

Being a carrier is not the same as having Sickle Cell Anaemia. Carrying Sickle Cell usually causes no health problems and will never develop into Sickle Cell Anaemia. But a person who carries Sickle Cell can pass the trait onto any children they may have. If their partner also carries Sickle Cell there is a 25% (1 in 4) chance that each and every child of theirs will have Sickle Cell Anaemia.

There is no cure for Sickle Cell Anaemia. Although a bone marrow/stem cell transplant is possible for some children. Treatment mainly consists of medications to control pain and infections, and sometimes blood transfusions.

Getting cold and wet can make the condition worse, so a person with Sickle Cell Anaemia should avoid strenuous outdoor games particularly in bad weather. Swimming is okay as long as the person stays warm and gets dry quickly. People with Sickle Cell Anaemia need to drink much more than usual and more often to avoid becoming dehydrated. Adolescents can have problems with their peers as puberty is delayed by 2-3 years. The kidney's reduced ability to concentrate urine not only means frequent trips to the toilet but also "bedwetting" can be a problem.

## Pre-natal testing

Pre-natal testing is available for couples who may wish to know if their baby may be affected with Sickle Cell. A very early test at 11 weeks called the chorionic villus sampling test also known as (CVS) can be performed during pregnancy to test the

baby. A test called the Amniocentesis is also available later in pregnancy.

If you wish to consider any of the tests above it is vital to contact your local Genetics Centre before nine weeks of pregnancy to make arrangements for the test.

## For more information

If you are interested in finding out more about Sickle Cell Anaemia, you can write (enclosing an A4 stamped addressed envelope) to:

### The Sickle Cell Society

54 Station Road

London

NW10 4UA

Tel: 020 8961 7795

Fax: 020 8961 8346

[www.sicklecellsociety.org](http://www.sicklecellsociety.org)

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**Birmingham Women's  
NHS Foundation Trust  
Edgbaston, Birmingham, B15 2TG  
Telephone: 0121 472 1377  
Fax: 0121 627 2602**

Reference Number: GG 13  
Author: Shagufta Khan, Asfa Ahmad,  
Genetic Counsellors  
Reviewed: June 2011 Next Review: June 2014

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# Sickle Cell Anaemia

An information leaflet for  
patients and families

If you need more advice about Sickle  
Cell Anaemia please contact:

**Clinical Genetics Unit**  
Birmingham Women's  
NHS Foundation Trust  
Mindelsohn Way  
Edgbaston  
Birmingham  
B15 2TG

Telephone: 0121 627 2630

Fax: 0121 627 2618

Email: [Clinicalgenetics.info@bwhct.nhs.uk](mailto:Clinicalgenetics.info@bwhct.nhs.uk)

# Sickle Cell Anaemia

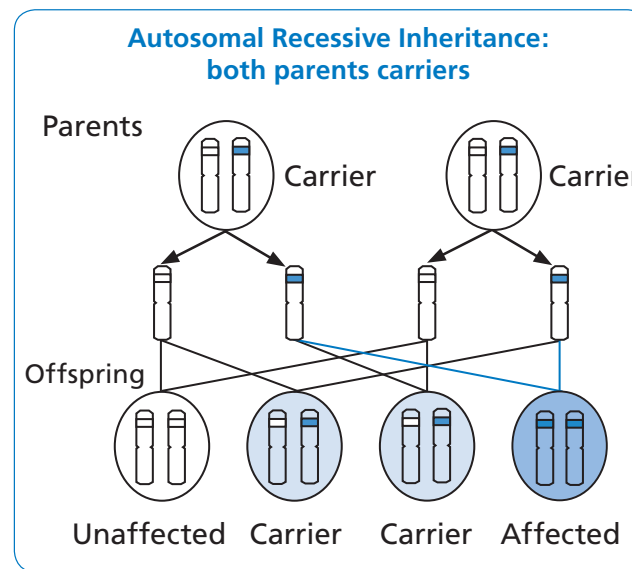
## What is sickle cell anaemia?

Sickle Cell Anaemia (pronounced er-nee-meeya) is an inherited blood disorder in which there is a defect in the structure of haemoglobin. Haemoglobin is a protein which is contained in the red cells of the blood. It picks up oxygen from the air in the lungs and carries it around the body to where it is needed. A person with Sickle Cell Anaemia has sickle haemoglobin in their blood (so-called because the red blood cells change from round to 'sickle' or crescent-shaped when they give up their oxygen). As the red blood cells in a person with Sickle Cell do not last as long as ordinary red blood cells, that person may become anaemic from time to time.

## How is sickle cell anaemia passed on?

The pattern of inheritance for Sickle Cell Anaemia is autosomal recessive. A person who inherits one altered gene for sickle cell will be a carrier. Carriers are usually unaffected but can pass the altered gene onto any children they may have. If one or both parents is a carrier, there is a 50% (1 in 2) chance that each child of theirs will also be a carrier. Carriers of Sickle Cell are sometimes said to have 'sickle cell trait'.

A child who inherits two copies of the altered gene (one from each parent) will have Sickle Cell Anaemia. If both parents are carriers, there is a 25% (1 in 4) chance of this happening.



## A person with sickle cell anaemia may be affected in some or all of the following ways:

Intelligence is not affected and most young people with the condition attend ordinary school and participate fully in normal school life. However, some will have Sickle Cell 'crises', perhaps quite often or maybe only every few years. A Sickle Cell 'crisis' is the sudden onset of any of the following:

- Pain. Because of their shape, sickle cells sometimes get stuck in the smaller blood vessels and block normal blood flow. The oxygen supply to nearby vessels is cut off which can cause severe pain in the arms, legs, back and stomach.
- Sickle Cell Anaemia can also cause the hands and feet to swell and make joints stiff and painful.
- Infections. People with Sickle Cell Anaemia may be on regular medication

to try and avoid infections which can be severe.

- Anaemia. It is normal for people with Sickle Cell to be anaemic, but if it gets worse, it may make them feel tired and ill.
- Jaundice. People with Sickle Cell Anaemia often have mild jaundice which can make the whites of their eyes look yellowish. This is not usually a problem but can make them self-conscious and some young people may even be bullied at school because of it.
- Over time, damage to vital organs in the body can occur. Other effects can include gall stones, slow growth, strokes and eye problems.
- The outlook for sickle cell patients regarding quality and length of life has been much improved as the condition becomes better understood, active management is introduced and parents are informed. The life expectancy in 1973 was 17 years; in 2005 it was 50 years.
- It is estimated that 348 sickle cell babies are born each year, which is 1 in every 2380 births.

## Other Information

Sickle Cell Anaemia is most common in people of African or African-Caribbean origin, but may also occur in any population group. This is probably because being a carrier of Sickle Cell gives some protection against malaria. One out of every 300-400 black Britons is born with Sickle Cell Anaemia. About 1 in every 8-10 black Britons are carriers of the sickle cell.