FACT SHEET

Sickle cell disease

A serious inherited blood disorder affecting millions worldwide

novo nordisk haemophilia & haemoglobinopathies foundation

Quick facts

- Sickle cell disease (SCD) is a genetic disorder affecting red blood cells.
- It mainly impacts people of African, Middle Eastern, Indian, and Mediterranean descent.
- Red blood cells become sickle-shaped, causing pain and organ damage.
- People inherit SCD when both parents pass on the sickle cell gene.
- Treatment exists to reduce symptoms and prevent complications.
- SCD is not contagious and is present from birth.
- Globally, around 515,000 babies are born with SCD each year, but many remain undiagnosed or lack access to care.

What is sickle cell disease?

Sickle cell disease (SCD) is an umbrella term for a group of inherited red blood cell disorders. In all forms of SCD, the red blood cells contain an abnormal type of haemoglobin called haemoglobin S. These cells can become rigid and shaped like a sickle, blocking blood flow and reducing oxygen delivery to tissues.

Types of sickle cell disease

- **Sickle Cell Anaemia (HbSS):** The most severe and common form. The individual inherits two sickle cell genes.
- **Sickle-Haemoglobin C Disease (HbSC):** Typically, a milder form than HbSS, caused by inheriting one sickle cell gene and one haemoglobin C gene, though complications can still occur.
- **Sickle Beta-Thalassemia (HbS/β^0 or HbS/β^+):** Caused by inheriting one sickle gene and one beta-thalassemia gene; severity varies.
- **Other Variants:** These include forms such as Sickle-E, which can present with a range of symptoms.

What is sickle cell trait?

Sickle cell trait (HbAS) occurs when a person inherits one sickle cell gene and one normal gene. These individuals usually don't have symptoms but can pass the gene to their children. Many are unaware they carry the trait until they are tested.

Symptoms and complications

Symptoms often begin in early childhood and vary in severity. Common symptoms include:

- **Chronic anaemia** (low red blood cell count)
- **Pain crises** (sudden, severe pain in bones or chest)
- **Fatigue and weakness**
- **Swelling in hands and feet**
- **Frequent infections**
- **Delayed growth**
- **Vision problems**

Sickle cell disease can also lead to life-threatening complications, such as stroke, acute chest syndrome, organ damage, and severe infections. Due to frequent pain crises and hospital visits, people with SCD may miss school or work, affecting education and income.

Who is affected?

SCD is most prevalent in regions where malaria was or is historically prevalent, as carrying the gene for SCD offered a survival advantage against severe malaria.

High-prevalence areas include:
- Sub-Saharan Africa
- India and the Middle East
- Southern Europe (e.g., Italy, Greece)
- The Americas and Caribbean (especially among people of African descent)

Each year, around 515,000 babies are born with SCD globally[1]. In some African countries, up to 2% of all births are affected. Migration has spread SCD worldwide.[2]

Diagnosis

SCD is diagnosed through:
- Newborn screening (routine in many countries)
- Haemoglobin electrophoresis
- Genetic testing (in selected cases)

Many people are unaware they carry sickle cell trait until they are tested. Early diagnosis, especially at birth, and consistent medical care can greatly reduce the risk of severe complications. Additionally, patient education and awareness are essential in endemic areas to ensure timely detection and management.

Treatment options

- **Hydroxyurea:** Reduces pain episodes and hospitalisations
- **Blood transfusions:** Used for severe anaemia or stroke prevention
- **Bone marrow transplant:** Potential cure for some, mainly in high-resource settings
- **Supportive care:** Includes folic acid, antibiotics, vaccinations, and pain relief

Treatment access varies:

- In high-income countries, full treatment options are often available
- In low-resource settings, basic care like transfusions and pain relief are most common

Living well with sickle cell disease

People with SCD can live long, fulfilling lives with proper care.
- Regular checkups and early treatment help prevent complications.
- Medications like hydroxyurea reduce pain episodes and lower hospital visits.
- Preventing infections and staying hydrated are key to staying healthy.
- A balanced diet and healthy lifestyle support overall well-being.

References:
1. World Health Organization – Regional Office for Africa, Sickle Cell Disease Overview, 2025. Available at: afro.who.int/health-topics/sickle-cell-disease Last accessed: Nov 2025.
2. World Health Organization, Global Guideline on Pregnancy Care for Women with Sickle Cell Disease, 2025. Available at: who.int/news/item/19-06-2025-who-issues-first-global-guideline-to-improve-pregnancy-care-for-women-with-sickle-cell-disease Last accessed: August 2025.

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