

Sickle Cell Disease: What You Should Know

This podcast is presented by the Centers for Disease Control and Prevention. CDC – safer, healthier people.

More than 70,000 people in the United States have sickle cell disease and more than 2 million people carry the gene that allows them to pass it on to their children. Here are some things you should know about one of the most common genetic diseases in the U.S.

African Americans are not the only people who get sickle cell disease. It affects millions of people throughout the world and is particularly common among people whose ancestors come from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere, such as South America, Cuba, and Central America; Saudi Arabia; India; and Mediterranean countries, such as Turkey, Greece, and Italy. Because of this, hospitals in the U.S. screen all newborn babies for sickle cell disease.

It's important to know whether or not you have sickle cell trait. People with sickle cell trait usually don't have any symptoms of the disease. However, it's possible for a person with sickle cell trait to have complications of the disease under extreme conditions, such as:

- High altitude;
- Increased pressure;
- Low oxygen; and,
- Dehydration

A person with sickle cell trait can pass the disease on to their children.

People with sickle cell disease can get malaria just like anyone else. However, they are *less likely* to get malaria. The trait doesn't completely protect a person from infection, but it makes death from malaria less likely.

A pain “episode” or “crisis” is the most common symptom of sickle cell disease. It's the top reason that people with the disease go to the emergency room or hospital. When sickle cells travel through small blood vessels, they can get stuck and clog the blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

A woman with sickle cell disease can have a healthy pregnancy, but she needs to be careful to avoid problems during pregnancy that can affect her health and the health of her unborn baby. During pregnancy, the disease may become more severe and pain episodes may occur more frequently. There's a higher risk of preterm labor and of having a low-birthweight baby. However, with early prenatal care and careful monitoring throughout pregnancy, a woman with sickle cell disease can have a healthy pregnancy.

During pregnancy, there's a test to find out if the unborn baby will have sickle cell disease, sickle cell trait, or neither one. A test is usually conducted after the second month of pregnancy. A woman with sickle cell disease might want to see a genetic counselor to get information about the disease and the chances that it will be passed to the baby.

There are several different types of sickle cell disease. People who inherit two sickle cell genes, one from each parent, have a type of sickle cell disease called SS. This is commonly called sickle cell anemia and is usually the most severe form of the disease. People who inherit a sickle cell gene from one parent and a gene for another type of abnormal hemoglobin from the other parent have a different type of sickle cell disease. Some types of sickle cell disease are very severe and some are milder. The disease affects each person differently.

Bone marrow or stem cell transplant can cure sickle cell disease. Bone marrow is a soft, fatty tissue inside the center of the bones where blood cells are made. A bone marrow or stem cell transplant is a procedure that takes healthy cells that form blood from one person -the donor- and puts them into someone whose bone marrow is not working properly. Bone marrow or stem cell transplants are very risky, and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match. Usually, the best donor is a brother or sister. Bone marrow or stem cell transplants are done only in children who have severe sickle cell disease and who have minimal organ damage from the disease.

People with sickle cell disease need to have their vision checked more often than people who don't have the disease. Vision loss, including blindness, can occur when blood vessels in the eye become blocked with sickle cells and the retina gets damaged. People with sickle cell disease should have their eyes checked every year for damage to the retina. If possible, this should be done by an eye doctor who specializes in diseases of the retina. If the retina is damaged, laser treatment can often prevent further vision loss.

There are lots of things someone with sickle cell disease can do to avoid some of the complications. People with sickle cell disease can live full lives and enjoy most of the activities that others do. Here are some things a person with sickle cell disease can do to stay as healthy as possible:

- **Get regular health checkups.** Regular checkups with a primary care doctor can help prevent some serious problems.
- **Prevent infections.** Common illnesses, like the flu, can quickly become dangerous for a child with sickle cell disease. The best defense is to take simple steps to help prevent infections.
- **Learn and practice healthy habits.** People with sickle cell disease should drink 8 to 10 glasses of water every day and eat nutritious food. They should also try not to get too hot, too cold, or too tired.
- **Look for clinical studies.** New clinical research studies are being conducted all the time to find better treatments and, hopefully, a cure for sickle cell disease. People who participate in these studies might have access to new medicines and treatment options.
- **Get support.** Find a patient support group or community-based organization that can provide information, assistance, and support.
- **People with sickle cell disease should get vaccinations.** They can protect against harmful infections.

To learn more about sickle cell disease, visit www.cdc.gov.

For the most accurate health information, visit www.cdc.gov or call 1-800-CDC-INFO 24/7.