Childhood stroke

Stroke Helpline: **0303 3033 100**
or email: **helpline@stroke.org.uk**

The causes of stroke in children are very different from those in adults. This guide explains the causes, treatment and impact of stroke on children and families, and lists sources of help and support.

What is a stroke?

A stroke 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. Ischaemic strokes are due to a blocked blood vessel in the brain. Haemorrhagic strokes are due to bleeding in or around the brain. In adults, 85% of strokes are caused by a blockage and 15% by a bleed in the brain. But in children, both types of stroke are equally common.

Children can also have transient ischaemic attacks (TIA or mini-stroke). A TIA is the same as a stroke, except that the symptoms last for a short amount of time. A TIA is a major warning sign for stroke, and should always be taken seriously. To find out more, turn to 'Diagnosing stroke in children' later in this guide.

Why has my child had a stroke?

Stroke can affect people of any age, including babies in the womb. But strokes happen for different reasons in in children and adults.

Strokes due to a clot (ischaemic stroke)

A main cause of ischaemic stroke in adults is the arteries becoming stiff and narrowed, and fatty deposits collecting inside the blood vessels. This is a process that tends to happen as we get older, and does not affect babies and children. For children, stroke due to a clot can happen for a number of other reasons.

Causes in babies

Stroke in unborn babies and newborns up to 28 days old (known as pre- and perinatal stroke) may be caused by clots travelling from the placenta to the child's brain. It can also be due to a blood clotting disorder that the mother or baby may have.

Causes in children

Strokes in children from 28 days to 18 years are often associated with existing conditions mostly commonly, congenital heart disease and sickle cell disease.

Other risk factors are infectious diseases, trauma to the head or neck, vascular problems and blood disorders. Strokes can also affect previously healthy children and in some cases, there can be no apparent cause.

Risk factors for ischaemic stroke in babies and children

There are several different conditions which can make children more likely to have an ischaemic stroke. These fall mainly into four categories:

1. Heart disorders.
2. Blood disorders.
3. Infections.
4. Vascular disorders.

1. Heart disorders

Heart disorders increase the risk of ischaemic strokes in children. Some children are born with a heart problem, known as congenital heart disease, and heart problems that develop in childhood are known as acquired heart disease. Sometimes a heart disorder is only diagnosed after a stroke.

Heart surgery and stroke

If a child has surgery for a heart condition, this can raise the risk of a stroke. But the outcome of any serious operation depends on the individual child and their unique health needs. If your child needs heart surgery, the doctor should explain the likely risks and benefits of the operation. If your child had a stroke after heart surgery, your medical team can help you understand why this happened. They can also support you and your child with recovery.

2. Blood disorders

Sickle cell disease (SCD)

Sickle cell disease is an inherited condition affecting red blood cells. These are the blood cells that carry oxygen around your body. In sickle cell disease, some red blood cells change shape from round to a narrow sickle (half moon) shape. The damaged cells are less able to carry oxygen around the body. They can also block blood vessels and cause clots in the brain. SCD can also lead to a bleed in the brain, but this is rare in children under 18.

SCD is most common among Black Caribbean, Black African and Black British people. It affects males and females alike.

Blood clotting disorders

Some types of rare blood clotting disorders make it more likely for clots to form, raising the risk of a stroke. Sometimes known as ‘sticky blood’ disorders, they may be diagnosed after a stroke.

3. Infections

Chickenpox is linked to an increased risk of childhood stroke for around six months after the infection. Although chickenpox is a very common childhood illness in the UK, stroke is an extremely rare complication. Other serious infections affecting the brain and other organs may cause a stroke, such as bacterial meningitis, encephalitis, sepsis and brain abscess.

4. Vascular disorders

Vascular disorders are problems with blood vessels in the body which can affect the blood flow. In children vascular problems can be caused by an injury, as well as malformations or inflammation. The type of vascular problems leading to stroke in adults tend to be changes due to age, and fatty deposits accumulating in the arteries, which do not affect children in the same way.

Arterial dissection
A cervical arterial dissection happens when a tear develops in the lining of one of the large arteries in the neck. The tear lets blood in between the layers of the blood vessel wall. Blood or a clot can leak into the brain, causing a stroke. It is one of the leading causes of stroke in children and young adults.

It can happen after an injury, or an activity like sport. It can also be related to an infection or a health condition such as Ehlers-Danlos and Marfan syndrome. A spontaneous dissection means there is no apparent cause.

An arterial dissection does not always have symptoms. However it can cause headaches, pain in the face and neck, and stroke-like symptoms such as a drooping eyelid and speech problems. It's important to get medical help if you suspect a dissection or a stroke.

Moyamoya syndrome
In Moyamoya syndrome, the main arteries in the brain become narrowed. To compensate for the reduced blood flow in the main vessels, a network of small blood vessels grows inside the brain. Moyamoya means 'puff of smoke' in Japanese, referring to the appearance of the abnormal blood vessels in the brain scan image.

It does not always have symptoms, but it can cause headaches and muscle weakness, as well as learning difficulties. It can lead to strokes and TIA in some children. Moyamoya syndrome has been found in children with sickle cell disease, Down syndrome and neurofibromatosis. It sometimes occurs in otherwise healthy children, when it is known as Moyamoya disease.

Moyamoya is very rare, with an estimated one person per million in the UK affected. It is more common among people from Japan and some other East Asian countries.

Vasculitis
A rare condition in which the blood vessels inside the brain become inflamed, known as central nervous system vasculitis, can lead to a stroke or TIA in children.

Cerebral venous thrombosis
Large veins drain the blood away from the brain through spaces under the brain known as the venous sinuses. If a clot (thrombosis) develops in this space it can cause stroke symptoms such as headaches, seizures and blurred vision.

It is sometimes known as a cerebral sinovenous thrombosis (CVST) or a cavernous venous thrombosis. It can be due to conditions including blood-clotting disorders, infections and heart disease.

Strokes due to a bleed (haemorrhagic stroke)

Up to 50% of strokes in children are haemorrhagic. They can be due to problems with the blood vessels in the brain and other conditions.

Arteriovenous malformation (AVM)
In an AVM, the blood vessels carrying blood to and from the brain grow together in a cluster, often in the brain or spine. An AVM can reduce the blood flow in the brain, and compress the surrounding brain tissue. The blood flow can be diverted from arteries into veins, damaging the veins and sometimes causing bleeding.

Aneurysm
An aneurysm is a weakness in an artery wall which can sometimes burst, causing bleeding in the brain. In children, this can happen for several reasons including head injury, connective tissue disorders, and heart conditions. Sometimes it may not be possible to find a cause.

Cavernous malformation or cavernoma

A cavernous malformation is a small cluster of abnormal blood vessels in the brain often said to look like a raspberry. It is made up of a series of connected ‘bubbles’, or caverns, filled with blood. Often these don’t cause any symptoms unless the structure is pressing on the surrounding brain tissues. But if the walls of the caverns are weak, blood can leak out or a large bleed can happen. Symptoms of a cavernoma or a bleed can include seizures, headaches and slurred speech.

Other disorders

Some of the disorders that have already been mentioned including moyamoya syndrome, some types of vasculitis, SCD and clotting disorders are also known risk factors for haemorrhagic stroke in children.

Diagnosing stroke in children

The FAST test can be used to identify strokes in children. However, children and young people may also have other symptoms including:

- Sudden, severe headache.
- Seizures (fits).
- New and sudden vertigo or dizziness.
- Neck pain or stiffness.
- Nausea/vomiting, fever or loss of consciousness.
- Sudden blurred vision or loss of sight in both eyes.
- Weakness or numbness on one side of the body.
- Changes in sensation, like pins and needles in arms or legs.

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
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.

In babies up to 28 days old, seizures are a common symptom of stroke. It may also be the case that a stroke in a baby is only identified later, when problems arise with their learning and development. They may have difficulties with movement on one side, known as hemiplegia.

It is important to remember that stroke symptoms that last a short amount of time can be a transient ischaemic attack (TIA or mini-stroke). A TIA is major warning sign of a stroke, and you should call 999.

Brain scans

A brain scan should take place within an hour. The type of scan used might be a magnetic resonance imaging (MRI) or computed tomography (CT). The scans show the affected area of the brain and the blood vessels in the brain. Your child may need a sedative to help them keep still.

If your child becomes very sleepy and the doctors are concerned about their levels of consciousness, they will have an urgent brain scan even if they have already had one scan.

Other checks

An echocardiogram uses ultrasound to look at the heart and surrounding blood vessels. Children with sickle cell disease have a transcranial Doppler test, which uses ultrasound to check the rate of blood flow through the arteries.

Angiography uses X-rays to look for problems with blood vessels in an area such as the brain or heart.

Looking for the cause

Your child's medical history may also provide clues as to the cause of the stroke, such as having sickle cell disease or congenital heart disease. Blood tests are used to check for any infections or blood clotting disorders.

What treatment will my child have?

If the stroke is due to a clot (ischaemic stroke), your child may be given blood-thinning medication such as aspirin to prevent another stroke.

A small proportion of children may be eligible for treatments to remove a clot.

Thrombolysis is a clot-busting treatment which uses a drug to break up the clot. Thrombectomy is a treatment which physically removes a clot using a retrieval device. Both treatments need to happen within hours of the stroke, and the child needs to meet strict criteria about their stroke and other health conditions.

In some cases, doctors will undertake neurosurgery to help ease pressure building up in the brain.

Treatment for sickle cell disease (SCD)

Children with sickle cell disease are not usually given blood thinning medication. They will be given an urgent blood transfusion, and they should be seen by a paediatric haematologist. After the stroke, your child should be monitored to check for any signs of cognitive problems and changes to the blood flow in the brain.

To treat the sickle cell anaemia and reduce the chance of another stroke, your child may need regular blood transfusions. Stem cell transplants can sometimes be used to treat sickle cell disease, but this does not happen very often due to the risks involved in the transplant.

Moyamoya syndrome

If a stroke was due to moyamoya syndrome, revascularisation surgery can help improve blood flow to the brain.

How will the stroke affect my child?

The effects of stroke are different for every child. The impact of the stroke depends on the part of the brain affected and the size of the damaged area. Children can have mobility problems or difficulty using hands and arms. Visual problems are common after a stroke.

Some issues can particularly affect education, such as communication problems and difficulties with memory and thinking. Damage to the language areas of the brain can affect reading, writing and using numbers as well as speaking and understanding. Concentration problems and fatigue can also affect learning.

Communication can be affected in different ways after stroke. Aphasia happens when the language centres of the brain are damaged. It can affect the ability to speak, understand speech, read, , write and use numbers. Dysarthria means having weakness of the facial muscles which can make it hard to speak.

With help, children can often make good progress with their speech and communication. See our guide 'Communication problems after stroke' for more information.

The emotional impact of a stroke can lead to anxiety or depression. Some people have difficulty controlling their emotions (emotionalism). Behaviour changes and emotional problems can have an impact at school and at home.

The effects of a stroke in a baby or very young child may emerge over time. A stroke can affect developmental stages like learning to walk and talk, and sometimes a stroke is only diagnosed when a child shows a developmental delay.

Usually the fastest recovery happens in the early weeks and months following a stroke, but can continue for months or years after a stroke. It takes time and hard work, and rehabilitation therapies are crucial. Some children will be able to leave hospital quickly but others will need to stay in for some time.

When your child is leaving hospital, you should have help from the hospital paediatric team. A portage service can help babies and young children.

Sadly, as with adult stroke, not every child survives. If you have lost a child through stroke, there are specialist support services that can support you and help you come to terms with your loss.

You can call our Helpline **0303 3033 100** to ask for advice on finding help after the death of a child, or just for someone to talk to.

Rehabilitation and recovery

Once your child is well enough, rehabilitation should begin. The recovery and progress each child makes is unique to them, and they should have support to enable them to make the best recovery possible. Rehabilitation also helps children to learn and develop in the years after a stroke. Rehabilitation may take place in hospital, community, home and school settings.

The Stroke Association has downloadable resources for families when working with different types of therapy services at **stroke.org.uk/childhood**.

Physiotherapy

A physiotherapist can help with movement problems such as weakness and balance problems. The therapist will assess and design a programme to improve muscle strength and movement.

They might use equipment to help your child move more easily, like an ankle foot orthosis (a brace to support the ankle) and hand splints.

Encourage your child to use their affected limbs as much as possible to help recover movement. Repeating therapeutic exercises and activities can make a big difference.

Spasticity affects some children after a stroke. This means that the muscles, often in the arm or lower leg, go into spasm. This can be painful, and may cause problems with walking and using the hand and arm. Physiotherapy and medication such as baclofen can help.

Children can also have botulinum toxin type A injections prescribed by a paediatric consultant. See our guide 'Physical effects of stroke' for more information.

Occupational therapy

Occupational therapists look at ways to help make everyday tasks such as tying shoelaces, getting dressed, washing and eating. The therapist might suggest aids and adaptations to make some tasks easier.

A therapist can also give support with adapting school activities to support learning. They can help the child develop strategies to improve concentration and processing information.

Speech and language therapy

A speech and language therapist (SLT) can help by assessing your child, and designing a programme to improve strengths and weaknesses in communication. If your child has severe speech problems other modes of communication such as signing can be used. There are communication devices to assist with speech, which an SLT can advise you about.

Speech and language therapists also support children with eating and drinking if they have swallowing difficulties. They can advise on ways to eat and drink safely and exercises to improve swallowing.

Emotional problems

Stroke can also affect a child's behaviour and emotions. Being aware of the emotional impact of stroke will help you identify any problems. It may take several years for your child to adjust to the effects of their stroke, and adolescence in particular can be a difficult time.

A psychologist can help assess and treat emotional problems, especially if a child's behaviour is affecting home and school life. Talking therapies may help your child understand why they feel the way they do.

Stroke can lead to behavioural changes such as being more irritable or impulsive. These changes in behaviour can also occur some time after the stroke.

As your child develops they may become more aware of the differences between them and other children. They might feel worried about having another stroke. Problems with learning and participating in school may highlight problems that they have, which can be difficult to accept. Coping with the physical changes or a disability after stroke can also be challenging.

Cognitive skills

Your child may have difficulty with learning and concentrating, spatial awareness and memory (called cognitive skills). A psychologist can assess your child's cognitive ability and make recommendations for supporting them at home and at school. As your child develops, their abilities will change. Follow-up assessments will help identify future problems.

Returning to school

This may feel like a scary prospect but see it as an achievement; it is a milestone in your child's recovery. It is also an opportunity for your child to see their friends and participate in class.

Our guide 'Supporting children after a stroke: Toolkit for teachers and childcare professionals' covers learning and development, communication and emotional changes. Download it from **stroke.org.uk**.

To make your child's return to school as smooth as possible, contact your child's headteacher or the Special Educational Needs Coordinator (SENCO) well in advance of the return to school. Let the school know about the stroke and how your child has been affected.

Ask for a meeting with all the professionals involved to discuss in more detail the support your child will need in the classroom and at break times. If your child is in secondary school, make sure that all of their teachers are made aware of the situation.

Schools must offer staged support for children with special educational needs and disabilities (SEND) (additional support needs (ASN) in Scotland) and if those needs are particularly complex you have the right to request a formal assessment from your local education authority or education board.

For more advice on this process, see the 'Where to find help and information section later in this guide.

It might be helpful for the school to speak to other pupils about any physical effects of your child's stroke, if your child agrees. It may be helpful if the other children know what changes to expect and how to support their classmate. The classroom can be a noisy place and it can be tiring to return to school and learning, so a gradual return may be advisable.

It might be a good idea for your child to sit in a quieter position in the class so it is easier for them to concentrate. Any therapy your child is still receiving should be planned in as part of their school day.

Research shows that children with SEND/ASN or disabilities are more likely to experience bullying. Some of the organisations listed at the end of this factsheet can advise and support you on how to work with the school to tackle bullying and support positive relationships within peer groups.

The impact of childhood stroke on the family
Childhood stroke can have an effect on the whole family. Parents often feel a range of emotions from shock and bewilderment to feelings of isolation and frustration. Childhood stroke can affect a parent's emotions and health, so it is important to look after yourself.

Other children in the family can be affected in different ways. They may not understand what is happening to their brother or sister, which can be upsetting and confusing. They might not be able to cope with what has happened, and could be embarrassed by their sibling, especially in a school environment. They may even be jealous of the attention, care and money that their sibling is receiving because of their stroke. All of these reactions and emotions are normal.

If family members want to help you, think of ways that they can ease some of the pressures you are facing. They might be able to help you with the other children's routine, food shopping or keeping your household chores under control. They could spend time at the hospital with your child so you could see your other children, or give you time to sleep and have a break from the situation. Working together will help you cope better and come to terms with the stroke.

Useful tips

Tips to help your child cope

1. Talk to your child about the stroke, try to answer all their questions. Encourage them to write lists of their questions to ask the doctor. Use simple and easy language.
2. Reassure them that it is ok to be scared or upset.
3. Try to keep your child in touch with their friends. Most hospitals have areas where mobile phones can be used. Friends can visit, or talk via video link on a mobile device.
4. Be involved in your child's recovery and help them practise their exercises regularly. Focus on small steps forward and be positive about the future. Celebrate progress.
5. Monitor your child's development and work with their teachers, carers and therapists to get the best results possible.

Tips to help you cope

1. Learn about your child's condition and do not feel scared to ask. Write down any questions you want to ask the nurses and doctors. The more you ask the more you will understand how best to support your child. You can ask for a second opinion, or ask to see a specialist doctor or therapist.
2. You might find it helpful to keep a diary or log of your child's treatment and recovery.
3. Ask if you can help with your child's care in hospital. Help to wash them, play with them and feed them.
4. Have a break! Taking time out is essential so you can revitalise yourself and come back feeling refreshed.
5. Family and friends will rally around at times like this. Their support and care is invaluable but it can be draining keeping everyone updated. Nominate someone to pass on the news or set up an email list.
6. Talk to people about how you are feeling. Speak to your family, friends, helplines and support groups so you can meet other people in a similar situation. Some parents tell us that they have found support from other parents of children with stroke on social media.

Tips to help your other children cope

1. Use simple, child-friendly language when talking about stroke. Use pictures and websites like the animations on **stroke.org.uk/childhood**.
2. Try to answer your children's questions honestly and prepare yourself for answers that can be upsetting or difficult. Do not avoid subjects. Your children will be more likely to worry and make up their own explanation for what is happening.
3. If you are visiting the doctor, ask your children to write down any questions that they have. Include them in the situation.
4. Spend a portion of time with each of your children. Having a dedicated time for each child may help to avoid jealousy or rivalry.
5. Include them in helping with any rehabilitation exercises and games, but ensure this should not become a big responsibility for them. You should also discourage them from talking on behalf of their brother or sister if they have a speech problem.
6. If you think they feel embarrassed by their sibling, talk to them about it. Try to see it from their perspective, and reassure them. Give them an explanation card explaining what a stroke is so if people stare they can hand it to them.
7. Contact Sibs for advice on supporting siblings of disabled children, and Carers UK for more information on younger carers' supports services.

Where to get help and information

From the Stroke Association

Helpline

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**.

Read our information

Get more information about stroke online at **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** today.

Other sources of help and information

Afasic: Association for All Speech Impaired Children

Website: **afasic.org.uk**
Helpline: **0300 666 9410**
A charity that supports parents and represents children and young adults with speech, language and communication needs.

Brain Injury Hub

Website: **braininjuryhub.co.uk**
Produced by the Children's Trust. It provides information, personal stories and advice about living and learning after a brain injury.

Carers Trust

Website: **carers.org**
Information about caring and help with finding your local carers' service.

Cerebra

Website: **cerebra.org.uk**
Helpline: **0800 328 1159**
Email: **info@cerebra.org.uk**
A charity that supports children with neurological conditions.

Child Brain Injury Trust

Website: **childbraininjurytrust.org.uk**
Supports children affected by acquired brain injury including stroke and their families.

Children's Heart Federation

Website: **chfed.org.uk**
Info line: **0300 561 0065**
Information and resources about heart problems in children.

Contact

Website: **contact.org.uk**
Helpline: **0808 808 3555**
Email: **helpline@cafamily.org.uk**
Charity giving advice and information to families of disabled children. Hemihelp, the charity for children with hemiplegia, is now part of the Contact advice service. You can also access a closed HemiHelp group on Facebook.

Council for disabled children

Website: **councilfodisabledchildren.org.uk**
Information about getting the support your child needs.

Different Strokes

Website: **differentstrokes.co.uk**
Helpline: **0345 130 7172**
Email: **info@differentstrokes.co.uk**
A charity for younger stroke survivors.

Disabled Living Foundation

Website: **dlf.org.uk**
Helpline: **0300 999 0004**
Email: **info@dlf.org.uk**
Advice on child-friendly equipment that can help mobility, development and play.

Evelina London Children's Hospital

Website: **evelinalondon.nhs.uk/stroke**
Online resources from the specialist children's stroke treatment unit working in partnership with the Stroke Association.

Sibs

Website: **sibs.org.uk**
Support for siblings of all ages with a brother or sister with a disability or chronic illness.

Sickle Cell and Young Stroke Survivors

Website: **scyss.org**
Helpline: **08000 842 809**
Email: **info@scyss.org**
Provides advice and support including counselling for children and parents.

Advice about education

ACE Education Advice

Website: **ace-ed.org.uk**
Free advice and information for parents on all aspects of state-funded education including getting support for children with SEND. England only.

Independent Parental Special Education Advice (IPSEA)

Website: **ipsea.org.uk**
Free legal support for getting support for children with SEND. England only.

Special Educational Needs Advice Centre (Northern Ireland)

Website: **senac.co.uk**
Helpline: **028 9079 5779**
Email: **info@senac.co.uk**
Advice and advocacy for children with SEND.

Government websites on education and special needs

Department for Education (DfE) (England)
Website: **gov.uk/children-with-special-educational-needs**

Department of Education (Northern Ireland)
Website: **education-ni.gov.uk/articles/sen-guidance-parents**

Scottish Government Education and Training
Website:
gov.scot/Topics/Education/Schools

Welsh Assembly Government: Education and Skills
Website:
gov.wales/topics/educationandskills

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 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.

Version 3.2. Published December 2021
To be reviewed: September 2022
Item code: **A01F34**

Every five minutes, stroke destroys lives. We need your support to help rebuild them. Donate or find out more at **stroke.org.uk**.

JN 2122-254.6