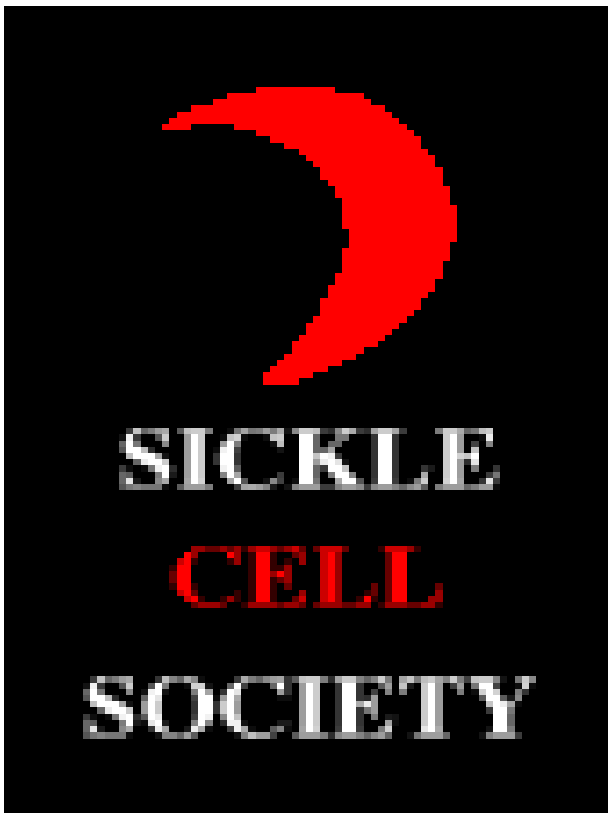
SICKLE CELL

A guide for teachers and others caring for children.



INFORMATION, COUNSELLING AND CARING FOR THOSE WITH SICKLE CELL DISORDERS AND THEIR FAMILIES

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What is this leaflet for?

This leaflet is intended to give you the information you need to understand sickle cell disorder and to help someone who has it to lead a good life.

What is Sickle Cell Disorder?

Sickle Cell Disorder is the name given to a group of inherited blood conditions which include **Sickle Cell Anaemia**, **Haemoglobin SC Disease** and **Sickle B-Thalassaemia**. Of those the most common and severe is sickle cell anaemia.

Who gets Sickle Cell Anaemia?

Sickle cell Anaemia is an inherited condition and is neither infectious nor contagious. In Britain it is most common in people of African or West Indian (Caribbean) descent, but it may also occur in people from India, Pakistan, the Middle East or the eastern Mediterranean. This has probably arisen because sickle cell trait gives some protection against malaria. (This is not the case for people with sickle cell anaemia who **must be adequately protected** when visiting tropical countries within the malaria zone.)

What causes Sickle Cell Anaemia?

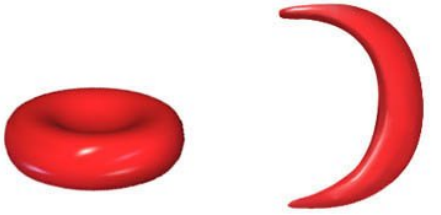
Sickle cell Anaemia is caused by an inherited disorder of the haemoglobin structure. Haemoglobin is a protein which is contained in the red cells in the blood. It picks up oxygen from the air in the lungs and carries it to the tissues of the body where it is needed. Someone who hasn't got enough haemoglobin is **anaemic**.

Types of Haemoglobin

We inherit the type of haemoglobin we have from both parents.

The most common type of haemoglobin is **Haemoglobin A** (Hb A) and most people inherit Hb A from both parents (Hb AA).

Sickle cell anaemia occurs when most of the haemoglobin inherited is **Sickle Haemoglobin** (Hb S). It is called sickle haemoglobin because it causes the red blood cells, which are normally round, to become sickle or crescent shaped when they give up oxygen.

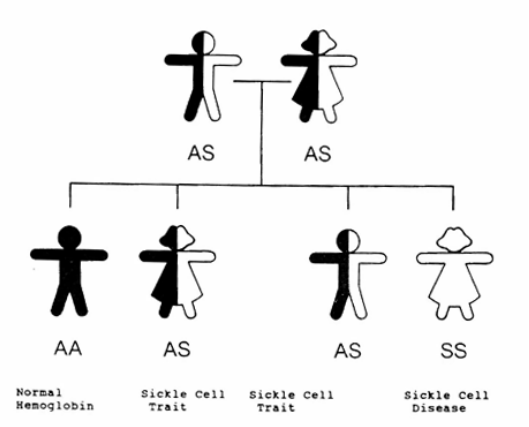


Normal red blood cell Sickled red blood cell

Inheritance

If someone inherits sickle haemoglobin from both parents he or she will have **Sickle Cell Anaemia**. (Hb SS)

If someone inherits sickle haemoglobin from only one parent he or she will have **Sickle Cell Trait** (Hb AS).
Sickle cell trait **is not an illness** and **cannot turn into sickle cell anaemia**.



If both parents are carriers of sickle cell **each** of their children has a **one in four** chance (25%) of being born with sickle cell anaemia (Hb SS). Each has a **two in four** (or one in two) chance (50%) of being born with sickle cell trait (Hb AS) and a **one in four** chance (25%) of having usual adult haemoglobin (Hb AA).

Parents can be screened to see whether they carry the sickle cell trait. If both expectant parents are carriers, a test can be done to check whether the foetus will definitely be affected and the parents may then be offered a termination.

What are the ill-effects of sickle cell anaemia?

Sickle cell anaemia does not affect a person's intelligence, except in extremely rare cases. Children with sickle cell anaemia can almost always attend an ordinary school and participate fully in normal school life.
This problem may also cause bed-wetting until the child reaches his or her teens. Never restrict the amount the child drinks because of this – discuss the problem with the child's parents and advise them to talk to the child's doctor about it.

Make sure a child with Sickle Cell is fully immunised against infectious illnesses and that he or she takes any vitamins (folic acid) and antibiotics prescribed.

How to recognise a sickle cell crisis

You can help by knowing how to recognise when someone is having a sickle cell crisis. A crisis is a sudden onset of any of the following:

Pain

Because of their shape, sickle cells sometimes get stuck in the small blood vessels and prevent normal blood flow. These blockages cause pain in the arms, legs, back and stomach. Sometimes the pain is quite severe. Sickle cell anaemia may also cause swelling of the hands and feet, or stiff and painful joints.

Infections

Someone with sickle cell anaemia is at risk of developing severe infections, and is strongly advised to take penicillin twice a day every day.

Anaemia

It is quite normal for children with sickle cell to be anaemic.
Most of the time they feel quite well, but if the anaemia gets worse they may feel lethargic and ill.

Jaundice

People with sick cell anaemia frequently have mild jaundice [yellow] in the whites of their eyes. This is not a cause for concern unless it becomes noticeably worse.

What to do if a child has a sickle cell crisis

A child having a crisis will suddenly becomes unwell or complain of severe of abdominal **or chest pain, headache, neck stiffness or drowsiness.**
Do not be over-protective, but if the symptoms persist the child **needs urgent hospital treatment.**

Get in touch with the child's parents without delay.
If the parents are not available, **contact the child's hospital doctor.**

People who only have sickle cell **trait** do not suffer any of the symptoms of sickle cell **anaemia**. Sickle cell trait is not an illness and people with trait are perfectly healthy. However, they require extra oxygen during anaesthetic and operation, and are advised against participating in some sports, such as scuba diving or climbing very high mountains, where the oxygen supply may become reduced.

It can be helpful if a school designates a person to have oversight of children with sickle cell anaemia and other serious conditions, who can also inform colleagues and disseminate information. Remember that as a teacher you can work with parents and doctors to help children with sickle cell anaemia to lead full and normal lives.

How you can give practical help

There are several practical steps you can take to help reduce the frequency and severity of sickle cell crises.

Listen to a sickle cell child. Take what the child says seriously.
Make sure sickle cell child is always warm and dry. The condition may get worse in the cold or wet.
Children with sickle cell disorder should not be sent outside in the cold or rain- it is important that **all teachers** and **support staff** are aware of and understand this.

Cross country running and strenuous outdoor games should be avoided in cold or wet weather. If possible arrange an alternative activity for children with sickle cell.
Also a child with sickle cell should only swim if the water is warm and care is taken to keep him or her warm when leaving the water. Some sickle cell children find they develop crises despite these precautions and should therefore avoid swimming.
However, you should encourage children with sickle cell to join in with as much exercise as possible.

Make sure a sickle cell child does not become dehydrated. This means allowing him or her to drink much more than normal and more often.
Because of this extra fluid intake, and the fact that the kidneys are sometimes affected by the sickle cell, the child may have to go the toilet more often than normal.
However their condition does make them prone to bouts of pain, infections, anaemia or jaundice. These are called **crises.** Some people get crises quite often; others may have them only once every few years. In between crises the child is usually quite well.

How you can help with the sickle cell child's education

There are several ways in which you can help a child with sickle cell disorder.

Give support.

Like any chronic illness, sickle cell disorder is sometimes difficult to come to teams with. A sickle cell child may sometimes feel unable to cope with the inconvenient and painful effects of the condition. You can help by being aware of the child's feelings and by making allowances when necessary.

Talk to the child's parents.

If the child has sickle cell disorder talk to the parents to find out how it is affecting him or her. You may be able to help if the child is experiencing stigma or isolation or some difficulties with school work.

Help with school work

Although sickle cell disorders has no effect on the intelligence, children with sickle cell may find it difficult to concentrate when they are in pain or get easily tired and lethargic if they are badly anaemic. Don't label a child as lazy when he or she is reluctant to work.
Regular visits to their GP and hospital doctor are essential and sickle cell children may also have to miss lessons or take a day off school when they have crises. All these in terruptions may cause them to fall behind with their school work. If this is the case you help by showing that you understand why they are behind and by helping them to keep up with their lessons. Try to ensure that a sickle cell child always has some work to do at home in case he or she has to be away from school for a day or two.
For longer stays away from school, home or hospital tuition may be necessary, and you can help by keeping an eye on the sickle cell child's progress.

Encourage consideration of career prospects

If children with sickle cell disorder consider appropriate careers at an early age they can give particular attention to keeping up in the subject which will be most relevant to them.

Involve other children.

By educating and involving other children in the class you can help them to understand and to give support when sickle cell has problems.

Use Sickle Cell Disorder in your teaching.

The sickle cell society has produced guidelines for the inclusion of sickle cell disorder in your teaching, which gives some suggestions referenced to the national curriculum in health education, science, mathematics, geography and English. This can help to raise the profile of genetic disorders.

The sickle cell society has produced a Video and work book to assist the teacher in the class room to inform children about sickle cell. Suitable for children with sickle cell and their class mates at the key stage 2.

Video - Hb Master Sickle,

Narrated by floella Benjamin.

Promotes awareness of the sickle cell children how to look after there self.

Work book – Hb Masters Sickle,

This publication is a companion to the video, which contains games, puzzles and quizzes the children, can take part in.

Suitable for pupils at the key stage 2.

WHERE TO GET FURTHER HELP AND INFORMATION

- School health service
- The child's general practitioner.
- The child's hospital doctor
- Local health education unit
- A local sickle cell centre or support group.

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Further information & address of sickle cell centre can be obtained by contacting:-

The Sickle Cell Society
54 STATION ROAD
LONDON NW10 4UA
TELEPHONE: 0208 961 7795
FACSIMILE: 0208 961 8346
Website: - www.sicklecellsociety.org
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