nurses, who specialise in caring for people with dementia. Admiral nurses aren't available in all areas, so call the Admiral Nursing DIRECT number to find out if there is one local to you, or to get advice over the phone.

Website: www.dementiauk.org
Admiral Nursing DIRECT: 0845 257 9406
(Mon–Fri 9.15am–4.45pm)
Email: direct@dementiauk.org

The following **dementia charities** support people affected by all kinds of dementia. They provide information and advice about living with dementia and caring for someone who has the condition.

Alzheimer's Society

(England, Northern Ireland and Wales) **Website:** www.alzheimers.org.uk

National dementia helpline: 0300 222 1122 (Mon–Wed 9am–8pm, Thu–Fri 9am–5pm,

Sat-Sun 10am-4pm)

Email: enquiries@alzheimers.org.uk

Alzheimer's Scotland Website: www.alzscot.org

Dementia Helpline: 0808 808 3000 (24 hour)

Email: helpline@alzscot.org

Carers UK is a charity that supports carers. They can give you information and advice about the kind of support you can get as a carer. They can also connect you to other carers through local groups and centres or through their online forum.

Website: www.carersuk.org **Adviceline:** 0808 808 7777 (Mon–Fri 10am–4pm)

Email: advice@carersuk.org

Citizen's Advice provides free, confidential advice about legal and financial matters. To find your local bureau visit one of the websites below or look in your local telephone directory. You can also find information online by visiting their Adviceguide website.

Citizen's Advice Bureau

(England, Northern Ireland and Wales) **Website:** www.citizensadvice.org.uk

Citizen's Advice Scotland Website: www.cas.org.uk

Citizen's Advice Bureau Adviceguide Website: www.adviceguide.org.uk

Tips for family and friends



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



Talk to each other

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.



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.

Talk to their doctor 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 is 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. So find out about carers' or other support groups that you could go along to. The organisations we've listed on page 13 will 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, like 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. Ask your GP or contact your local council if you've not had a carer's assessment.

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**





We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke.

We're here for you. If you'd like to know more, please get in touch.

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk
Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100



Text STROKE 5 to 70300 to donate £5. It only takes a couple of seconds to make a BIG difference. For more information visit **stroke.org.uk/savelives**

Texts cost your donation amount plus one message at your standard network charity rate. The Stroke Association will receive 100% of your gift. Always ask the bill payer's permission. For questions about donating by text call 0330 6600 425.

Together we can conquer stroke

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