

What is a stroke?

A stroke is the loss of blood supply to part of the brain. A stroke is caused when either a blood vessel in the brain is blocked or there is bleeding of the blood vessels inside the brain. Strokes are more likely to happen in children with sickle cell disease because:

- Blood vessels can get blocked by sticky sickle red blood cells (RBCs).
- Sickle cells cause the blood vessels in the brain to become narrow, making it easier for the sickle cells to get stuck.
- Blood vessels damaged by sickle cells can bleed more easily.

Strokes are more common with hemoglobin SS but can also occur in other types of sickle cell disease. They also occur more in children ages 2 to 5 years old but can occur at any age.

What happens when a

stroke occurs?

A stroke cuts off the normal blood and oxygen supplies to part of the brain, causing brain cells to die. When this happens, brain damage occurs.

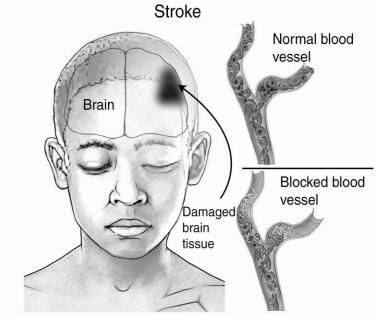
- The damaged part of the brain does not work as it should.
- The parts of the body that the brain area controls do not work well either. This is why an arm or a leg can be weak or not able to move after a stroke.
- After a stroke, a child may also have problems with memory and learning.

What are the symptoms?

Strokes can occur all of a sudden without warning. They can also occur with other sickle cell problems.

A stroke can cause 1 or more of these:

- Slurred or confused speech (when speech was clear before)
- Muscle weakness or unable to move 1 side of the body (face, arm or leg)
- Unsteady walk (when walking was normal before)
- Numbness or tingling of the arms or legs on 1 side of the body
- A very severe (very bad) headache that does not go away



- Confusion
- Seizures (jerking or twitching of the face, arms or legs)
- Loss of consciousness (passing out)
- Changes in vision (seeing)

Rarely, stroke symptoms may last for a short time and then get better. **Call your child's sickle cell provider** <u>right away</u>. Sometimes, a more severe stroke can follow.

What should I do if I think my child is having a stroke?

If your child has any of the symptoms listed above and on page 1:

- Call your child's sickle cell provider <u>right away</u>.
- Then, take your child to the nearest emergency department (ED).

Call 911 right away if your child:

- Has trouble breathing.
- Does not respond to you or passes out (is unconscious).
- Has a seizure.

What tests could my child have?

Your child will need tests to see if a blood vessel in the brain is blocked or if bleeding has occurred. Tests may include:

- A physical exam
- Blood tests, including a cross match for a blood transfusion
- CT scan or MRI of the brain
- Neurological exam to check how well the brain, nerves and muscles are working

What is the treatment?

Some guidelines for treating a stroke include:

- Intravenous (I.V.) fluids.
- Medicines to help prevent or treat seizures.
- Oxygen treatment if oxygen levels are low.
- Blood transfusions to help get more oxygen to the brain through the blood.
- An exchange transfusion to replace the sickle cells with normal RBCs. This may help the damaged brain tissue recover more quickly.
- In rare cases, your child may need surgery relieve pressure from bleeding inside the brain.
- Further treatment with specialists, such as neurologists (doctors who treat problems with the brain and nerves).
- Treatment of fever and infection as needed.

• Steps to reduce crying and hyperventilation (very fast breathing and exhaling more than you inhale).

What follow-up care does my child need?

After your child goes home from the hospital, follow-up care is very important. Your child will need more treatment and care, which may include:

- Check-ups, exams, blood tests and a treatment plan in the sickle cell clinic.
- Physical, occupational and speech therapy to help retrain and strengthen parts of the body affected by the stroke.
- Follow-up with a neurologist to check your child's progress and watch for any problems.
- Follow-up with a psychologist (a doctor who helps with problems with learning and behavior) to find out if other treatments are needed.
- Working with teachers and other learning specialists to get special help with schoolwork. This is needed because a stroke can damage parts of the brain that control learning, reading, language or math.

How can I help decrease the risk of another stroke?

Seventy percent (7 out of 10) of children with sickle cell disease who have had a stroke will have another stroke if they do not get proper treatment. Treatment to help prevent another stroke may include:

- Blood transfusions each month to help decrease the number of sickle cells that block blood vessels in the brain.
- Exams, tests and MRI scans to check the nerves and brain.
- Special brain blood vessel surgery to go around blockages in the brain.
- A bone marrow transplant, which can cure sickle cell disease.

What can I do to help prevent my child from ever having a

stroke?

A brain ultrasound test called a transcranial doppler (TCD) can show if your child is at a higher risk of having a stroke. Talk with your child's doctor or nurse and ask for a teaching sheet to learn more about TCD.

- If your child has SS or S beta zero thalassemia, your child should get a TCD at least every year starting at around 2 and until 16 years old.
- If TCD results are not normal, your child may need blood transfusions each month to help prevent a stroke.
- TCD screening has decreased the number of children with sickle cell disease who have strokes, so it is very important to make sure your child gets this test at least 1 time each year. In some cases, the doctor may want your child to have the test more often.
- Hydroxyurea treatment may also decrease your child's risk of stroke.
- Bone marrow transplant to cure sickle cell disease can also prevent stroke.

What is a "silent stroke"?

A silent stroke is when abnormalities are seen on an MRI in a person who has not had symptoms of a stroke (like the ones listed on pages 1 and 2). Silent strokes are common in children with sickle cell disease and may cause learning problems. Research is being done to better understand how to prevent and treat silent strokes.

Where can I find more details?

For more details on sickle cell disease and services, visit the Children's Healthcare of Atlanta website at <u>choa.org/sicklecell</u>.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.