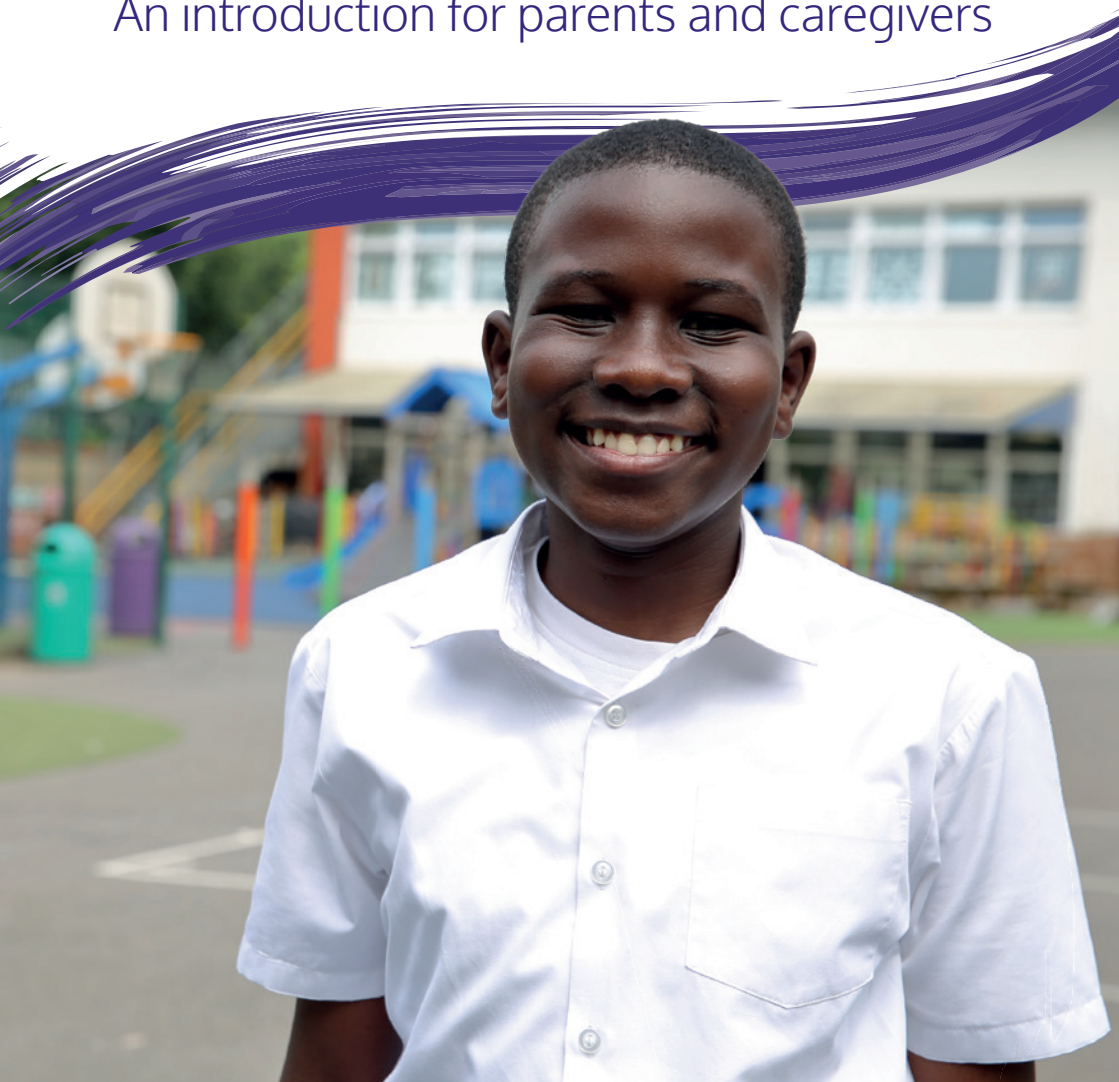


My child has had a **stroke**

An introduction for parents and caregivers



We're here to support you

Our dedicated Childhood Stroke Support Team is here to support you, whenever you need us.

Call us on **0303 3033 100** or email **childhoodstroke@stroke.org.uk**

'We found out about the Stroke Association's Support Team who were a huge help at a time when we were desperately in need of guidance and support.'

Jess, mother of five-year-old girl



Dear parent or caregiver,

If you're reading this guide, you may be going through one of the hardest times of your life. Seeing your baby, child or teenager fall ill is difficult enough. Learning they have had a stroke is a further shock.

We are here to support you.

A diagnosis of stroke in a child is especially hard to understand and accept because many people believe that stroke only affects older people.

Parents who have been through this experience told us what they wished they had known when their child had a stroke. The result is this simple guide. It provides information about childhood stroke, with details of where to go to find out more when you're ready.

We understand the impacts of stroke are different for every child and family, and that they change as a child gets older. That's why our dedicated Childhood Stroke Support Team is here – to support you with guidance, emotional support, and practical information, whenever you need us.

Call us on **0303 3033 100** or email
childhoodstroke@stroke.org.uk

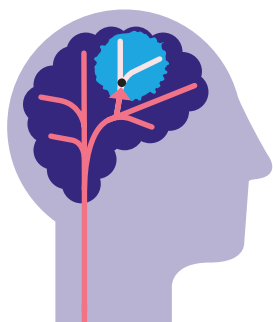
As you read this, it may feel like your world has been turned upside down. Please remember you are not alone. We're here to support you and your family.

Childhood Stroke Support Team

What is a **stroke** and how does it **happen**?

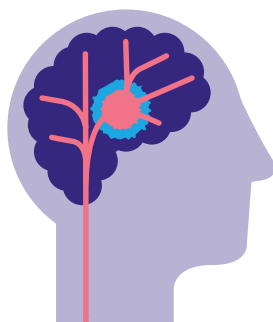
A stroke happens when part of the brain has its blood supply disrupted. Stroke can happen in a baby, child or teenager of any age. Your child's doctors will try and find out if an underlying condition, like a heart or blood disorder, played a part. Sometimes, it's not possible to find out what caused it.

The two main types of stroke



Ischaemic:

due to a blocked blood vessel in the brain (often called a 'clot').

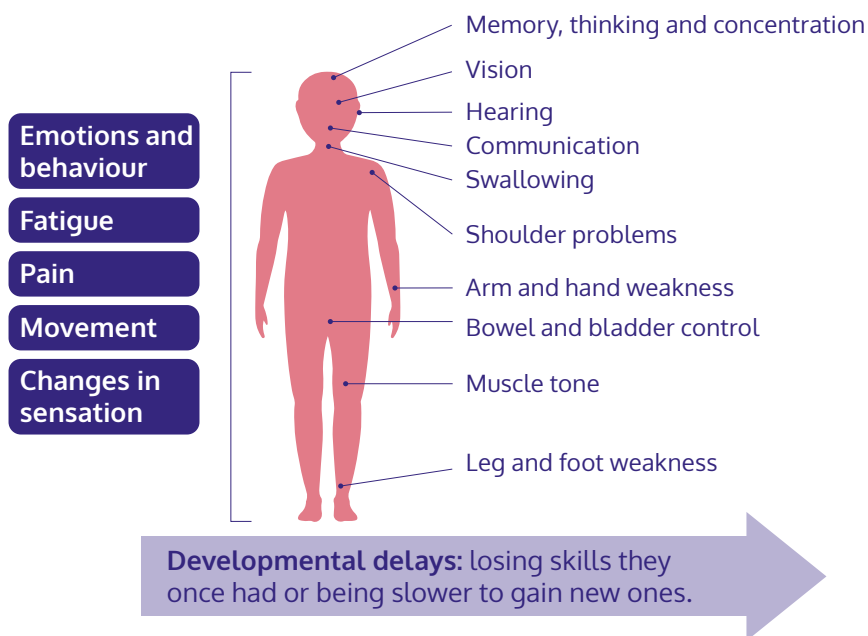


Haemorrhagic:

due to bleeding in or around the brain (often called a 'bleed').

The image below shows some of the problems that stroke can cause. Some of these will be temporary, while others may last longer. Every stroke is different. Your child's stroke and recovery are unique to them. Not every child will make a full recovery. But with the right support, they can make progress, build confidence and lead a happy life.

Possible effects of stroke on a child or young person



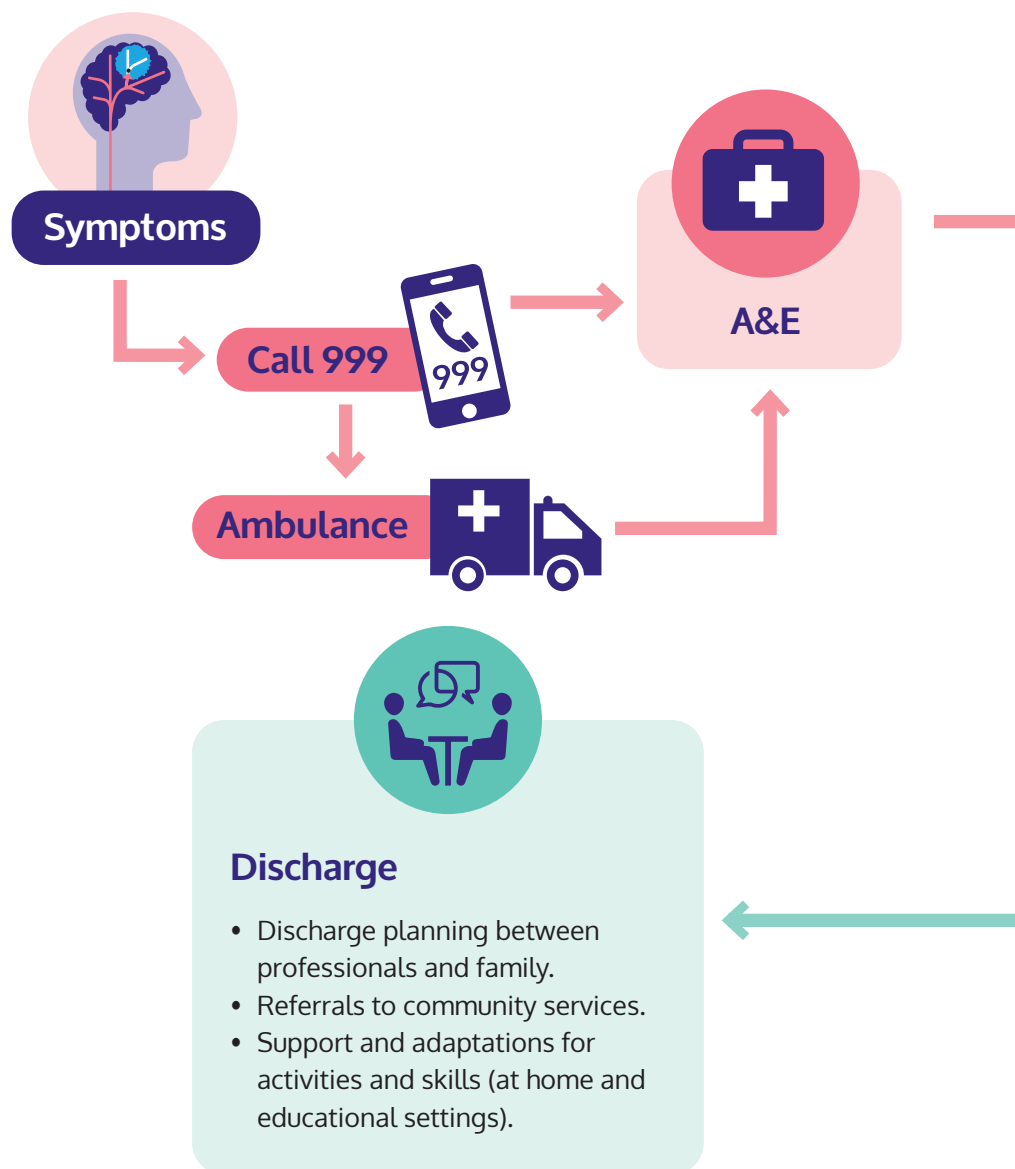
Visit stroke.org.uk/childhood for more information.

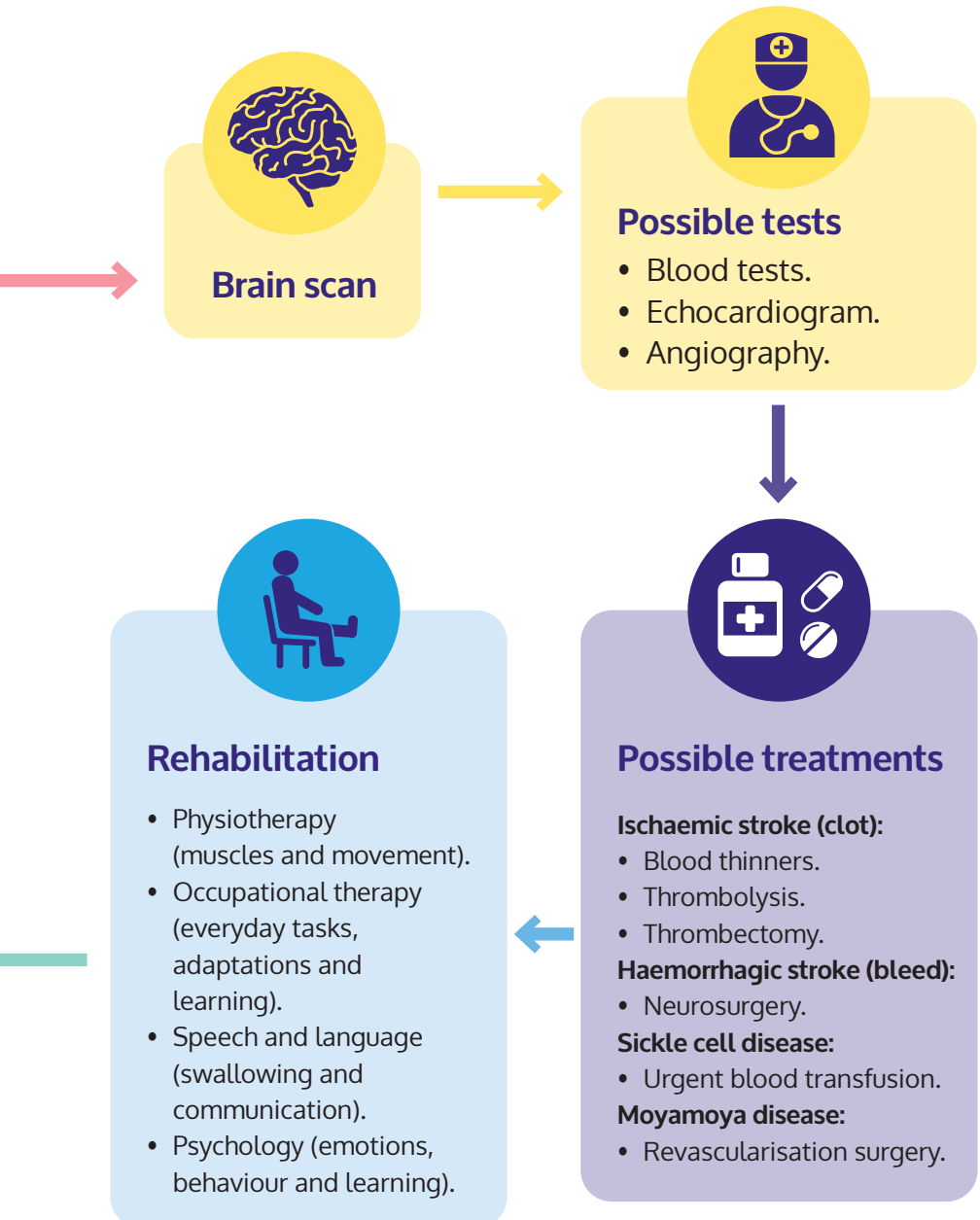
Your child's brain is amazing!

Straight after their stroke, your child's brain may start to rewire itself so they can recover skills. This process is called neuroplasticity. It begins after a stroke and can continue for years.

A child's stroke journey

Healthcare support your child may receive after a stroke





Coping with hospital life

In the early days and weeks after your child's stroke, you may spend a great deal of time at hospital. Your child may have moved to a different hospital which provides specialist care. Parents describe this as a surreal time where normal life is completely put on hold.

As well as the initial shock of the stroke and fears about your child's health and future, you may be worried about your other responsibilities. You may be missing other family members or concerned about how this period will affect your work or income. Here are some things you can try that might help.

Talk to the healthcare team

You know your child better than anyone, so don't be afraid to ask questions or speak up. Talk through your worries and play an active role in making decisions.

Understanding what is happening may also help you feel more in control. This can be helpful in a situation where so much is out of your hands.



Tip: Note down any questions you have about your child's treatment or medical terms you don't understand.

Find ways to help things feel normal

Where possible, continue familiar activities and routines with your child. This could include reading a bedtime story, playing games or watching TV together.

Look after yourself

Even if you don't feel like it, try to eat healthily and get some sleep, so you can be there for your child. Ask friends to bring in whatever you need to feel comfortable or to stay with your child for a while, so you can get outside for some fresh air.

Talk to the discharge team

Before you leave, find out what ongoing healthcare your child will receive and what will be available in the community. This might include medication, therapy, care and other support. If you're worried about how you'll cope, talk to the team.

Reach out to others

Call our Childhood Stroke Support Team on **0303 3033 100**. You can talk to us about any questions or worries you may have, however big or small. You might also find it helpful to speak to one of our trained parent volunteers.



Visit the parent-run '**My child had a stroke**' Facebook group to connect with other parents.

Practical tips



Others you care for: Think about who will look after anyone else who relies on you (including your pets) during this time.



Other commitments: Check your calendar. Are there any plans coming up you need to change?



Money: Find out about benefits and employment rights at Citizens Advice.



Education: Tell your child's nursery, school or college what has happened, in case they need to plan for support or a phased return.

Visit stroke.org.uk/childhood for more information.

'My memory of that time is a bit of a blur.
They did lots of assessments and tests and
she just slept a lot.'

Kim, mother of 17-year-old girl

Going home

The healthcare team will discuss with you when your child is ready to be discharged from hospital.

Going home is a huge milestone. But it's not the end of the story. The next phase may bring a host of new challenges as you start to support your child with everyday life.



'As a family, we've had to make some big changes. It hasn't just been one thing - it's been everything.'

Jess, mother of five-year-old girl

Adjusting to life afterwards

Flex routines

From work patterns to dinner time, life may look very different – at least for now. Try to be kind to yourself and take each day as it comes.

Family dynamics

Everyone in the family will need get used to any changes. If you have other children, try to spend some one-to-one time with them every day. Even 15 minutes a day can make a difference.

Coordinating care

You may need to allocate lots of time to coordinating appointments, delivering therapy and managing prescriptions. Setting up a folder will help you keep on top of the admin.

Lower expectations

When your child becomes more active again, start small and be flexible. If you tried going somewhere new and left early because your child was tired, see the experiment as a success.

Symptoms to look out for

It's natural to worry that your child may have another stroke. Strokes in children are rare, but it's important to know the warning signs of another stroke. For more information, go to stroke.org.uk/childhood and always call **999** if your child has any stroke symptoms.

What to **tell** people

Most people don't realise children and young people can have a stroke. Many effects may be invisible or hard to notice. So, it may be hard for some people to understand how things have changed for you all.

Some parents have experienced people thinking they are being overly anxious or precious about their child's needs. You can always talk through any concerns with our Childhood Stroke Support Team.

Talking to your child

What you say will depend on how much your child can understand. Try to pick a time when you're feeling calm. Keep your explanation simple and honest. Balance difficult news with positives. For example, remind them how much everyone loves them. Explain to older children that neuroplasticity is already building new connections in their brain (see **page 5**).

Talking to other family members

If you have other children, they will need help to understand changes at home, as well as changes in their brother or sister. Other people in your family may process information differently to you. They may find it easier to talk about it than you do, or may focus on solutions rather than feelings. Explore what works between you.

'When I explained to family and friends that our son had a stroke, they kept asking why. And that's really hard, because we don't know.'

Anna, mother of seven-year-old boy

Talking to wider family and friends

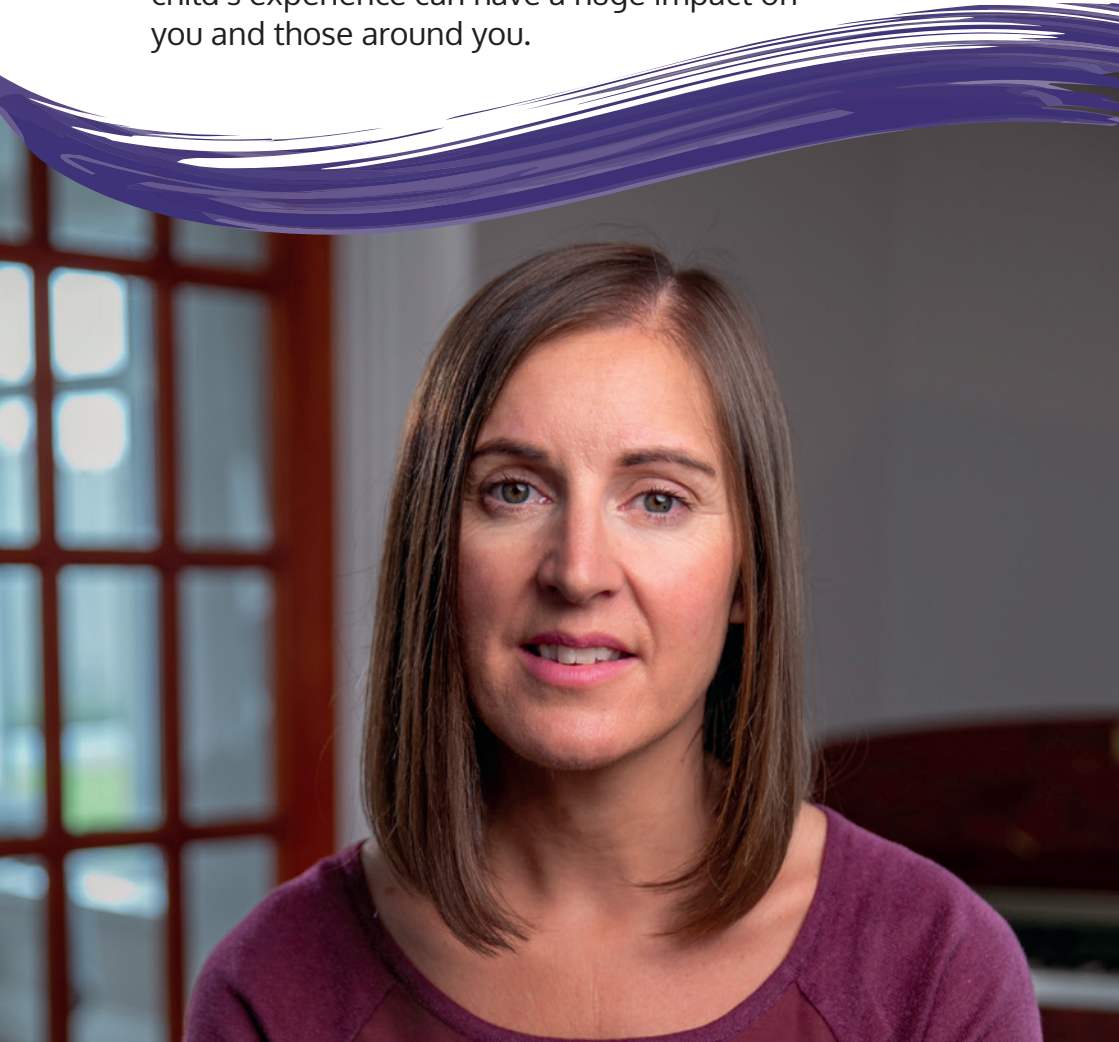
Some parents gather strength from regular contact with their social network. If you find this draining, update people through a WhatsApp group or do a weekly email or social media post. Alternatively, nominate someone you trust to be your main point of contact with other friends.



Tip: It's not usually clear exactly what a child's recovery will look like. So, when someone asks about your child's prognosis, this may be very painful. Explain clearly that you don't know exactly what will happen and that you're taking each day as it comes.

Looking **after** **yourself**

However mild or severe the effects of your child's stroke are, and whatever recovery looks like for them, your child's experience can have a huge impact on you and those around you.



Feelings parents said they had soon after their child's stroke

In denial
Traumatised Misunderstood
Uncertain Overwhelmed Numb
Grief Isolated Angry Frightened
Frustrated Despair

Some of the challenges you may face

Coping with uncertainty

For many parents, living with so many unknowns is the hardest aspect of stroke.

Coping with multiple changes

Your lifestyle, routine, job and role as a parent may all change overnight. This is a major shift, with no warning, and it may take time to adjust.

Finding a balance

The intensity of care can become overwhelming. Do as much as you can, while making sure your own and others' basic needs are met too.

Managing services

Navigating healthcare appointments, as well as the benefits, education and disability systems, can be stressful. You may find you have to speak up for your child and their needs.

What can help


- Connect with others who have been through similar experiences – through social media, groups or reading people's stories that offer hope.
- Think about how those around you could help – and let them know.
- Embed regular routines that help you feel calm, such as breathing exercises, meditation, essential oils, time out for a cup of tea or spending time in nature.
- Think about how to keep doing some things that you enjoy. These could include hobbies, creative activities, exercising, watching your favourite TV show or spending time with loved ones.
- Focus on your child's progress, however small. Writing down three positive things every day can change how you feel about a situation.
- Talk things through at support groups or with a counsellor.
- Remember, the Stroke Association is here for you too. Call the Childhood Stroke Support Team on **0303 3033 100** or find us online at **stroke.org.uk/childhood**

'Other parents' stories can provide hope in a way that doctors, professionally, can't.'

Elise, mother of three-year-old boy

Know when to ask for help

If you find you're often feeling low, overwhelmed or anxious, talk to your GP. Even if your main focus is your child, getting the support you need for yourself is crucial.

A photograph of a woman with long blonde hair and a young girl with long blonde hair, both smiling and looking at each other. The woman is on the left, and the girl is on the right. They are in a casual indoor setting. A thick, wavy purple brushstroke graphic is positioned above the photo.

'Expect good and bad days. One day, they could be tired and the backlash can be horrendous. Then tomorrow will be fantastic and you can sit in the sun together and have a cup of tea.'

Kim, mother of 17-year-old girl

Where to get **support** and **information**

From the Stroke Association

Our **Childhood Stroke Support Team** can support you with practical information on a range of topics, answer questions or concerns, and provide emotional support or a listening ear – whenever you need us. Fill out a short form at **stroke.org.uk/childhood** and we'll get in touch. Alternatively, you can call **0303 3033 100** or email **childhoodstroke@stroke.org.uk**

You might find it helpful to speak to one of our **trained parent volunteers** who understands what you are going through.

You could also attend '**Learn and Chat**' sessions where you can hear from a healthcare professional who specialises in stroke in childhood. You can ask questions, chat with other parents and share experiences.



Our dedicated team can provide an **online information session** for **teachers and school staff**, to support them to understand more about childhood stroke, its impacts and offer practical tips for the classroom.

Visit **stroke.org.uk/childhood** to find out more. Our website also has more information about the causes and effects of stroke, as well as rehabilitation, recovery and returning to education.

Other sources of help and information

Bliss

Website: bliss.org.uk

Tel: 020 7378 1122

Emotional and practical support for families with babies born premature or sick.

Cerebra

Website: cerebra.org.uk

Tel: 0800 328 1159

Support and information for children with brain conditions and their families.

Child Brain Injury Trust

Website: childbraininjurytrust.org.uk

Tel: 0303 303 2248

Information, training, grants and counselling for anyone affected by childhood acquired brain injury.

Contact

Website: contact.org.uk

Tel: 0808 808 3555

Information, advice and support for children with additional needs.

Different Strokes

Website: differentstrokes.co.uk

Tel: 0345 130 7172

Information and support for teenagers and young adults affected by stroke, including befriending and groups.

IPSEA

Website: ipsea.org.uk

Tel: **0300 222 5899**

Free legal advice on education for children with special educational needs and disabilities in England.

Sickle Cell and Young Stroke Survivors

Website: scyss.org

Tel: **0800 084 2809**

Support and activities for children, young people and families affected by sickle cell disorders.

The Brain Charity

Website: thebraincharity.org.uk

Tel: **0151 298 2999**

Support and social activities for anyone with a neurological condition, their families and carers.

UK guideline for treatment of childhood stroke

Find the 'Stroke in childhood' guideline, videos and more at rcpch.ac.uk/resources/stroke-in-childhood-clinical-guideline

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**



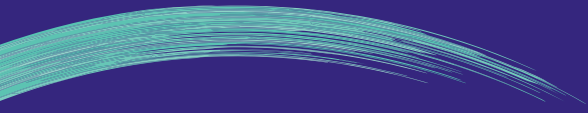
Accessible formats

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

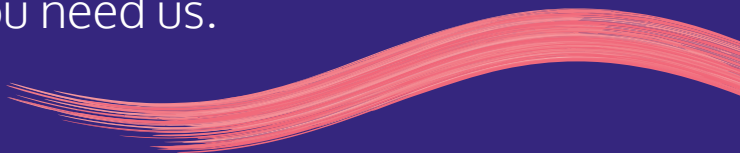


Always get individual advice

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 Stroke Support 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.



Remember, you are not alone.
We are here to support you
throughout your recovery,
whenever you need us.



Contact us

Stroke Support Helpline: **0303 3033 100**

From a textphone: **18001 0303 3033 100**

Email: **helpline@stroke.org.uk**

Website: **stroke.org.uk**



Finding **strength** through **support**

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