URL of this page: https://medlineplus.gov/sicklecelldisease.html

# Sickle Cell Disease

**Also called: Hemoglobin SS disease, Sickle cell anemia**

## What is sickle cell disease (SCD)?

Sickle cell disease (SCD) is a group of inherited red blood cell disorders. If you have SCD, there is a problem with your hemoglobin. Hemoglobin is a protein in red blood cells that carries oxygen throughout the body. With SCD, the hemoglobin forms into stiff rods within the red blood cells. This changes the shape of the red blood cells. The cells are supposed to be disc-shaped, but instead they are crescent, or sickle, shaped.

The sickle-shaped cells are not flexible and cannot change shape easily. Many of them burst apart as they move through your blood vessels. The sickle cells usually only last 10 to 20 days, instead of the normal 90 to 120 days. Your body may have trouble making enough new cells to replace the ones that you lost. Because of this, you may not have enough red blood cells. This is a condition called anemia [https://medlineplus.gov/anemia.html] , and it can make you feel tired.

The sickle-shaped cells can also stick to vessel walls, causing a blockage that slows or stops the flow of blood. When this happens, oxygen can't reach nearby tissues. The lack of oxygen can cause attacks of sudden, severe pain, called pain crises. These attacks can occur without warning. If you get one, you might need to go to the hospital for treatment.

## What causes sickle cell disease (SCD)?

SCD is caused by a variant (change) in a gene [https://medlineplus.gov/genetics/condition/sickle-cell-disease/] that has instructions for your body to make one part of the hemoglobin. This changed gene is sometimes called a sickle cell gene. People with SCD are born with two sickle cell genes, one from each parent.

If you are born with one sickle cell gene, it's called sickle cell trait. People with sickle cell trait are generally healthy, but they can pass the defective gene on to their children.

## Who is more likely to have sickle cell disease (SCD)?

In the United States, most of the people with SCD are African Americans:

- About 1 in 13 Black or African American babies are born with sickle cell trait
- About 1 in every 365 Black or African American babies are born with sickle cell disease

SCD also affects some people who come from Hispanic, southern European, Middle Eastern, or Asian Indian backgrounds.

## What are the symptoms of sickle cell disease (SCD)?

People with SCD start to have signs of the disease during the first year of life, usually around 5 or 6 months of age. Early symptoms of SCD may include:

- Painful swelling of the hands and feet
- Fatigue or fussiness from anemia
- A yellowish color of the skin (jaundice [https://medlineplus.gov/jaundice.html] ) or the whites of the eyes (icterus)

The effects of SCD vary from person to person and can change over time. Most of the signs and symptoms of SCD are related to complications of the disease. They may include severe pain, anemia, organ damage, and infections.

## How is sickle cell disease (SCD) diagnosed?

A blood test can show if you have SCD or sickle cell trait. Genetic tests [https://medlineplus.gov/genetictesting.html] can tell if you have one or two copies of the sickle cell gene. Genetic tests can help confirm an SCD diagnosis if the results from blood tests are not clear.

All states now test newborns for SCD (as well as many other treatable conditions) as part of their screening programs [https://medlineplus.gov/newbornscreening.html] . These programs help find the conditions early, so treatment can be started right away.

Health care providers can also diagnose SCD before a baby is born. That test uses a sample of amniotic fluid (the liquid in the sac surrounding the baby) or tissue taken from the placenta (the organ that brings oxygen and nutrients to the baby).

People who are thinking about having children can have the test to find out how likely it is that their children will have SCD.

## What are the treatments for sickle cell disease (SCD)?

There are many ways to manage sickle cell disease. Your medical team will probably include a hematologist, a doctor who specializes in blood diseases. You will work with your medical team to set up a treatment plan. Possible treatment options may include:

- Treatments that can help relieve symptoms and lessen complications, including:
  - Hydroxyurea, a medicine to reduce sickling of red blood cells. This can help prevent serious symptoms of sickle cell disease. This medicine can be used in adults and in children as young as 9 months old. But this medicine is **not** safe during pregnancy.
  - Voxelotor, another medicine to prevent the sickling of red blood cells. It can be used in adults and children ages 4 years and older.
  - Pain relievers [https://medlineplus.gov/painrelievers.html] for acute or chronic pain.
  - Antibiotics [https://medlineplus.gov/antibiotics.html] to try to prevent infections in younger children.
  - Blood transfusions [https://medlineplus.gov/bloodtransfusionanddonation.html] for severe anemia. If you have had some serious complications, such as a stroke [https://medlineplus.gov/stroke.html] , you may have transfusions to prevent more complications.
  - Other treatments for specific complications, such as medicines to lower blood pressure [https://medlineplus.gov/bloodpressuremedicines.html] and vitamins [https://medlineplus.gov/vitamins.html] to treat a vitamin deficiency.
- Bone marrow [https://medlineplus.gov/bonemarrowtransplantation.html] or stem cell [https://medlineplus.gov/stemcells.html] transplantation, which can cure SCD. Because these transplants are risky and can have serious side effects, they are usually only used in children with severe SCD. For the transplant to work, the bone marrow must be a close match. Usually, the best donor is a brother or sister.
- Gene therapies to treat SCD in people who are 12 years and older and have had repeated sickle cell crises. These new therapies involve taking some of your blood stem cells and either adding new DNA to them or changing their existing DNA. Then these cells are given back to you, and they can make a type of hemoglobin that is healthy. This can reduce the complications of SCD, including the SCD crises.

Complementary and alternative medicine [https://medlineplus.gov/complementaryandintegrativemedicine.html] (CAM) seems to help some people deal with pain caused by SCD. These types of CAM may lower your pain, especially if it is not well managed with medicines::

- Cognitive behavioral therapy (a type of counseling)
- Acupuncture [https://medlineplus.gov/acupuncture.html]
- Exercise or movement programs, such as yoga
- Massage
- Meditation and mindfulness practices

- Virtual reality, a computer-generated 3D environment you can see with special goggles

It's also important to take steps to keep yourself as healthy as possible:

- Get regular medical care
- Get your routine vaccinations [https://medlineplus.gov/vaccines.html]
- Live a healthy lifestyle
- Avoid situations that may set off a pain crisis

*NIH: National Heart, Lung, and Blood Institute*

## Start Here

- About Sickle Cell Disease [https://www.cdc.gov/sickle-cell/about/] (Centers for Disease Control and Prevention)
- Sickle Cell Disease [https://familydoctor.org/condition/sickle-cell-disease/?adfree=true] (American Academy of Family Physicians)
  Also in Spanish [https://es.familydoctor.org/condicion/anemia-falciforme-es/?adfree=true]
- Sickle Cell Disease (SCD) [https://www.nmdp.org/patients/understanding-transplant/diseases-treated-by-transplant/sickle-cell-disease-treatment-by-transplant] (National Marrow Donor Program)
- What Is Sickle Cell Disease? [https://www.nhlbi.nih.gov/health/sickle-cell-disease] NIH (National Heart, Lung, and Blood Institute)
  Also in Spanish [https://www.nhlbi.nih.gov/es/salud/enfermedad-de-celulas-falciformes]

## Diagnosis and Tests

- Blood Smear [https://medlineplus.gov/lab-tests/blood-smear/] NIH (National Library of Medicine)
  Also in Spanish [https://medlineplus.gov/spanish/pruebas-de-laboratorio/frotis-de-sangre/]
- Complete Blood Count (CBC) [https://medlineplus.gov/lab-tests/complete-blood-count-cbc/] NIH (National Library of Medicine)
  Also in Spanish [https://medlineplus.gov/spanish/pruebas-de-laboratorio/conteo-sanguineo-completo/]
- Hemoglobin Electrophoresis [https://medlineplus.gov/lab-tests/hemoglobin-electrophoresis/] NIH (National Library of Medicine)
  Also in Spanish [https://medlineplus.gov/spanish/pruebas-de-laboratorio/electroforesis-de-hemoglobina/]

## Treatments and Therapies

- Bone Marrow Transplantation: MedlinePlus Health Topic [https://medlineplus.gov/bonemarrowtransplantation.html]
  NIH (National Library of Medicine)
  Also in Spanish [https://medlineplus.gov/spanish/bonemarrowtransplantation.html]
- Complications of Sickle Cell Disease [https://www.cdc.gov/sickle-cell/complications/] (Centers for Disease Control and Prevention)
- FDA Approval of Gene Therapies for Sickle Cell Disease: Q&A with NHLBI Director Dr. Gary Gibbons and NHLBI's Division of Blood Diseases and Resources Director Dr. Julie Panepinto [https://www.nhlbi.nih.gov/news/2023/fda-approval-gene-therapies-sickle-cell-disease-dr-gibbons-dr-panepinto] NIH (National Heart, Lung, and Blood Institute)
- Treatments for Blood Disorders [https://www.nhlbi.nih.gov/health/blood-bone-marrow-treatments]
  NIH (National Heart, Lung, and Blood Institute)
  Also in Spanish [https://www.nhlbi.nih.gov/es/salud/sangre-y-medula-osea-tratamientos]

## Living With

- Acute Sickle Cell Pain [https://kidshealth.org/en/teens/sickle-crisis.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/sickle-crisis.html]

## Related Issues

- A1C Test and Race/Ethnicity [https://www.niddk.nih.gov/health-information/diagnostic-tests/a1c-test-race-ethnicity]
  NIH (National Institute of Diabetes and Digestive and Kidney Diseases)
- Could My Kids Be Born with Sickle Cell Disease Someday? [https://kidshealth.org/en/teens/sickle-cell-genes.html]
  (Nemours Foundation)

Also in Spanish [https://kidshealth.org/es/teens/sickle-cell-genes.html]

- Hemoglobin C, S-C, and E Diseases [https://www.merckmanuals.com/home/blood-disorders/anemia/hemoglobin-c-s-c-and-e-diseases] (Merck & Co., Inc.)
  Also in Spanish [https://www.merckmanuals.com/es-us/hogar/trastornos-de-la-sangre/anemia/enfermedades-de-la-hemoglobina-c-s-c-y-e]
- Understanding the Blood Cell [https://www.genome.gov/research-at-nhgri/Projects/Democratizing-Education/understanding-red-blood-cell] NIH (National Human Genome Research Institute)
  Also in Spanish [https://www.genome.gov/es/research-at-nhgri/Projects/Democratizing-Education/entender-las-c%C3%A9lulas-sangu%C3%ADneas]
- Your Mental Health and Sickle Cell Disease Gene Therapy Participation [https://www.genome.gov/research-at-nhgri/Projects/Democratizing-Education/your-mental-health-scd-gene-therapy] (National Human Genome Research Institute)
  Also in Spanish [https://www.genome.gov/es/research-at-nhgri/Projects/Democratizing-Education/salud-mental-y-terapia-g%C3%A9nica-c%C3%A9lulas-falciformes]

## Specifics

- Hemoglobin SC (HbSC) Disease: A Type of Sickle Cell Disease [https://kidshealth.org/en/parents/hbsc-disease.html] (Nemours Foundation) - **In English and Spanish**
  Also in Spanish [https://kidshealth.org/es/parents/hbsc-disease.html]

## Genetics

- About Sickle Cell Disease [https://www.genome.gov/Genetic-Disorders/Sickle-Cell-Disease] NIH (National Human Genome Research Institute)
- Genetic Counseling (For Parents) [https://kidshealth.org/en/parents/genetic-counseling.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/parents/genetic-counseling.html]
- Navigating Sickle Cell Disease Gene Therapy [https://www.genome.gov/research-at-nhgri/Projects/Democratizing-Education/navigating-sickle-cell-disease-gene-therapy] NIH (National Human Genome Research Institute)
  Also in Spanish [https://www.genome.gov/es/research-at-nhgri/Projects/Democratizing-Education/proceso-estudios-cl%C3%ADnicos-sobre-la-terapia-g%C3%A9nica]
- Sickle Cell Disease Gene Therapy Education Project [https://www.genome.gov/research-at-nhgri/Projects/Democratizing-Education] NIH (National Human Genome Research Institute)
- Sickle Cell Disease Gene Therapy FAQ [https://www.genome.gov/research-at-nhgri/Projects/Democratizing-Education/sickle-cell-disease-gene-therapy-FAQ] NIH (National Human Genome Research Institute)
  Also in Spanish [https://www.genome.gov/es/research-at-nhgri/Projects/Democratizing-Education/preguntas-frecuentes-terapia-g%C3%A9nica-c%C3%A9lulas-falciformes]
- Sickle cell disease: MedlinePlus Genetics [https://medlineplus.gov/genetics/condition/sickle-cell-disease] NIH (National Library of Medicine)
- Understanding Gene Therapy Approaches [https://www.genome.gov/research-at-nhgri/Projects/Democratizing-Education/understanding-gene-therapy-approaches] NIH (National Human Genome Research Institute)
  Also in Spanish [https://www.genome.gov/es/research-at-nhgri/Projects/Democratizing-Education/entender-los-enfoques-de-la-terapia-g%C3%A9nica]
- What Is Sickle Cell Trait? [https://www.cdc.gov/sickle-cell/sickle-cell-trait/] (Centers for Disease Control and Prevention)

## Statistics and Research

- Data and Statistics on Sickle Cell Disease [https://www.cdc.gov/sickle-cell/data/] (Centers for Disease Control and Prevention)

## Clinical Trials

- ClinicalTrials.gov: Anemia, Sickle Cell [https://clinicaltrials.gov/search?cond=%22Anemia,+Sickle+Cell%22&aggFilters=status:not%20rec] NIH (National Institutes of Health)

## Journal Articles

**References and abstracts from MEDLINE/PubMed (National Library of Medicine)**

- Article: Usage of a Multipurpose mHealth App Among Adults With Sickle Cell... [https://www.ncbi.nlm.nih.gov/pubmed/40472251]
- Article: The feasibility of pharmacokinetic-based dosing of hydroxyurea for children with sickle... [https://www.ncbi.nlm.nih.gov/pubmed/40441700]
- Article: Severe inflammation and lineage skewing are associated with poor engraftment of... [https://www.ncbi.nlm.nih.gov/pubmed/40169559]
- Sickle Cell Disease -- see more articles [https://pubmed.ncbi.nlm.nih.gov/?term=%22Anemia%2C+Sickle+Cell%22%5Bmajr%3Anoexp%5D+AND+humans%5Bmh%5D+AND+english%5Bla%5D+AND+%22last+1+Year%22+%5Bedat%5D+AND+%28patient+education+handout%5Bpt%5D+OR+guideline%5Bpt%5D+OR+clinical+trial%5Bpt%5D%29++NOT+%28letter%5Bpt%5D+OR+case+reports%5Bpt%5D+OR+editorial%5Bpt%5D+OR+comment%5Bpt%5D%29+AND+free+full+text%5Bsb%5D+]

## Find an Expert

- Find a Genetic Counselor [https://findageneticcounselor.nsgc.org] (National Society of Genetic Counselors)
  Also in Spanish [https://sp.findageneticcounselor.nsgc.org/]
- National Heart, Lung, and Blood Institute [https://www.nhlbi.nih.gov/] NIH
- Sickle Cell Disease Association of America [https://www.sicklecelldisease.org/]

## Children

- Dr. Allison King on Sickle Cell Disease and Learning [https://newsinhealth.nih.gov/2020/09/dr-allison-king-sickle-cell-disease-learning] NIH (National Institutes of Health)
  Also in Spanish [https://salud.nih.gov/recursos-de-salud/nih-noticias-de-salud/allison-king-habla-sobre-la-enfermedad-de-celulas]
- Hydroxyurea for People with Sickle Cell Disease [https://kidshealth.org/en/parents/hydroxyurea.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/parents/hydroxyurea.html]
- Sickle Cell Disease (For Kids) [https://kidshealth.org/en/kids/sickle-cell.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/kids/sickle-cell.html]
- Sickle Cell Disease (For Parents) [https://kidshealth.org/en/parents/sickle-cell-anemia.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/parents/sickle-cell-anemia.html]
- Understanding sickle cell disease and its impact on your baby [https://www.marchofdimes.org/find-support/blog/understanding-sickle-cell-disease-and-its-impact-your-baby] (March of Dimes Foundation)
  Also in Spanish [https://nacersano.marchofdimes.org/complicaciones/anemia-falciforme.aspx]

## Teenagers

- Crizanlizumab for People With Sickle Cell Disease [https://kidshealth.org/en/teens/crizanlizumab.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/crizanlizumab.html]
- I Have Sickle Cell Trait: Is It Safe to Fly or Travel to the Mountains? [https://kidshealth.org/en/teens/sickle-cell-trait-altitude.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/sickle-cell-trait-altitude.html]
- Prevent Problems from Sickle Cell Disease [https://kidshealth.org/en/teens/center/sickle-cell-treatment.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/center/sickle-cell-treatment.html]
- Sickle Cell Disease (For Teens) [https://kidshealth.org/en/teens/sickle-cell-anemia.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/sickle-cell-anemia.html]
- Sickle Cell Trait: 3 Ways to Stay Healthy [https://kidshealth.org/en/teens/sickle-cell-trait-healthy.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/sickle-cell-trait-healthy.html]
- Sickle Cell Trait: 5 Problems to Know about [https://kidshealth.org/en/teens/sickle-cell-trait-problems.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/sickle-cell-trait-problems.html]

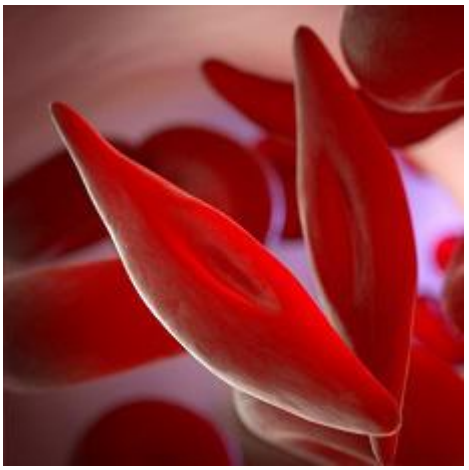
- Transitioning Your Medical Care: Sickle Cell Disease (For Teens) [https://kidshealth.org/en/teens/care-sickle-cell.html] (Nemours Foundation)
  Also in Spanish [https://kidshealth.org/es/teens/care-sickle-cell.html]

## Women

- Women with Sickle Cell Disease and Preconception Care [https://www.cdc.gov/sickle-cell/communication-resources/women-with-sickle-cell-disease-and-preconception-care.html] (Centers for Disease Control and Prevention)

## Patient Handouts

- Hemoglobin electrophoresis [https://medlineplus.gov/ency/article/003639.htm] (Medical Encyclopedia)
  Also in Spanish [https://medlineplus.gov/spanish/ency/article/003639.htm]
- Sickle cell disease [https://medlineplus.gov/ency/article/000527.htm] (Medical Encyclopedia)
  Also in Spanish [https://medlineplus.gov/spanish/ency/article/000527.htm]
- Sickle cell test [https://medlineplus.gov/ency/article/003666.htm] (Medical Encyclopedia)
  Also in Spanish [https://medlineplus.gov/spanish/ency/article/003666.htm]



### MEDICAL ENCYCLOPEDIA

Hemoglobin electrophoresis [https://medlineplus.gov/ency/article/003639.htm]

Hemoglobinuria test [https://medlineplus.gov/ency/article/003363.htm]

Sickle cell disease [https://medlineplus.gov/ency/article/000527.htm]

Sickle cell test [https://medlineplus.gov/ency/article/003666.htm]

Total iron binding capacity [https://medlineplus.gov/ency/article/003489.htm]

### National Institutes of Health

The primary NIH organization for research on *Sickle Cell Disease* is the National Heart, Lung, and Blood Institute [http://www.nhlbi.nih.gov/]

### NIH MedlinePlus Magazine

Tesha Samuels Advocates for Others After Living with Sickle Cell Disease [https://magazine.medlineplus.gov/article/tesha-samuels-advocates-for-others-after-living-with-sickle-cell-disease]

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