

Supporting a stroke survivor

Stroke
association

Supporting a stroke survivor

Information for family, friends and carers
of people who have had a stroke



stroke.org.uk



Shared reading

After a stroke it can be hard to understand things. Reading and talking about our guides with the person who has had a stroke can help. They may need to hear something several times.

Inside this guide

Stroke: what you need to know	Page 4
Quick guide to the effects of a stroke	Page 12
Rehabilitation	Page 18
The emotional impact of a stroke	Page 20
Support after leaving hospital	Page 23
Where to get help and information	Page 29



We're here for you

Contact the Stroke Helpline on **0303 3033 100**, email info@stroke.org.uk, or visit stroke.org.uk



About you

If you are supporting a family member or friend after a stroke, this guide will help you understand what has happened. It offers tips on supporting a stroke survivor, and ideas on where to go for advice.

Stroke: what you need to know



Stroke: what you need to know

A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off, killing brain cells. Damage to the brain can affect how the body works. It can also change how someone thinks and feels.

There are two main types of stroke

1. Ischaemic stroke

Due to a blocked blood vessel in the brain.



2. Haemorrhagic stroke

Due to bleeding in or around the brain.



You may hear an ischaemic stroke referred to as a clot. Haemorrhagic stroke is often called a bleed.

About 85% of all strokes are ischaemic, and 15% are haemorrhagic.

Different names for haemorrhagic stroke

Haemorrhagic stroke is sometimes called a brain haemorrhage, a subarachnoid haemorrhage or an intracerebral haemorrhage.

TIA or mini-stroke

A TIA (transient ischaemic attack) is the same as a stroke, except that symptoms last for a short amount of time. In a TIA, a blood vessel in the brain gets blocked, but the blockage clears by itself. TIA is also known as a mini-stroke and some people think of it as a 'funny turn'. But a TIA is a major warning sign of a stroke.



Turn to page 8 to learn how to spot the signs of a stroke and TIA.

Every stroke is different

After a stroke, some people recover very well. But a stroke can lead to disabilities, which could be mild or more severe. Stroke causes a greater range of disabilities than any other condition. However, many of the effects of a stroke can be treated, and rehabilitation can help people make the best recovery possible for them.



Tip: a person can look fine but still need help with the 'hidden' effects of stroke. See page 17.

The risk of another stroke

The chances of a second stroke can be a big worry for a stroke survivor and their family and friends. Research tells us that after a stroke, around one in four stroke survivors will have another stroke within five years. A second stroke is most likely to happen in the first 30 days. This is why, when someone has a stroke, doctors always check if the person has a health condition that increases the risk of a stroke.

The main health conditions that raise the risk of a stroke are:

1. high blood pressure
2. atrial fibrillation (irregular heartbeat)
3. diabetes
4. high cholesterol.

These conditions can all be treated to help reduce the risk of a stroke. If someone has one or more of these conditions, the best thing they can do to reduce their risk is to follow any treatment they are given.

They may also be given advice on healthy lifestyle changes, such as giving up smoking and losing weight.

How you can help

You can support the person to reduce their risk of another stroke by encouraging them to follow any treatments they are given. If they need to lose weight or change their diet, they might welcome some practical help. The GP or a specialist stroke nurse can help someone understand their individual risk of a stroke, and offer support with reducing their risk.

Spotting the signs of a stroke

It's important to know how to spot the common signs of a stroke in yourself or someone else. Using the FAST test is the best way to do this.

FAST test

F**Face**

Can the person smile?
Has their face fallen on one side?

**A****Arms**

Can the person raise both
arms and keep them there?

**S****Speech problems**

Can the person speak clearly
and understand what you say?
Is their speech slurred?

**T****Time**

If you see any of these three
signs, it's time to call **999**.



The FAST test helps to spot the three most common signs of stroke. But there are others that you should always take seriously. These include:

- sudden weakness or numbness on one side of the body, including legs, hands or feet
- difficulty finding words or speaking in clear sentences
- sudden blurred vision or loss of sight in one or both eyes
- sudden memory loss or confusion, and dizziness or a sudden fall
- a sudden, severe headache.



Stroke can happen to anyone, at any age. Every second counts. If you spot any of these signs of a stroke, don't wait. Call 999 straight away.

What to do about symptoms more than 24 hours ago

If you had a 'funny turn' that might have been a TIA (mini-stroke) more than one day ago, call the GP and ask for an emergency appointment. You can also go to the nearest NHS walk-in clinic or a local accident and emergency department. TIA is a major warning sign of a stroke. So it's essential to get medical help, even if the TIA was some time ago.



Treating a stroke emergency

When someone has a suspected stroke, they should be taken to a specialist stroke unit in a hospital. Brain scans and other checks are used to help diagnose a stroke and its causes.

Ischaemic stroke (due to a blockage) – treatments include clot-busting drugs (thrombolysis), and drugs that prevent the blood from forming clots. Thrombectomy is a treatment that removes the clot with a mechanical device. As yet this is only available in a small number of UK hospitals.

Haemorrhagic stroke (due to bleeding) – treatments include medication to lower blood pressure, and surgery to stop bleeding or reduce pressure on the brain.



If you are supporting someone who has just had a stroke, ask the medical staff to explain what tests and treatments are being used.

End-of-life care

For some people, a stroke can be life-threatening. If your loved one is seriously ill and their condition worsens, you can get support from the palliative care team at the hospital, which provides end-of-life care. The Stroke Helpline is there for you too.



For more in-depth information about stroke and how to reduce the risk of having a stroke, read our guide *Next steps after a stroke* or visit stroke.org.uk.

Quick guide to the effects of a stroke



Quick guide to the effects of a stroke

The effects of a stroke depend on where it takes place in the brain, and the size of the damaged area.

Some people have problems with physical activities like speaking, walking and swallowing. Other stroke effects are less easy to spot, like fatigue, memory loss and emotional problems.



Tip: Some effects improve quickly

Problems like weakness, incontinence, and swallowing difficulties often improve in the days following a stroke.

Visible effects of a stroke

Movement and balance

Stroke often causes weakness down one side affecting the arms and legs. This can lead to problems with walking, balancing and holding things.

Continence problems

Problems with bowel or bladder control are very common after a stroke. Continence often improves in the early weeks. It can be embarrassing, so offer reassurance and understanding and encourage the person to seek medical help.

Behaviour changes

After a stroke some people show behaviour changes, such as losing interest in things they used to enjoy, being very impulsive or getting angry more easily. It's important to seek help if someone's behaviour poses a danger to themselves or others.

Problems noticing things to one side (spatial neglect)

Spatial neglect, or inattention, means that the brain does not process sensory information from one side. Someone might bump into things because they are not aware of one side of their body. They might miss half the food on their plate because the brain is not processing all the visual information it gets from the eyes.

Swallowing problems (dysphagia)

A stroke can cause problems with swallowing due to weak muscles in the mouth and throat. This is known as dysphagia. Someone with dysphagia may need to have soft foods or be tube-fed for a time to avoid lung infections caused by food and drink being breathed in. Around half of all stroke survivors have swallowing problems, but these often improve in the early weeks.



Tip: Listen to stroke survivors

Some effects of stroke are obvious. Other changes are not so easy to see. Give the person time to talk about their problems and show how they feel.

Communication difficulties

Aphasia

Around one third of stroke survivors have a problem with language called aphasia. It often comes from a stroke in the left side of the brain. Aphasia can affect all aspects of language including speaking, reading, writing, and understanding speech. The person does not become less intelligent, but they find it difficult to use language.

Weak face muscles

Weakness in the face, mouth, tongue and throat muscles can make speech slurred.

Problems with concentration and memory

After a stroke, a person might find it hard to concentrate on a conversation. They may forget what they hear, and they may not be able to recognise objects or even people's faces. All of these things can affect communication.



Tip: Communicate with confidence

You can help a person with communication problems by giving them time to answer questions. Don't rush – it can take up to 30 seconds or more for someone to respond. Ask one question at a time, and try not to answer for them. Tell them if you have not understood something.



Hidden effects of a stroke

Fatigue

Fatigue, or tiredness that doesn't get better with rest, can remain for months or years after a stroke. It is common after a stroke, and can be a serious problem for some.

Emotional effects

Stroke is closely linked to emotional problems. After a stroke, around a third of people have depression. About 20% of people have emotionalism in the first six months after a stroke. This means crying or laughing unexpectedly, sometimes for no obvious reason.

Memory and thinking

Problems with memory and concentration are very common after a stroke. They are also known as cognitive problems. Stroke survivors often feel confused at first, but for many this recovers in the early weeks.

Vision

About 60% of people have vision problems after a stroke. Problems can include double vision or being very sensitive to light. Some people lose part of the visual field, which means not being able to see everything you are looking at.

Pain

Some people experience long-term pain such as burning sensations.

Get help

Many of the effects of a stroke can be treated, and a GP can give help and advice.

Rehabilitation



Rehabilitation

Everyone who needs it should receive rehabilitation soon after a stroke, often starting in hospital. Therapies include:

- **occupational therapy:** helps people re-learn skills for everyday activities to support independent living
- **physiotherapy:** improves mobility, strength and balance
- **speech and language therapy:** helps with communication and swallowing
- **psychological therapies:** help with memory and thinking difficulties, and anxiety and depression
- **dietician:** advises on food and drink for people with swallowing problems, and healthy eating.

What you can do to help

Many people find it really helpful to have some support with their rehabilitation from friends and family. You can try asking the therapists how you can help, as you may be able to take part in rehabilitation sessions, and help the person to practise later.

Ask the stroke survivor about things that might motivate them. For example, keeping notes of their progress can help by allowing them to see the improvements they have made.

Remember that rehabilitation can be incredibly difficult and hard work for the person. They may be attempting to re-learn some fundamental skills such as walking or talking, and this is a big challenge. You can help by giving encouragement and taking an interest.



For more about rehabilitation, read our guide
***Next steps after a stroke* or visit stroke.org.uk.**

The emotional impact of a stroke



The emotional impact of a stroke

Stroke can have a powerful emotional effect on the individual and the people around them.

How survivors feel about themselves

Stroke can change how people see themselves. Stroke usually comes as a big shock, and this shock can have a big emotional impact. Around a third of stroke survivors experience depression after a stroke.

Changing roles at work or at home can also cause difficulties. For instance, if someone is less able to provide for their family, this can be upsetting. They may feel a sense of loss if they can no longer do the things they enjoy.

Professional's view: relationships

"I've had two men say to me 'I can't protect my wife now.' Rightly or wrongly, they felt that they had headed up the family, but that they couldn't do that anymore."

Colin, Stroke Association Coordinator

Depression and anxiety are common after a stroke. If you sense that your family member may be feeling low, try talking to them about it. The GP may be able to offer advice.

The emotional impact on family and friends

People can react in very different ways when a family member has a stroke. You might feel grief, worry, guilt or anger, as well as shock.

Personal story: anger

"I wanted to find someone to blame for what had happened to Mum. I felt really, really angry."

Carol, daughter of a stroke survivor

There can be a sense of loss at the changes in the person and your relationship with them. Although they are still the same person, changes to their communication skills, memory and other effects of stroke can mean changes to your usual routines, and alter family roles.

Support after leaving hospital



Support after leaving hospital

The discharge process aims to ensure that everyone has the right support and treatment after they leave hospital. This can include rehabilitation therapies, help with daily tasks or full-time support. The patient and their family or carers should be part of discharge planning, so tell hospital staff if you wish to be involved. The discharge process and the level of support offered can vary between areas.

Reviewing progress

People should have at least one review after leaving hospital to make sure that they are receiving the right support if their needs have changed. This is often six months after discharge. If it doesn't take place, or you feel that not enough treatment and support are being provided, contact the GP.

Early supported discharge

Some people can leave hospital early and continue their rehabilitation at home, provided they are able to move from a bed to a chair and have a safe home environment to return to.

Professional's view: discharge

"From the very first meeting with patients and their family, we talk about the discharge plan. We're very open about the fact that discharge is always better as soon as possible."

Simon, occupational therapist

Information for carers

If you become a carer for someone after a stroke, it can be very demanding. Being a carer can take many forms, and you might not even think of yourself as a carer.

Caring can mean doing the shopping, cleaning the house or sorting out the bills. It can also mean being involved with personal care or helping with rehabilitation.

It is important to look after yourself too. If you lose out on sleep or miss meals, for example, it can make it harder for you to carry out your caring role.

Carers can also be at risk of emotional problems such as stress, depression and carer burnout, so don't be afraid to ask for support.

Family and friends may be able to offer their time to support you. There are carers' centres in many local areas where you can get advice and information.

Accommodation

Some people who have a disability after a stroke may be able to live independently. Some will need some adaptations to their home, or a little support for daily tasks such as shopping and cooking.



If someone needs help with many aspects of living, they may need to move to a residential home or live with a relative.

If you can, talk to your loved one about what they want.



For sources of information and advice on care and accommodation, see page 33.

Carer's assessment

Your local authority social services can carry out an assessment of your support needs, called a carer's assessment. You do not have to be a full-time carer, and you do not have to be living with the person you are caring for.

The assessment will identify the kind of help you need. This might include help to reduce your stress, such as a gym membership, and help towards travel costs. The person you are caring for might be able to have a short stay in residential care to allow you a break, or a place in a day centre. The council may do a financial assessment to decide what contribution you should make to the costs.

Care and support needs assessment

The person you are caring for can have an assessment of their own needs. Social care is not free, but the local council will decide what financial help is available to meet the costs. The carer's assessment can be carried out at the same time, if you both agree to this.

Financial impact

A stroke can have a big financial impact. For example, a family could lose its main income while a parent is recovering from a stroke, or a family member might reduce their working hours to care for a parent or partner.

Support available

Some financial support is available from the government, including Carer's Allowance, which you can claim if you care for someone 35 hours a week or more without pay.

Financial help available to people with a disability includes Personal Independence Payments (PIP). This is a tax-free benefit to meet some of the extra costs of being long-term ill or disabled, for people between 16 and 64. People with a disability aged 65 and above can claim Attendance Allowance if they need someone to help look after them.



For information about benefits and to start a claim online visit gov.uk.

Life After Stroke Grants

The Stroke Association provides one-off grants of up to £300 to help fund equipment or support for a stroke survivor. To find out how to apply for a Life After Stroke grant, call our Helpline on **0303 3033 100** or email grants.external@stroke.org.uk.



For more details on financial support for people affected by stroke read our factsheet ***Benefits and financial assistance***, available to download from stroke.org.uk.

Where to get help and information



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 telephone **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 from the Stroke Association. Log on to find easy-to-read information, advice and videos about stroke. And our chat forums can connect you to our online community, to hear how others manage their recovery.

Log on at **mystrokeguide.com**.

Our dedicated Enquiry Line is on hand to 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 and carers. Call our Helpline or visit stroke.org.uk/support for more information on stroke groups and other face-to-face support.

You can meet people on our My Stroke Guide online chat forum mystrokeguide.com, and on our Facebook page facebook.com/TheStrokeAssociation.

Childhood stroke

This guide is about stroke in adults. For information about childhood stroke visit stroke.org.uk/childhood.

Help with health and everyday living

Stroke symptoms

If you or someone you know has any stroke symptoms, don't wait. Call **999** straight away. **See page 8** for the FAST test.

Get the help you need

In some parts of the UK it can be hard to get all the therapy and support needed by stroke survivors and carers. For information on getting the support you need, contact our Helpline **0303 3033 100**.

Request a post-stroke review

There should be a review of the stroke survivor's needs after the stroke, usually at about six months. If this does not happen, ask the GP to arrange it.

Daily support needs

For support with daily living and accommodation, contact your local council social services department.

Legal and money advice

For free, confidential advice about money, legal and employment issues, contact Citizens Advice ([see page 33](#)).

Other sources of help and information

Support with reducing your risk

British Heart Foundation

Website: www.bhf.org.uk

Helpline: 0300 330 3311

Diabetes UK

Website: www.diabetes.org.uk

Helpline: 0345 123 2399

Drinkaware

Website: www.drinkaware.co.uk

Drinkline: 0300 123 1110

Sickle Cell Society

Website: www.sicklecellsociety.org

Tel: 0208 961 7795

Smokefree

Website: www.nhs.uk/smokefree

Help for carers

Carers UK

Website: www.carersuk.org

Adviceline: 0808 808 7777

Cruse Bereavement Care

Website: www.cruse.org.uk

Tel: 0808 808 1677

Help with money and accommodation

Citizens Advice

Website: www.citizensadvice.org.uk

Adviceline: England 0344 411 1444, Wales 0344 477 2020,
Scotland 0808 800 9060, TextRelay 0344 411 1445

GOV.UK government services and information

Website: www.gov.uk

Independent Age

Website: www.independentage.org

Helpline: 0800 319 6789

Help with the effects of a stroke

Alzheimers Society

Website: www.alzheimers.org.uk

Helpline: 0300 222 1122

Aphasia resources from the Stroke Association

Website: stroke.org.uk/aphasia

Chest Heart & Stroke Scotland

Website: www.chss.org.uk

Advice Line: 0808 801 0899

Different Strokes: support for younger stroke survivors

Website: www.differentstrokes.co.uk

Strokeline: 01908 317618

Disability Rights UK

Website: www.disabilityrightsuk.org

Tel: 020 7250 8181

Email: enquiries@disabilityrightsuk.org

Headway, the brain injury association

Website: www.headway.org.uk

Helpline: 0808 800 2244

Mind

Website: www.mind.org.uk

Infoline: 0300 123 3393

RNIB (Royal National Institute of Blind People)

Website: www.rnib.org.uk

Helpline: 0303 123 9999

Joining a research study



You may be eligible to take part in a research study.

Research helps us improve stroke diagnosis and care. If you are asked to be in a study, you can discuss any questions with the researchers, and you can also talk to your GP.

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.



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Together we can conquer stroke



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.

© Stroke Association 2018
Version 1.1. Published March 2018
To be reviewed: September 2019
Item code: **A01L11**

