



PATIENT EDUCATION HANDOUTS

Sickle Cell Disease

Topic Overview

What is sickle cell disease?

Sickle cell disease changes normal, round red blood cells into cells that are shaped like crescent moons. The name “sickle cell” comes from the crescent shape of the cells. A sickle is a farm tool with a curved blade that is used to cut crops like wheat.

Normal red blood cells move easily through your blood vessels, taking oxygen to every part of your body. But sickled cells can get stuck and block blood vessels, which stops the oxygen from getting through. That can cause a lot of pain. It can also harm organs, muscles, and bones.

See an illustration of [sickle cells blocking a blood vessel](#) .

Having sickle cell disease means a lifelong battle against the health problems it can cause, such as pain, infections, anemia, and stroke. But many people are able to have a very good quality of life by learning to manage the disease.

What causes sickle cell disease?

Sickle cell disease is inherited, which means it is passed from parent to child. To get sickle cell disease, a child has to inherit two sickle cell [genes](#)—one from each parent.

When a child inherits the gene from just one parent, that child has [sickle cell trait](#). Having this trait means that you do not have the disease, but you are a carrier and could pass it on to your children.

What are the symptoms?

Painful events are the most common symptom of sickle cell disease. They are periods of pain that happen when sickled cells get stuck in blood vessels and block the blood flow. These events usually cause pain in the hands, feet, belly, back, or chest. The pain may last for hours or for days.

People with sickle cell disease often have [anemia](#), caused by a shortage of normal red blood cells. Anemia makes you feel weak and tired. People with sickle cell anemia may look pale or washed out. They may have a yellowish look to their skin and the whites of their eyes ([jaundice](#)).

Doctors cannot yet tell which symptoms a child born with sickle cell disease will have, when they will start, or how serious they will be.

How is sickle cell disease diagnosed?

A simple blood test can show whether a person has sickle cell disease. In some states, all infants are tested for sickle cell disease before they go home from the hospital.

How is it treated?

Early treatment includes daily [antibiotics](#) from 2 months to 5 years of age to help prevent infections. Routine childhood [immunizations](#) are also important.

Managing pain is often a big part of having sickle cell disease. You can prepare for a painful event ahead of time by creating a pain management plan with your doctor. The plan should include what you can do at home to relieve pain for yourself or your child. The plan should also tell you when it is best to call a doctor or go to a hospital.

Some people need regular blood transfusions to keep down the number of painful events and lower the risk of stroke and other problems.

Regular checkups are an important part of life with this disease. People with sickle cell disease need a good working relationship with a doctor who is an expert in treating it.

How do you manage life with sickle cell disease?

- Learn what triggers, or sets off, painful events. Triggers often include cold temperatures, [dehydration](#), and too much exercise. Low oxygen caused by cigarette smoke, high altitude, and plane flights is another common trigger.
- Make sure that your child takes antibiotics regularly until age 5 to prevent infections. And make sure he or she receives all the usual immunizations on schedule.
- Your child can take part in normal school activities. Make sure that teachers understand your child's special needs, like needing frequent drinks and bathroom trips and avoiding overexertion and cold temperatures.
- People with sickle cell disease and their families face ongoing stress. A support network can help ease stress and worry. Ask your doctor if there is a support group in your area. You can also find Web sites on the Internet where you can ask questions, share your feelings, and get advice.

Frequently Asked Questions

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