

Childhood stroke

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

Childhood stroke affects around **400 children** a year in the UK. The term, 'childhood stroke', covers from the 28th week of pregnancy up to the age of 18. The causes and the effects of a stroke are likely to be different depending on how old the child is.

What is a stroke?

A stroke happens when the **blood supply** to part of the brain is **cut off**. There are two main types of stroke. **Ischaemic** strokes are caused by a blockage in the blood supply to the brain. **Haemorrhagic** strokes occur when blood leaks from a burst blood vessel into the brain. In adults, about 85% of strokes are caused by a blockage and 15% by a bleed in the brain. In children, both types of stroke are equally common.

Children can also have **transient ischaemic attacks (TIAs)**. A TIA happens when the brain's blood supply is interrupted for a very brief time. The symptoms only last for a few minutes or hours and then completely disappear within 24 hours.

In adults, a TIA does not cause any permanent damage to the brain. However, in children, a brain scan after a TIA may show

an area of brain injury even if there are no remaining symptoms.

Signs of stroke in a child

It can sometimes be **difficult to recognise** if your child has had a stroke. The effects of the stroke may not be so noticeable if your child is very young and in the early stages of development, or if their symptoms are mild. Some children, especially newborn infants, may not show any symptoms. In babies up to 28 days old, **seizures** are a common symptom of stroke.

Children and babies may experience sudden **weakness or paralysis on one side of the body, facial drooping, speech problems and headaches**. These symptoms are most commonly associated with ischaemic strokes. Signs of haemorrhagic strokes can be **vomiting, seizures and occasional headaches**.

For some children with strokes presumed to have happened around or before birth, the stroke is first detected when problems arise with the child's learning and development. Most noticeably there may be problems with movement on one side of the body (hemiplegia).

Why has my child had a stroke?

Stroke can affect any person at any age, and it can even happen before birth. It is the **risk factors** for stroke in children that make this condition different from adult stroke. Ischaemic strokes, in particular, occur for very different reasons in children compared with adults.

Adult stroke is predominantly caused by atherosclerosis, the 'furring up' of arteries.

Stroke in **babies during pregnancy to 28 days after birth** (known as pre- and perinatal ischaemic stroke) is usually caused by **clots breaking off** from the **placenta** and lodging in the child's brain, or because of a **blood clotting disorder** that the mother or baby may have.

Stroke in **children from 28 days to 18 years** is associated with **existing conditions**, most commonly **congenital heart disease** and **sickle cell disease (SCD)**. Other risk factors are infectious diseases, trauma to the head or neck, vascular problems and blood disorders.

In many cases of childhood stroke, there is more than one risk factor.

Strokes can also affect previously healthy children and in some cases, there can be no apparent cause.

Ischaemic stroke in children

There are two main ways an ischaemic stroke can happen (stroke caused by a blockage in an artery):

- A blood clot can form somewhere in the body and travel to the brain. This is an

embolus.

- A clot can form directly in a blood vessel in the brain and remain there, causing a blockage. This is a thrombosis.

There are **several different risk factors** for ischaemic stroke in children. These fall mainly into the following categories:

- heart disorders
- blood disorders
- infections
- vascular disorders.

Heart disorders

Heart disorders cause up to 25% of ischaemic strokes in children. They can be a result of congenital heart disease (CHD) – an abnormality present since birth or acquired heart disease (AHD). They commonly occur around the time of operations on the heart. Most children with a heart disorder have this diagnosed before their stroke. For some, the problem is only discovered after a stroke has happened.

Blood disorders

Sickle cell disease (SCD)

Sickle cell disease is an inherited condition which affects the development of red blood cells. They change from their normal round shape to a sickle (half moon) shape. Because sickle cells are less flexible, they can get stuck in blood vessels and block them. SCD can cause strokes if a vessel in the brain becomes blocked. In rare circumstances, it can cause bleeds in the brain.

SCD is most common among Black Caribbean, Black African and Black British people. It affects males and females alike. Children with SCD are at the greatest risk of stroke between the ages of two and 16.

Blood clotting disorders

There are several types of **blood clotting disorders**, which are risk factors for ischaemic strokes in children. Sometimes referred to as 'sticky blood' disorders, there is an increased tendency for clots to form. The doctor may take blood samples to see if your child has one of these disorders if they have had a stroke.

Infections

Infections have also been associated with ischaemic stroke. **Chicken pox** is a highly contagious condition, which mainly affects children under the age of 10. It is caused by a virus. Usually the virus runs its course but research has shown that it can be a risk factor for ischaemic stroke in children though this is rare. It is thought that the virus causes blood vessels in the head to narrow. Research suggests that children with underlying heart and blood vessel conditions, who become infected with the virus, may be at a higher risk of stroke.

Other infectious disorders that have been associated with childhood ischaemic stroke are bacterial meningitis, encephalitis, sepsis and brain abscess.

Vascular disorders

Vascular disorders are problems with blood vessels in the body.

Arterial dissection

An **arterial dissection** is a tear in the lining of an artery. It occurs when blood gets between the layers of the blood vessel wall. This can cause blood to escape from the vessel into the brain, or to form a blood clot in the artery causing a stroke. Carotid and vertebral artery dissection (damage to the arteries in our necks) can cause strokes in children. Common

symptoms of arterial dissection are sudden and severe headache, face and neck pain followed by stroke-like symptoms. These types of stroke are more common in males. Often the cause of the dissection is a trauma to the neck.

Moyamoya disease

Moyamoya disease affects around one in every million people in the UK. It is a rare disease, associated with narrowing and blockages in the main blood vessels in the brain. In children symptoms are recurrent headaches, weakness on one side of the body, seizures and learning difficulties. Moyamoya disease has been reported in all ethnic groups but mainly in Japanese people. Researchers believe that it is a genetic condition, though more evidence is needed to support this theory. It has also been linked with sickle cell disease (SCD).

Vasculitis

There is also evidence of **vasculitis** causing stroke or TIA in children. Vasculitis means inflammation of the blood vessels. It can affect any vessel in the body and can cause narrowing and vessel wall weakness. A stroke can happen if a blood clot blocks an affected vessel in the brain or if the vessel wall bursts and causes a bleed into the brain.

Sinovenous thrombosis

Sinovenous thrombosis is a disorder that affects a vein in the brain. It occurs when a **blood clot** develops in the **large veins** (known as the venous sinuses) that bring blood from the brain back to the heart. Symptoms include headaches, fits and raised pressure in the brain. This can affect all ages including babies. Common risk factors are infections in the head and neck (such as an ear or sinus infection), dehydration or blood clotting disorders.

Haemorrhagic stroke in children

Up to 50% of strokes in children are haemorrhagic. The most common cause is an **arteriovenous malformation (AVM)**.

Arteriovenous malformation (AVM)

An AVM is a rare malformation of blood vessels where arteries (taking blood to the brain) become tangled with veins (draining blood from the brain), often appearing as a tangle of abnormal vessels. They can occur anywhere in the body but most commonly in the brain. This means that the high pressure of blood in arteries is transmitted directly into veins, which are not built to take this pressure – they may therefore burst.

Aneurysm

An **aneurysm** is a bulge in an artery wall. If the bulge grows too big, it can burst and cause bleeding into the brain. Aneurysms may arise as a result of an infection or without warning.

Cavernous malformations can also cause haemorrhagic stroke in children. A cavernous malformation is a small cluster of abnormal, enlarged blood vessels, often resembling a blackberry shape.

They are mainly found in the brain and around the spine but they can occur anywhere in the body.

Other disorders

Some of the disorders that have already been mentioned, moyamoya syndrome, types of vasculitis, SCD and clotting disorders (such as a lack of vitamin K, which helps with clotting) are also known risk factors for haemorrhagic stroke in children.

How will my child's stroke be diagnosed?

If your child is displaying stroke-like symptoms (see page one) you should **dial 999 immediately**. At the hospital, your child should see a consultant paediatrician, neurosurgeon or paediatric neurologist.

A **brain scan** should take place as soon as possible to confirm whether your child has had a stroke. The scan will show the affected area of the brain and the blood vessels in the brain. It is preferable to use an MRI scan as it shows a more detailed image of the brain.

This should last around an hour and it requires your child lying still whilst the machine takes a picture of their brain. Your child may be given a sedative to help them keep still. If an MRI scan is not available then a CT scan is a good alternative.

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

Because there are many risk factors associated with childhood stroke, the doctor may carry out a **number of tests** to help identify the cause. Your child's medical history may also provide clues as to the cause of the stroke, such as having SCD.

Blood tests might be used to check for any infections, chemical problems or blood clotting disorders that may have caused the stroke. If an infection is suspected, your child might have a **lumbar puncture**.

This procedure takes a sample of cerebrospinal fluid that surrounds the brain and spinal cord.

Your child may have an **echocardiogram** to help determine if there are any problems with their heart. This scan works by using ultrasound and it looks at the structure of the heart.

An **angiogram** test can help reveal a burst vessel, a tear or blockage in a blood vessel in the brain. Dye is injected into an artery using a fine tube and then an x-ray machine is used to take pictures of the blood vessels in the brain.

What treatment will my child have?

Ischaemic stroke

If the stroke was caused by a blockage, long-term **blood-thinning medication** like aspirin may be prescribed to help prevent another from happening. (Read our factsheet *F11 Blood thinning medication after stroke* for more information.)

Treatment for sickle cell disease (SCD)

If your child has **SCD**, they will have an **urgent blood transfusion**. The transfusion will help replace the sickled red blood cells in your child's body with normal blood cells.

Regular blood transfusions should follow, to reduce the risk of a second stroke. This should take place every three to six weeks and should continue for at least three to five years.

One of the side effects of the blood transfusions is too much iron in the body. Iron removal therapy, known as chelation therapy, is given to remove the excess iron

and to help to keep your child's body healthy.

Moyamoya syndrome

If your child has **moyamoya** syndrome, revascularisation surgery can help improve blood flow to the brain by opening narrowed blood vessels.

How can a stroke affect my child?

The **effects of stroke vary** from very mild to severe, and depend on the part of the brain affected and how much damage it has caused. Your child may have problems with movement or speech, or have behavioural or learning difficulties. Stroke in children can also cause pain, seizures and visual problems.

It is possible to recover from a stroke. It does, however, take time and **rehabilitation therapies are crucial**. Usually, recovery happens in the early weeks and months following a stroke, but can continue for longer.

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. (See our factsheet F23, Bereavement and stroke for more advice.)

Rehabilitation and recovery

Once your child is well enough, rehabilitation should begin. Many people believe that children fully recover after stroke because their brain is still developing. It is more accurate to say that **children are better at adapting** to the effects of stroke.

Physiotherapy

A **physiotherapist** can help with **movement problems** such as weakness or paralysis, spasticity (a stiffness that develops in the muscles after stroke) or muscle spasms. The therapist will assess and design a programme to improve muscle strength (which can reduce the risk of spasticity) and movement. They might use equipment to help your child move more easily, like ankle foot orthoses (AFOs) and hand splints.

If your child has spasticity, they may be given botulinum toxin (botox) to help reduce muscle tightness and stiffness. It is licensed for use in certain muscle groups, but can be used 'off-licence' for some children. Ask your GP if this treatment is funded in your area, and request a referral if your child needs help with spasticity.

Occupational therapy

Occupational therapists often work closely with the physiotherapist. They will look at ways to help make **daily living tasks** such as tying shoelaces, getting dressed and eating food easier.

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

Communication

Communication can be affected in different ways after stroke.

- Aphasia describes difficulty with speaking, understanding speech, reading or writing.
- Dysarthria describes difficulty speaking because of weakness of the facial muscles.

See factsheet F3, *Communication problems after stroke* for more information.

Most children make significant improvements with their speech within the first year.

A speech and language therapist (SLT)

can help by assessing 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.

Emotional problems

Stroke can also affect a child's **behaviour** and their **emotions**. Many parents notice that their child's behaviour changed after the stroke, and may want to seek help and support with managing this.

Research has shown that children with hemiplegia (weakness and stiffness on one side) often experience **behavioural changes**. These changes in behaviour can also occur over time. As your child ages they may become more aware of the differences between them and other children.

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Problems with learning and participating in school may highlight problems that they have, which can be difficult to accept. Coping with the physical changes in their body can also be challenging.

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; adolescence in particular can be a difficult time. A **psychologist can help assess and treat emotional problems**, especially if behaviour is affecting home and school life. Talking therapies may help your child understand why they feel the way they do.

Cognitive skills

Your child may have difficulty with learning and concentrating, spatial awareness and language (called cognitive skills). A **psychologist** can assess your child's cognitive ability and make recommendations to help support your child 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.

To make your child's return to school as smooth as possible, contact your child's teacher or the **Special Educational Needs Coordinator (SENCO)** and let them know about the stroke and how your child has been affected. Ask for a meeting to discuss in more detail the support they will need, and, 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 (SEN), 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 our 'Useful organisations' section.

It might be helpful for the school to **speak to other pupils** about any physical effects of your child's stroke, as it may feel less daunting if their classmates know what changes to expect.

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 part of their school day.

Research shows that children with SEN/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 this.

The impact of childhood stroke on the family

Childhood stroke can affect the whole family. Parents often feel a range of emotions from shock and bewilderment to feelings of isolation and frustration. Research shows that 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 by the stroke. 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 the effects of the stroke 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.**

Your own parents may feel guilty that a stroke has affected their grandchild, since stroke primarily affects older people. Reassure them that strokes in children are different to adult stroke and happen for very different reasons. Give them this factsheet to help them understand.

If they 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 and encourage them to speak to 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.
4. Be involved in your child's recovery and help them practise their exercises regularly.
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.
2. Ask if you can help with your child's care in hospital. Help to wash them, play with them and feed them.
3. Have a break! Taking time out is essential so you can revitalise yourself and come back feeling refreshed.
4. 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.
5. 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.

Tips to help your other children cope

1. Use simple, child-friendly language when talking about stroke. Use pictures and websites (like www.kidshealth.org or www.gosh.nhs.uk) to help you.
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 that they are not in trouble. Give them an explanation card explaining what a stroke is so if people stare they can hand it to them.
7. Contact SIBS and Carers UK for more information on younger carers' support services.

Useful organisations

All organisations are UK wide unless otherwise stated.

Disclaimer: The Stroke Association provides the details of other organisations for information only. Inclusion in this factsheet does not constitute a recommendation or endorsement.

Stroke Association

Stroke Helpline: 0303 3033 100

Web: stroke.org.uk/childhood

Email: info@stroke.org.uk

Contact us for information about stroke, emotional support and details of local services and support groups. The page listed here gives information about childhood stroke, the Childhood Stroke Project, and other sources of help and information.

Afasic: Association for All Speech Impaired Children

Website: www.afasic.org.uk

Helpline: 0300 666 9410

A charity that supports parents and represents children and young adults with speech, language and communication needs. They have information that can help you spot problems and find support.

Carers Trust

Website: www.carers.org

Email: info@carers.org

This organisation supports unpaid carers, including younger carers.

Cerebra

Website: www.cerebra.org.uk

Helpline: 0800 328 1159

Email: enquiries@cerebra.org.uk

A charity that supports children with neurological conditions and their parents. Their helpline offers free telephone counselling to parents.

Child Brain Injury Trust

Website: childbraininjurytrust.org.uk

Helpline: 0303 303 2248

Email: helpline@cbituk.org

Supports children affected by acquired brain injury (including those caused by stroke) and their families. They provide information, grants and emotional support

Contact a Family

Website: www.cafamily.org.uk

Helpline: 0808 808 3555

Email: helpline@cafamily.org.uk

A national charity for families with disabled children. Provides information and resources to help parents understand their rights and get financial support, as well as find local parent support groups.

Different Strokes

Website: www.differentstrokes.co.uk

Helpline: 0345 130 7172

Email: info@differentstrokes.co.uk

A charity that supports younger stroke survivors. You can download their 'Care after stroke in childhood' information pack from the website.

Disabled Living Foundation

Website: www.dlf.org.uk

Helpline: 0300 999 0004

Email: info@dlf.org.uk

Provides information and advice on child-friendly equipment including information on aids that can help mobility, development

and play as well as household aids and adaptations.

Great Ormond Street Hospital for Children

Website: www.gosh.nhs.uk/children

Provides information and advice for children and parents about visiting and staying in hospital, including information on childhood stroke.

HemiHelp

Helpline: 0345 123 2372

Website: www.hemihelp.org.uk

Provides information and support to children and families affected by hemiplegia. They have activity groups, support groups for parents and siblings, advice on aids and equipment.

SIBS

Website: www.sibs.org.uk

Support for siblings of disabled children and adults. For help and advice use the online contact form.

Sickle Cell and Young Stroke Survivors

Helpline: 08000 842 809

Website: www.scyss.org

Email: info@scyss.org

Provides advice and support, counselling for children and parents, group support, talks and clubs.

Organisations providing advice about education

Advisory Centre for Education (ACE)

Helpline: 0300 0115 142

Website: www.ace-ed.org.uk

Free advice and information for parents in England and Wales on all aspects of state funded education including getting support for special educational needs (SEN) and bullying.

Special Educational Needs Advice Centre (SENAC)

Helpline: 028 9079 5779

Website: www.senac.co.uk

Advice, information and advocacy for children and young people with special educational needs in Northern Ireland.

Independent Panel for Special Education Advice (IPSEA)

Website: www.ipsea.org.uk

England and Wales. Offers free and independent legally-based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities. To speak to an advisor use the online booking form.

Government information on schools and special needs

Resources to help you find support for children with special educational needs.

Department for Education (DfE) England

Website: www.gov.uk/children-with-special-educational-needs

Department of Education (Northern Ireland)

Website: www.education-ni.gov.uk/articles/sen-guidance-parents

Scottish Government Education and Training

Website: www.gov.scot/Topics/Education/Schools

Search the site for guidance on children with additional support needs.

Welsh Assembly Government: Education and Skills

Website: www.gov.wales/topics/educationandskills

Search the site for information on education and development for children with special educational needs.

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.

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