

# What is Sickle Cell Disease?

## The Basics — A Guide for Patients, Caregivers & Community Members

### WHAT IS SICKLE CELL DISEASE?

Sickle cell disease (SCD) is an inherited blood disorder affecting red blood cell function. Unlike round, flexible healthy cells, sickle cells become stiff, sticky, and crescent-shaped. These abnormal cells can block blood flow, causing pain and other health complications.

### HOW IS IT INHERITED

Sickle cell disease is a genetic condition passed from parents to children. It develops when a person inherits the gene from both parents. Those inheriting only one gene are "carriers" (sickle cell trait); they usually don't have the disease but can pass the gene on. Sickle cell disease is not contagious.

### COMMON SYMPTOMS

Symptoms vary and change over time.

Common signs include:

- Pain crises
- Fatigue
- Swelling in hands and feet
- Frequent infections
- Shortness of breath
- Delayed growth

Experiences range from frequent symptoms to milder episodes; every person's journey with sickle cell disease is unique.

### PAIN CRISIS—WHAT HAPPENS

A pain crisis occurs when sickled red blood cells block blood flow, causing sudden, intense pain in the chest, back, abdomen, arms, or legs. These episodes can last hours or days. If you are unsure whether your pain requires medical care, it is always safer to seek help.

### POSSIBLE COMPLICATIONS

Sickle cell disease can affect various body parts, causing complications like infections, stroke, lung problems, vision issues, and organ damage. Fortunately, regular monitoring and proper care can effectively manage or reduce many of these health risks.

### HOW IS SICKLE CELL DISEASE MANAGED?

While approaches vary, regular care manages symptoms and improves quality of life.

Management may include:

- Pain strategies and hydration
- Preventing infections and vaccinations
- Regular medical checkups
- Prescribed medications

Some individuals may qualify for advanced treatments. Speak with your healthcare provider to understand your specific options.

## LIVING WELL DAY TO DAY

Many people with sickle cell disease live full, active lives. Simple habits like drinking plenty of fluids, avoiding extreme temperatures, managing stress, and getting enough rest make a meaningful difference. Seeking medical care early and relying on support from your healthcare team and community further contributes to your well-being.