

Childhood stroke

Stroke is a condition that is often associated with older people but anyone can have a stroke including babies and children. The causes of stroke for children are very different from those for adults. This factsheet explains the causes, treatment and impact stroke could have on your child and your family, and lists other sources of help and support.

Childhood stroke affects around **five out of every 100,000 children** a year in the UK. The term, 'childhood stroke', covers from the twenty-eighth week of pregnancy up to the age of eighteen. 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, 80 percent of strokes are caused by a blockage and 20 percent 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, usually within 24 hours.

In adults, a TIA does not cause any

permanent damage to the brain. However, research has shown that children who have TIAs often have an area of brain injury even if they have no remaining symptoms.

How do I know if my child is having a stroke?

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 may not even have any symptoms. In babies up to 28 days old, **seizures** are a common symptom of stroke.

Children aged from 28 days old to 18 years may experience **weakness or paralysis on one side of the body, facial drooping, speech problems and headaches**. These symptoms are most commonly associated with ischaemic strokes. Symptoms for haemorrhagic strokes can be **vomiting, seizures and occasional headaches**.

For some children, the stroke is first detected when problems arise with their 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, it can even happen during pregnancy. 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. Other contributing factors are medical conditions such as high blood pressure, high cholesterol and diabetes, and the impact of lifestyle choices, like smoking or drinking alcohol excessively and lack of exercise.

Stroke in **babies during pregnancy to within 28 days of birth** (known as pre and perinatal ischaemic stroke) are 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** are 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.

Stroke can also affect previously healthy children and in some cases, there can be no apparent cause. In about 10 per cent of childhood stroke cases, the cause is unknown.

The following section describes in detail the different risk factors for childhood stroke. See page 5 onwards for information on diagnosis, treatment and support for your child in school.

What are the risk factors for ischaemic stroke?

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 cause up to 25 per cent 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, like sickle cell disease (SCD), are another risk factor for childhood

ischaemic stroke. SCD 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 both males and females alike. Children with SCD are at the greatest risk of stroke between the ages of 2 and 16. (For more information about sickle cell disease read our leaflet *Sickle cell and stroke*.)

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 have also been associated with ischaemic stroke. **Chicken pox** is a highly contagious condition, which mainly affects children under the age of ten. 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 cardiac and vascular 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 are problems with vessels in the body. 'Furring up' of arteries are a common cause of stroke in adults but vessel problems can also cause stroke in children. In children they occur for very different reasons however, due to rare conditions such as arterial dissection, moyamoya syndrome and vasculitis.

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. Recent studies have shown that carotid and vertebral artery dissection (damage to the arteries in our necks) accounts for five to 20 per cent of 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 affects 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 SCD.

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

Strokes can also be caused by a problem with the veins of the brain. Veins bring deoxygenated blood (without oxygen) back to the heart.

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 but is under-recognised in babies under twenty-eight days old. Common risk factors are infections in the head and neck (such as an ear or sinus infection), dehydration or blood clotting disorders.

What are the risk factors for haemorrhagic stroke?

Fifty percent of strokes in children are haemorrhagic. Between 30 and 50 percent of these are caused by **arteriovenous malformations (AVMs)**. 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.

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 are thought to account for 20 to 25 percent of 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. Research is currently underway to understand why these occur. Evidence suggests that structural changes (mutations) in genes may trigger the abnormality in the vessels in some people.

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 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 is very sleepy and the doctors are concerned about their levels of consciousness, they will have an urgent brain 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, i.e. if they have SCD.

Blood tests might be taken 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 removes 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?

Once the doctor knows the cause of the stroke, they will be able to decide what treatment is best. 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.)

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, as the risk of a second stroke is very high (about two thirds of children with SCD have another 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.

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

How will the 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.

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 the tightness and stiffness in a group of muscles (not a recommended treatment in Scotland). See factsheet *F33, Physical effects of stroke* for more information.

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, eating food and using aids and adaptations easier.

Research shows that children tend to recover the ability to walk, though it can be more difficult to recover hand movement.

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 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.
- Dyslexia is a learning difficulty that affects literacy and numeracy skills.

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

Some children may also find it difficult to socialise and may be unwilling to talk. This is known as mutism.

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. It is also a good idea to look into communication devices to assist with

speech. (Our resource sheet *R5, Electronic communication aids and software* has a list of contacts, but speak to your child's SLT first.)

Stroke can also affect a child's **behaviour** and their **emotions**. Many parents notice that their child's behaviour changes after the stroke and can find it difficult to cope.

Research has shown that children with hemiplegia (paralysis on one side) are more likely to 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. 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 their behaviour is affecting home and school life. Talking therapies may help your child understand why they feel the way they do.

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.

Bullying at school may be a problem for some children after a stroke. 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 and some hospitals have cyber cafes so they can email as well.
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.
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.

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.childrenfirst.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.

Useful organisations

All organisations are UK wide unless otherwise stated.

Stroke Association

Stroke Helpline: 0303 3033 100

Web: stroke.org.uk

Email: info@stroke.org.uk

Contact us for information about stroke, emotional support and details of local services and support groups.

AFASIC: Association for All Speech Impaired Children

Helpline: 0845 3 55 55 77

Website: www.afasicengland.org.uk

Represents children and young adults with communication impairments. They work for their inclusion in society and support parents and carers. They have websites for all UK countries, which are accessible through the above website.

All about ABI: Acquired Brain Injury c/o The Brain and Spine Foundation

Helpline: 0808 808 1000

Website: www.aboutbraininjury.org.uk

Has lots of online information for children and teenagers affected by an acquired brain injury. Advice provided on returning to school, participating in sports, sex and other related topics.

Child Stroke Support Site

Website: www.childstrokesupport.com

This website has been set up for parents of children who have had stroke or AVMs. It is a good place to access information and emotional support.

Children's Brain Injury Trust

Helpline: 0845 601 4939

Website: www.cbituk.org

Supports anyone affected by childhood acquired brain injury, from the child or young person to his or her family and professionals. They provide information, grants and emotional support.

Contact a Family

Helpline: 0808 808 3555

Website: www.cafamily.org.uk

Provides support and advice to the parents of disabled children. They have community services, grant and benefit information and publications.

Different Strokes

Helpline: 0845 130 7172

Website: www.differentstrokes.co.uk

Offers a children's information pack and an online forum for parents to talk to each other.

DLF – Disabled Living Foundation

Helpline: 0845 130 9177

Website: www.dlf.org.uk

Provides advice on child friendly daily living equipment including information on mobility, development and play and household aids and adaptations.

Great Ormond Street Hospital for Children

Tel: 020 7405 9200

Website: www.gosh.nhs.uk/gosh_families

Provides information and advice on childhood stroke, associated risk factors and tips on how to cope.

HemiHelp

Helpline: 0845 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

Telephone: 01535 645453

Website: www.sibs.org.uk

Support to siblings of disabled children and adults.

Sickle Cell and Young Stroke Survival

Helpline: 08000 842 809

Website: www.scysss.org

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

Study of Outcome in Childhood Stroke

Tel: 0117 342 0176

Website: www.childstroke.org.uk

Research project aiming to find out what impact stroke has on a child's health and development. The website lists medical guidelines and information for professionals and families.

Young Carers: The Princess Royal Trust for Carers

Tel: 0844 800 4361

Website: www.carers.org

This organisation supports younger carers. They have information, groups and online forums to talk to other people in a similar situation.

Cerebra

Tel: 01267 244 200

Website: www.cerebra.org.uk

Provide information, a grant scheme,

benefits advice, and a counselling helpline for parents with disabled children. Has a sleep support network, an innovation centre for aids and adaptations, and a recycling service for aids that have been outgrown.

Organisations providing advice about education

Advisory Centre for Education (ACE)

Helpline: 0808 800 5793

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.

Department for Education (DfE) England

Website: www.education.gov.uk

Information and resources to support children and young people with special educational needs and disability in England.

Department of Education (Northern Ireland)

Website: www.deni.gov.uk

Advice on providing for children with special educational needs in Northern Ireland.

Scottish Government: Education and Training

Website: www.scotland.gov.uk

Guidance on support for any child with additional support needs in Scotland.

Welsh Assembly Government: Learning and Skills

Website: www.wales.gov.uk

Advice identifying and assessing children's special educational needs in Wales.

Childhood stroke

Independent Panel for Special Education Advice (IPSEA)

Advice Line: 0800 018 4016

Website: www.ipsea.org.uk

Free legal advice to parents of children with special educational needs in England and Wales.

Special Educational Needs Advice Centre (SENAC)

Helpline: 028 9079 5779

Website: www.senac.co.uk

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

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

Produced by the Stroke Association's Information Service.

For sources used, visit stroke.org.uk

© Stroke Association

Factsheet 34, version 02, published March 2011, updated April 2012 (next review due June 2013).

Item code: **A01F34**



£5 could help us answer a helpline call from a desperately worried person looking for answers about stroke. Text 'stroke' to 70007 to donate £5 today.

Texts cost £5 plus your standard network rate of which a minimum £4.70 will go to the Stroke Association. Full terms and conditions at www.stroke.org.uk/textterms

Stroke Association is a Company Limited by Guarantee, registered in England and Wales (No 61274). Registered office: Stroke Association House, 240 City Road, London EC1V 2PR. Registered as a Charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Isle of Man (No 945), Jersey (NPO 369) and serving Northern Ireland.