



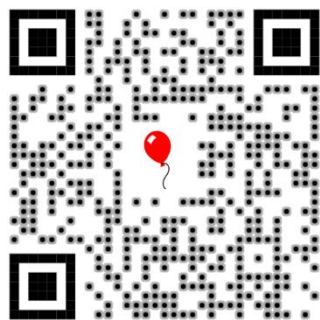
all about sickle cell

**PEDIATRIC SICKLE CELL DISEASE PROGRAM
AT CHILDREN'S HEALTHSM**



a note for caregivers

This book is designed to be an educational tool for children with sickle cell disease. The Pediatric Sickle Cell Disease Program at Children's HealthSM has additional resources available for caregivers on our website. For more information, visit childrens.com/sicklecell or scan the QR code.



Resources for Caregivers:

- *Children's Health Sickle Cell Resources*
 - Sickle Cell Disease Parent Handbook
 - Sickle Cell Disease Emergency Guide
 - Sickle Cell School Brochure
- *Sickle Cell Disease Association of America*

Contact Numbers:

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Dallas, TX 75235
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all about me page

This book helps you learn more about sickle cell disease. But first, let's learn more about you!

My name is _____. I am _____ years old!

I live with

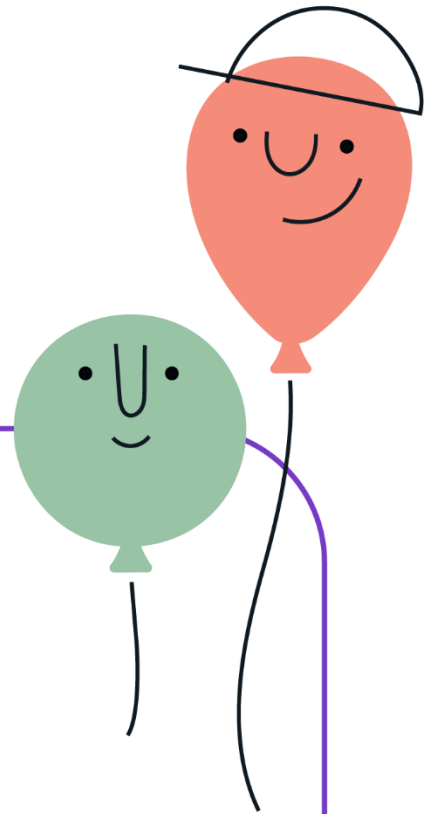
**My favorite
thing to do**

My favorite food

My favorite animal

family drawing page

Draw a picture of your family below.



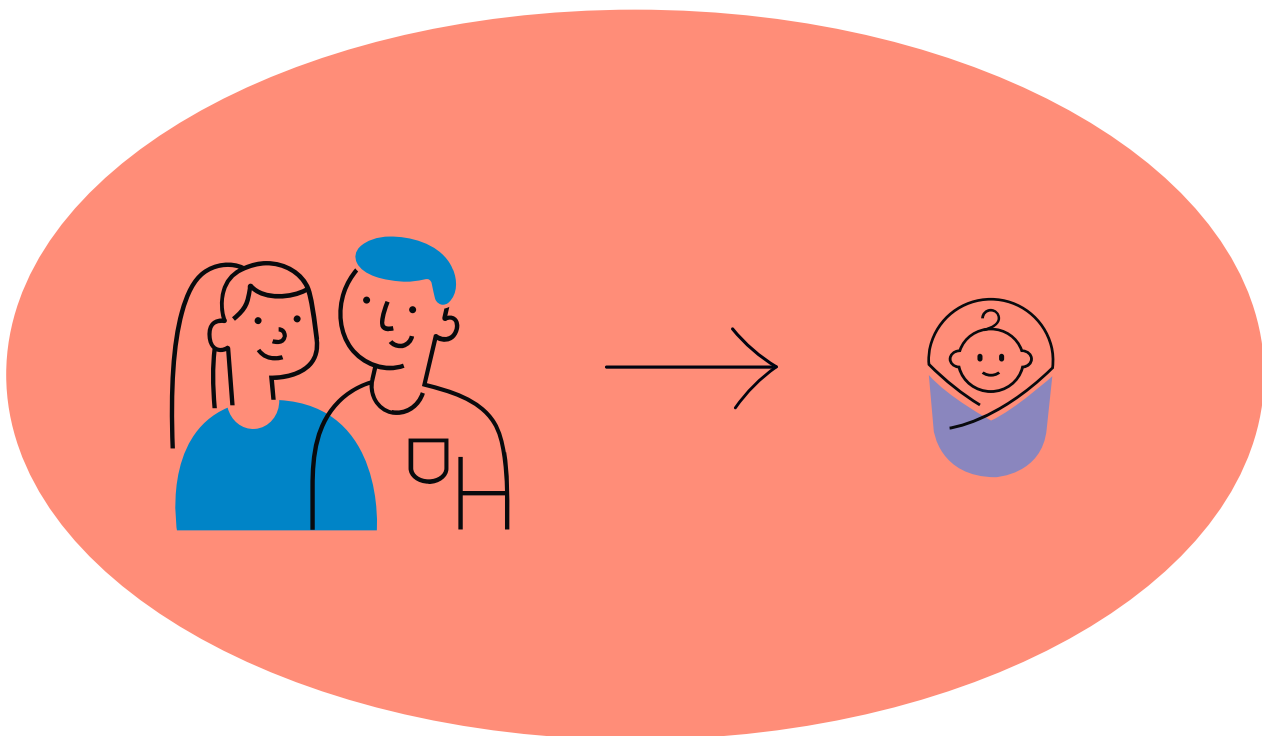
how do you get sickle cell disease?

You were born with something called sickle cell disease. Some people call it “sickle cell” for short.

- Children inherit traits from their parents, which means physical qualities or genes are passed on from your parents to you.
- For example, you may have brown eyes because your parents have brown eyes.

Sickle cell is **not** contagious, so it isn't spread by germs. This means that you cannot give sickle cell to your friends at school.

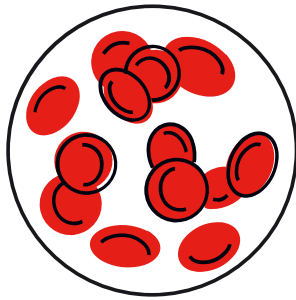
You did not do anything wrong to get sickle cell.



all about your blood cells

Cells are tiny building blocks that make up all living things. Your body is made up of millions of cells, and they all work together to do different jobs in your body.

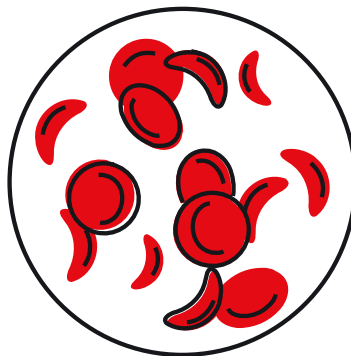
- One type of cell found in your blood is called a **red blood cell**.
- The **red blood cell** has something inside it called **hemoglobin**, which carries oxygen throughout the body. These cells help give your body energy so you can do activities each day, like playing and going to school!



Normal red blood cells are shaped like a circle.



Sickle cells are red blood cells that are shaped like a banana.

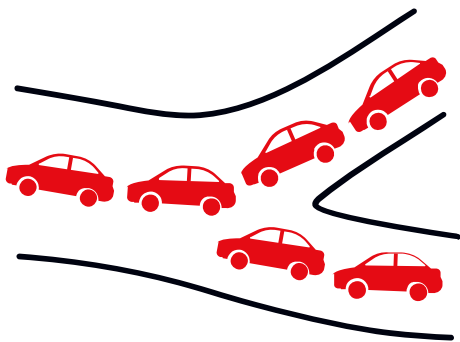


Since you have sickle cell, you have red blood cells that are both shapes in your blood.

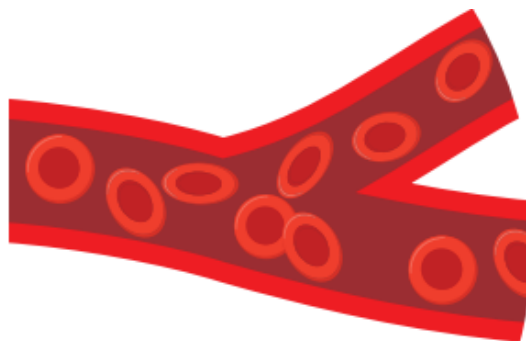
all about blood flow

Blood flows throughout your entire body in tiny tubes called **blood vessels**. You have blood vessels from the top of your head to the tips of your toes.

Blood cells move through blood vessels in your body like cars on a highway.



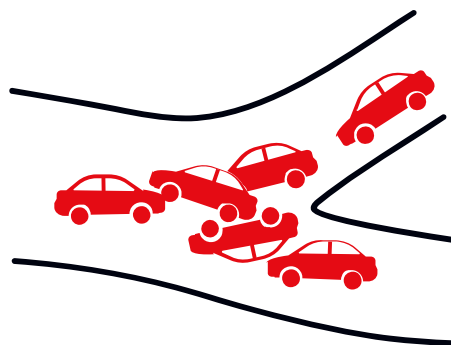
Normal red blood cells are smooth and shaped like circles. This shape helps them move easily through your blood vessels.



When **sickle cells** move through blood vessels, they can get stuck easily because they are shaped like a banana instead of being round and smooth.



Sickle cells that clump together can create a “traffic jam” in your blood vessels. This can cause pain or other problems in your body.



coming to the hospital

Sometimes, you may need to come to the hospital so the doctors and nurses can help you.

Listed below are some reasons you may need to come to the hospital. There are some other problems or “complications” that can happen when you have sickle cell, but these are the most important ones for you to start learning about at your age.



Remember: Having sickle cell does not mean all these things will happen to you, but it’s important to know about these complications so you and your family can be prepared if they do happen.

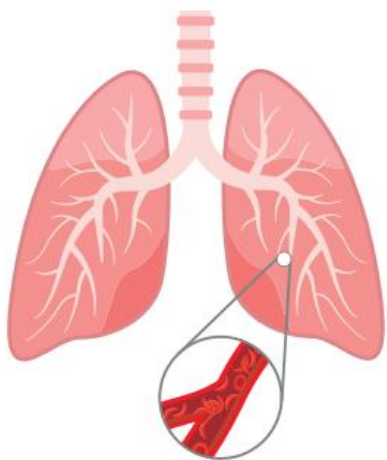
Fever



A **fever** happens when the temperature of your body is higher than normal (above 100.4 degrees Fahrenheit). If you have a fever, it is important to come to the hospital so doctors can do tests on your blood and give you the right medicine to help you.

Always tell an adult if you think you have a fever.

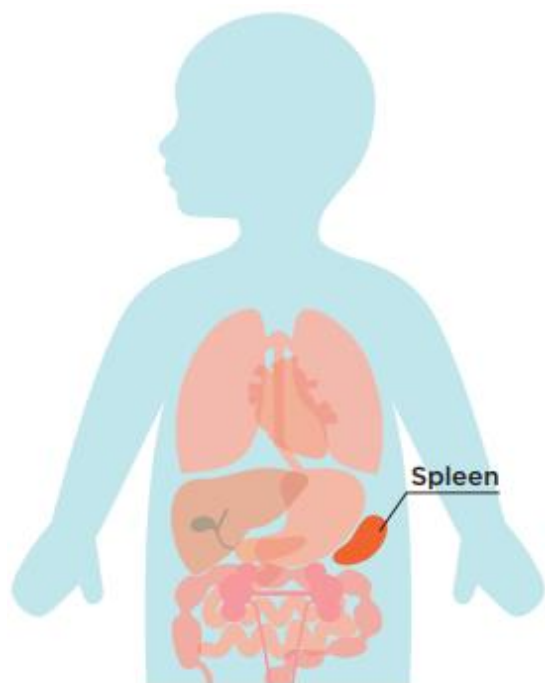
Acute Chest Syndrome



Blood flows all throughout your body, including through your lungs. **Acute chest syndrome** happens when the sickle cells get clumped together in the blood vessels in your lungs.

It is important to tell an adult if you feel like your chest hurts, have a hard time breathing, or have a cough because you may need to come to the hospital.

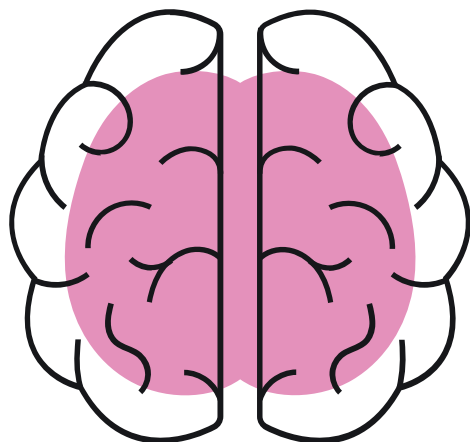
Splenic Sequestration



Your **spleen** is an organ in the top left side of your belly. The job of the spleen is to clean your blood. Sometimes, a lot of sickle cells can clump together in your spleen and trap blood inside, which makes your spleen grow bigger.

Your doctors and caregivers can check your spleen size by feeling your belly. If your spleen is big, you may need to come to the hospital.

Stroke



The brain is the boss of your body and controls everything your body does. Different parts of your brain have different jobs, like telling your heart to beat, your lungs to breathe, or your body to move. A **stroke** can happen when the sickle cells block blood flow to a part of your brain.

A stroke can be very serious, so it is important to know the signs of what it can feel like. Tell an adult if you have or have:

- Weakness or trouble moving your body
- Numbness or tingling in your body
- Strong pain in your head
- A hard time seeing
- Trouble thinking or remembering things
- Nausea or have thrown up

Pain

Check out the next pages to learn more about sickle cell pain.

pain episodes

When sickle cells clump together, it causes a “traffic jam” in your blood vessels and the red blood cells carrying oxygen cannot get through as easily.



When this happens, you may feel pain in one part of your body, or you may feel it all over your body.

When your pain is severe, it is called a **pain episode or “crisis.”** It can last a few hours or a few days.

Learning Check

Draw a picture of the different kinds of cells that flow in **your** blood vessels.

A large, empty rounded rectangular box with a blue border, intended for a student to draw different kinds of cells that flow in blood vessels.

Draw what is happening in your blood vessels during **a pain episode.**

A large, empty rounded rectangular box with a blue border, intended for a student to draw what is happening in blood vessels during a pain episode.

what to do when you are in pain



Rest



Drink lots of water



Take a warm bath or shower or use heating pads



Massage or rub the part of the body that hurts



Talk to a grown up about how you are feeling. They can help get you medicine, talk to a doctor, or take you to the hospital if needed.

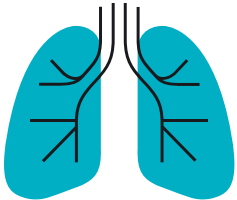
Who do you tell **at home**
when you are in pain?

Who do you tell **at school**
when you are in pain?

all about coping skills

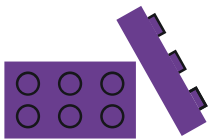
Your brain is powerful and can help your body relax when you have pain.

Coping skills are tools you can use to help your brain and body feel calmer.



Take deep breaths

- Slowly breathe air in through your nose like you are smelling flowers. Breathe out through your mouth like you are blowing out birthday candles.



Try to focus on something else.

- Play a game, draw a picture, watch a movie, talk with friends, or listen to music.



Use your mind to travel to another place

- Think about a place that makes you happy.
- What do you see? What do you hear? What does it feel like?



Squeeze a stress ball or hold a stuffed animal



Talk with an adult or friend about how you are feeling

my coping skills page

Use this page to write down coping strategies you already use or would like to try using in the future. It's great to practice these skills so you can remember them when you need to use them!



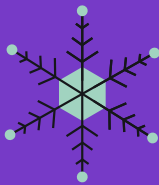
triggers to pain episodes

Triggers are things that can cause sickle cell pain or make it worse. It is important to learn about triggers, so you can try to avoid them when you can.

Illness or fever



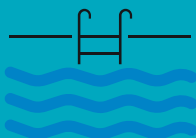
Big changes in temperature



Not drinking enough water



Swimming or exercising for a long time



Being in a high-altitude place (like the mountains)



taking care of yourself

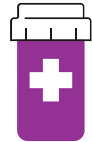
When you have sickle cell, it is important to listen to what your caregivers and doctors tell you about taking care of yourself.

Here are some ways you can help take care of your body:

- Drink lots of water.



- Take medicine that your doctor or caregiver tells you to take.



- Get plenty of rest.



- Try not to let your body get too hot or too cold.

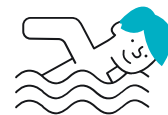
- When it's hot outside, take breaks from the heat to rest and drink water.



- When it's cold outside, dress in warm clothes and wear a hat when you're outside.



- Take breaks during activities like sports or swimming.



- Wash your hands often to help stop the spread of germs.



how to tell others about sickle cell disease

It's YOUR body, so you get to decide WHEN and WHAT you tell friends about sickle cell.

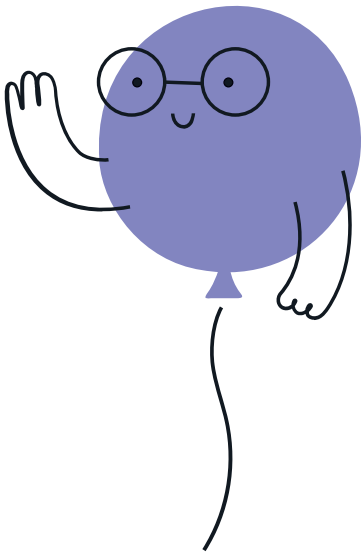
Ask your family or someone on your care team for tips if you need help talking to people in your life.

This book can be used as a guide when helping people in your life learn about sickle cell.

What would you like to tell people?

questions

Use this page to write down questions you may have for your care team or family.



Handwriting practice lines consisting of horizontal lines for writing questions.



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