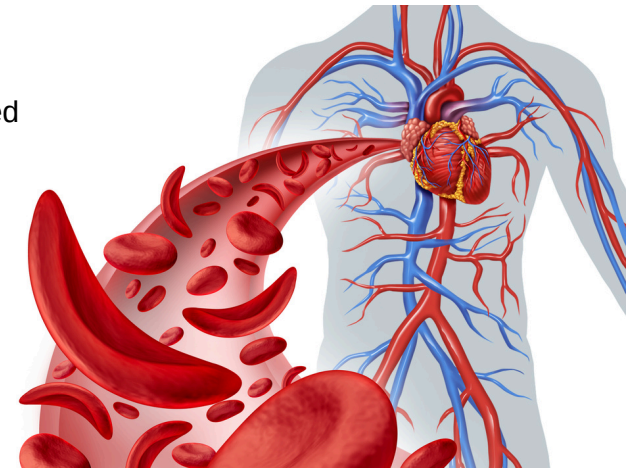
WORLD SICKLE CELL DAY 2024
we are Stronger Together
Building a Future for Sickle Cell Care

SICKLE CELL SOCIETY

Sickle Cell Fact Sheet

About Sickle Cell Disorder

Sickle cell disorder is a genetic condition that affects red blood cells, making them ‘sickle’ or crescent- shaped instead of the normal round shape.
These abnormal cells are sticky, break down quickly, and can block blood flow, leading to pain and potential organ damage. This pain, known as a "crisis," can be severe and may require hospitalisation. The disorder also causes anaemia due to the rapid destruction of red blood cells.



Living with the condition

Living with sickle cell disorder can be a challenge. Crises can occur without warning and cause intense pain that can last for days or weeks. These episodes can affect any part of the body, but are most common in the limbs and back.

The frequency of pain episodes varies widely among individuals, with some experiencing them weekly and others less than once a year. Triggers include weather changes, dehydration, stress, and strenuous exercise.

Frequent pain and medical visits disrupt daily activities, work, and education. Anaemia can lead to severe fatigue, making it hard to maintain normal life.

Over time, complications such as infections, delayed growth in children, and damage to organs like the spleen, heart, liver, kidneys, and eyes can occur. Other complications include stroke (children aged between 2 and 16 most at risk), acute chest syndrome, and priapism—a condition involving prolonged, painful erections which can cause permanent damage if not treated quickly. Mental health can also be affected.

Care

Managing sickle cell disorder requires regular medical care, including medications to reduce pain and prevent complications, and blood transfusions.

Patients must stay hydrated, avoid extreme temperatures, and be cautious about infections.

Despite these challenges, many people with sickle cell disorder lead full lives with support from family, friends, and healthcare providers. Advances in treatment have generally been slow in this area, but can make a big difference in people's lives. Along with increased awareness these advances are improving the quality of life for those affected.

Prevalence

Sickle cell disorder mainly affects people of African and Caribbean descent, but also those from the Mediterranean, Asia, and the Middle East.

In the UK, about 17,500 people have the condition, making it the fastest-growing genetic disorder.

Newborn screening (the heel prick test), introduced in 2004, helps detect the disorder early, allowing for timely treatment and care.

Approximately 300 babies are born with sickle cell disorder (SCD) each year in the UK, and 1 in 79 babies carry the sickle cell trait (When one SCD gene and one normal gene are inherited, there is a 50% chance of passing the SCD gene to offspring. Individuals with this genetic makeup largely escape the symptoms and complications of full SCD, which occur when the faulty gene is inherited from both parents.)

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Our work

Sickle cell is often an invisible condition, with many young people reluctant to discuss it in order to fit in with their peers. The symptoms are not obvious on sight of someone with the condition, and individuals may conceal it from colleagues to avoid unfair judgment.

Our mission is to **raise awareness** about sickle cell disorder, fostering a more understanding society where individuals feel confident to be open about their condition. We provide support through our **children and young people's mentoring program**, annual **family retreat**, and telephone and email **advice line** services.

Building on our successful campaign for **newborn and pregnancy screening**, we continue to advocate for informed family planning through increased awareness of **pre pregnancy screening** options. Additionally, we focus on improving the delivery of screening results and providing support during this critical time.

Regular blood transfusions are a common treatment for people with sickle cell disorder. To avoid complications, blood must be carefully matched, which creates a significant demand for compatible blood stocks. We actively recruit **blood donors** from the black community to meet this vital need.

We advocate for improved medical services and more treatment options for individuals living with sickle cell disorder. As part of our efforts, we support the **Sickle Cell and Thalassaemia All-Party Parliamentary Group**, which actively engages MPs in pursuing better outcomes for those affected by sickle cell.

Looking to the future, we collaborate with partners to secure better experiences and outcomes for people with sickle cell for generations to come. Our partnership with **Genomics England** aims to **support sickle cell research** by providing precise, accurate data, ensuring continued advancements and improved care for years ahead.

While sickle cell can be life-limiting, many individuals lead fulfilling lives with robust support systems and comprehensive medical care. We aim to enhance these support networks and ensure that everyone affected by sickle cell can enjoy the vibrant and fulfilling quality of life they deserve.

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