Next steps after a stroke
Information for people who have had a stroke

stroke.org.uk
About you
After a stroke you need information and support, whether you feel fully recovered or have a disability. This guide provides useful information for anyone who has had a stroke, with advice on where to go for help if you need it.

We're here for you
Contact the Stroke Helpline on 0303 3033 100, email info@stroke.org.uk, or visit stroke.org.uk
Understanding stroke

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 you think and feel.

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.

Ischaemic stroke is often referred to as a clot. Haemorrhagic stroke is often called a bleed.

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 36 to learn how to spot the signs of a stroke and TIA.
The effects of a stroke

Every stroke is different. The effects of a stroke depend on where it takes place in the brain, and how big the damaged area is.

Some effects of a stroke

Movement and balance:
- weakness down one side of the body
- problems with balancing and walking
- difficulty using legs, feet, arms or hands.

Other physical problems:
- swallowing problems
- losing bowel and bladder control
- fatigue: tiredness that does not go away with rest
- muscle and joint pain.

Thinking and communicating:
- problems with memory, concentration and problem-solving
- problems with speaking, understanding, reading and writing
- spatial neglect: not being aware of things to one side.

Sensory problems:
- eyesight problems including double vision, being very sensitive to light, and losing part of the visual field
- numb skin, and pins and needles.

Hidden effects

A stroke can have ‘hidden’ effects, like emotional problems and fatigue. These hidden effects can happen to people who do not have any other health problems or disabilities after a stroke.

Personal story: fatigue

“I phoned the Stroke Helpline in desperation because I did not have any energy. The woman on the Helpline said ‘Well, that’s completely normal.’ It was a huge relief.”

Richard, stroke survivor
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.
Communication difficulties can also be due to weak face muscles causing slurred speech, and problems with memory and concentration.

Emotional effects of a stroke
After a stroke, many people have feelings like shock, anger, guilt and grief. It is common to have emotional problems such as anxiety and depression after a stroke. Although it can be hard to talk about your feelings, it can help to talk to a loved one or a counsellor.

Emotionalism
Some people find it hard to control their emotions after a stroke. This is called emotionalism. It means you could laugh or cry unexpectedly, sometimes for no reason.

Behaviour changes
Some people’s behaviour changes. They may change their habits and start drinking tea instead of coffee, for instance. Some people become very irritable, or say and do things without thinking.

Many effects of a stroke are temporary
They can get better in the first days and weeks after a stroke. Some effects last longer. You may need rehabilitation to help your recovery.

For more information on all of these problems visit stroke.org.uk.

Personal story: emotionalism
“I can laugh about things that aren’t all that funny – a kind of laughter mixed with crying, which is a really strange thing.”
Josh, stroke survivor
Impact on relationships
A stroke affects the people around you. They often feel worry and shock. A stroke can change your relationships, and illness or disability may change people’s roles in a family.

Your friends and family might find it hard to understand what you are going through, so try talking to them about how you feel, if you can.

Many people say that having a stroke has affected their sex life. This can be due to the physical and emotional impact of a stroke. People often find it hard to talk about, but it’s not something you need to be embarrassed about.

Getting help
Don’t be afraid to seek help for emotional, sexual and relationship problems, including behaviour changes. Visit your GP, or call the Stroke Helpline on 0303 3033 100.

Personal story: depression
“I kept thinking, ’Why has this happened to me?’, and got very, very down. Almost straight away, I was put in touch with a counselling service.”

Celia, stroke survivor

For more information visit stroke.org.uk
Recovery and rehabilitation

After a stroke, the body and brain need time to heal. For the first few weeks, some people feel very tired and confused.

Everyone recovers differently. Some people recover fully. Other people will have health problems or a disability.

Speed of recovery

The fastest recovery takes place in the first few months. After that progress can be slower. However, people can continue to improve for months or years.

Personal story: recovery

“I’m still slowly recovering 10 years later.”

Alan, stroke survivor
Next steps after a stroke

Understanding rehabilitation

Rehabilitation means trying to restore function to as near normal as possible and helping you adapt to disability. The focus is to enable you to do your usual activities of daily living, and to help you communicate, move around and be as independent as possible.

You should have rehabilitation soon after a stroke. It may begin in hospital and should carry on at home if you need it.

Types of rehabilitation:

- **Occupational therapy**: helps you re-learn everyday skills like dressing and getting around.
- **Physiotherapy**: helps you move and balance. It strengthens muscles, and improves mobility, balance and coordination.

- **Speech and language therapy**: can help improve your communication and can also help with eating and drinking.
- **Psychological therapies**: helps people with memory and thinking difficulties, and emotional problems like depression and anxiety.
- **Diet support**: a dietician makes sure you are getting the food and drink you need. A dietician can help if you find eating difficult.

How rehabilitation works

During rehabilitation, you work with therapists. The therapist carries out a full assessment, and designs treatment tailored to your needs. Together, you will set your goals for success. You make plans for reaching your goals. Depending on the type of therapy, you may have exercises to practise. You may work towards building up stamina, or learn new ways of doing things.
Rehabilitation tips

Stroke survivors tell us that it can take a lot of effort and determination to keep going with rehabilitation. It can be very hard work, physically and mentally, but many people find it helps them make vital progress with speaking, walking and other key skills. Here, stroke survivors and professionals share their tips on staying positive and motivated:

Recruit some helpers
Practising your exercises can be very hard work, so get help from family members or friends. Having help from other people can really help you practise regularly and succeed.

Stay positive
Some stroke survivors say a positive attitude can help you succeed in rehabilitation.

Keep moving
Try to work movement or exercises into everyday tasks.

Set goals
Setting achievable goals gives a feeling of success when you reach them.

Record your progress
Making a regular note of your activities lets you see how well you are doing. You might not be able to cope with much rehabilitation at first. When you feel stronger, you can do more.
Support after leaving hospital

If you have been in hospital for some time, going home can come as a big relief. But for some people, going home feels daunting.

The discharge process should ensure that you get all the support and information you need. You and your family can also be involved in planning your discharge.

The discharge plan covers:

- rehabilitation
- medical treatment
- care at home
- equipment you may need
- follow-up.

Early supported discharge

You may be able to leave hospital soon after a stroke, as long as you can move from your bed to a chair and have a safe home environment to go to. Rehabilitation continues at home.
Reviewing your needs

Around six months after you leave hospital, you should get a review of your progress. This makes sure you are getting the right support if your needs have changed. The review is sometimes carried out by a Stroke Association Coordinator, or by a specialist nurse or other stroke professional.

If a review does not take place, contact your GP.

People who support you after you leave hospital

• Your GP is the person to ask for help with health problems or support needs.

• You might need support from therapists, such as physiotherapists and occupational therapists.

• You might have a community stroke nurse.

• You may have a social worker.

• Depending on where you live, you may have help from a Stroke Association Coordinator.

Accommodation

If you have a disability after a stroke, you might need to make some changes to your home to help you live independently. This can mean adapting the bathroom or kitchen, with advice from an occupational therapist. Some people need to find a new home with extra support. Your social worker can help you think about your options.

This can include:
• sheltered housing: living independently with some support such as a warden or alert system
• residential care: may provide basic personal care or nursing care.

Financial impact of a stroke

A stroke can have a big financial impact on you and your family.

Time off work
If you work, you may be able to get sick pay while you are recovering. Some insurance policies include cover for serious illness. You may be able to claim a state benefit such as Employment and Support Allowance. Some people feel embarrassed about claiming a state benefit, but they are there to help everyone who needs them.
Disability
If you have a disability, there is some help available such as 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.

Carers
If you have an unpaid carer for more than 35 hours a week, they can claim Carer’s Allowance. If you are aged 65 and over and need someone to help look after you, you can claim Attendance Allowance.

Care and support needs assessment
If you have a disability after a stroke, you can have a care and support needs assessment. This looks at your care needs, and any financial help with costs of care. It is carried out by the local social services.

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.

For more information visit stroke.org.uk
Enjoying life after a stroke

As time goes on, you will discover your personal goals for success. Recovery and rehabilitation can be a long slow process, but many survivors say they find new ways to enjoy life after a stroke.

Staying happy and healthy

Emotional wellbeing
One way to improve your emotional wellbeing is by doing physical exercise. Exercise releases chemicals into your brain that make you feel better.

Keeping in touch with friends and family helps you avoid feeling isolated.

Don’t bottle things up – try talking about your feelings. Creative activities such as music and art can also let you express your feelings.

It is common to have emotional problems after a stroke. If you are having problems such as anxiety or depression, ask your GP for help.

Read more about the emotional impact of stroke on page 9.
Keeping life interesting

Take part in activities you enjoy. Challenge yourself by trying new things and meeting new people.

You can get support from other people who have had a stroke. The Stroke Association has a network of groups, and there are independent stroke clubs around the UK. Going to a group can give you a new purpose and enable you to create new friendships.

For more information on stroke groups see page 42.

Working

If you are back at work after a stroke, or planning to return to work, there are some resources on work and stroke at stroke.org.uk/back-to-work.

Equality law protects people with disabilities at work, and your employer has a duty to help you stay in work if it is possible. You may be eligible for benefits and other support to help you back into work.

Professional’s view: work

“We’ve had people go back to work even with huge problems after the stroke – they are amazing.”

Colin, Stroke Association Coordinator

Driving and getting around

You are not legally able to drive a car or motorcycle for a month after a stroke or TIA (mini-stroke). Before you start driving again, you must tell the DVLA if your driving ability has been affected by the stroke. If you have had some types of brain surgery or seizures you will need to inform the DVLA straight away.

If you are a bus, coach or lorry driver, you must tell the DVLA as soon as you have a stroke or TIA.

For more information visit stroke.org.uk/driving

The Blue Badge scheme helps you get around more easily by letting you park in convenient spots.

Local councils have community transport schemes, and you can get cheaper rail travel if you have a disabled person’s railcard.
Reducing your risk of another stroke

Everyone has a different risk of having a stroke, which depends on their body and their lifestyle.

The main risk factors for stroke are:

1. Age
As you get older, your arteries naturally become harder, making them more likely to become blocked.

2. Health problems
Some health problems make you more likely to have a stroke.
• TIA and stroke: if you have had a TIA (mini-stroke) or a stroke, it means you are at greater risk of having another stroke. But you can take action to reduce your risk – see page 32 for more information.

Other conditions that increase your risk of a stroke are:
• high blood pressure
• atrial fibrillation (irregular heartbeat)
• diabetes
• high cholesterol.
3. Lifestyle
Stroke risk can be increased by things we do in everyday life, including:
• smoking
• being overweight
• drinking too much alcohol
• not getting much exercise
• eating unhealthy food.

4. Family history
Strokes can run in families. So you are more likely to have a stroke if someone in your family has had one.

5. Ethnicity
Strokes happen more often to black people from African or Caribbean families. They are also more common in people from South Asian countries such as India, Pakistan and Bangladesh.

Managing your stroke risk
It’s vital to ask your GP to explain more about your own risk of a stroke, so that you know what steps you can take to reduce your risk.

When you are diagnosed with a stroke or TIA (mini-stroke), doctors will try to find out what caused the stroke. They give treatments to reduce the chance of you having another stroke. For example, if you have high blood pressure, they give you treatment to control it, which in turn reduces your stroke risk.

Overall, 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. That’s why it’s important to follow any treatment you are given for health conditions linked to stroke, such as high blood pressure and atrial fibrillation. It’s also important to keep your treatment going over the long term if you are advised to, so you can keep your risk as low as possible.

We know that around 90% of strokes worldwide are linked to a treatable health condition or a ‘lifestyle’ factor like smoking. If you know that you have any of the risk factors listed here, you can help to lower your risk by following treatments and taking some healthy lifestyle steps.

Coping with uncertainty
Uncertainty is part of a stroke. Many people worry about the future. This worry can lead to anxiety and depression. If you feel overwhelmed by worry, speak to your GP. Or you can call the Stroke Helpline 0303 3033 100.
Steps you can take

Your GP can give you ideas and support with reducing your risk. One of the best ways to reduce your stroke risk is to get treatment for any health conditions linked to stroke.

After an ischaemic stroke or TIA (mini-stroke): antiplatelet drugs reduce the risk of another clot forming by making the blood less sticky.

High blood pressure: there are several different types of medication for high blood pressure. You might hear about diuretics, calcium-channel blockers, ACE inhibitors, and beta blockers. Healthy lifestyle steps include stopping smoking, cutting down alcohol and being more active.

Atrial fibrillation (irregular heartbeat): a range of drugs can be used to restore a normal heart rhythm or control the heart rate. Anticoagulant drugs may be used to reduce the risk of a clot forming. Sometimes a surgical procedure is used to restore a normal rhythm.

Diabetes: treatments can include drugs to control blood sugar and insulin injections. Healthy diet, weight loss and exercise can help to manage blood sugar levels.

High cholesterol: statins are the main type of drug used to reduce blood cholesterol levels. Healthy diet, exercise and stopping smoking can also help to lower cholesterol.

Remember, don’t stop any treatment without speaking to your GP.

Call the Stroke Helpline on 0303 3033 100
**Healthy lifestyle steps**

Staying active and eating well reduces your risk of another stroke. Having a healthy lifestyle can help you to manage conditions like high blood pressure, diabetes and high cholesterol, which in turn reduces your risk of a stroke. Steps like eating healthy food, stopping smoking, drinking less alcohol, and being more active can all help reduce your risk.

**Stopping smoking**

Smoking doubles your risk of dying from a stroke, so it’s well worth getting advice on giving up. As soon as you stop smoking, your stroke risk starts to go down.

**Eating well**

Eat lots of vegetables and fruit, and have home-made food if you can, as it usually has less fat and salt than ready meals and snacks. Cutting down on salt can help with controlling blood pressure, and eating less fat can help with weight loss.

**Personal story: getting active**

“Being active doesn’t mean getting into trainers and puffing away at the gym – it simply means being active. A little movement can go a long way.”

Michael, stroke survivor

**Moving around more**

Move as much as you can. Try walking for half an hour a day, if you can, and try to keep moving at home too. Just walking around the room every 20 minutes can lower your stroke risk.

**Drinking less alcohol**

You can reduce your stroke risk by drinking less alcohol. In the UK, the government advises that to keep health risks from alcohol low, it’s best not to have more than 14 units spread over a week. The limit is the same for men and women.

**Managing your weight**

Staying a healthy weight cuts your risk of a stroke. Losing weight can also help you to control high blood pressure, and to manage your blood sugar if you have diabetes.

**Get started**

For practical tips on making healthy lifestyle changes visit stroke.org.uk or call our Helpline.

For individual help with giving up smoking, weight loss and drinking less alcohol, visit your GP.
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

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

- **Arms**
  - Can the person raise both arms and keep them there?

- **Speech problems**
  - Can the person speak clearly and understand what you say?
  - Is their speech slurred?

- **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.
Diagnosing a stroke and its causes

A stroke is diagnosed with an examination and a brain scan. This shows what kind of stroke it is, and where it is in the brain.

If the stroke is caused by a clot, a scan and other tests are used to find out if it comes from inside the brain, or if it came from the heart.

If the stroke is caused by a bleed, a scan can show if there is a problem with the blood vessels in your brain.

Types of scan:
- computed tomography scan (CT)
- magnetic resonance imaging scan (MRI).

Other tests and checks:
- ECG (electrocardiogram): checks the heartbeat
- Doppler ultrasound: checks for blockages in the neck arteries
- blood pressure is measured.

Your blood is checked for:
- blood clotting
- blood sugar
- cholesterol levels.

Emergency stroke treatments

Stroke treatments try to restore the blood supply to the brain. This can stop more damage to the brain, and can sometimes mean that symptoms improve.

If you have a clot in your brain, doctors sometimes try to remove it using clot-busting drugs (thrombolysis). 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.

If you have a bleed in your brain, doctors might use surgery to stop the bleeding or reduce pressure.

Treatments to stop another stroke

In hospital, doctors also try to stop another stroke happening. They sometimes use surgery to remove a blockage in the neck arteries (carotid arteries).

They use drugs to lower blood pressure and reduce blood cholesterol. They also use drugs to stop the blood forming clots. These include antiplatelet drugs, which make your blood less sticky. Anticoagulants also reduce the risk of a clot.

For more details on treatments and ways of reducing your risk of a stroke, see page 32.
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.
Our main guides about stroke
When you have a stroke – a short guide for someone who has had a stroke.

Next steps after a stroke – information for people who have had a stroke.

Supporting a stroke survivor – information for family, friends and carers.

How to reduce your risk of a stroke – tips and information on reducing your risk of a stroke.

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 online forum TalkStroke stroke.org.uk/talkstroke and on our Facebook page www.facebook.com/TheStrokeAssociation.

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

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 36 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
You should have a review of your 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 45).
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.co.uk**
Website: www.drinkaware.co.uk
Drinkline: 0300 123 1110

**Sickle Cell Society**
Website: www.sicklecellsociety.org
Tel: 020 8961 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
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.

The quotes used in this guide have been anonymised.

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.

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.
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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