

Sickle cell disease

Sickle cell disease is a group of red blood cell disorders that are passed down from your parents. This means that you are born with it. People with sickle cell disease have some red blood cells that are shaped like a “sickle” or crescent, instead of round. Sickle-shaped red blood cells can stick to each other inside blood vessels, blocking blood flow and oxygen and causing pain crises, problems with pregnancy, organ damage, and other serious health problems. Sickle cell disease, sometimes called sickle cell anemia, affects more people in the United States who are black or African-American than other racial or ethnic groups.

Q: What are the symptoms of sickle cell disease?

A: Symptoms can be different for each person with sickle cell disease. The most common symptom is pain caused by sickle cells blocking blood flow in blood vessels. Having fewer red blood cells than normal causes anemia or not enough oxygen in the blood, making you feel tired and weak. You may also have symptoms of other health problems if the disease causes damage to a part of the body, such as the spleen, heart, lungs, eyes, kidneys, liver, or other organs.

Q: How does sickle cell disease affect women?

A: Sickle cell disease can cause unique problems in women, including:

- **Delayed puberty.** Girls who have sickle cell anemia may get their period about 2 years later than girls who do not have the disease, while those with milder types of sickle cell disease may have less of a delay.
- **More pain crises before and during your period.** This may be caused by changes in hormone levels. Hormonal treatment such as progesterone injections may help.

- **Problems getting pregnant.** Some common treatments for sickle cell disease and pain medicines may affect fertility.
- **Increased sickle cell disease complications during pregnancy.** These complications can include worsening anemia, higher risk of blood clots and infections, more frequent pain crises, and stroke.
- **Problems during pregnancy for you and for your baby.** Women who have sickle cell disease have an increased risk of preterm birth, infection, cesarean section delivery, pregnancy loss, and preeclampsia. Babies have an increased risk of having low birth weight, birth defects, and hemolytic disease.
- **Pain during sex.** Women who often experience acute pain crises, or women with chronic (long-term) pain, may be more likely to have pain during sex. If you are taking opioids to manage sickle cell disease pain, they may affect hormone levels. Abnormal hormone levels may cause pain during sex.

Q: How can I stay well with sickle cell disease?

A: Sickle cell disease is a chronic disease, but you can live a full and active life by learning how to stay as healthy as possible. Follow these tips to manage your sickle cell disease:

- **Find a doctor who specializes in sickle cell disease.** You will probably need to see a hematologist, a doctor who specializes in blood diseases. You may have other types of doctors who treat complications from organ damage, such as a nephrologist for kidney problems.

- **Find ways to manage pain.** Talk to your doctor about ways to manage pain, including taking medicines and staying hydrated. Your doctor can also help you make a pain management plan. A pain management plan has clear, written instructions for when to take medicine, which medicine to take, what dose to take, and what to do if the pain gets worse.
- **Get an annual checkup.** An annual checkup can help you keep track of other health conditions or concerns.
- **Prevent infections.** Infections can cause complications from sickle cell disease, so it is important to get all of the vaccines your doctor or nurse recommends.
- **Try to have healthy habits.** Try to drink 8 to 10 glasses of water a day. Choose healthy foods and get regular physical activity, but be sure to drink enough water and take breaks when you need to, and don't get overheated. Get enough sleep. Do not smoke.
- **Get support.** Support can come from friends and family or patient groups and community organizations. Talk to a professional counselor or therapist if you are feeling overwhelmed or depressed.

For more information...

For more information about sickle cell disease, call the OWH Helpline at 1-800-994-9662 or contact the following organizations:

Centers for Disease Control and Prevention, HHS
1-800-232-4636
www.cdc.gov/ncbddd/sicklecell/index.html

Sickle Cell Disease Association of America
1-800-421-8453
www.sicklecelldisease.org

National Heart, Lung, and Blood Institute, NIH, HHS
301-592-8573
www.nhlbi.nih.gov/health-topics/sickle-cell-disease

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