

Stroke  
Association

# Supporting a **stroke** survivor

Information for family, friends and carers





## We're here for you

Contact our Stroke Helpline  
on **0303 3033 100**,  
email [helpline@stroke.org.uk](mailto:helpline@stroke.org.uk)  
or visit [stroke.org.uk](http://stroke.org.uk).

# Inside this guide

- This guide gives an overview of useful things to know when a friend or family member has a stroke.
- Follow our tips on finding more information and support.
- For more detailed information read 'Stroke, a carer's guide'. Read it online or order a print copy from [stroke.org.uk/caring](https://stroke.org.uk/caring).
- Our Helpline is here if you need someone to talk to.

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# When stroke happens

Stroke is unlike most other health conditions, because it changes lives in an instant. It usually happens without any warning, and often comes as a huge shock. And the impact of a stroke doesn't stop with one person. It can also reach out to family and friends.

## About stroke

A stroke happens when the blood supply to the brain is cut off, damaging brain cells. A stroke can affect the way the body works. It can also change how you think and feel.



If you'd like to find out more about the types of stroke, treatments and recovery after stroke, visit our comprehensive information resources at [stroke.org.uk](https://stroke.org.uk). You can call our Helpline **0303 3033 100** for more suggestions on finding information and support.

# What is the impact of a stroke?

If you are a family member or friend of someone who's had a stroke, you might be wondering what the future holds.

Some people make a full recovery and go back to their usual activities within a short time. But many others will live with the effects of a stroke for many months or years, and some effects last a lifetime.



Stroke can have hidden effects. These can happen to anyone, and they can remain after someone has recovered from the physical effects. Hidden effects can include low mood, concentration problems and fatigue. Help and treatment is available, and the first point of contact for help is the GP.

The effects of a stroke depend on where it takes place in the brain, and the size of the damaged area. But even a small stroke or a transient ischaemic attack (TIA or mini-stroke) can have a big impact on someone's life.

Every stroke is different, and the effects of a stroke will be unique to each person. Their recovery will also be unique to them. They will recover at their own pace and in their own time.

Because the brain controls everything we do, a stroke can affect every part of the body, as well as thoughts, senses and emotions. It can also cause communication problems and fatigue. Our brain makes us who we are, and a stroke can affect behaviour and make someone seem different to those around them.



Turn to our 'Quick guide to the effects of stroke' on **page 25**.



### Driving

By law, you can't drive for one calendar month after a stroke or transient ischaemic attack (TIA). Whether someone can go back to driving depends on their individual circumstances. Find out more in our guide 'Driving after a stroke' online or order a print copy at [stroke.org.uk/driving](https://stroke.org.uk/driving).





## Recovery from stroke

People can and do make good recoveries from even very serious strokes, but many people are left with a disability. Not everyone can go back to how they were before a stroke, but with the right support and treatment, many people can rebuild their lives.

Recovery begins in hospital with help from doctors and therapists. It continues at home after therapy ends. The person who's had a stroke will practise therapeutic activities to help them relearn skills and regain strength. They can keep the learning process going by staying active, having conversations, and using their new skills in daily life.

The fastest recovery takes place in the weeks and months after a stroke, but recovery can continue at a slower pace for years. There is no set time limit for recovery.

### Reviewing progress

A stroke survivor 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 a six-month review doesn't take place, or the person needs more treatment and support at any time, contact the GP.



# How can I support someone after a stroke?

## Be there for them

You don't have to be living with someone to give help and support. You don't have to be there in person either: just showing someone you are thinking of them can help them feel that they haven't been forgotten. You could send a regular message, or make a phone call to share your news and ask how they are.

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

"...be there with help and reassurance, as the one you care for will have lost all confidence."

Chris, carer

## Offer practical support and time

It's not always obvious when someone needs support, or what kind of help they need. Their needs may change over time, and some people are reluctant to ask for help. They might also prefer to try to do certain things on their own, even if it's difficult for them. Practising tasks can be helpful for recovery in the long term.



**Tip:** if you're not sure what you can do to help someone who's had a stroke, ask them.

You can offer practical help to the stroke survivor or their family and carers. This could include things like shopping, cleaning or childcare.

If you're a close family member or a main carer, you can ask the person and their therapists if you can support with rehabilitation therapies. For example, keeping notes of their progress can help by allowing them to see the improvements they have made.

As time goes on, they might value company for leisure activities, or a regular coffee and conversation.

*"One of the hardest things is to find a balance between being in 'carer mode' 24/7 and accepting my partner's need for their own space and independence."*

**Josh, carer**



# Informal care-giving

Many people might not think of themselves as carers, but simply as family members or friends helping out.

You don't have to live with someone to be their carer, and it's sometimes called being an informal care-giver. You might look after them in different ways. Informal care can mean helping with cleaning or dressing, but it could also mean a daily phone call, delivering shopping or emotional support.

## Get information and advice

Carers often tell us that it's important to have reliable information and support. You can find ideas for ways to get support in this guide, including other organisations that can help. Our website has a wealth of information for stroke survivors and carers, including 'Stroke: a carer's guide.' Our trained Helpline officers can advise you on how to find the support you need.



**Tip:** If you are likely to be the main carer for someone who is leaving hospital after a stroke, ask the stroke team to explain what you are expected to do. Be open about what you can and can't do, and ask what help is available.



### Young carers

Young people and children often get involved in caring in different ways, such as helping adult carers in the household, or supporting the stroke survivor with communication. Find out about support available to young carers on the Carer's Trust website [carers.org](https://www.carers.org).

## The emotional impact of a stroke on family and friends

People can react in very different ways when a loved one has a stroke. You might feel grief, worry, guilt or anger, as well as shock. 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, they might have changed in some ways such as being more emotional, or seeming less motivated to do things.

You might need to find new ways to communicate, and they might need support with daily activities. You might not be able to do things together like you used to. All these things can affect your usual routines, and change people's roles in a family.

### Changes to intimate relationships

A stroke can also affect the intimate relationship between spouses or partners, including changes to your sex life. For more information, and ways to get help with relationships, read our guide on [stroke.org.uk/sex-and-relationships](https://www.stroke.org.uk/sex-and-relationships).

## Looking after yourself

If you spend a lot of time on caring responsibilities, it's important to look after yourself too. It can sometimes be difficult to do things like eating regular meals or getting a good night's sleep. But remember that your wellbeing matters.

There's an emotional side to caring, and it's common for carers to feel stressed, anxious or low at times. This can make it harder for you to cope, so don't be afraid to ask for support. This could include contacting your GP or having some talking therapy.

Many people find it helpful to talk to others who understand their situation, such as carers in a local group or on social media. The Stroke Association's free online tool **mystrokeguide.com** has a forum where you can read other carers' stories, and chat online if you wish to. It can be reassuring to know that you're not alone.



Taking regular breaks and trying to be active or exercise regularly can help with your energy levels and improve your sleep. It's not always easy to find time for a break. Family or friends may be able to help out with some practical tasks, or spend time with the person who's had a stroke while you have a rest.

Back injuries can be a risk if you are helping someone move around. You should have advice from a community nurse or occupational therapist on how to move someone safely.

Contact your local council adult social services department for advice about paid respite care such as day centres.

It's not unusual to feel isolated as a carer, and this can also affect your ability to cope. Try to reach out to family and friends. If you can't meet in person, try to keep in touch in other ways like phone or video calls and social media.



**Tip:** there are carers' hubs or centres in many local areas which can help you meet other carers, and find advice and information.

# If you're a main carer

If you're responsible for managing someone's support and care, it's natural to feel overwhelmed by all the information there is to take in. Help is available, such as advice on funding, and practical help with applying for benefits. Try to get professional advice for yourself and the person you're supporting.

- You can get advice and practical support from specialist organisations including Citizen's Advice, Independent Age and Age UK. See the end of this guide for contact details, or search online.
- You're not alone, and our Stroke Helpline is here if you have any questions or need someone to talk to.

## Getting help with caring

1. You can register as a carer with your GP, which will give you access to some help with your health and wellbeing, and referrals to local support.
2. Request a carer's assessment by contacting your local council adult social services department. They can also assess the needs of the person who's had a stroke.

## Managing someone else's finances and legal affairs

If the person you're caring for can't look after their own affairs, like banking, paying bills or selling a house, they can give you power of attorney. This can allow you to manage their finances, property and healthcare decisions. Learn more about power of attorney online at [stroke.org.uk/caring](https://stroke.org.uk/caring).

## Care and accommodation

Funding for health and social care comes from the local council and the NHS.

Your local council looks at someone's needs and produces a 'care and support needs plan'. The assessment includes a means test, and the amount the council will contribute towards the costs.

People with very significant health needs may qualify for NHS continuing healthcare, which pays for care in your home or a care home. You can be referred by a health professional or social worker.

For more information visit [stroke.org.uk/accommodation](https://stroke.org.uk/accommodation).

## Benefits and financial help

A stroke can have a big financial impact, and many carers lose out on income when they reduce their working hours. There is a range of help available, including grants, benefits, loans, and discounts.

To find out about the main types of financial help for carers and stroke survivors, visit **[stroke.org.uk/financial-support](https://stroke.org.uk/financial-support)**.



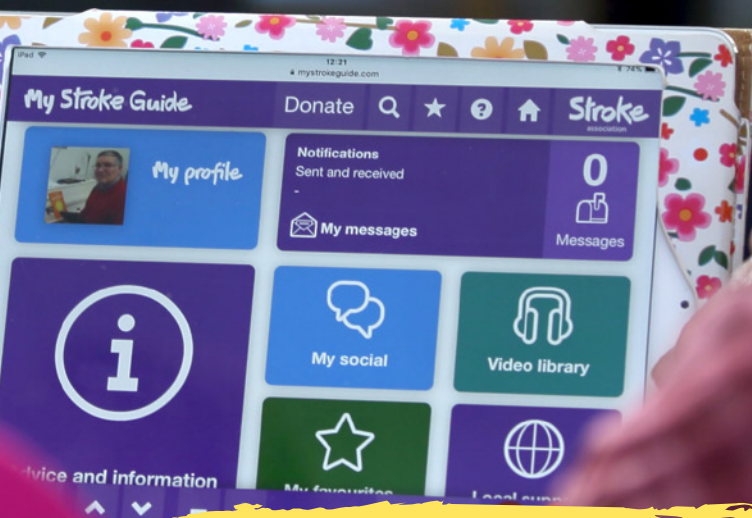
**Tip:** to find out what benefits you could be entitled to, use an online benefits calculator such as **[entitledto.co.uk](https://entitledto.co.uk)**.

## Using technology

Many services including benefits and funding applications are now done online. Appointments and assessments may be done via video calls.

If you can't use an online service or video call for any reason, make sure you let the service know what you need such as a telephone call, letter or in-person appointment.

For accessible tips on using technology visit **[stroke.org.uk/getting-online](https://stroke.org.uk/getting-online)**.



“[Technology] can be a real lifeline, as it allows me to connect with friends and family without having to leave the house.”

Natalie, carer

# Support for health and wellbeing

The chance of having a second stroke can be a big worry for a stroke survivor and their family and friends.

After a stroke, the risk of another stroke is much higher. The risk goes down over time, but someone who's had a stroke can keep their risk as low as possible by following any treatment they are given. They might also need to make some lifestyle changes.

## How you can help

You can support someone to reduce their risk of another stroke by offering encouragement and asking what practical support they would value. The GP or a specialist stroke nurse can help someone understand their individual risk of a stroke, and offer support with reducing their risk.

### Medical treatment

Someone might like help such as collecting prescriptions, or a phone call to remind them about a dose. If they have questions about medications or side effects, their GP or pharmacist can do a medications review.

### Lifestyle changes

After a stroke, many people are advised to make lifestyle changes like being more active, stopping smoking or changing their diet. They might welcome some practical help, and many people find that sharing their goals with someone can help them stay motivated.

You could:

- Listen to and encourage someone trying to quit smoking.
- Support someone to become more active by joining them for a walk.
- If they are trying to lose weight, plan a treat such as a day out when they reach a goal.
- Help someone cut down on alcohol by not drinking when you're together.



For more information about how to stay healthy and reduce the risk of a stroke, read our guide 'How to reduce your risk of a stroke'. We also have detailed online information about health and wellbeing at [stroke.org.uk](https://stroke.org.uk).



**Tip:** many effects of a stroke improve quickly.



# Quick guide to the effects of a stroke

Get more information about all the effects of stroke and how they are treated on our website [stroke.org.uk/effects-of-stroke](https://stroke.org.uk/effects-of-stroke).

Many problems can improve quickly in the days and weeks following a stroke. The hospital stroke team will support the person to become mobile from 24 hours after their stroke, and they should have treatment and support to help them make the best recovery possible.

## Visible effects of a stroke

### Movement and balance

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

### Vision

About 60% of people have vision problems after a stroke. Problems can include double vision, light sensitivity, and losing part of the visual field.

## **Continence problems**

Problems with bowel or bladder control are very common after a stroke. Continence often improves in the early weeks. Continence problems 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 (also known as spatial neglect)**

Spatial inattention, or neglect, means that the brain does not process sensory information from one side. Someone might bump into things because the brain is not processing all the visual information it gets from the eyes.

## **Swallowing problems (dysphagia)**

In around half of all stroke survivors, a stroke affects the muscles in the mouth and throat, causing swallowing problems. This is known as dysphagia. Someone with dysphagia may need to have soft foods or be tube-fed. It often improves in the first few weeks.

## 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, understanding speech, reading, writing, and using numbers. The person does not become less intelligent, they simply find it difficult to use language.

### Slurred speech

A stroke can affect the face and tongue muscles, causing slurred speech.

### Problems with concentration and memory

Cognitive problems can affect communication. For instance, someone might find it hard to concentrate on a conversation, forget information, or not be able to recognise objects or people.



#### **Tip: communicate with confidence**

You can help a person with communication problems by giving them time to answer questions, asking one question at a time, and trying not to answer for them.



**Tip:** for more tips and advice about communication problems visit [stroke.org.uk/communication-problems](https://stroke.org.uk/communication-problems).

# 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. Someone may look well, but still be struggling with fatigue. It is common after a stroke, and can be a serious problem for some.

## Emotional effects

Stroke is closely linked to emotional problems like low mood, depression and anxiety. Some people have emotionalism, and find it hard to control their emotional responses like laughing and crying.

## 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.

## Pain

Stroke can cause different types of long-term pain such as burning sensations or muscle and joint pain.

## Get help

Many of the effects of a stroke can be treated, so if a stroke survivor has any of these problems after being discharged from hospital, they should visit their GP.



**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.

# 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 symptoms of stroke. But there are other signs 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.

### **Transient ischaemic attack (TIA, or mini-stroke)**

A TIA is the same as a stroke, but the symptoms last a short time. Having a TIA is a major warning sign of a stroke, so if someone has any stroke symptoms, always call **999** even if the symptoms pass.

# Where to get help and information

## From the Stroke Association

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](mailto:helpline@stroke.org.uk).

### Read our information

Get more information about stroke online at [stroke.org.uk](http://stroke.org.uk), or call the Helpline to ask for printed copies of our guides.

### My Stroke Guide

The Stroke Association's online tool My Stroke Guide gives you free access to trusted advice, information and support 24/7. My Stroke Guide connects you to our online community, to find out how others manage their recovery.

Log on to [mystrokeguide.com](http://mystrokeguide.com) today.



### 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](https://stroke.org.uk/support) for more information on stroke groups and other face-to-face support.

### 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

If the person you are supporting does not have a review of their needs after the stroke, usually at about six months, ask the GP to arrange this.

### Daily support needs

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

### Legal and money advice

For free, confidential advice about money, legal and employment issues, contact Citizens Advice [citizensadvice.org.uk](https://citizensadvice.org.uk).

# Other sources of help and information

## Help for carers

### Carers UK

Website: [carersuk.org](http://carersuk.org)

Adviceline: 0808 808 7777

### Cruse Bereavement Care

Website: [cruse.org.uk](http://cruse.org.uk)

Tel: 0808 808 1677

## Help with benefits and funding

### Citizens Advice

Website: [citizensadvice.org.uk](http://citizensadvice.org.uk)

Adviceline: England 0800 144 8848,

Wales 0800 702 2020, Scotland 0800 028 1456,

RelayUK 18001 0800 144 8884

### Gov.uk: benefits information and online claims

Website: [gov.uk](http://gov.uk)

### Independent Age

Website: [independentage.org](http://independentage.org)

Helpline: 0800 319 6789

### Turn2Us

Website: [turn2us.org.uk](http://turn2us.org.uk)

Helpline: 0808 802 2000

## 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](mailto: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. 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](https://stroke.org.uk)

## Contact us

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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](mailto:helpline@stroke.org.uk)

Website: [stroke.org.uk](https://stroke.org.uk)

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Rebuilding lives after stroke



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