

SICKLE CELL DISEASE

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States. People with SCD are born with it. This disease gets its name from the abnormal crescent or “sickle” shape that some red blood cells develop. Because of this shape and other abnormalities, sickled red blood cells can block the flow of blood through the body and cause recurring episodes of pain, or pain crises.

CAUSES

SCD is caused by a change in hemoglobin, the protein in red blood cells that carries oxygen to all parts of the body. This type of hemoglobin is called hemoglobin S. When red blood cells with hemoglobin S go through the smallest blood vessels, called capillaries, some of the cells form into rigid strands and become sticky. These rigid, sticky strands often get stuck, clogging the capillaries. As a result, different parts of the body do not get the oxygen they need.

SIGNS AND SYMPTOMS

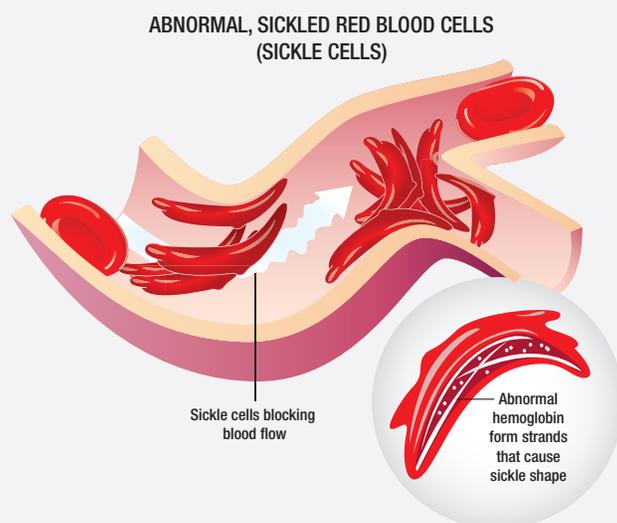
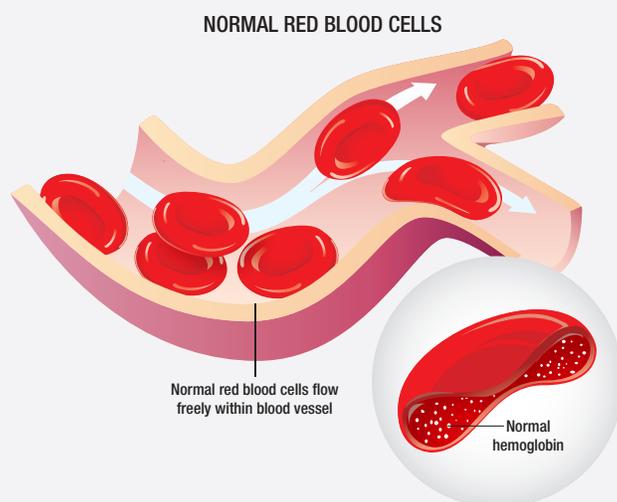
Most newborns who have SCD do not have symptoms until they are about 5 or 6 months old.

Symptoms can vary from person to person and can change over time. A person may or may not have symptoms depending on how SCD affects their health. Some people have symptoms once in a while; others have symptoms very often.

EARLY SIGNS AND SYMPTOMS

Early symptoms of SCD may include:

- Yellowing of the skin and whites of the eyes
- Fatigue or fussiness from anemia
- Painful swelling of the hands and feet



National Heart, Lung,
and Blood Institute

Blood Diseases
& Disorders
Education Program

For more information, visit sicklecell.nhlbi.nih.gov
NIH Publication No. 22-HL-3058 July 2022

SICKLE CELL DISEASE

DIAGNOSIS

Doctors diagnose SCD using different screening blood tests. People who do not know whether they have the gene that makes sickle hemoglobin or another abnormal hemoglobin, such as SC, Sβ thalassemia, and SE, can find out by having their blood tested.

This helps them learn whether they carry a gene—or have the sickle cell trait—for an abnormal hemoglobin that they could pass on to a child. Every state in the United States, the District of Columbia, and the U.S. territories require that hospitals test babies for SCD as part of a newborn screening program.

TREATMENT

SCD is a lifelong illness. The good news is that several new medicines that will help ease the symptoms have been approved over the last few years. After a diagnosis, your doctor may recommend one of these medicines. In certain situations, blood transfusions may work better to manage complications, including chronic pain.

Currently, a bone marrow transplant is the only cure for SCD. But this is not for everyone. Many patients who have SCD either are too old for a transplant or do not have a donor who is a good genetic match. A patient needs a well-matched donor to have the best chance for a successful transplant.

Researchers are also exploring genetic therapies. Genetic therapies aim to repair a faulty gene or add a missing or new gene. These may help lead to new treatments or help cure SCD.

CLINICAL TRIALS

The National Heart, Lung, and Blood Institute continues to fund and conduct clinical trials for SCD. People who participate in clinical trials play an important role in helping to develop safe and effective new treatments and potential cures. Because of patients' contributions, researchers understand more about the causes of SCD and are developing ways to prevent and treat complications. Learn more about participating in a [clinical trial](#).

REDUCING COMPLICATIONS

Here are a few ways to help relieve symptoms and reduce the chances of serious problems:



RECEIVE ROUTINE MEDICAL CARE.



STAY UP TO DATE ON VACCINES.



LEARN HOW TO MANAGE PAIN.

- When pain worsens, drink lots of fluids and take a nonsteroidal anti-inflammatory pain medicine such as ibuprofen. If you have kidney problems, doctors recommend acetaminophen instead.
- If you cannot control the pain at home, go to a SCD day hospital/outpatient unit or an emergency room to receive additional, stronger medicines and intravenous fluids.



ADOPT A HEALTHY LIFESTYLE.

- Exercise regularly.
- Choose [heart-healthy foods](#).
- Drink water to avoid dehydration.
- Quit smoking. For free help and support, visit www.smokefree.gov.
- Get 7-9 hours of sleep a night.



National Heart, Lung,
and Blood Institute

Blood Diseases
& Disorders
Education Program

For more information, visit sicklecell.nhlbi.nih.gov
NIH Publication No. 22-HL-3058 July 2022