# A complete guide to vascular dementia

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 can 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. Dementia often gets worse over time.

There are different types of dementia and it’s possible to have more than one. This is called mixed dementia. Up to 20% of people with dementia in the UK have vascular dementia, and a further 10% have mixed dementia.

Vascular dementia happens when the blood supply to parts of your brain is reduced. This can be due to blood vessels being clogged up, or a series of mini-strokes. Over time, areas of brain cells stop working, leading to symptoms of dementia.

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

#### Some terms you may hear

* Alzheimer’s disease: the most common type of dementia, caused by clumps of proteins building up in the brain.
* Mild cognitive impairment: 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.
* Other types of dementia: you may hear about dementia with Lewy bodies, frontotemporal dementia, young-onset dementia as well as rarer types.
* Small vessel disease: damage to the blood vessels deep inside the brain, often caused by high blood pressure
* Vascular cognitive impairment: this describes all memory and thinking problems associated with stroke. It includes vascular dementia and mild cognitive impairment.
* Vascular dementia: problems with memory and thinking due to damage to the blood vessels in your brain.

### 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 in learning new tasks
* seeming down or depressed.

At a later stage, signs may include:

* becoming confused
* behaving differently, especially if you’re 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 while the symptoms of vascular dementia often get worse over time.

## How is it 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. 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.

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.

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.

Sometimes symptoms of vascular dementia can be confused with the effects of stroke. Both stroke and vascular dementia can cause problems with memory, thinking and mood. Strokes happen suddenly while the symptoms of vascular dementia often get worse over time. 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 are not aware of, or may be able to say 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
* perform a brief memory test
* ask you some questions about your mood
* 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 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. 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 **dementia specialist**. This could be:

* 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 dementia nurse.

It is possible that your assessment may happen at a **memory clinic or a clinic at a hospital outpatients department.**

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 ask you to perform pencil- and paper-based 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.

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**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 are worried about this, visit your GP.

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## Will it get better?

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 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?

Although there is no proven treatment for vascular dementia, it may be possible to prevent mild problems developing into dementia. Treatments may also slow down how quickly dementia progresses. Vascular dementia also causes 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 have medication for anxiety, or physiotherapy to reduce falls.

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 thin your blood and stop clots forming
* stop smoking
* eat a healthy diet

**Alzheimer’s medications**

Cholinesterase inhibitors, also known as AChE inhibitors, are drugs that are used to help with the symptoms of Alzheimer’s disease.These medications have been tried in vascular dementia, but they do not work as well as they do in Alzheimer’s disease. They also have side effects. Sometimes doctors will try using these medications in vascular dementia, especially if they think a patient has a mix of vascular and Alzheimer’s disease. Memantine is a dementia drug that is only recommended for people with Alzheimer’s.

Other treatments that can help improve your symptoms include:

* **Medication**

Some medications may worsen memory and thinking problems. These include antihistimines for hay fever and other allergies, as well as some sleeping tablets. Doctors sometimes stop certain medications when they make a diagnosis of vascular dementia.

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. 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**

Memory and stroke services often have a team of experts that can help with various dementia problems. If your dementia is causing physical problems, such as falls, then you may be able to work with a physiotherapist to try to improve them.

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, particularly in your home environment.

* **Other forms of therapy**

There are other therapies available that haven’t been proven to help people with vascular dementia, but might be suggested to you. Cognitive stimulation therapy, for example, aims to improve memory and concentration. Speak to your GP 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 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. 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**

* 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?

### 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 GP surgery is closed
* when your plan will be reviewed.

You and your GP 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 who 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 we’ve listed in the *Where to get help and information* section 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, 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** 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 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 **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 or a solicitor can advise you.
* An **advance decision, sometimes called a living will,** allows you to refuse medical treatments you might be offered in the future. In England and Wales, doctors and family have to follow what it says. In Scotland and Northern Ireland an Advance Directive is not legally binding, but it has a strong influence on the decisions doctors make. 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 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.

## Where to get help and information

### From the Stroke Association

#### Talk to us

Our Stroke Helpline is for anyone affected by a stroke, including family, friends and carers. The Helpline can give you information and support on any aspect of stroke.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100** or email info@stroke.org.uk.

#### Read our publications

We publish detailed information about a wide range of stroke topics including reducing your risk of a stroke and rehabilitation. Read online at **stroke.org.uk** or call the Helpline to ask for printed copies.

#### My Stroke Guide

My Stroke Guide is the online stroke support tool and online community from the Stroke Association. Log on at **mystrokeguide.com**.

Our Enquiry Line can support you with using My Stroke Guide. Call **0300 222 5707** or email **mystrokeguide@stroke.org.uk****.**

#### Talk to others affected by stroke

There may be a stroke group in your local area where you can meet other stroke survivors. You can meet people on our My Stroke Guide online chat forum at mystrokeguide.com, and our Facebook page **Facebook.com/TheStrokeAssociation**.

Call our Helpline or visit **stroke.org.uk/support** for more information on stroke groups and other face-to-face support.

### Other sources of help and information

**Alzheimer’s Society (England, Northern Ireland and Wales)**

**Website**: www.alzheimers.org.uk

**National dementia helpline**: 0300 222 1122

**Email**: enquiries@alzheimers.org.uk

Publishes a range of factsheets about dementia and how it can be managed and treated. Their helpline offers advice for people with dementia, as well as their carers and families.

**Alzheimer Scotland**

**Website**: www.alzscot.org

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

**Email**: helpline@alzscot.org

Provides information and advice for people living with dementia in Scotland.

**Carers UK**

**Website**: www.carersuk.org

**Adviceline**: 0808 808 7777

**Email**: advice@carersuk.org

A charity that supports carers. They offer 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.

**Citizen’s Advice**

**Website**: www.citizensadvice.org.uk

Provides free, confidential advice about legal and financial matters.

**Dementia UK**

**Website**: www.dementiauk.org

**Dementia Helpline**: 0800 888 6678

**Email**: direct@dementiauk.org

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 Dementia Helpline to find out if there is one local to you, or to get advice over the phone.

## 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 in the *Other sources of help and information* section 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 haven’t 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**.

#### Accessible formats

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

#### Always get individual advice

Please be aware that this information is not intended as a substitute for specialist professional advice tailored to your situation. We strive to ensure that the content we provide is accurate and up-to-date, but information can change over time. So far as is permitted by law, the Stroke Association does not accept any liability in relation to the use of the information in this publication, or any third-party information or websites included or referred to.

#### 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**: info@stroke.org.uk

**Website**: 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 rely on your support to fund life-saving research and vital services for people affected by stroke. Join the fight against stroke now at **stroke.org.uk/fundraising**. Together we can conquer stroke.



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Version 2. Published April 2018

To be reviewed: April 2021

Item code: A01F29CG

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