



Supporting children after a stroke

Toolkit for teachers and childcare professionals Part 3

Training resources for professionals

Rebuilding lives after stroke

Stroke
Association

 Evelina London

Training resources for professionals around the child or young person

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1. Professionals and services supporting children and young people after stroke

The types of professionals and services who support a child/young person who has had a stroke will vary depending on their needs and outcomes, but they may include some of those outlined below.

When completing healthcare plans, SEN support plans or Education Health and Care Plans, it is useful to consider if any of these services can complete supportive assessments or provide evidential reports.

1. **Paediatric neurologists** are doctors who diagnose and treat children affected by stroke. They may liaise with schools in providing information for care plans, or Education Health and Care Plans.
2. **Community paediatricians** are doctors who help monitor and support child and adolescent development. They may not be involved in the early care of the child, but may have a longer term overview of their needs and liaise with school around related issues.
3. **Clinical nurse specialists** support children affected by stroke while in hospital. They may liaise with schools in providing information for care plans, or about conditions related to stroke like epilepsy.

4. Therapists

Children are likely to see different therapists in hospital and at home, and there may also be different teams who visit school settings.

- a. **Physiotherapists** support children with movement and mobility difficulties. They may liaise with schools in providing advice around therapy programmes and how to support participation in activities that involve whole body movement, like sport.
- b. **Occupational therapists** support children affected by stroke in using their arms and hands, and in being independent in skills like dressing and using the toilet. They may liaise with schools in providing advice around equipment, therapy programmes and how to support participation in activities like writing, typing, managing school lunch and play times. They may also be able to give advice around managing fatigue and strategies to support learning.
- c. **Speech and language therapists** support children with communication and swallowing difficulties. They may liaise with schools in providing advice around therapy programmes and how to support eating and drinking safely, as well as communication.

5. **Ophthalmologists** are doctors who support children with vision problems after a stroke. They are usually based in hospitals, and children are referred to them by neurologists and paediatricians. They will assess vision, and offer ongoing review and advice as needed. They may refer children on to local visual support services if needed.
6. **Psychologists** may specialise in one of the three areas outlined in more detail below. All of these disciplines may look more broadly at both cognitive/thinking skills alongside emotional wellbeing.
 - a. **Clinical neuropsychologists** support children when there are concerns about learning and thinking skills and their effects on wellbeing. They are usually based in specialist children's hospitals. Not all children affected by stroke will see a neuropsychologist, and those who do are often assessed after a certain number of months to allow time for a period of initial recovery. If any difficulties are suspected with skills like attention, memory or language they can complete detailed assessments and will usually liaise with schools as part of this process. Their reports will provide information for schools, and can be used as part of an application for an Education Health and Care Plan (EHCP).
 - b. **Educational psychologists** support children when there are concerns about attainment, wellbeing and behaviour in educational settings. They are usually based in community teams and will undertake classroom observations, staff consultations and school-based assessments. They will liaise with schools about their findings and provide recommendations about how to support the young person in the school setting. Their reports will provide information for schools, and can be used as part of an application for an EHCP if needed.
 - c. **Clinical psychologists** support children affected by stroke when there are concerns about emotional and psychological wellbeing, adjustment and coping. They are often based in hospital settings and support young people in this environment, but would typically liaise with schools as appropriate or needed. The young people may also be referred to local counselling services, Targeted Mental Health in Schools Services (TAMHS) or Child and Adolescent Mental Health Services (CAMHS) where there are concerns about their emotional and psychological wellbeing.
7. **Equipment services** support children who need additional resources like wheelchairs, splints or orthotics. Physiotherapists and occupational therapists may also give advice about equipment, and liaise with these services. It can be helpful to establish who can provide support for schools around any equipment that a young person may be using.
8. **Portage or early years services** support children in the pre-nursery and pre-school years with play skills, learning and development. If a child had a stroke around the time of birth or before school has started, a portage or early years service may be able to liaise with schools and provide useful information for care planning. These services may initiate EHCPs for some children.
9. **Children with disabilities teams** may support children affected by stroke if they meet their referral criteria. These teams include rehabilitation therapists, social workers and occupational therapists. They may be able to undertake social care assessments, carers assessments and housing assessments. They can also advise on other community services, respite services or financial support options.

10. Assistive technology services

may support children if they need equipment to support their participation, communication, sensory functions or learning. They assess children in school settings, and liaise with school staff around how to support learning environments.

11. Visual/hearing/sensory support services

may support children if they have identified difficulties in these areas. If a child has had a stroke around the time of birth or before school has started, these services may be able to liaise with schools and provide useful information for care planning.



2. Spotting the signs of stroke in a child

The FAST test can be used to identify strokes in children:

Face: Can the young person smile? Has their face fallen on one side?

Arms: Can they raise both arms and keep them there?

Speech: Can they speak clearly and understand what you say?

Is their speech slurred?

Time: If you see any one of these three signs, it's time to call 999

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.

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's important to remember that stroke symptoms that last a short amount of time can be a transient ischaemic attack (TIA or mini-stroke). In a TIA, a blood vessel in the brain gets blocked, but the blockage clears by itself. A TIA is still a medical emergency, and you should call **999**.

When supporting a child in an educational setting it is important to be aware of the symptoms of stroke, and also to talk to the family specifically about how their child first experienced stroke symptoms. Documenting this discussion is an important aspect of care planning.

Parent's story

" It is so important for teachers and supply staff to know what to do in the event of an emergency when they have a child who has had a stroke in their class. The person who is responsible for them at school needs to have clear basic information close to hand."

Download our poster about FAST signs in children with this toolkit. For more information about the FAST test visit stroke.org.uk/FAST.

3. Understanding the causes of childhood stroke

What is a stroke?

A stroke happens when the blood supply to part of the brain is cut off, killing brain cells. Blood provides the brain with essential oxygen and nutrients, and when supply is cut off by a stroke, this damages the brain. Brain cells that have died cannot start working again, but those around the area of stroke may recover as swelling reduces. Sometimes, other parts of the brain can take over from the damaged part, allowing children to develop or recover skills. This is known as neuroplasticity.

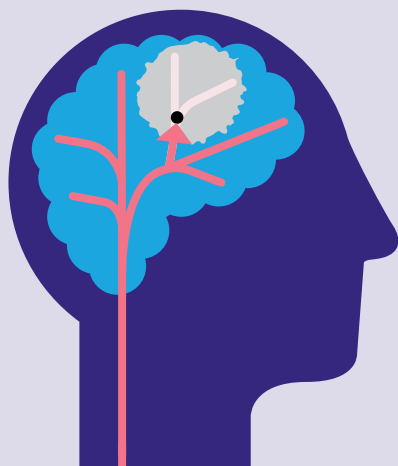
There are two main types of stroke. Ischaemic strokes are caused by a blocked blood vessel in the brain. Haemorrhagic strokes are when there is bleeding in or around the brain.

Stroke can happen at any age, including before birth. In terms of diagnosis and medical care, a stroke before or around the time of birth would be described as antenatal, perinatal or neonatal, and a stroke from 29 days up to 18 years old would be described as a stroke in childhood or adolescence.

Stroke can have different effects depending on where it has happened in the brain, the size of the damaged area and any underlying health conditions. The age of the child at the time of the injury can affect their recovery. A child or young person's brain continues to develop throughout adolescence and early young adulthood, so the full impact of stroke may only be seen over time. When considering how to support young people in educational settings it is crucial to be aware of stroke in their medical history, and be vigilant for new support needs as they become apparent.

1. Ischaemic stroke

Due to a blocked blood vessel in the brain.



2. Haemorrhagic stroke

Due to a bleeding in or around the brain.



Why do childhood strokes happen?

The causes of stroke in babies and children are different to those in adults. There are also different causes of strokes in babies and older children. Children who have a stroke are usually born with one or more health conditions that raises their risk, unlike adults whose stroke risk increases with age, as well as conditions, like high blood pressure, and activities, like smoking.

Babies and children are equally likely to have a haemorrhagic stroke (caused by a bleed) or an ischaemic stroke (caused by a clot). In adults most strokes are ischaemic, and haemorrhagic strokes are much less common.

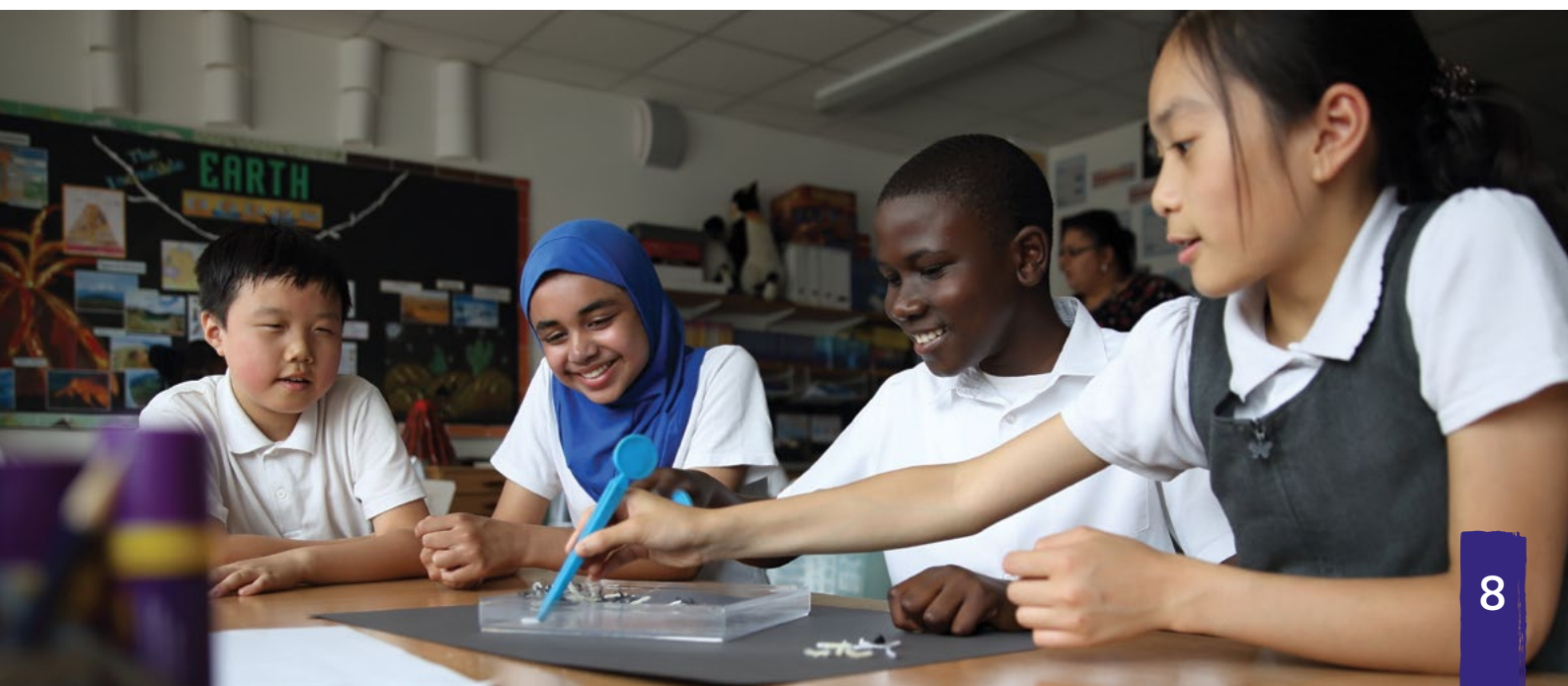
Strokes in babies before, during and just after birth are mainly caused by blood clots from the placenta, or because of a blood clotting disorder the baby or the mother may have.

Strokes in children from 28 days to 18 years are often linked with heart disorders. Sometimes these are only diagnosed after a stroke. Sickle cell disease is an inherited blood condition that can cause strokes in children and young adults. Blood clotting disorders can make blood more sticky and likely to clot, or they may cause excess bleeding which can make a bleed in the brain more likely.

Rare problems with blood vessels (vascular disorders) such as a tear in an artery wall (arterial dissection), moyamoya disease, and inflammation in the blood vessels (vasculitis) can cause a stroke. An infection like chicken pox can raise the risk of a stroke, especially if there is an underlying problem with the heart or blood vessels. A bleed in the brain can be due to a malformed area of blood vessels in the brain. Children can also have an aneurysm, which is a bulge in an artery wall that may lead to bleeding in the brain.

Often a stroke is due to more than one risk factor, such as an infection on top of a heart problem. But in some cases, there is no obvious reason why a stroke has happened. It's not always possible to say why a stroke happened. If any parent is worried about another stroke happening, they can talk to their child's paediatrician or neurologist who may be able to provide information and reassurance.

When supporting a child, it's important to be aware that the whole family may be affected by the stroke diagnosis, and that investigations and tests may continue for some time.



4. Childhood stroke diagnosis and treatment

When a child has had a stroke they should be taken to hospital for diagnostic tests and checks, assessment, treatment and rehabilitation. If a baby has had a stroke, they might be treated in a neonatal or special care baby unit, while an older child is usually admitted to a children's ward or specialist neurology centre. Older teenagers are sometimes admitted to adult stroke units. A brief summary of each stage of this process is outlined below.

Diagnosis

As part of confirming the stroke diagnosis and deciding on possible causes and treatments, a child may undergo some of the following tests:

- brain scans to identify the area of the brain affected and examine the blood vessels in the brain
- blood tests to check for infections or blood clotting problems
- echocardiogram to look at the structure of the child's heart
- ultrasound examination of the blood vessels in the brain if the child has sickle cell disease.

Treatment

A child with a stroke due to a clot may be given blood-thinning medication as part of their treatment, and to reduce the risk of another clot forming.

Clot-busting drugs (thrombolysis) to remove the clot, and surgery to remove the clot (thrombectomy) may be appropriate in a small number of cases.

Some children need brain surgery for different reasons – this includes relieving pressure on the brain, restoring blood flow, or repairing an area of weakness in blood vessels supplying the brain.

A child might be given blood transfusions and anti-sickling treatment for sickle cell disease.

Assessment and rehabilitation

A swallowing assessment should be carried out after a stroke to make sure the child can eat and drink safely and aren't at risk of choking. Children and young people usually undergo multidisciplinary assessment by different therapists looking at a range of skills including balance and movement, speech and language and memory and thinking skills. A dietician can advise along with a speech and language therapist on eating and drinking.

5. The impact on the family

The process of getting a stroke diagnosis, undergoing assessment and accessing treatment and rehabilitation may involve a number of different challenges for families. Here are some things to be aware of when planning longer-term family support:

- Children may have been to more than one hospital in order to access assessments and treatments, such as going from a local hospital to a specialist children's hospital. This may have involved travelling some distance from the family network, and separation from family and siblings.
- Children may have gone through many tests and procedures, like scans, blood tests and surgery, and might be aware that they may have to go through some of these again on future visits to hospital.
- Children may have been too unwell while in hospital to do much therapy or rehabilitation, for example if they were recovering from heart surgery, or a sickle crisis. So access to intensive therapy at home and at school can be very important.
- Some children and young people may be discharged home relatively quickly, sometimes within a week, if they are medically well. The chance to process what has happened and talk about it may only come once they are home and in a familiar setting.
- It is unlikely that families will have met anyone else in the hospital with the same diagnosis, and they might be feeling isolated.

- Children will have missed time off school and time with friends – they may have missed events that are important to them.

Parent's story

" Finding out your child has had a stroke is a huge shock and can be extremely isolating as so few people are aware of stroke affecting younger people. We did lots of research ourselves at home as there was little provided for us by the hospital and his stroke was secondary to other major health issues, where much more support and information was available."

Parent's story

" We found it difficult not having anyone else who understood what we were going through. Our daughter got upset when a supply teacher didn't believe her when she said her brother had had a stroke. Getting in touch with other parents through the Stroke Association really helped."

Parent's story

" You feel completely lost and overwhelmed. Having someone to point you in the right direction for support makes all the difference."

Parent's story

" To most people, strokes are associated with old age. The first comment is always 'he's very young for a stroke' – natural but not helpful."

Did you know?

- There are over 400 childhood strokes a year in the UK. (4)
- Around three quarters of all childhood strokes are in children aged under 10 years old. (4)
- In children, around 50% of strokes will be due to a clot (ischaemic stroke), and 50% to a bleed (haemorrhagic). (4)
- The risk of stroke is 19 times higher in children with congenital heart disease. (4)
- Children with sickle cell disease are over 300 times more likely to have a stroke than other children. (4)
- Stroke can affect previously healthy children, and it's not always possible to identify the cause. (2)

Childhood stroke survivors often have to manage long-term consequences of their stroke. These may be changes in mobility and movement, or changes in communication, learning skills, mood and confidence. (2)

New childhood stroke guidelines were launched by the Royal College of Paediatrics and Child Health and the Stroke Association in 2017 (rcpch.ac.uk/stroke-guideline). If you are a professional who works with young people, be aware that babies, children and young people can have strokes too and be vigilant for the signs of stroke.



When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

We're here for you. If you'd like to know more please get in touch.
Stroke Helpline: **0333 567 0841**
Website: stroke.org.uk/gethelp
Email: info@stroke.org.uk
From a textphone: **18001 0303 3033 100**

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