

# Stroke in childhood



**Guideline for parents, carers, and families of children and young people affected by stroke**

*Based on the 2017 Stroke in Childhood: Clinical guidelines for diagnosis, management, and rehabilitation*

**May 2017**

**Stroke**  
Association

**RCPCH**  
Royal College of  
Paediatrics and Child Health  
*Leading the way in Children's Health*

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# Acknowledgments

This guideline is based on the 2017 Royal College of Paediatrics and Child Health (RCPCH) guideline, *Stroke in Childhood: clinical guidelines for diagnosis, management, and rehabilitation*.

## Funding

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## Guideline preparation

The content in this guideline was developed and reviewed by the Royal College of Paediatrics and Child Health (RCPCH) Clinical Standards Team, led by Dr Anne Gordon:

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- Dr Claire Friedemann Smith - Systematic Reviewer
- Sara Haveron - Project Coordinator

## Guideline review

The guideline was reviewed by the Stroke Association, the parents and carers of the parent/carer and young people engagement workshops (via workshops and discussions), and parents from the RCPCH Stroke in Childhood guideline development group.

# Who is this guideline for and what does it cover?

This guideline is for parents, carers, and families of children and young people who have had a stroke. It is about children from the age of 29 days to 18 years, and does not cover babies who have a stroke in the womb, or from birth to 28 days.

The information is based on detailed clinical guidelines produced for healthcare professionals who are involved in the care of children and young people affected by stroke. These guidelines are available from the Royal College of Paediatrics and Child Health (RCPCH) at [www.rcpch.ac.uk/stroke-guideline](http://www.rcpch.ac.uk/stroke-guideline).

This information is designed to help you understand what a stroke is, why strokes occur, and how children and young people affected by stroke should be treated and cared for. It describes the usual journey from diagnosis to rehabilitation that a child or young person will follow after a stroke and will outline what you should expect at each stage of treatment and rehabilitation.

The information given here may not answer all of your questions, but it is a starting point to guide you to find further information and advice. You will find a *Glossary* with definitions that your doctor might use on pages 24 to 27 (throughout this document, terms that are included in the *Glossary* are written in **bold**).

You may also use this guideline to help raise awareness and as a source of information for people that will come into contact with your child. This guideline was created with the input of parents of children and young people who have had a stroke and also includes advice from them which you will find in the *Parent Advice* boxes.



Look for this symbol throughout the guideline for advice just for you.

We hope this guideline helps you to make more sense of childhood stroke and the journey you and your family are about to begin.

As parents of the workshop said:



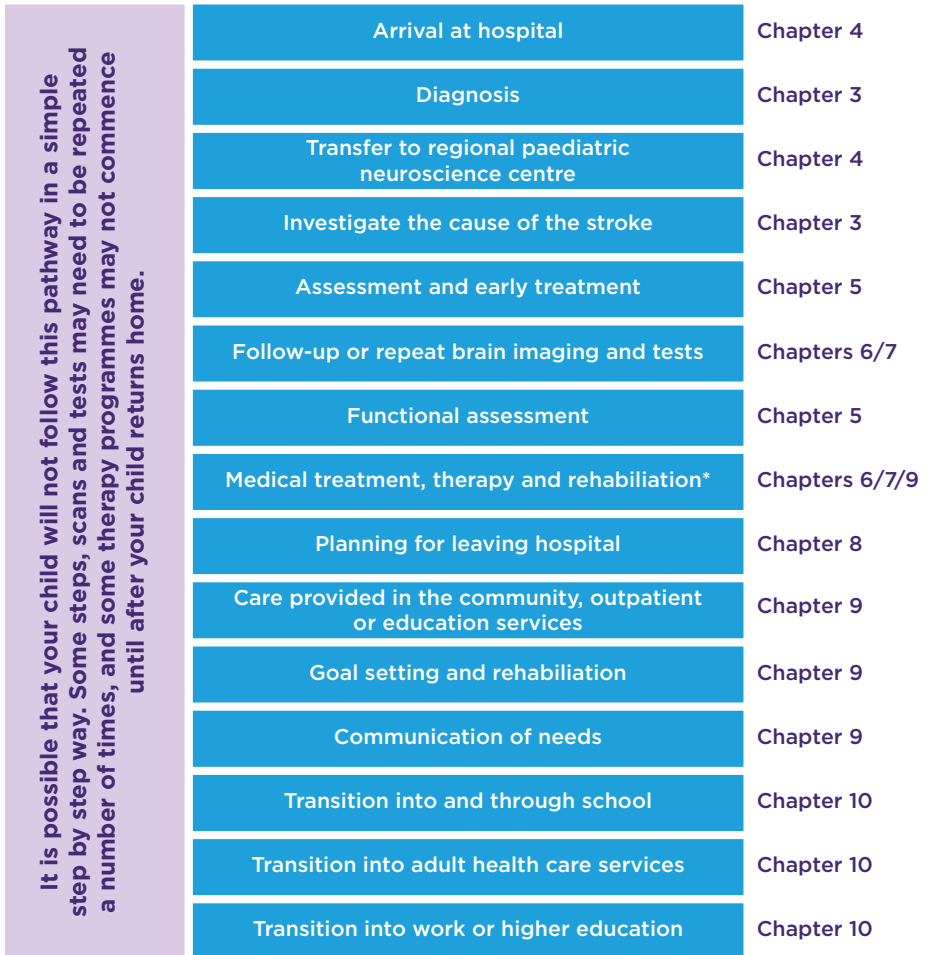
**This is a difficult time and a big shock. You will need time to come to terms with this.**

**We would have liked to have had access to more information on stroke.**

# Childhood stroke care pathway

Image 1 shows a care pathway that children and young people who have had a stroke typically follow. This is included as a guide and you can find a more detailed version towards the back of this guideline.

Each stroke and each child are different, and therefore your child may not follow each stage of the pathway consecutively and may need to repeat or skip stages. The following care pathway also provides a reference to the relevant Chapters in the full guideline, which offer more information on each of the stages. A more detailed version of this image, with descriptions of each stage, can be found on pages 18 to 21.



\* rehabilitation needs and access to services may start in hospital but should be reviewed periodically in the months and years after diagnosis.

Image 1: Diagram of treatment pathway following childhood stroke

# What is a stroke?

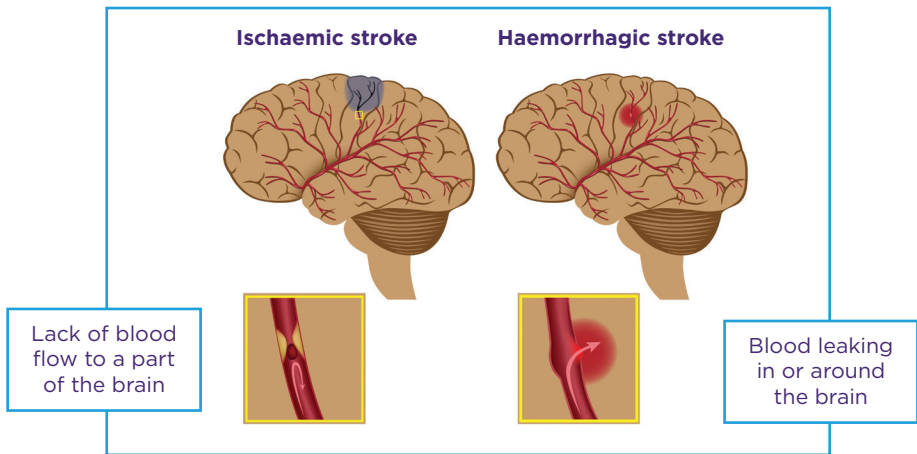
A stroke occurs when part of the brain becomes injured due to a disturbance of its blood supply. Stroke affects several hundred children in the UK each year. Over the last 15 years there have been improvements in the diagnosis and treatment of childhood stroke, but the condition is still not as well recognised as strokes in adults.

Stroke affects neurological functions, that is, functions that are controlled by the brain. For example, a stroke may affect memory, movement, and speech.

Since a child's brain is still developing, the full effect of the stroke may only be seen as the child grows.

As shown in Image 2, there are two main types of stroke:

- **Ischaemic:** this is caused by a blockage of the blood supply to an area of the brain
- **Haemorrhagic:** this is caused by bleeding in or around the brain.



*Image 2: Side-view of brain showing the blood vessels for both ischaemic and haemorrhagic stroke*

Both types of stroke cause damage to brain cells and therefore the resulting difficulties experienced by your child will depend partly on which area of the brain is affected.

When a stroke occurs, some brain cells die. Brain cells that have died cannot start working again; however, those just outside the area of the dead cells may recover as the swelling caused by the stroke reduces. Recovery can also occur as other parts of the brain take over from areas that have died. Stroke may affect children in different ways, some of which may be longer lasting than others. These changes may vary as your child grows and develops.

# What are the signs of stroke in children?

Similar to adults, the most common sign that a child is having or has had a stroke is weakness on one side of their body (**hemiplegia**). A child's face may droop on one side and their speech might be affected. It is possible to use the **FAST** (Face, Arms, Speech, Time) criteria, as illustrated in Image 3, which are used to identify strokes in adults. It is important to remember that these symptoms can come and go, and a child or young person may seem to have recovered from the symptom. If you see anything that concerns you or is unusual for your child you should speak to your doctor urgently.

You can find more information on the **FAST** criteria at [www.stroke.org.uk/FAST](http://www.stroke.org.uk/FAST).

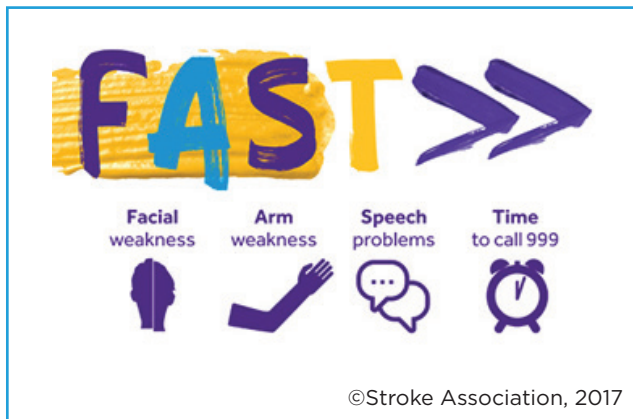


Image 3: FAST criteria

Children and young people can also show the following signs:

- Some children and young people may complain of a headache and others may have seizures (fits) at the time of the stroke. New and sudden onset of vertigo, dizziness, neck pain or neck stiffness are also sometimes signs that a child or young person is having/has had a stroke.
- Nausea/vomiting, fever or loss of consciousness can also be signs of a stroke in children, so do not discount these.

# What causes stroke in children, who is at risk, and will it happen again?

## Causes of stroke and who is at risk

The causes of stroke in children and young people are often different to adults. In adults, a stroke is often brought on by smoking, high blood pressure or 'furring up' of the arteries. There are many possible causes of childhood stroke, and these also vary with the type of stroke the individual has had and their age.

Certain conditions can make it more likely for a child or young person to have an **ischaemic** or **haemorrhagic** stroke. Examples of conditions which may increase the risk that a child has a stroke include:

- Diseases of the blood vessels (for example, **focal cerebral arteriopathy of childhood**, **moyamoya**, **arterial dissection** (torn artery), **central nervous system vasculitis**, **arteriovenous malformations** and **cavernous malformations**, **aneurysms**)
- Cardiac (heart) disease and surgery
- **Sickle cell disease (SCD)** and other blood clotting disorders
- Infections (for example, Varicella zoster virus (Chicken Pox virus), upper respiratory tract infections)
- Illicit drug use.

This list is not exhaustive and further information can be found in Chapters 6 and 7 of the full guideline.

It is important to note that not all children who have these conditions will necessarily go on to have a stroke, but if your child has a stroke it may have been caused by one of these conditions.

For around 10% of children who have a stroke, no cause is identified. Some parents ask if the fact that an older member of the family might have had a stroke is linked to their child's stroke, but it is usually not relevant.

## Will a stroke happen again?

Whether or not a stroke will happen again depends very much on the cause of the first stroke. There are some conditions or risk factors which research has shown may increase the risk that a child or young person will have another stroke. If your child has one of these conditions their doctors will try to reduce the risk of another stroke. Your doctor will be able to give you individual help and advice about your child.

Further information can be found in Chapters 6 and 7 of the full clinical guideline which is available from [www.rcpch.ac.uk/stroke-guideline](http://www.rcpch.ac.uk/stroke-guideline).

# How is healthcare organised for children affected by stroke?

Most children affected by stroke will be admitted to their local hospital for initial care and assessment. A number of tests may be carried out to explore the cause of the stroke, as this will help with the planning of your child's medical treatment. Tests may include brain scans, such as **computed tomography (CT)**, **magnetic resonance imaging (MRI)** or **magnetic resonance angiography (MRA)** scans, **catheter angiograms (CA)**, and blood tests. Medical, nursing and therapy assessments will also help plan your child's care.

Once a stroke has been diagnosed your child may be moved to and treated in a regional neuroscience unit, or in the case of children and young people with **SCD**, a haematological unit. Your child should be treated by a team of healthcare professionals from different specialities. The pathways at the back of this guideline detail the people who may be caring for your child at each stage of their care. Your child may be kept on a ward or in intensive care depending on their needs.

In the longer term, community child health services (along with your general practitioner (GP)) should coordinate services according to your child's needs. Your child should start receiving rehabilitation treatment while they are still in hospital, and after discharge this may continue either in an inpatient or residential specialist rehabilitation facility, or with community child health workers at home or in school. It is much more common for children and young people to receive rehabilitation treatment at home or in school than at a specialist or inpatient facility.

Your child's rehabilitation may involve health, education and social services and include doctors, nurses, therapists, teachers, social workers, and many other professionals. You may find it useful to have a named key contact who can help you to navigate the health and care systems. Talk to the health professionals involved with your child's health.

Good communication between your child's medical team, rehabilitation team, teachers, and your family is key, and you and your child should be involved in all decisions relating to their care.



**When you are in the hospital, ask if there is anyone who can help you coordinate information, plan your child's care/therapy needs and how you can reach them when you get home.**

**Most hospitals can now provide you with a hospital passport to complete, so you can let all health professionals dealing with the child or young person know of any specific needs they have.**

**Ask doctors to explain medical terms they use, especially when they write them in a report you might need to share with others.**

# What treatment might my child receive?

The tests that your child receives will depend on the type of stroke they have had, the cause of it and what their needs are. Some of the tests and treatments that your child may receive are listed and may be carried out at any time during their care if needed.



Scans and medical assessments will provide lots of useful information, but they cannot fully predict how your child will improve and recover.

## Investigations/tests

### Brain scans:

- **MRI** or **CT** scans might be carried out to identify the area of the brain affected and to examine the blood vessels in the brain. Depending on their age or how poorly they are, some children may need to be sedated or have a general anaesthetic to have their scan
- If your child has **SCD** they should also receive **transcranial Doppler ultrasonography**.



### Blood tests:

- Blood tests may be carried out to check for infection or blood-clotting problems.

### Echocardiogram (ECHO):

- **ECHO** looks at the structure of your child's heart. This test checks whether a clot travelling from the heart to the brain may have caused the stroke. **ECHO** is an **ultrasound** scan which is painless and safe, and is usually done by placing a small probe on the skin of your child's chest.

## Medical treatment (early treatment)

This will depend on the factors that caused the stroke. Medication to make the blood thinner and therefore less likely to clot (such as Aspirin, Heparin or Warfarin) may be considered for children and young people who have had an **ischaemic stroke**. Clot-busting medications may be considered if your child meets a set of strict criteria; your child's doctors will discuss this treatment (called thrombolysis) with you if it is being considered.

If your child has a stroke that is caused by **SCD**, they may receive a blood transfusion and anti-sickling treatment; blood transfusions may continue to reduce the risk of further strokes.

## Surgical treatment

Some children and young people are offered surgery to relieve pressure on their brain, to restore blood flow to the affected area of their brain either by removing a clot or improving the blood vessels supplying blood to the area, or to remove or protect an area of weakness in the blood vessels.

If surgery is being considered your child's doctors and surgeons will speak with you about the treatment they are proposing and the risks and benefits. The terms underlined within the *Glossary* at the back of this guideline include some common procedures and briefly explain how each procedure treats the cause of your child's stroke.



**Don't be afraid to ask about the tests that are being done, why they are being done and what the results are.**

**You can ask the medical team to try and give you as much advanced warning as possible so that you can plan the best way to prepare your child for tests and procedures.**

# What happens when my child leaves hospital?

Your child may spend only a short time in hospital, going home when safe to do so. You should be assigned a named key contact who will coordinate your child's discharge. Your child should be discharged with a plan for ongoing care in the community which takes into account their functioning, rehabilitation needs, and a list of the people needed to provide the therapies or treatments to meet their needs.

You and your family should be involved in meetings to plan your child's discharge, as should medical, educational, and social care professionals (when appropriate). These meetings should take place either before or shortly after your child has been discharged from hospital. At these meetings you should discuss the needs of your child as they settle into home and school life, as well as any needs they may have for support in the future.

You may find it useful to create an action plan or checklist so that you can keep track of progress as your child prepares to return home and through the early stages at home and in rehabilitation.

There may be financial resources you can access if your child has a disability or other support needs (for example, Carer's Allowance and Personal Independence Payment (PIP) also known as Disability Living Allowance (DLA)). In addition, you may be able to access other sources of practical advice and support (for example, respite and help with activities of daily living).

For a list of organisations that may be able to help, please see the Useful Contacts section at the back of this guideline. You may also be able to access advice before you go home through a hospital social worker or discharge planning coordinator.



**Going home from hospital can feel sudden and many parents feel alone when their child leaves hospital. Try to prepare by gathering as much information as possible about what you will need to know when you get home.**

**Ask if you can talk or meet other parents - most local authority areas will also have a Parent Carer Support group where you can get help from other parents.**

**Ask who you can expect to see for follow-up, therapy and support, and who you can contact if you have any questions when you get home.**

# What kind of rehabilitation and support should my child receive?

The effects of a stroke in childhood vary according to your child's age, development level, cognitive abilities (for example, ability to pay attention, to problem solve and to remember), and the area of the brain in which the stroke happened.

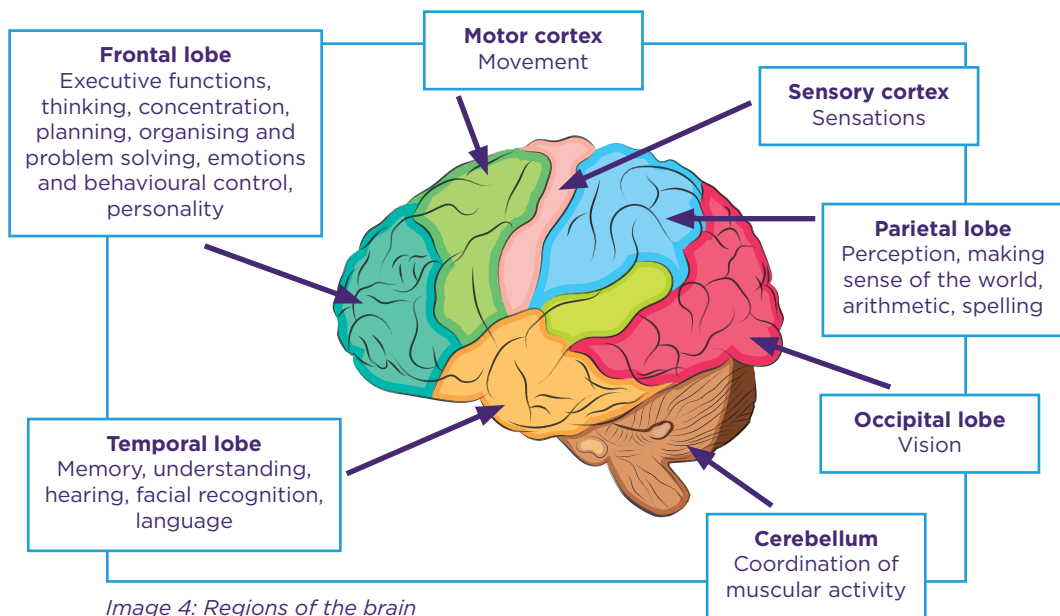


Image 4: Regions of the brain

As shown in Image 4, different parts of the brain are involved in different functions. In young children the brain is continuously developing and changing rapidly, and so the functions may not yet be fixed in specific areas as shown in this image.

As the brain and body are healing and recovering from having had a stroke it is normal for your child to feel tired. This symptom may last many months or years after the stroke has taken place.

## How will the rehabilitation needs of my child be measured?

You and your child should be actively involved in decisions about their rehabilitation. Your priorities will be used to set goals for therapy and you are likely to be actively involved in the therapy programme with your child. The kind of rehabilitation that your child will receive will be based on assessment of their unique needs and priorities. Treatments and therapies will be tailored to help your child continue to develop the skills they need in daily life.

## When will my child's rehabilitation start?



After your child's stroke, rehabilitation should begin as soon as possible. In the first few days your child's movement and positioning, swallowing, speech and communication will be assessed; this should form a baseline to measure your child's progress against.

These assessments should involve a number of different healthcare professionals, and they will inform the community health team in your local area so that care can continue once your child goes home. The healthcare professionals will agree some goals for rehabilitation with you and your child, which will also be used to evaluate the effect of the rehabilitation.

You should be informed and involved in all aspects of rehabilitation for your child.

The healthcare professionals should involve you and your family in all aspects of this process and you should be able to ask questions or express concerns if you have any. The needs of your family should also be considered in rehabilitation planning.

## Where will rehabilitation take place and what will it involve?

Your child's rehabilitation should take into account all aspects of their health and wellbeing. Once your child has left hospital their rehabilitation may take place:

- At the hospital as an outpatient
- In a rehabilitation unit
- At home, school or community clinics with the input of community therapists.

The areas that rehabilitation therapies may aim to improve include any abilities affected by the stroke (for example, movement or speech, making adaptations to cope with changes in abilities, developing skills in daily activities like self-care, school, and play, and social, emotional and practical support).



Your child's rehabilitation will include **interventions** or therapies to address any problems they might be experiencing, and assess their environment so that they can be supported in their recovery. The healthcare professionals working with you and your child will be able to recommend specific therapies that will help with their recovery.

Your child should be given a rehabilitation plan to guide you around what to do and how much. It is worth noting that rehabilitation is unlikely to be continuous, and may happen in packages (for example, in sessions over a number of weeks).

During rehabilitation your child should be working towards SMART goals (Specific, Measurable, Agreed, Realistic, and Time-bound) which have been agreed with you, your family, and your child. Progress against these goals should be measured and tracked. It is likely that these goals will change as your child achieves them, or as they grow and their needs and priorities change.



## When will my child's rehabilitation finish?

Recovery from a stroke in childhood is different for each individual and is a process that can take many years and may continue into adulthood. Support needs may change or emerge over time and your child's progress may need to be reviewed periodically.

Wherever rehabilitation is being delivered, you should have a named key contact. This person can also be used to help you find out about the different types of support available and what to expect next. The Useful Contacts section at the back of this guideline contains contact details of organisations that may provide you with additional support if needed.



**Ask which type of rehabilitation and therapy will benefit your child.**

**The needs of a child can also change, so talk to your local doctor or therapist if you have any concerns or if your situation changes. They can make a referral back to specialist services if needed.**

**Talk about what your child was able to do before they had their stroke so that therapists have a sense of their abilities and interests.**

**Your paediatrician is a key person in your child's recovery and they are able to help in many different ways. Speak to your paediatrician if there is something that you need.**

**So many different things can be affected by a stroke that you would not think of, things like memory and emotions. Fatigue can be a factor in this and may affect school and home life.**



”

The impact of a childhood stroke on any family is devastating. There's certainly an element of shock. You've had a previously healthy child and suddenly you're in a world dealing with hospitals, disability, long-term rehabilitation and educational problems.

# What long-term care will my child receive and how will they be supported?

## School

After discharge from hospital, returning to or starting school for the first time may be a major milestone for your child. This is something which needs to be carefully planned and a gradual return may be advisable. Fatigue is very common after stroke and a reduced time-table and introduction of rest breaks may help. Keeping in touch with friends during your child's recovery period can help them to settle back into school and home life.

There should be regular communication between health professionals (and possibly social care professionals), and your child's school to ensure that the school is prepared for any new needs your child may have. Your child's teachers should be given information on childhood stroke so that they are also prepared to support your child, including any relevant medical therapy or psychology reports. Your child's peers should also be informed about the effects of the stroke, and the changes it has made. This will ease your child's return to school and to minimise the risk of bullying.

You and your family should also have an easy way to communicate with the school and the school should keep you informed of your child's progress.



Part of your child's rehabilitation may take place at school so that absence is minimised and to help them feel more included. This rehabilitation can range from extra support in the classroom or **interventions** to target particular difficulties, to a comprehensive Education, Health and Care Plan (EHCP - formerly called a Statement of Special Educational Needs). Your child's health professionals and teachers should discuss the kind of support needed with you and your child.

When your child reaches the stage that they need to transition to another school, higher education or work, meetings to plan this should be held as early as possible. Your child should be actively involved in planning for their future and should receive support to plan for adult life and to build life skills. This support in life skills can involve planning for housing, money management, and employment as appropriate.

If your child has additional needs for support at school, whether this is short-term or long-term, the Special Educational Needs and Disabilities Coordinator (SENCo) at school will be able to support your child and your family as they transition into and through their education. The role of the SENCo or a named key contact may change as your child grows and their needs change.

## Young person to adult healthcare

Some young people may require specialist support into adulthood.

The transition from child to adult healthcare can present challenges as the young person is expected to take more responsibility for their own health. The young person should be supported to manage their physical and mental health in advance of and during this transition time as well as any other issues that may become relevant, such as relationships.

You should have the opportunity to meet with health professionals to make a plan according to your and the young person's needs and priorities. You and the young person should be told in writing who the healthcare professionals are that will be involved in their future care, what each of the professionals' roles and responsibilities are, and how you can contact them.

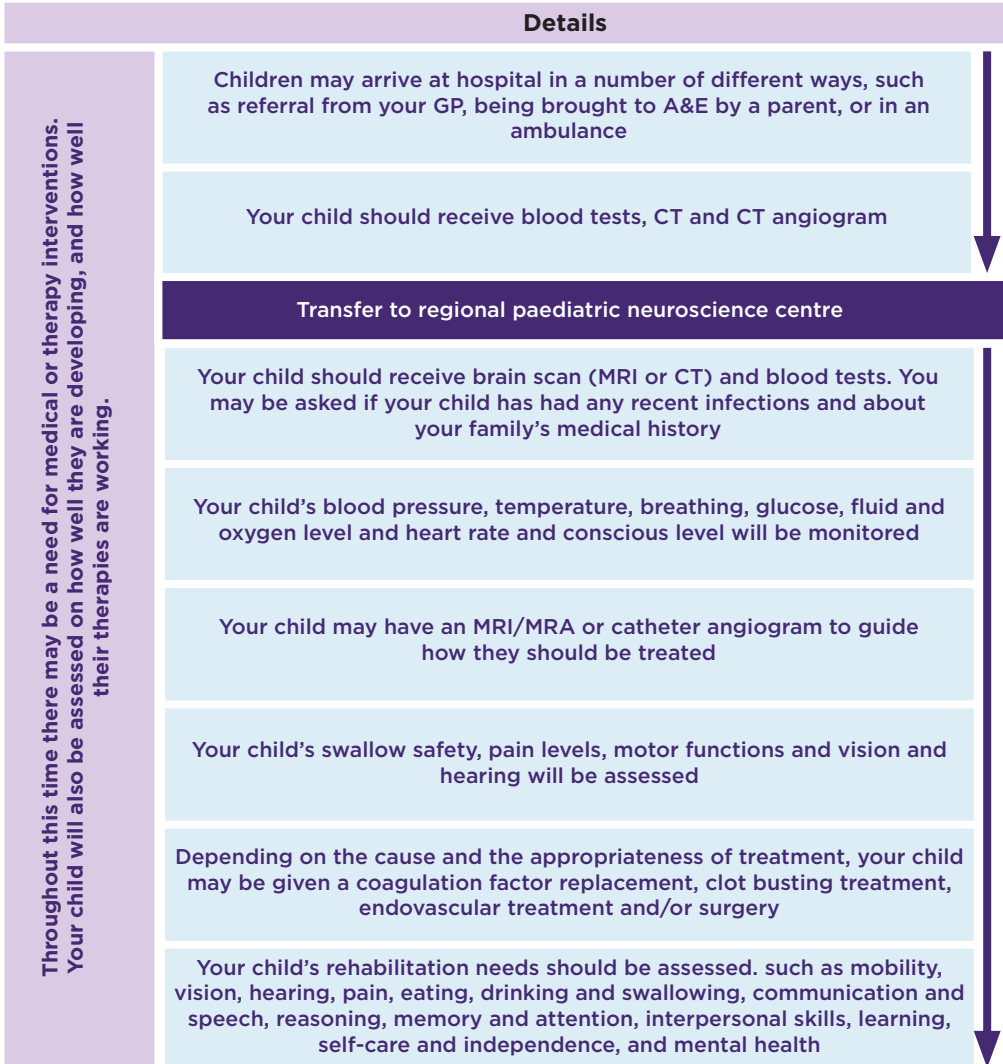


**You may find it helpful to ask a medical team or charity to visit your child's school to explain about stroke and the impact on everyday life.**

# Childhood stroke care pathway

Below shows the treatment pathway that your child will follow and is a more detailed version of the pathway earlier on.

During the time your child spends in hospital they may be placed in intensive care or on a ward. Your child may not follow each stage of the pathway in order but may skip or repeat stages at any time. You should be kept informed throughout this pathway, both in hospital and after your child is discharged.



## People you might meet

Arrival at hospital

Consultant emergency doctors, neurologists, paramedics

Diagnosis

Neurologists, nurses, radiographers, radiologists

Investigate the cause of the stroke

General paediatricians, haematologists, neurologists, paediatric nurses, radiologists

Assessment and early treatment

General paediatricians, neurologists, occupational therapists, paediatric nurses, physiotherapists, speech and language therapists

Follow-up or repeat brain imaging and tests

Neuroradiologists, neurosurgeons, radiologists

Functional assessment

Haematologists, neurologists, neuroradiologists, neurosurgeons

Medical treatment, therapy and rehabilitation\*

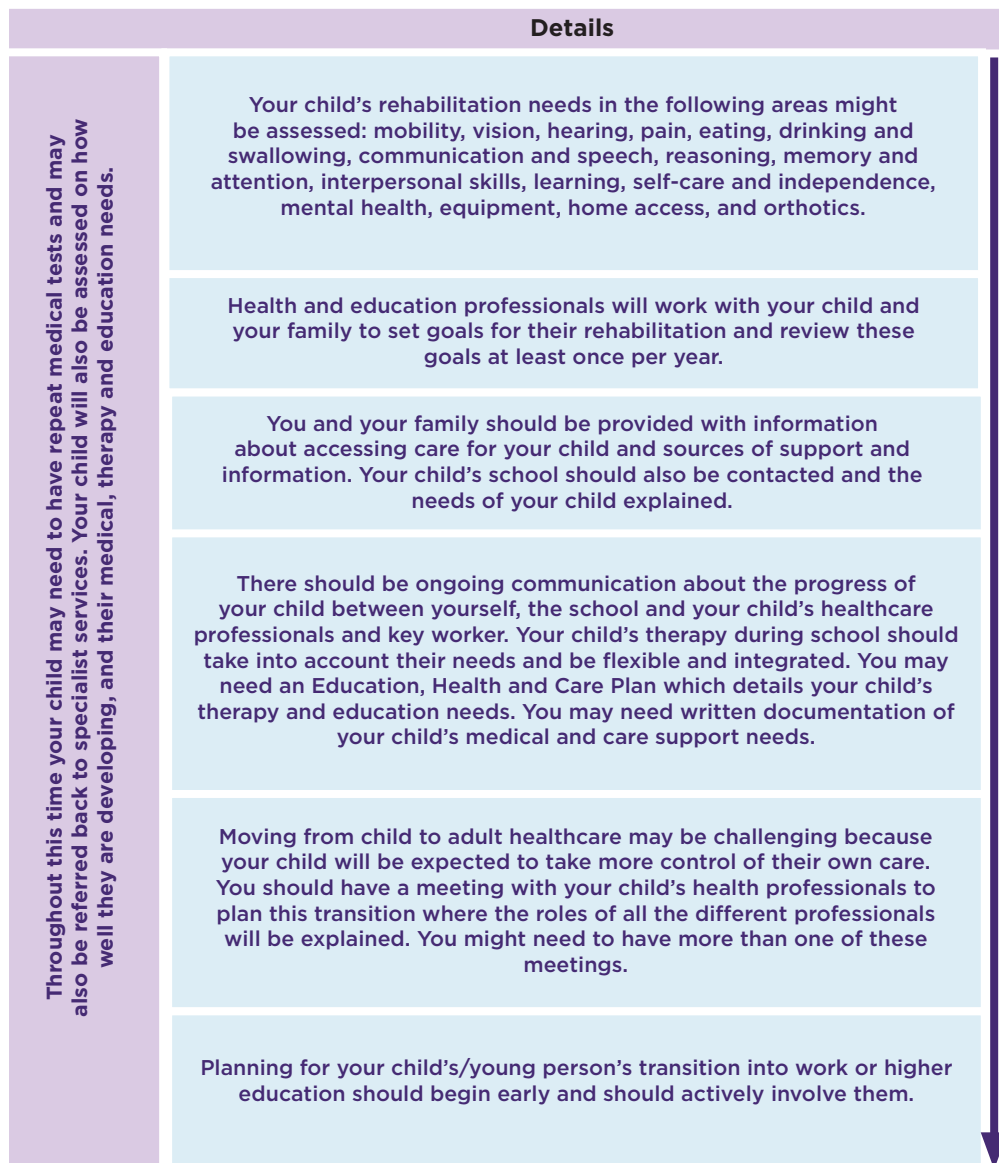
General paediatricians, haematologists, neurologists, paediatric nurses, radiologists

Assess rehabilitation needs

Physiotherapists, occupational therapists, clinical psychologists, community nurses, counsellors, neuropsychologists, orthotics and splinting services workers, paediatricians, speech and language therapists, visual and hearing support workers

# Childhood stroke care pathway (cont.)

Below shows the continued treatment pathway that your child will follow, focussing on the care provided in the community, as an outpatient, or via education services.



## People you might meet

### Assess rehabilitation needs

Child psychologist, clinical psychologists, community nurses, counsellors, educational psychologists, neuropsychologists, occupational therapists, orthotics and splinting services workers, paediatricians, physiotherapists, visual and hearing support workers, speech and language therapists, teachers, your child's school's Special Educational Needs and Disability Co-ordinator (SENCo)

### Goal setting

These goals should be set with your child, yourself, your family and the relevant health and education professionals as listed

### Communication

You should be referred to the Children with Disabilities Team. You may also meet your educational psychologists, paediatricians, social workers, teachers, your child's school's SENCo

### Transitions into and through school

Depending on your child's needs you may meet educational psychologists, occupation therapists, physiotherapists, neuropsychologists, social workers, speech and language therapists, the school's SENCo, teachers

### Transitions through health care services

Adult health professionals (for example doctors, therapists), general practitioners, occupational therapists, psychologists, social workers, your paediatrician. Your key worker should also be present. Bear in mind that your child's key worker may change as their needs change

### Transition into work or higher education

College/university staff, educational psychologists, job centre advisors, social workers, your key worker

## Where can I get more help and information?

There are number of organisations that will be able to provide support and advice. Those listed have been recommended by clinicians and parents.

| Organisation                                  | How can they help?                                                                                        | Contact details                                                                                  |
|-----------------------------------------------|-----------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
| <b>Brain Injury Hub</b>                       | Information and resources for children and young people with brain injury.                                | <a href="http://www.braininjuryhub.co.uk">www.braininjuryhub.co.uk</a>                           |
| <b>Cerebra</b>                                | Advice and guidance on a wide range of topics including the Disability Living Allowance.                  | <a href="http://www.w3.cerebra.org.uk">www.w3.cerebra.org.uk</a>                                 |
| <b>Child Brain Injury Trust</b>               | Practical and emotional support of children, young people and their families.                             | <a href="http://www.childbraininjurytrust.org.uk">www.childbraininjurytrust.org.uk</a>           |
| <b>Contact a Family</b>                       | Provide information, advice and support to bring families together to support each other.                 | <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>                                     |
| <b>Council for Disabled Children</b>          | Range of resources for parents, social workers, teachers and other professionals.                         | <a href="http://www.councilfordisabledchildren.org.uk">www.councilfordisabledchildren.org.uk</a> |
| <b>Disability Grants UK</b>                   | Search for grants from local and national funders for a range of purposes.                                | <a href="http://www.disability-grants.org">www.disability-grants.org</a>                         |
| <b>HemiHelp</b>                               | Provide information, support and guidance to people with hemiplegia and their families in the UK.         | <a href="http://www.hemihelp.org.uk">www.hemihelp.org.uk</a>                                     |
| <b>Sickle Cell and Young Stroke Survivors</b> | Support for children, young people and their families who have been affected by SCD and childhood stroke. | <a href="http://www.scyss.org">www.scyss.org</a>                                                 |

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| <b>Stroke Association</b> | Source of information and support for people who have had a stroke and their families. Provides resources for children and families and links to peer and social media support.                                                      | <a href="http://www.stroke.org.uk/childhood">www.stroke.org.uk/childhood</a> |
| <b>YouGov</b>             | At the heart of our company is a global online community, where millions of people and thousands of political, cultural and commercial organisations engage in a continuous conversation about their beliefs, behaviours and brands. | <a href="http://www.yougov.co.uk">www.yougov.co.uk</a>                       |

# Glossary

| Term                                     | Definition                                                                                                                                                                                                                                                                                                                                                                                                     |
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| <b>Aneurysm</b>                          | A bulge like a balloon in a blood vessel which is caused by a weakness in the blood vessel wall. An aneurysm can grow over time (or rupture) and can cause bleeding in the brain.                                                                                                                                                                                                                              |
| <b>Arterial dissection</b>               | A partial tear in an artery wall. Once a tear develops, blood can clot at the site of the tear which can block the artery, or the clot can break free and block the artery further up.                                                                                                                                                                                                                         |
| <b>Arteriovenous malformation (AVM)</b>  | A tangle of blood vessels which connect arteries carrying oxygen rich blood to veins carrying oxygen depleted blood. Blood from the arteries gets diverted into the veins before it can supply brain tissue with oxygen and nutrients. The tissue that is no longer being supplied properly by the arteries may malfunction and the AVM itself can rupture and bleed into the brain.                           |
| <b>Catheter Angiography (CA)</b>         | A technique used to get an image of blood vessels. A dye is injected to make the blood vessels more clearly visible and an image is taken using an x-ray to generate a movie of the blood flowing through the vessels.                                                                                                                                                                                         |
| <b>Cavernous malformation</b>            | A cluster of abnormal, dilated blood vessels which often looks like a raspberry. Blood flows more slowly through these dilated vessels and since the cell lining of the cavernous malformation is often thinner than that of normal blood vessels, they can leak blood and sometimes haemorrhage into the brain.                                                                                               |
| <b>Central nervous system vasculitis</b> | Inflammation of the blood vessel walls in the brain or spine. The inflammation in the blood vessel walls reduces the space through which the blood can flow, blocking the flow of oxygen to the brain.                                                                                                                                                                                                         |
| <b>Clipping</b>                          | A surgical treatment for aneurysms where a small metal clip is placed at the bottom of the aneurysm, preventing blood entering the aneurysm and removing the risk of bleeding.                                                                                                                                                                                                                                 |
| <b>Computed Tomography (CT)</b>          | A technique similar to an x-ray that is used to get images of the inside of the body which can be used to diagnose a stroke. During the scan multiple x-ray beams are aimed at the person being scanned and x-ray detectors measure how much of the x-rays are being absorbed. A computer turns this data into an image. For children, the CT scanner technique will be adjusted to reduce the radiation dose. |

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| <b>Computed Tomography Angiography (CTA)</b>    | A technique used to get an image of blood vessels. A dye is injected to make the blood vessels more clearly visible in the image and a CT scan is performed. CTA is generally not painful but there may be some discomfort from having to lie still and having the dye injected. Children may need to be sedated to keep them still during scanning.                                                                                                            |
| <b>Decompressive craniectomy</b>                | A surgical procedure where a portion of the skull is temporarily removed to relieve pressure on the brain when there is bleeding or swelling. Later a 'cranioplasty' is put back to protect the area.                                                                                                                                                                                                                                                           |
| <b>Echocardiogram (ECHO)</b>                    | A scan used to look at the heart and the surrounding blood vessels. Your child will need to remove any clothing covering their upper half and small sticky sensors called electrodes will be attached to their chest to monitor their heart rhythm during the test. Gel will be put on their chest and a probe will be moved across their skin. This probe will send images to a machine nearby. The scan is painless and no radiation is used.                 |
| <b>Embolisation or endovascular surgery</b>     | Endovascular surgery is used to treat problems with blood vessels, for example, aneurysms. A small cut is made near the hip and a catheter is passed up the artery to the location of the aneurysm. A material such as coils or glue is then placed permanently in the aneurysm to seal it off and prevent it rupturing.                                                                                                                                        |
| <b>FAST criteria</b>                            | <p>An acronym to help recognise the signs of a stroke. The letters stand for:</p> <ul style="list-style-type: none"> <li>• Face: can the person smile? Has their face fallen on one side?</li> <li>• Arm weakness: can the person raise both arms and keep them there?</li> <li>• Speech problems: can the person speak clearly and understand what you say? Is their speech slurred?</li> <li>• Time: if you see these signs it's time to call 999.</li> </ul> |
| <b>Focal cerebral arteriopathy of childhood</b> | A narrowing in the blood vessels in a part of the brain for which the cause is not known.                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Haemorrhagic stroke</b>                      | A kind of stroke where a weakened part of a blood vessel in the brain bursts and leaks blood into and around the brain causing swelling and pressure and damaging the surrounding cells.                                                                                                                                                                                                                                                                        |
| <b>Hemiplegia or hemiparesis</b>                | A condition where one side of the body is paralysed which is caused by injury to the brain.                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Intervention</b>                             | An act or procedure used to improve health or reduce risk of injury. This could mean surgery, a drug, counselling, or a therapy like physiotherapy.                                                                                                                                                                                                                                                                                                             |

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| <b>Ischaemic stroke</b>                     | A kind of stroke where a blood vessel in the brain becomes blocked and a part of the brain is deprived of blood. This lack of blood supply causes damage to the affected cells.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Microsurgery</b>                         | Surgery using an operating microscope to perform operations on very small structures. It aims to remove abnormalities in blood vessels in the brain like arteriovenous malformations or cavernous malformations minimising the damage to the surrounding brain tissue. A small part of the skull will be temporarily removed and the surgery is performed under a microscope.                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Moyamoya</b>                             | A rare disease caused by the narrowing of or a blockage in the main blood vessels in the brain called the internal carotid arteries. Because the blood flow in these blood vessels is restricted, a network of small blood vessels forms to compensate. Moyamoya means 'puff of smoke' in Japanese and the name describes the appearance of the small blood vessels. The cause of moyamoya is not known and many children with it are otherwise healthy, but it can be associated with injuries to the brain, infections, or genetic conditions.                                                                                                                                                                                                                                                                                                         |
| <b>Magnetic Resonance Angiography (MRA)</b> | A technique used to get an image of brain blood vessels. In MRA usually a dye is injected or sometimes the flow of the blood itself is used to make the blood vessels clearly visible. MRA uses a magnetic field and radio waves to measure the energy emitted by hydrogen atoms in the body. The energy they emit varies depending on the body tissue that they come from and the scanner turns the measurements of this energy into images of the tissues scanned. Your child will need to lie on a moveable table that slides into the scanner. Children often need sedation so that they lie still for the whole scan. Children may be given earplugs or headphones during the scan and you may be allowed to stay in the room with your child, but you will need to be screened for safety in the magnetic environment. MRA does not use radiation. |
| <b>Magnetic Resonance Imaging (MRI)</b>     | A technique used to get an image of the brain, MRI uses a magnetic field and radio waves to measure the energy emitted by hydrogen atoms in the body. The energy they emit varies depending on the body tissue that they come from and the scanner turns the measurements of this energy into images of the tissues scanned. Your child will need to lie on a moveable table that slides into the scanner. Children often need sedation so that they lie still for the whole scan. Children may be given earplugs or headphones during the scan and you may be allowed to stay in the room with your child, but you will need to be screened for safety in the magnetic environment. MRI does not use radiation.                                                                                                                                         |

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| <b>Revascularisation</b>                    | A surgical procedure used to restore blood flow to an organ or area of the body by either unblocking or bypassing a blocked blood vessel or implanting new blood vessels. Revascularisation is used to treat moyamoya and bypasses blocked arteries in the brain either by attaching a healthy scalp artery directly to a brain artery or to the surface of the brain. New arteries then grow from this artery into the brain, restoring blood flow.                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Sickle cell disease (SCD)</b>            | An inherited disease that mainly affects people of African, Caribbean, Eastern Mediterranean, Middle Eastern, and Asian origin. People with SCD produce 'sickle' shaped red blood cells which can become stuck in blood vessels.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stereotactic radiosurgery</b>            | A very precise type of radiation therapy that uses beams of radiation to damage the cells of the abnormal blood vessels in the brain (for example in an arteriovenous malformation). After treatment and over a few years the walls of the abnormal blood vessels thicken and close off, reducing the chance of a haemorrhage. During the procedure your child will have to wear a head frame or a mask and your doctor will prepare them for this with a local anaesthetic. A CT or MRI scan will be performed to find the precise location of the abnormal blood vessels. During the treatment your child will be positioned on a treatment couch so that their head is completely still. The treatment itself is painless although your child may have some pain from the headframe. You will not be able to be in the room with your child during treatment. |
| <b>Transcranial Doppler ultrasonography</b> | A technique to monitor blood flow in the arteries using Doppler ultrasound that measures the echoes of ultrasound waves moving through the cranium (skull). The soundwaves bounce off red blood cells in the brain and a computer calculates the speed at which the cells are travelling. As with other types of ultrasound, gel will be placed on the area that is being examined and a probe will be moved over your child's skin. Your child will need to keep their head still and avoid talking during the scan. The scan is painless and does not use radiation.                                                                                                                                                                                                                                                                                           |
| <b>Ultrasound</b>                           | A technique to create an image of the inside of the body that uses high-frequency sound waves. As the sound waves bounce off different parts of the body they are picked up by a probe which creates an image. A gel will be placed onto your child's skin that will allow the probe to move smoothly over it. An ultrasound should not cause any discomfort and does not use radiation.                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |

## Key contacts and notes

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## **Stroke in childhood**

### **Guideline for parents, carers, and families of children and young people affected by stroke**

*Based on the 2017 Stroke in Childhood: Clinical guidelines for diagnosis, management, and rehabilitation*

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