PAULINE ALLEN GILL CENTER FOR CANCER AND BLOOD DISORDERS

PEDIATRIC SICKLE CELL DISEASE PROGRAM

children'shealth®

MAKING LIFE BETTER FOR CHILDREN WITH CANCER AND BLOOD DISORDERS.

OUR MISSION

Since 1913, the mission of Children's Health℠ has always been to make life better for children. Our unique skills and experience, combined with the latest research and technology, allow us to provide the most comprehensive pediatric sickle cell care available. These attributes help us achieve our vision of making Children's Health among the very best medical centers in the nation. We believe there is no better affirmation of our mission than seeing happy, healthy patients leave the hospital.

PAULINE ALLEN GILL CENTER FOR CANCER AND BLOOD DISORDERS

The Pauline Allen Gill Center for Cancer and Blood Disorders at Children's Health provides diagnosis, treatment, prevention of complications and management of sickle cell disease in children. Each year the blood disorder specialists here care for more than 700 children with various forms of sickle cell disease, often with the very treatments researchers developed here.

In addition to diagnosing and treating sickle cell disease, we strive to equip our children with the knowledge of common complications and the importance of preventative care to ensure readiness before transitioning to adulthood.

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SICKLE CELL BASICS

About Sickle Cell

At Children's Health, we're here to help you understand the different types of sickle cell disease, prevent complications and help you and your child manage it. Let's start with the basics.

What is sickle cell disease?

It's a lifelong condition caused by an abnormal gene that impacts your child's red blood cells.

What are normal red blood cells?

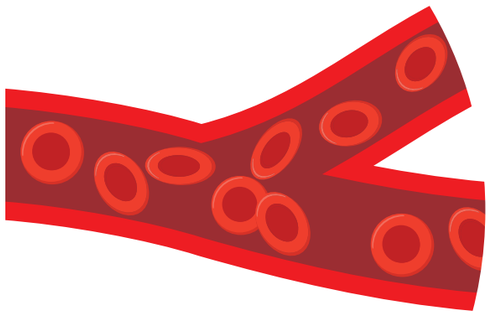
Red blood cells are made up of a protein called hemoglobin and carry oxygen throughout the body. Normal red blood cells are round, smooth and flexible. This helps them to move easily through the bloodstream to deliver oxygen.

How does sickle cell disease impact your child's red blood cells?

In sickle cell disease, some of your child's red blood cells become abnormally shaped and look more like a crescent or "sickle." Sickle cells are rigid and get stuck easily in blood vessels, interfering with normal blood flow and delivery of oxygen. This can be painful or even cause organ damage.

Normal Red Blood Cells

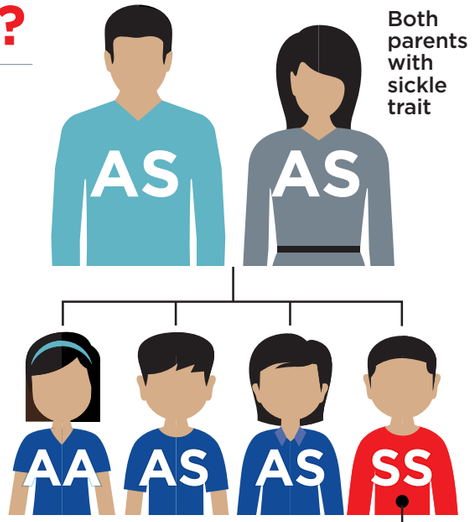
Sickled Red Blood Cells



WHAT ARE THE DIFFERENT TYPES OF **SICKLE CELL DISEASE?**

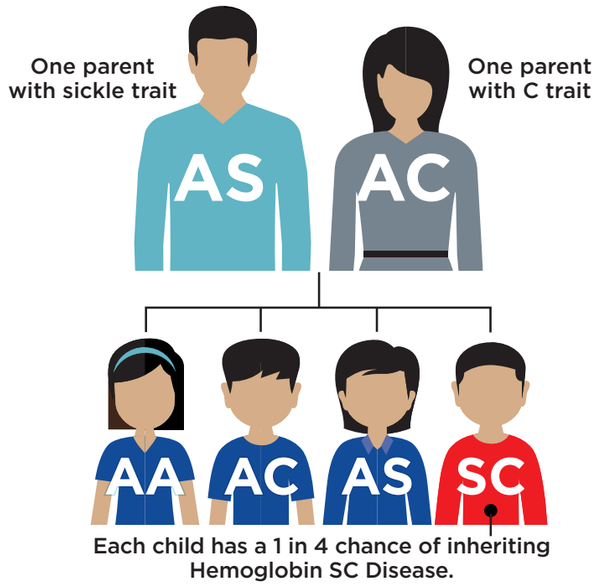
Hemoglobin SS Disease

Hemoglobin SS disease – or sickle cell anemia – is the most common form of sickle cell disease. It occurs when your child inherits two copies of the sickle (S) hemoglobin gene (one from each parent). Sickle hemoglobin is found within all red blood cells of the child and causes the red blood cells to take on a crescent or "sickle" shape. When both parents have sickle cell trait as shown on the right, there is a one in four chance (25%) that the baby will have sickle cell anemia. This chance is the same with every pregnancy.



Hemoglobin Sickle C (SC) Disease

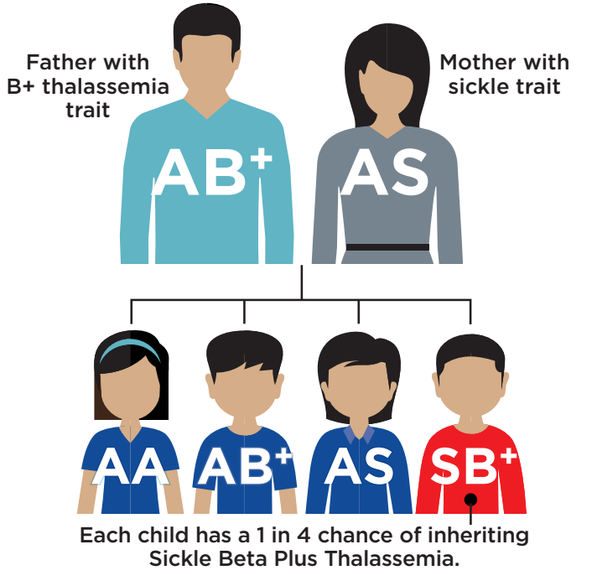
Hemoglobin SC disease is another form of sickle cell disease. It occurs when a child inherits one copy of the sickle (S) hemoglobin gene from one parent and one copy of the C hemoglobin gene from the other parent. Sickle and C hemoglobin are found within all red blood cells and cause some cells to take on a crescent or "sickle" shape. When one parent has sickle cell trait and the other C-trait, there is a one in four chance (25%) the baby will have hemoglobin SC disease. This chance is the same with every pregnancy.



WHAT ARE THE DIFFERENT TYPES OF SICKLE CELL DISEASE?

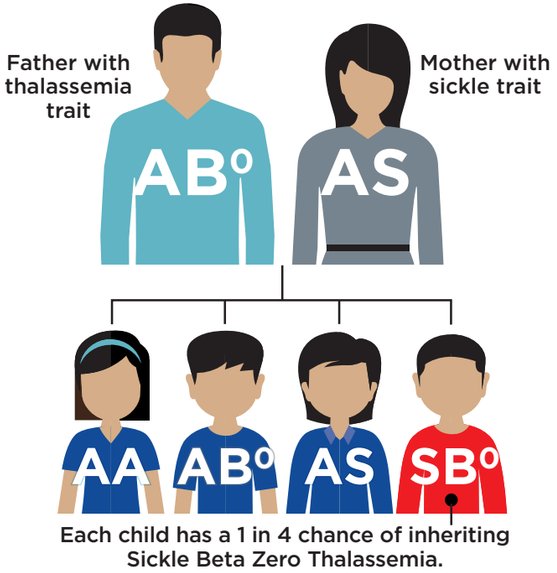
Hemoglobin Sickle Beta Plus Thalassemia (SB+) Disease

Hemoglobin SB+ Thalassemia disease is another form of a sickle cell disease. It occurs when a child inherits one copy of the sickle hemoglobin gene from one parent and one copy of the beta plus thalassemia gene from the other. The child's red blood cells contain sickle hemoglobin and a small amount of normal hemoglobin called hemoglobin A. This causes the red blood cells to be small, pale and deformed. Some cells may take on a crescent or "sickle" shape. When one parent has sickle cell trait and the other beta thalassemia trait, there is a one in four chance (25%) that the baby will have Hemoglobin SB+ Thalassemia disease This chance remains the same for each pregnancy.

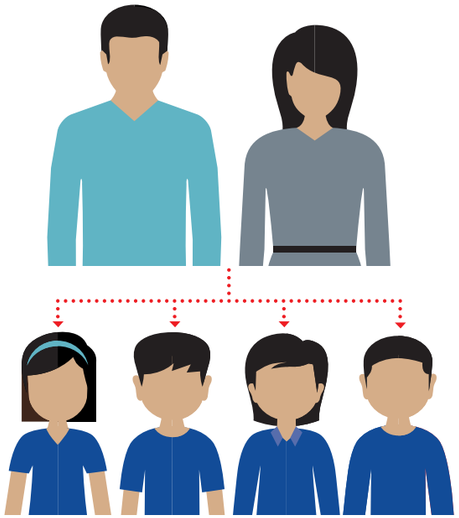


Hemoglobin Sickle Beta Zero Thalassemia (SB^0) Disease

Hemoglobin SB^0 Thalassemia disease is another form of sickle cell disease. It occurs when a child inherits one copy of the sickle hemoglobin gene from one parent and one copy of the beta thalassemia gene from another parent. Sickle hemoglobin is found within all red blood cells of the child and causes the red blood cells to take on a crescent or "sickle" shape. When one parent has sickle cell trait and the other beta thalassemia trait, there is a one in four chance (25%) that the baby will have Hemoglobin SB^0 Thalassemia disease. These chances remain the same for each pregnancy.



WHAT ARE THE DIFFERENT TYPES OF SICKLE CELL DISEASE?

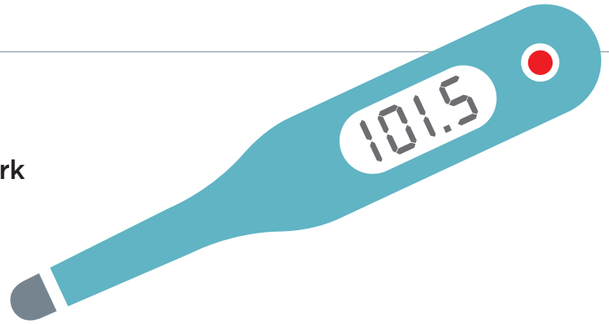


Hemoglobin S-other Diseases

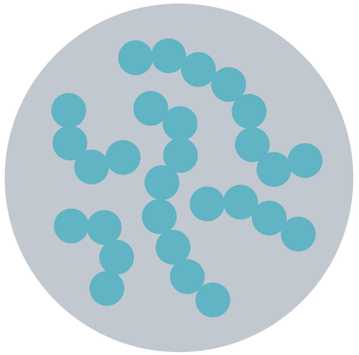
There are a variety of other rare sickle cell disorders in which the child inherits one copy of the sickle hemoglobin gene from one parent and one copy of another type of abnormal hemoglobin from another parent. Sickle hemoglobin is found within the red blood cells of the child and causes the red blood cells to take on a crescent or “sickle” shape. Your hematologist will discuss your child’s specific type of sickle cell disease during your visit.

SICKLE CELL **COMPLICATIONS**

Fever and Infection



Children with sickle cell disease have an increased risk of getting certain types of infections because their spleen does not work normally. The spleen acts as part of the body's defense against infections by removing bacteria from the bloodstream. When your child is a baby, the sickled red blood cells can damage the spleen, and it may no longer work. This can allow bacteria to grow in the bloodstream and cause infections.



What is sepsis?

Sepsis is a life-threatening illness that occurs because of the body's response to a severe infection. Children with sickle cell disease are at an increased risk of certain types of infections. An expecially dangerous bacteria is the pneumococcal bacteria.

What are the symptoms of sepsis?

- Fever 101.5 degrees or higher
- Fussiness, irritability
- Unusual sleepiness
- Vomiting, diarrhea
- Rapid breathing or trouble breathing
- Pale color

What should you do if your child has symptoms?

If your child is older than 3 months old and has a fever of 101.5 degrees or higher and/or any of the above symptoms, they should be evaluated in the Emergency Room (ER) immediately. Do not administer ibuprofen or Tylenol® for treatment of a fever. These medicines bring down a fever, but they do not treat the infection.

What should you do if your child is younger than 3 months old?

Young babies are at a higher risk of infections and should be brought to the ER immediately for a temperature of 100.4 degrees or higher and/or any of the above symptoms. Do not administer any medications for treatment of a fever.

Who is at risk of sepsis?

All children with sickle cell disease are at risk of sepsis. Some children are at higher risk and may need to take penicillin twice a day to help prevent infection. Your hematologist will discuss whether this is recommended for your child. It is also important that your child receive all recommended vaccinations to help boost their immunity and prevent infections.

Acute Splenic Sequestration

The spleen is a small organ located on the upper left side of the abdomen under the rib cage. It acts as part of the body's defense system by removing bacteria from the blood.

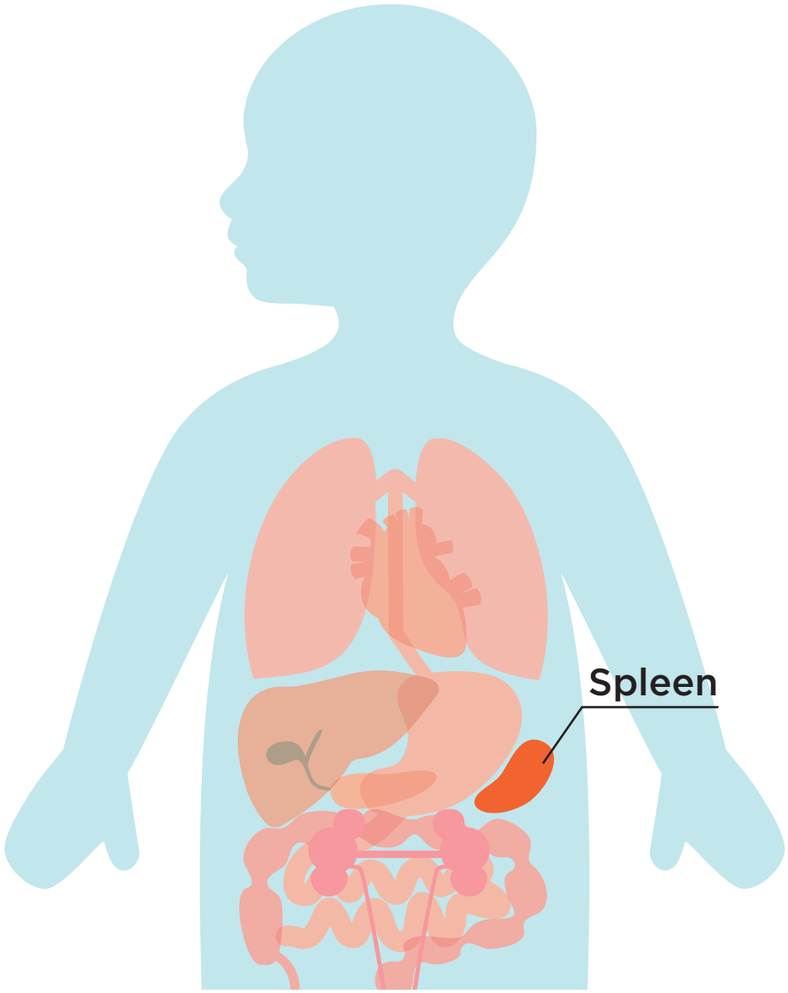
Sickle cells can get trapped in the blood vessels of the spleen, causing a blockage in blood flow. When blood stays inside the spleen instead of flowing back out into the body, this is called splenic sequestration. During splenic sequestration, the blood cell count falls, and the spleen becomes enlarged. This is a serious and potentially life-threatening problem.

What are the symptoms of splenic sequestration?

- Unusual sleepiness, weakness
- Big spleen that can be felt below the left ribcage
- Pale color
- Pain in the left side of the abdomen
- Fast heartbeat

How do you recognize a splenic sequestration?

Parents should check their child's spleen regularly by feeling on the left side of the abdomen from the left hip bone up to the left ribs. Normally the spleen is not felt. If you can suddenly feel the spleen or if the spleen gets bigger, your child should be brought to the ER immediately. Sometimes during a splenic sequestration, there is not enough blood circulating in the body, and the red blood cell count becomes very low. If this happens, your child may need to stay in the hospital and receive a blood transfusion.



SICKLE CELL **COMPLICATIONS**

Vaso-occlusive Pain Episode

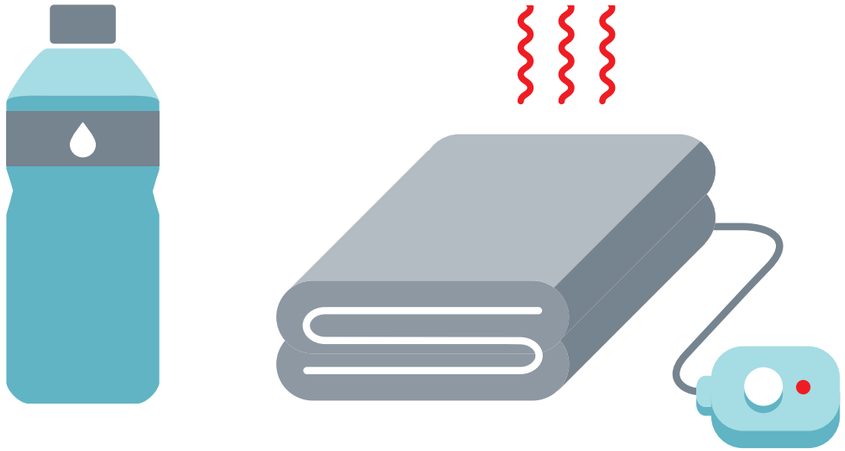
Episodes of pain are common in children with sickle cell disease. Sickled red blood cells can become trapped inside of blood vessels, causing an obstruction in blood flow that can cause pain. This can occur anywhere in the body and can last several hours or even days. Sometimes swelling is seen at the area of pain. If your child is under the age of 2, swelling and pain may occur in their hands and feet — this is called dactylitis.

What can contribute to pain episodes?

Painful episodes can be provoked or worsened by fever/illness, dehydration, injury, prolonged swimming or activity, and exposure to extreme cold or extreme heat. Emotional stressors and difficulties with mood can also trigger and worsen pain episodes. However, the majority of painful episodes have no identifiable cause.

What can you do when your child is in pain?

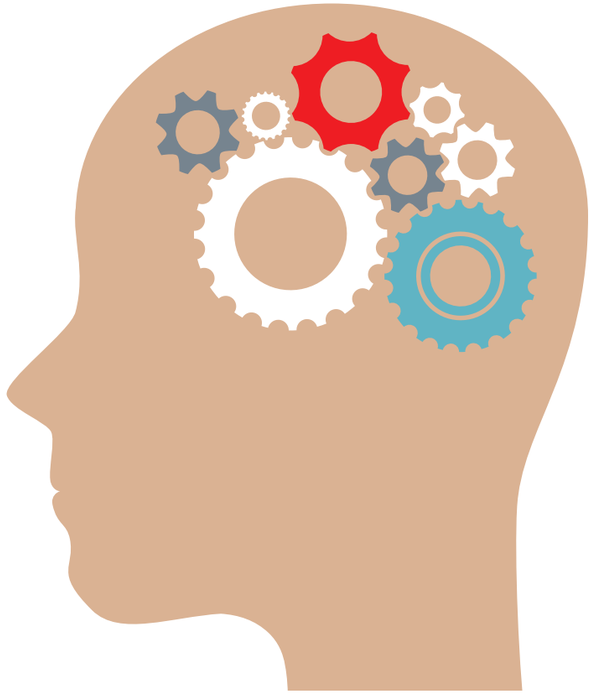
Painful episodes can often be treated at home with pain medications and other non-medication treatments, like applying heating pads, massaging the area, relaxing, distraction and drinking plenty of water.



If you are unable to control pain with home treatments or if pain does not improve within one to two days, your child should be brought to the ER. Sometimes stronger pain medications are necessary to manage the pain. If these medications don't help, your child may need to stay in the hospital for further treatment.

What are some non-medication treatments you can try?

Brain-Body Connection



Research shows that pain has physical and emotional causes. The brain-body connection is the way a person's thoughts, feelings, and actions affect their body (like the experience of pain), and how the body affects the brain. This means that your child's brain plays a role in how they feel pain and their ability to cope with pain. Although your child's pain is very real, emotions and thoughts can make the pain worse or better. If your child is feeling angry, sad or worried, they are likely to experience more pain. If your child is focused on the pain and thinks about it often, they are also likely to experience more pain. Your child also has the ability to improve pain using their thoughts and actions, otherwise known as coping skills.

Coping Skills

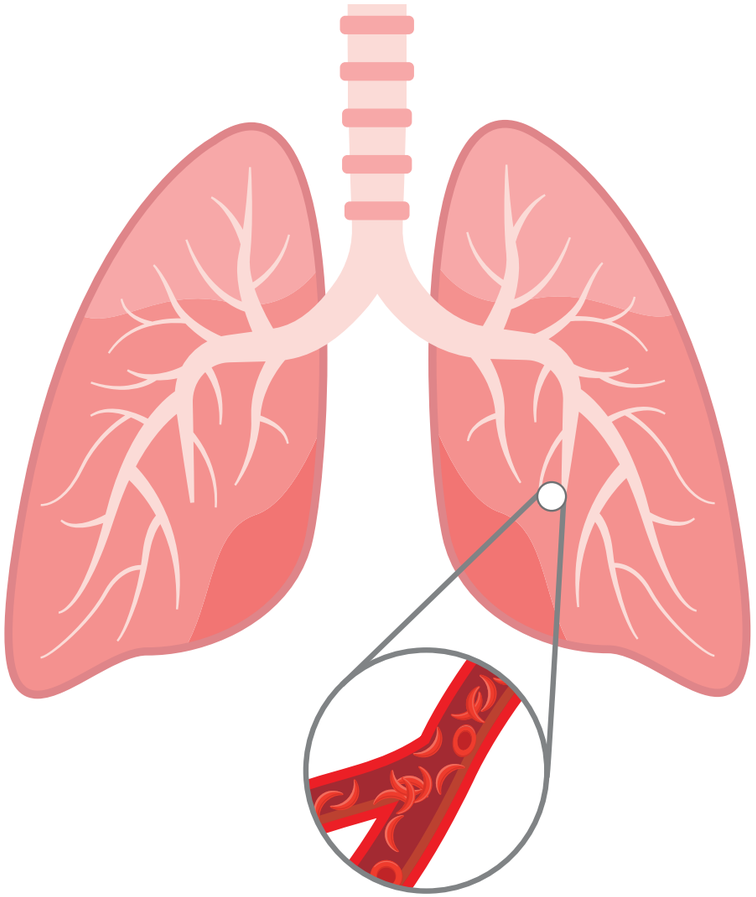
Painful episodes are managed using many different skills. Learning to relax the body helps lower pain and stress.

- Deep breathing – Breathe in through your nose for 4 seconds and out through your mouth for 6 seconds for at least 1-2 minutes or until the pain goes down. Imagine smelling flowers and then blowing out birthday candles or blowing bubbles.
- Guided imagery – Choose a relaxing place to go to in your mind. Imagine all 5 senses, like what you see, touch, smell, hear and feel. It is helpful to have someone guide your child through all of the sensations they imagine.
- Massages, warm baths and heating pads help calm your child's body and allow them to feel relaxed.
- Physical comfort, like holding a stuffed animal or someone's hand, helps with relaxation and comfort.

Additional ways of coping with pain include actions (behavioral skills) and changing thoughts (cognitive skills).

- Active distraction, like listening to music, playing games, talking with friends or watching a favorite TV show, helps your child focus less on pain.
- Doing usual activities and keeping a normal schedule (like school and chores) helps your child not focus on pain as much and allows them to focus instead on living their life.
- If your child is focusing on pain, help them change their unhelpful thoughts by "changing the channel" in their brain. Help them think about something more helpful, fun, or positive instead.
- Try to avoid asking your child about their pain often. When people are asked about their pain, they tend to think about it more, which makes it feel worse. Instead, ask about how comfortable your child feels and what skills help them feel more comfortable instead of asking about pain.

SICKLE CELL **COMPLICATIONS**



Acute Chest Syndrome

In acute chest syndrome, sickled red blood cells become trapped in the blood vessels of the lungs. This is a serious and potentially life-threatening problem that can be caused by or lead to a lung infection.

What are the symptoms of acute chest syndrome?

- Chest pain
- Fast breathing
- Difficulty breathing
- Coughing
- Fever of 101.5 degrees or higher

What should you do if your child has symptoms?

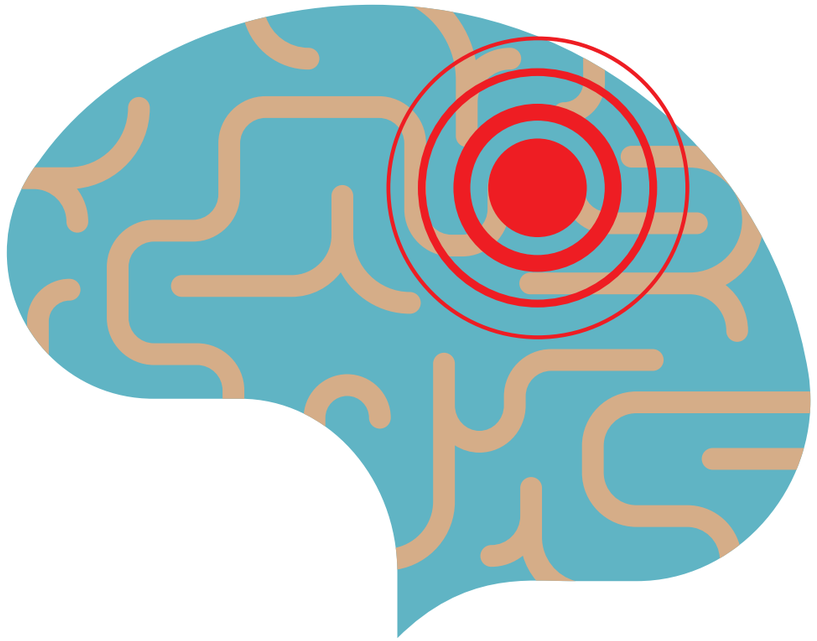
If your child experiences these symptoms, they should be seen in the ER immediately. Treatment often includes antibiotics, supplemental oxygen, fluids and pain medications. Sometimes a blood transfusion is needed if the red blood cell levels are too low.

Stroke

Stroke is a sudden and severe complication of sickle cell disease that occurs because of a lack of oxygen to part of the brain. Red blood cells carry oxygen throughout the body. Sickled red blood cells can form an obstruction in the bloodstream of the brain that prevents oxygen from being delivered to parts of the brain. This is called a stroke.

What are the symptoms of a stroke?

- Inability to move part of the body
- Weakness or numbness in part of the body
- Seizures
- Strange or abnormal behavior
- Sudden blurry vision
- Severe vomiting
- Severe headaches that are not relieved with acetaminophen or ibuprofen



What should you do if your child has symptoms?

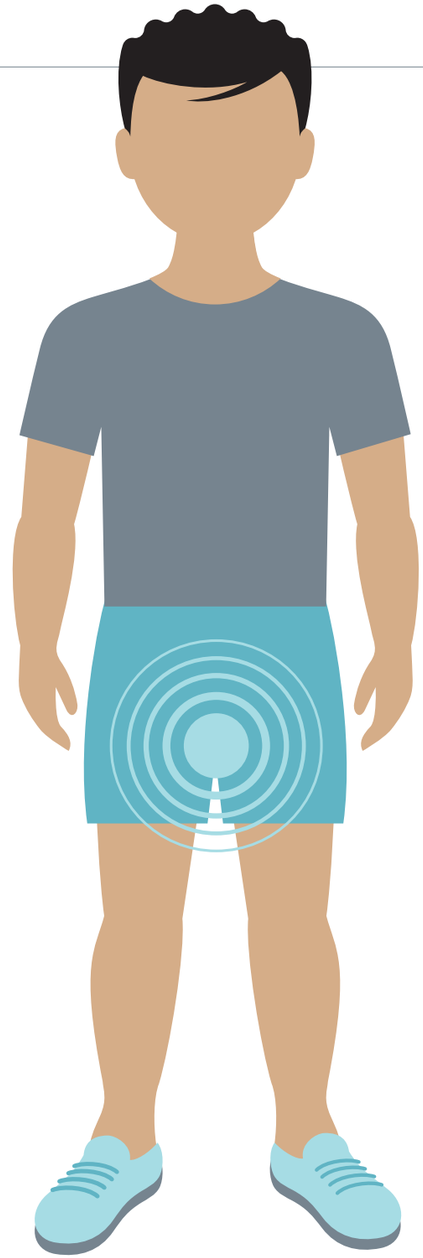
If your child experiences any of these symptoms, they should be seen in the ER immediately.

Priapism

Priapism is a painful erection that is unwanted and lasts a long time. It occurs in boys when sickled red blood cells become trapped in the bloodstream of the penis. This blocks the drainage of the blood out of the penis, causing the erection and pain.

What should you do if your child has priapism?

As soon as priapism occurs, have your son use the bathroom, take a warm shower, drink plenty of water and take medicine for the pain. If the erection does not go away within **three** hours, go to the ER. Your child may also need to see a urologist. Talk to your hematologist about other medications, such as Sudafed®, that may help to resolve or prevent priapism.



Avascular Necrosis

Avascular necrosis is a bone condition that occurs in joints when sickled red blood cells block the flow of blood to the joints. When the joint does not receive enough blood supply, it can become weak and die. This can lead to persistent pain in the affected joint.

What joints does avascular necrosis often affect?

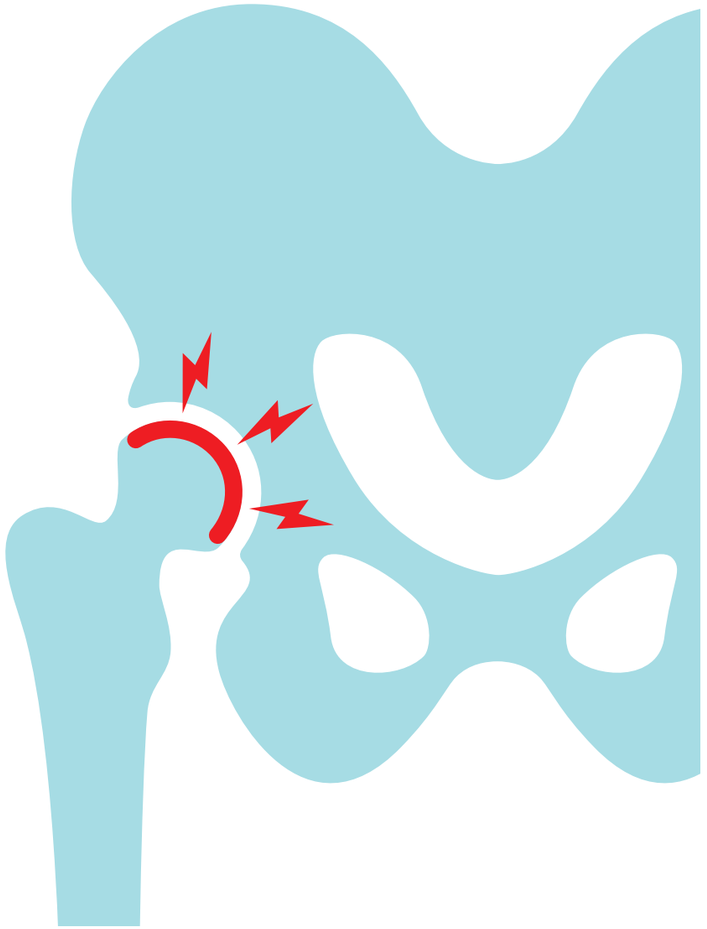
- Hips
- Knees
- Shoulders

What are the symptoms of avascular necrosis?

- Persistent pain in the hip, knee or shoulder
- Pain in hips or knees when walking up or down stairs
- Pain in shoulders when throwing
- Limping

What should you do if your child has symptoms?

If your child complains of these symptoms, contact your sickle cell team. Your child may need an X-ray to look for avascular necrosis. They should avoid activities like running, jumping and certain sports.



Aplastic Crisis

Aplastic crisis occurs when the body temporarily stops making red blood cells. This is often caused by an infection with a virus called parvovirus B19. In children with sickle cell disease, red blood cells only live about 10 to 15 days compared to 120 days in children who do not have sickle cell disease. Since the body is not making any new red blood cells during the infection, the red blood cell count can drop to dangerously low levels.

What are the symptoms of aplastic crisis?

- Pale color
- Unusual sleepiness
- Weakness
- Fever

What should you do if your child has symptoms?

If the above symptoms develop, your child should go to the ER for evaluation. The treatment for aplastic crisis usually involves a blood transfusion to raise your child's blood count until the body starts making its own red blood cells again.

Gallstones

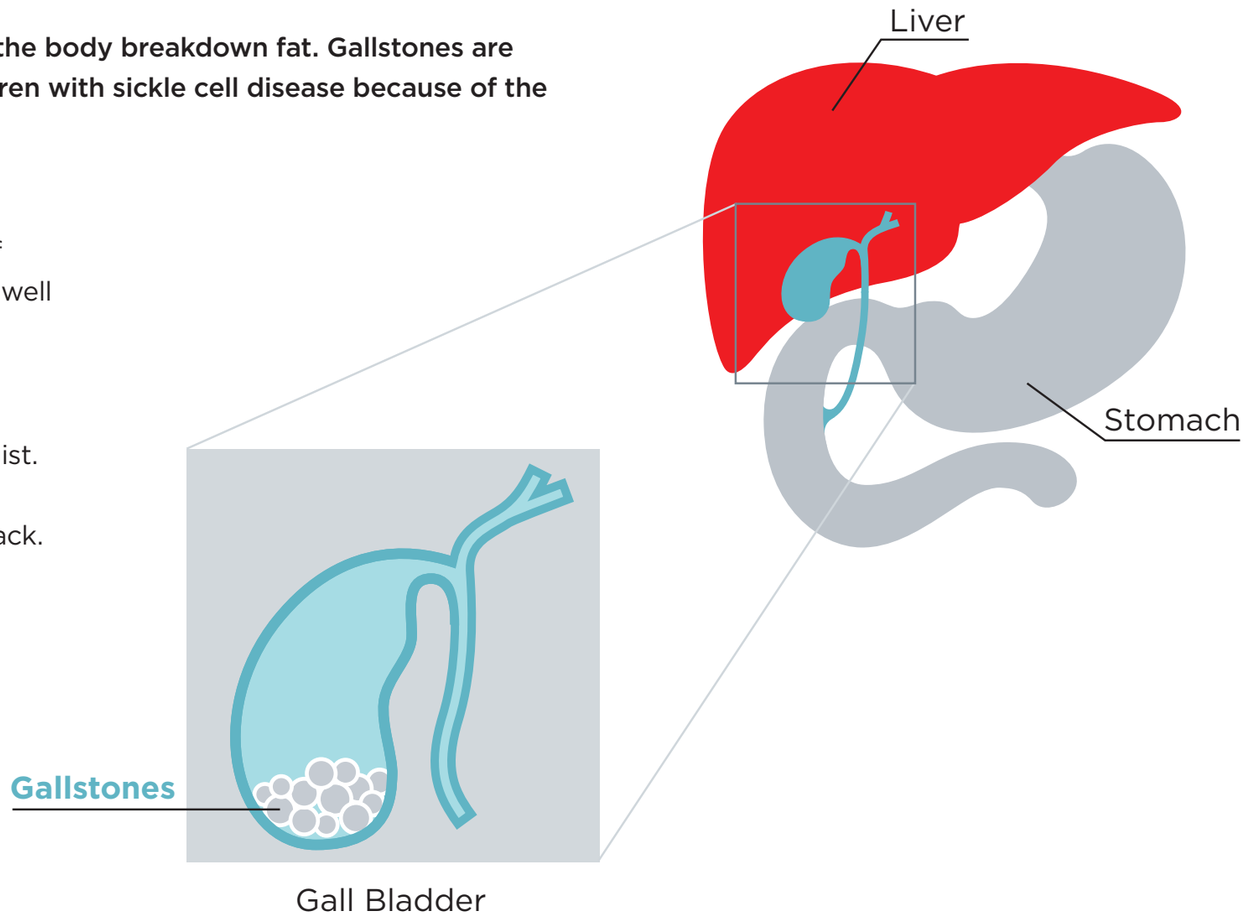
The gallbladder is a small organ tucked under the liver that stores bile and helps the body breakdown fat. Gallstones are small stones that can form inside the gallbladder. Gallstones are common in children with sickle cell disease because of the increased breakdown of red blood cells.

What are the symptoms of gallstones?

Sometimes gallstones do not cause symptoms, but some children may complain of frequent abdominal pain, typically on the right side or in the middle upper area, as well as nausea and vomiting.

What should you do if your child has symptoms?

If your child complains of these symptoms, discuss this with your child's hematologist. Your child may need an ultrasound to evaluate the gallbladder. Sometimes the gallbladder may need to be surgically removed to prevent the pain from coming back.



Sickle Retinopathy

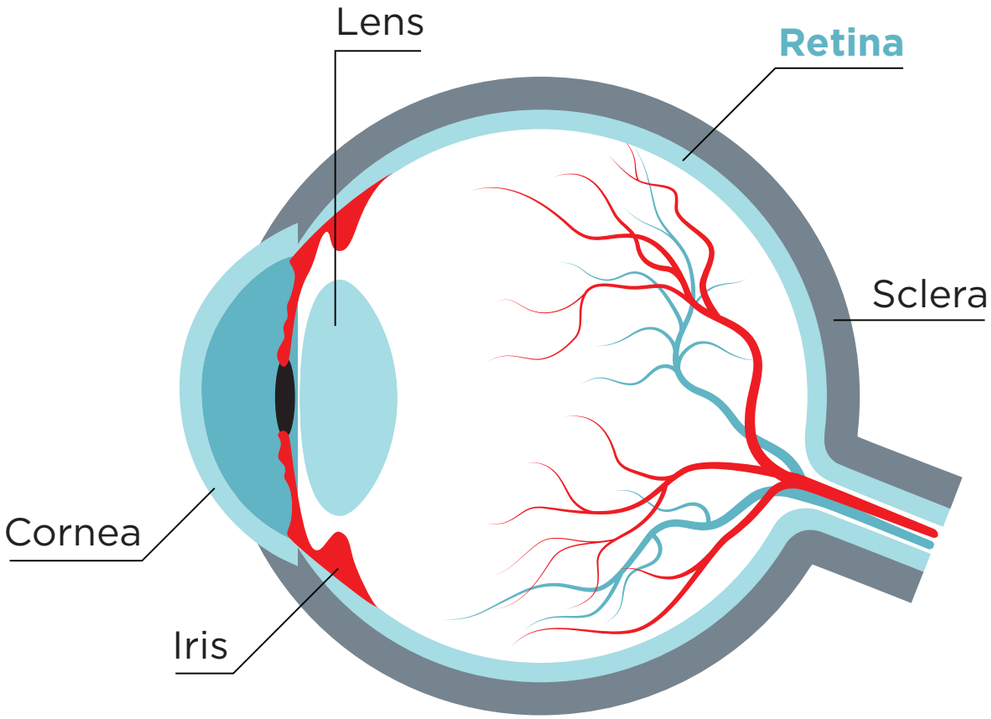
Sickle retinopathy is an eye condition in which the tissue at the back of the eye, called the retina, is damaged because it's not receiving enough oxygen. This is more commonly seen in adolescents with hemoglobin SC disease but can be seen in any type of sickle cell disease.

What are the symptoms of sickle retinopathy?

Some children with sickle retinopathy have no symptoms initially, but vision problems can occur over time.

How do you screen for sickle retinopathy?

Your child should have a dilated eye exam at least once per year starting at age 10 to look for this condition before it impacts vision.



Obstructive Sleep Apnea

Obstructive sleep apnea (OSA) is a condition where a person stops breathing for short periods while sleeping. Untreated OSA in someone with sickle cell disease can lead to more frequent pain episodes and put extra strain on the heart and lungs.

What are the symptoms of OSA?

- Loud snoring when sleeping
- Pauses between breaths or sudden gasping for breath when sleeping
- Feeling very tired during the day even after getting enough sleep

What should you do if your child has symptoms?

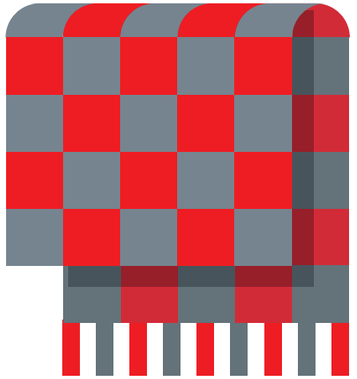
If your child has these symptoms, you should discuss them with your hematologist. Your child may also need to see an Ear, Nose and Throat (ENT) specialist and undergo a sleep study.

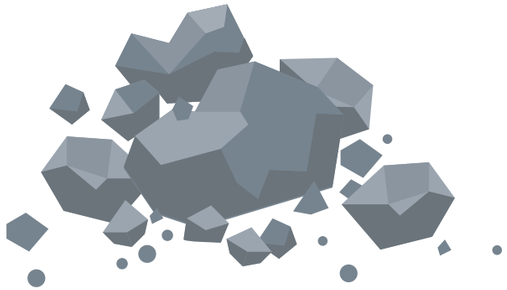
Pica

Pica is a condition where someone craves and eats non-food items such as soil, paper, wall material or cloth. A craving for ice is also common. Pica commonly occurs in people who have chronic anemia, such as children with sickle cell disease.

What should you do if your child has symptoms?

If your child has symptoms of pica, it is important to supervise them closely and discourage them from eating non-food items. It can also be helpful to move these items out of their reach and to provide a food alternative such as dry crackers, which may satisfy the craving.



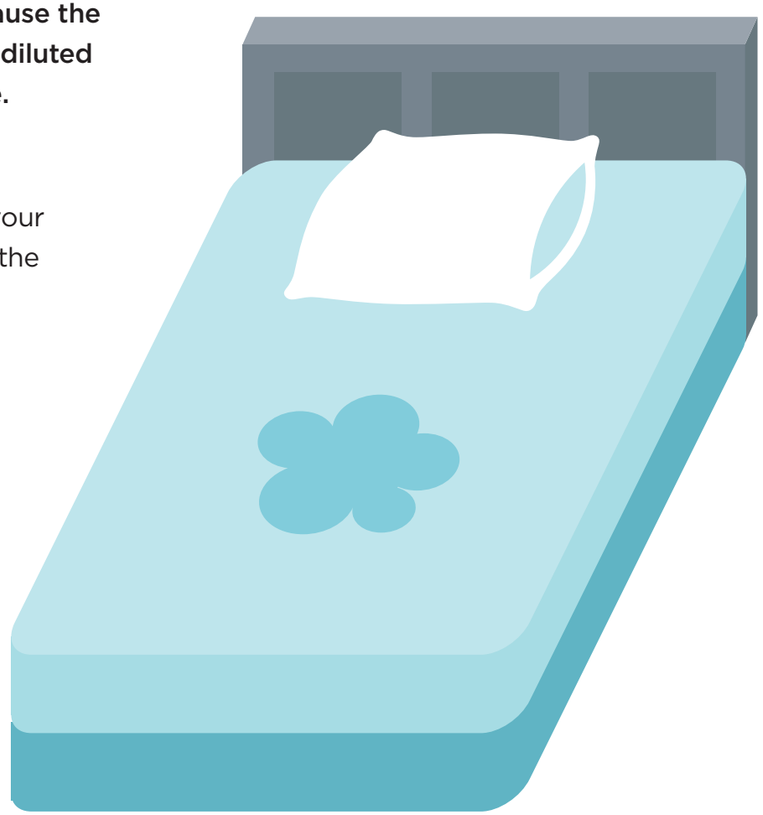


Enuresis

Enuresis, or bedwetting, can occur in children and adolescents with sickle cell disease. This happens because the kidneys are unable to concentrate urine as well and instead produce a large amount of diluted urine. The diluted urine can fill up the bladder quickly and cause the child to urinate more frequently, including at nighttime.

What should you do if your child has symptoms?

If your child has enuresis, it is important to avoid punishment for bedwetting and rather offer praise when your child is dry. It can also be helpful to limit water one to two hours before bedtime, to ask your child to go to the bathroom right before bed and to wake your child one or two times a night to use the bathroom.



Penicillin

For some children with sickle cell disease, it is recommended to take penicillin twice a day. Penicillin is an antibiotic that helps prevent sepsis caused by Streptococcus pneumoniae. It works by killing the bacteria before it has a chance to make your child sick. Your hematologist will discuss whether penicillin is recommended for your child.

How often should your child take penicillin?

Penicillin must be taken every 12 hours. If a dose is missed, the body is not protected against the bacteria.

What forms of penicillin are available?

Penicillin can be taken as pills or liquid. The liquid form has a short shelf life and lasts only 14 days once it has been mixed. If your child is taking the liquid form, you should discard extra medication after 14 days and pick up a new prescription.

Hydroxyurea

Hydroxyurea is a medicine used to treat both adults and children with sickle cell disease. Hydroxyurea works by helping the red blood cells stay rounder and more flexible, which makes them less likely to turn into a sickle shape. By reducing the number of sickle cells in the bloodstream, this helps to reduce the frequency of problems from the disease.

Hydroxyurea is also used to treat certain types of cancer, but doctors use a much lower dose to treat sickle cell disease than to treat cancer.

Why take Hydroxyurea?

Children who take hydroxyurea usually have less pain episodes, fewer incidences of acute chest syndrome and fewer hospital stays. This medication can also help prevent or slow down the damage done to organs from sickle cell disease.

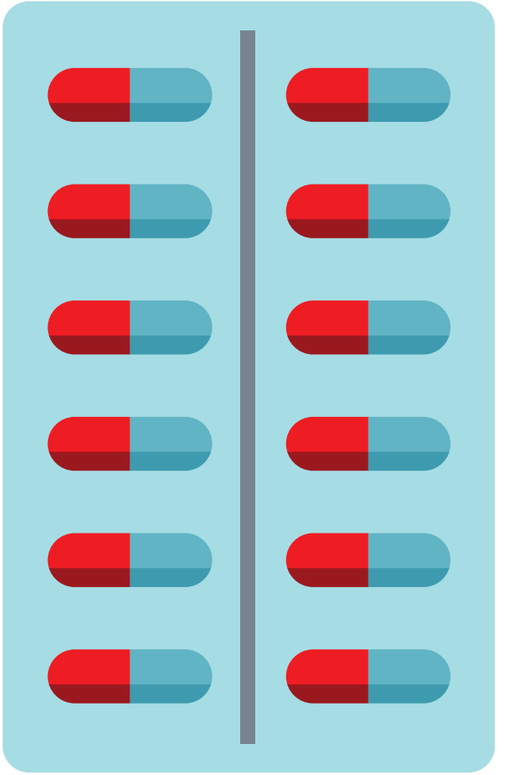
How often should your child take Hydroxyurea?

Hydroxyurea only works if it is taken every day. It can sometimes take time to work, and it is important to stick with it for at least six months to see how your child responds.

What are the side effects of Hydroxyurea?

While your child is taking hydroxyurea, they will need to have their blood counts checked regularly, because sometimes the medicine can cause platelets and white blood cells to get too low. If this occurs, your doctor may stop the medicine for a while or lower the dose.

While taking hydroxyurea, some people may experience thinning of the hair, darkening of the fingernail bed or upset stomach. Very rarely, more serious side effects can occur, but most people who take hydroxyurea do not experience any serious side effects.



Transcranial Doppler (TCD) Screening

TCD is an ultrasound of the brain that measures how fast blood is flowing through certain blood vessels in the brain. This test is used to identify children at a higher risk of having a stroke because of sickle cell disease.

Who should have a TCD screening?

Your hematologist will discuss whether TCD screening is recommended for your child. If screening is recommended, your child will begin having TCDs performed at 2 years old, and this will be repeated every year if the results are normal.

What does it mean if the TCD is conditional?

If your child's TCD is conditional, this means the blood is moving faster than normal through the blood vessels of the brain. The TCD will be repeated in 3 months rather than waiting a year.

What does it mean if the TCD is abnormal?

If your child's TCD is abnormal, this means the blood is moving very fast through the blood vessels of the brain, and your child is at a higher risk of having a stroke. The TCD will be repeated in 1 month and if it remains abnormal, your hematologist will discuss treatments to prevent a stroke.

What treatments are recommended if my child is at a high risk of stroke?

If the results are abnormal, it may be recommended that your child receive monthly blood transfusions to help decrease the chance of having a stroke.

Chronic Transfusion Therapy

A blood transfusion is a common, safe medical procedure in which healthy donated blood is given through the vein. A single transfusion may be given when a child is very sick and their red blood cell count is too low. Chronic transfusions are transfusions that are given regularly, usually once a month, to help prevent certain sickle cell problems, like a stroke.

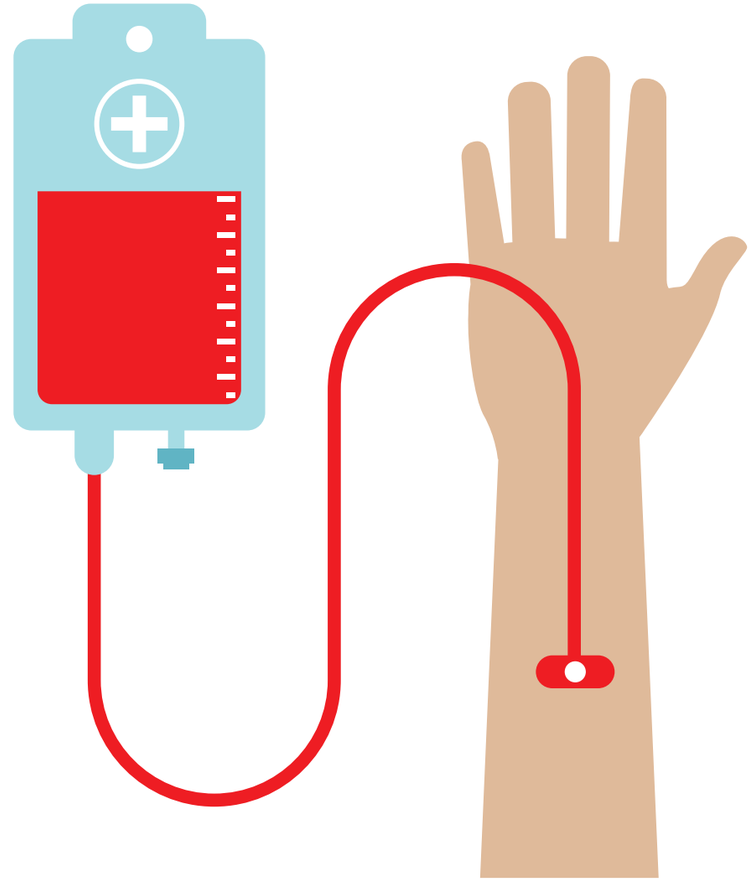
When are chronic blood transfusions recommended?

Chronic transfusion therapy is recommended if a child has previously had a stroke or if they are at a high risk of having a stroke, such as children who have had 2 abnormal TCDs. A stroke occurs when sickled red blood cells form an obstruction in the bloodstream of the brain and prevents oxygen from being delivered to parts of the brain. When blood transfusions are given every month, most of the red blood cells in the blood stream contain normal hemoglobin instead of sickle hemoglobin. This reduces the number of sickled cells in the bloodstream and prevents them from causing an obstruction in the brain.

What are the risks of blood transfusions?

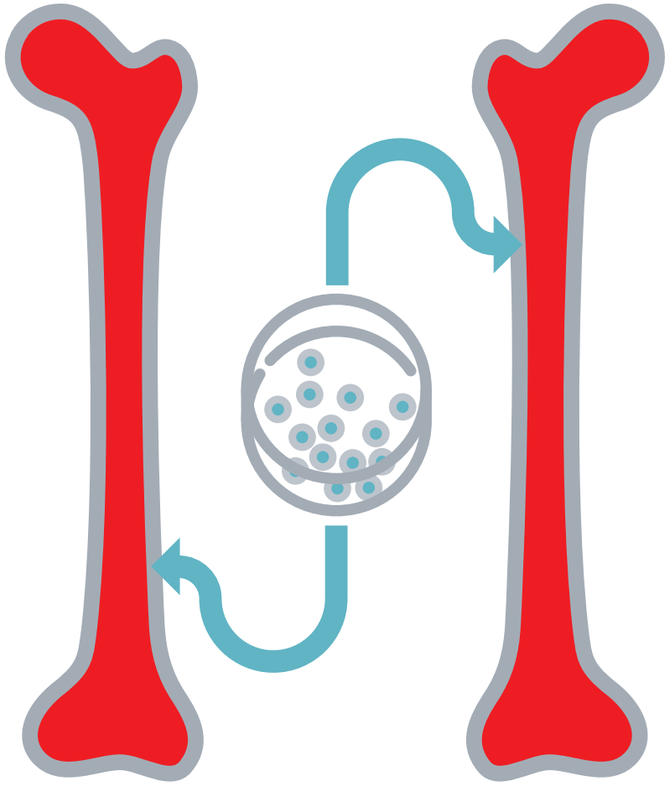
Sometimes a blood transfusion can cause a transfusion reaction. This occurs when the body's immune system reacts to the transfused red blood cells. Symptoms include hives, itching, rash, trouble breathing or fever. If this occurs, the transfusion will be stopped. The child will be evaluated by their medical team and treated for the reaction.

Chronic transfusions can cause too much iron to build up in the bloodstream over time; this is called iron overload. Every transfused red blood cell contains iron. Monthly transfusions can cause this extra iron to build up in the body, and can cause damage to the heart, liver and other organs. Iron levels are monitored closely each month. When the iron begins to build up, a medication is started to remove the extra iron and prevent organ damage.



Stem Cell Transplant

A stem cell transplant is a potential cure for sickle cell disease. Blood cells are made in bone marrow. A stem cell transplant kills a person's bone marrow that is making sickled blood cells and replaces it with a stem cell donor's normal bone marrow to make normal red blood cells. Chemotherapy is given before the transplant to destroy the patient's bone marrow.



Who can be a stem cell donor?

A stem cell donor is typically a full sibling with the same parents. The donor must have the same proteins on their cells in order to be a match for your child. A blood test called HLA typing is performed to find out if the donor is a match. Sometimes a transplant can be performed from a donor who is not related to the patient but who is still a match. This is called a matched unrelated donor. This type of transplant has higher risks and is only considered if there is not a matched sibling donor available.

What are the risks associated with stem cell transplant?

- **Infection:** Chemotherapy given before a transplant will lower white blood cell counts, which increases the risk for certain infections.
- **Graft-versus host disease (GVHD):** GVHD is a dangerous reaction in which the donor cells (or graft) can attack the patient (or host). This can be life-threatening, and it occurs in 10% of patients who undergo a transplant with a matched full sibling.
- **Graft failure**: Sometimes transplants don't work, and your child will continue to have sickle cell disease. This occurs in 5% of patients who undergo a transplant with a matched full sibling.
- **Infertility:** After a stem cell transplant, some children aren't able to have their own children because chemotherapy can damage the ovaries and testicles.

Additional FDA-Approved Treatments

Recently, new medications have been approved for use in children with sickle cell disease. There is also ongoing research being performed that may lead to additional medications or treatments to help children with sickle cell disease in the future. Talk to your child's hematologist to get more information.

What other medications are available to treat sickle cell disease?

Oxbryta® (voxelotor):

Oxbryta® is a medicine which helps to prevent the process that causes red blood cells to sickle. Studies have shown it increases hemoglobin, but further research is being done to determine whether it reduces other complications from sickle cell disease. Oxbryta is taken by mouth once a day and is approved for use in adults and children 12 years of age and older.

Adakveo® (crizanlizumab):

Adakveo® is a medicine approved for use in adults and children 16 years of age and older to help reduce pain episodes. There is also research being done to determine if it is safe and effective in younger patients. Adakveo is given via an IV infusion over 30 minutes once a month.

Endari (L-glutamine powder):

Endari is a medicine approved for use in adults and children 5 years of age and older to help reduce complications from sickle cell disease, such as pain episodes. Endari is a powder medication that is mixed into 8 oz. of liquid and taken twice a day.

What treatments are currently being studied?

Doctors are studying gene therapy as a potential treatment for sickle cell disease, but it is not yet approved for use outside of research studies. Gene therapy changes a gene within the patient's own cells in order to reduce sickling of red blood cells.

Sports Participation

Can my child still exercise and play sports?

Children with sickle cell disease can get tired easily during long periods of exercise or activity. Exercise can also lead to dehydration, which may lead to a pain episode.

What precautions can I take if my child does participate in sports?

When participating in sports or exercise, your child needs to drink plenty of water and take frequent breaks when they are tired or hot. If certain activities always seem to cause a pain episode, it is best to stop participating in this activity.

What precautions should I take if my child participates in water-based activities?

Sometimes swimming and water-based activities can lead to a pain episode, especially if your child spends a long time in the water without taking a break. These steps can help prevent pain while allowing your child to enjoy water-based play:

- After 30 minutes in the water, take a 30-minute break out of the water to rest and completely dry off.
- During the break, drink plenty of fluids. It is possible to get dehydrated even while playing in water.
- When you are done participating in water-based activities, take a warm bath or shower and quickly change into dry clothes.
- Avoid going from water-based activities into a cold/air-conditioned building.

If you have questions or for more information
call your sickle cell team at 214-456-6102

or visit **childrens.com/sicklecell**

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