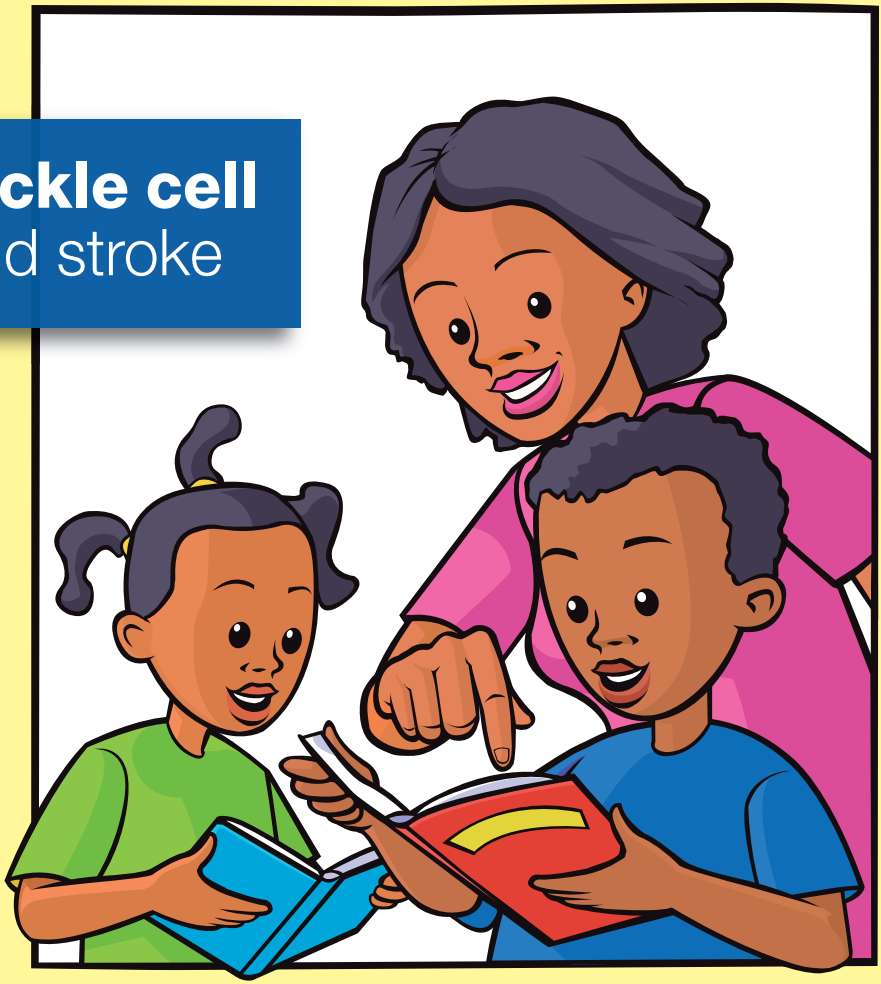
Sickle cell and stroke



The following leaflets are are also available from The Stroke Association:

- **The Stroke Association**
- **What is a stroke?**
- **Preventing a stroke**
- **When a stroke happens**
- **After a stroke**
- **Stroke rehabilitation**

The Stroke Association is the only UK-wide charity solely concerned with helping everyone affected by stroke. We are working to create a world where there are fewer strokes and all those touched by stroke get the help they need.

The Stroke Association also produces free leaflets and factsheets on specific stroke issues. To find out how to order leaflets or factsheets, or for more information on stroke, call us on **0845 3033 100**, email us at **info@stroke.org.uk** or visit our website **www.stroke.org.uk**.

We distribute two million free leaflets and factsheets every year. Help us to continue this vital service by making a donation on our website or by phoning **01604 687 777**.

The Stroke Association is 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 in Northern Ireland.

Forward by Carol Nwosu
Founder of Sickle Cell and Young Stroke Survivors

Childhood stroke is often a difficult maze to navigate; without effective support and guidance, parents and children can find it hard to find the information and help they need. This leaflet is a brief introduction to some of the issues children with sickle cell face in relation to stroke.

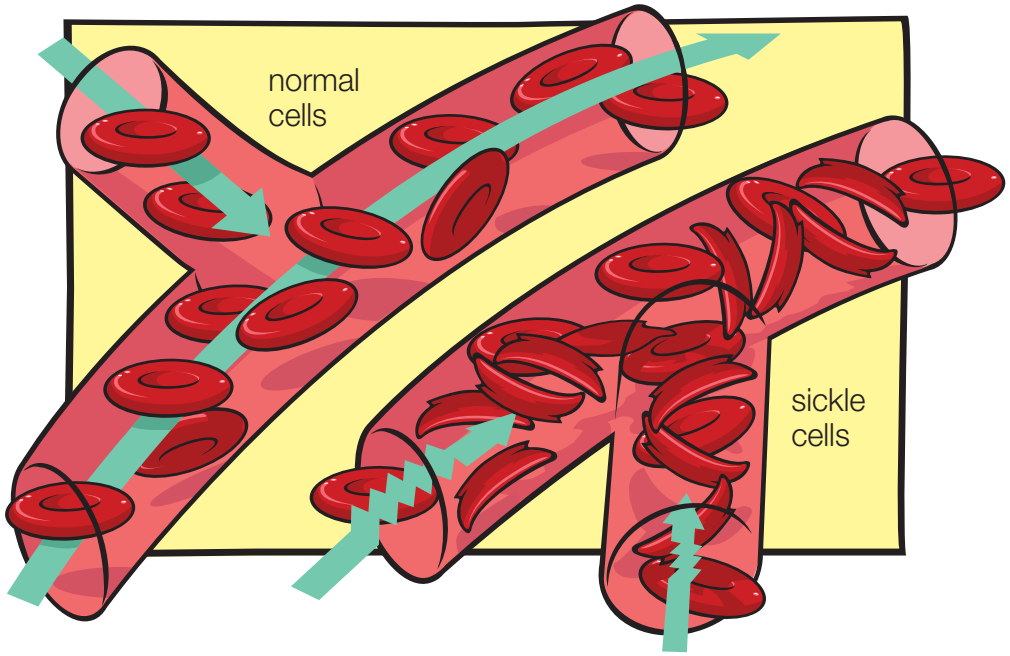
Not all the issues can be covered here, but at the end of this leaflet you will find a list of organisations that can help answer other questions you may have.

We hope this leaflet will help you understand some of the complex needs of children with sickle cell and stroke and help you to get the support necessary in providing the best care for your child.

Carol Nwosu
Founder and chief executive
Sickle Cell and Young Stroke Survivors

What is sickle cell disease?

Sickle cell disease (SCD) is a family of inherited disorders, of which the most severe and common is sickle cell anaemia (HbSS). SCD affects how red blood cells carry oxygen around the body, is a lifelong condition that affects both males and females, and is the most common genetic disorder in England. Sickle cell disease can cause fluctuating symptoms ranging from pain and infection to anaemia and fatigue.



What do sickle cells look like?

Normal red blood cells (see above illustration, left) are disc-shaped, flexible and can squeeze easily through small blood vessels. These cells contain haemoglobin which delivers oxygen to where the body needs it and give the blood cells their red colour.

People with SCD have abnormal haemoglobin. When this haemoglobin gives away oxygen it sticks together to form long rods in the red blood cell. These rods become rigid and can change the red cell from round and flexible to a shape like a sickle. It is because of this shape that sickled red blood cells cannot flow easily through small blood vessels (see illustration on previous page, right). This means the small blood vessels can get blocked and stop oxygen from flowing.

Who does sickle cell disease affect?

SCD affects mainly people of African and Caribbean descent, but people from Mediterranean and Asian backgrounds can also be affected by it.

How many people have it?

There are about 12,500 people with SCD in the UK. It is thought that the number will increase in the next 10 years.

Why do I need to know about stroke?

Children with SCD are more likely to have strokes than those without the disease. Of all people with SCD, the risk of stroke is highest in the most commonly detected type of sickle cell disease – sickle cell anaemia (HbSS).

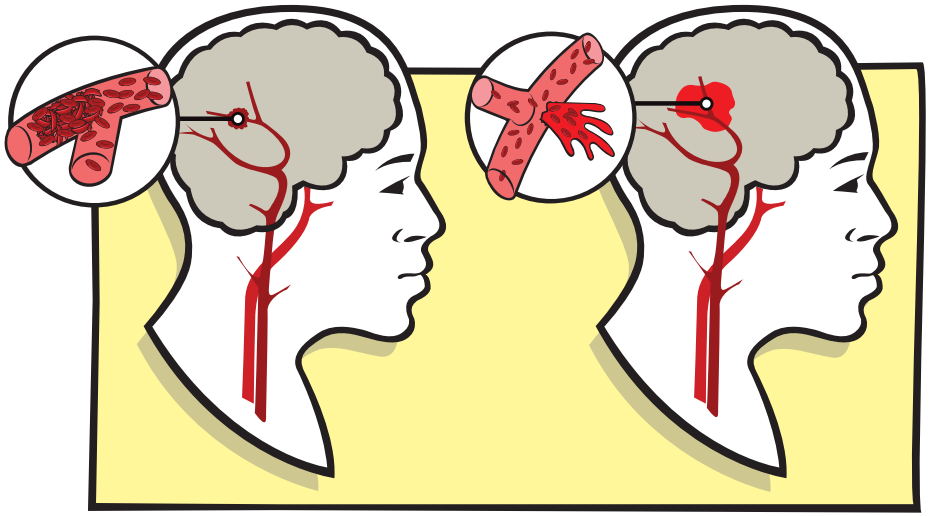
The risk of stroke in children with SCD is greatest between the ages of 2 and 16. About 10% of all children with SCD will have a stroke by the time they are 20 years old. Stroke recurrence is also a major concern for children and their families. Stroke recurs in over 60% of children with SCD.

If you have a child with SCD, make sure you speak to their doctor about the risk of stroke.

What is a stroke?

A stroke is a brain attack. It happens when the blood supply to the brain is cut off due to:

- a clot blocking the flow of blood to the brain (also known as an ischaemic stroke)
- or a bleed in or around the brain from a burst blood vessel (also known as a haemorrhagic stroke).



clot bleed

When the blood supply is disrupted, parts of the brain become damaged or destroyed. Some strokes are fatal whilst others can cause permanent or temporary paralysis to one side of the body and the loss of the ability to speak, read or write. Recovery is possible but may be slow and can vary from person to person. Children with sickle cell are at risk of having both ischaemic (a blockage; created by the build up of deformed sickle cells) and haemorrhagic (bleed) strokes, although ischaemic strokes are more common.

What are the signs of a stroke?

It is important for you to know what the signs of a stroke are.

A simple reminder is the **FAST test**.

Facial weakness
– can the person smile? Has their mouth or eye drooped?

Arm weakness
– can the person raise both arms?

Speech problems
– can the person speak clearly and understand what you say?

Time to call 999.

If you suspect a stroke, it is important to call an ambulance so that your child can be taken to hospital and have a brain scan **as quickly as possible**. This will determine what type of stroke it is, and will help with any possible treatment.

'Silent' stroke

About 17% of children with SCD also have 'silent infarcts' – strokes with no obvious symptoms at the time but which can lead to cognitive impairment (such as diminished memory, attention, emotion, concentration or reason) in the long term.

In the case of 'silent' strokes, because there are no obvious signs it is important to look out for possible long term changes in children with SCD. These could include changes in behaviour, concentration, memory, fatigue levels or handwriting.

Many parents and teachers do not know the potential risk of 'silent' stroke and can overlook or misinterpret changes in behaviour or concentration, putting it down to children playing up. In the case of children with SCD, it is important to investigate these changes just in case they ***are*** a result of 'silent' stroke.

Look out for changes in your child's behaviour and concentration. These could indicate a 'silent stroke'.

How can the risk of stroke be reduced?

It is recommended that children with SCD between the ages of 2 and at least 16, should be screened for stroke on an annual basis using an ultrasound test called Transcranial Doppler scan (TCD). TCD is a device that uses painless and harmless ultrasound (sound waves) to find areas of abnormal blood flow in the brain's blood vessels which could indicate a higher risk of stroke.

A large American study performed in the 1990s, called the *Stroke Prevention Trial in Sickle Cell Anaemia*, showed that children with abnormal TCD who receive regular monthly blood transfusions have a 90% lower risk of stroke. Children with abnormal TCD should be offered long term blood transfusions, although, as this is linked to iron overload (excess build up of iron in the body), medical decisions will need to be made on a case-by-case basis.

What is the role of schools?

Most children with SCD will attend mainstream schools and participate fully in everyday school life.

It is important for schools to be aware of children with SCD so they can ensure they are getting the best support possible from an early age in order to achieve their full potential.

The children may also look for support from their school in explaining their condition to other pupils.

Special Educational Needs (SEN)

If you are a parent of a child with SCD, make sure you ask their school about its SEN policy. Your child may not automatically qualify for special assistance, but it is important for schools to be aware of the learning and behavioural difficulties children can experience if they have had a stroke. The school should also be asked to write up a long term care plan. This would help prevent health complications within the school environment – and also help your child enjoy and get the best out of their education and school experience.

Tips for parents

- If your child has SCD, make sure you speak to their doctor to find out more about reducing the risks of stroke and other complications.
- Make sure that the school is aware of your child's condition and has drawn up a care plan.
- Provide the school with booklets to explain what SCD is.
- Make sure family members and teachers are aware of the signs of stroke and the possible indications of 'silent' stroke.

Tips for teachers

- Be aware of children with SCD in your school and draw up a care plan.
- Listen to the needs of children with sickle cell, especially regarding fatigue, dehydration and toilet needs.
- Make sure you are in regular dialogue with parents of children with SCD.
- Learn the signs of stroke and 'silent' stroke. Look out for changes in behaviour or attention as these may be signs that a child has had a 'silent' stroke.

Useful contacts

The Stroke Association
www.stroke.org.uk
Helpline 0845 3033 100

Sickle Cell & Young Stroke Survivors (SCYSS)
www.scyss.org
Tel 020 7635 9810

Sickle Cell Society
www.sicklecellsociety.org
Tel 020 8961 7795

HemiHelp
www.hemihelp.org.uk
Helpline 0845 123 2372

Different Strokes
www.differentstrokes.co.uk
Tel 0845 130 7172

Cerebra
www.cerebra.org.uk
Parent support helpline 0800 328 1159

Child Brain Injury Trust
www.cbituk.org
Helpline 0845 601 4939

Copyright © The Stroke Association 2009