What Is Sickle Cell Disease?

Sickle cell disease (SCD) is an inherited blood disorder that affects red blood cells. Red blood cells carry oxygen through the body. SCD causes these cells to become sticky, stiff, and C-shaped – making it hard to move through blood vessels and distribute oxygen. Sickle cells die faster, causing a shortage of red blood cells, which is why the condition is also called sickle cell anemia.

Most children are diagnosed through a newborn screening test. Symptoms range from mild to severe, usually starting in the first year of life. They include slow growth, pain, infections, or swelling in the hands and feet. Pain attacks – called "pain crises" – can be triggered by cold weather, stress, illness, or dehydration.

Serious complications include:

- **Acute chest syndrome:** Blocked blood flow in the lungs causes pain, coughing, trouble breathing, and fever.
- **Severe anemia:** Can cause fatigue, a fast heartbeat, and pale skin.
- **Painful, prolonged erections:** Can cause long-term problems if not treated quickly.
- **Strokes:** Can occur if sickle cells block blood flow in the brain.

Frequently Asked Questions (FAQ)

How common is sickle cell disease?
SCD most commonly affects people with African, Mediterranean, and Middle Eastern heritage. In the United States, about one out of every 365 Black or African American babies is born with SCD.

What should I do if I suspect my child has sickle cell disease?
Talk to a medical provider. They can check the newborn screening results or order a blood test. They'll likely refer you to a hematologist – a doctor who specializes in blood conditions.

What kind of help is there for sickle cell disease?

- **Medication:** There are several medicines and supplements your doctor may recommend that can ease pain, help make new red blood cells, and prevent certain complications.
- **Vaccinations:** SCD can impact the immune system, so it's important to stay up to date on vaccinations, including pneumococcal, flu, COVID-19, and meningococcal vaccines.
- **Blood transfusions**: Sometimes, doctors may recommend transfusions to help treat or prevent anemia complications.

- **Bone marrow or stem cell transplants; gene therapies:** Transplants and gene therapies are options for people with more severe symptoms.

What other conditions are common in people with sickle cell disease?
Some people with SCD may also have asthma, frequent infections, or bone and joint problems. Be open with the medical provider about all symptoms.

Talking with a Medical Provider

When talking with medical providers or specialists, you might want to:

- **Bring notes:** Write down symptoms, concerns, or changes that you or others have noticed.
- **Ask:** Discuss if daily medications might help and if there are there any activities to avoid.
- **Advocate:** Talk about how to share the diagnosis with your child's school and others. Ask about what is needed to make sure your child can participate meaningfully.

What You Can Do at Home

Getting help can take time. While waiting for your appointment, it may help to:

- **Make healthy choices:** Eat nutritious foods and stay active as a family.
- **Go to all appointments:** Keep track of symptoms and update your doctor frequently.
- **Help prevent pain crises:** Focus on getting plenty of fluids and good rest to help prevent pain.
- **Practice stress management:** Find activities that bring joy to help combat stress.

Learning about sickle cell disease and getting help is a journey. You're not alone.

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About This Series

This series of handouts on health conditions was written by clinicians in Weill Cornell Medicine's Pediatric Mental Health Integration Program, partners in the ACT for Youth CYSHCN Program Center of Excellence at Cornell University.