

Haematology Department

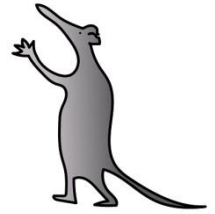
Living with Sickle Cell Disease – Observation

Information for parents and carers

Introduction

This leaflet aims to provide you with general information about living with Sickle Cell Disease. If you are ever worried about your child please contact your Sickle Cell Team or take your child to the Accident and Emergency Department.

What things should I be observing my child for on a daily basis and what should I do if I see any?



You need to be checking your child every day for signs of sickle cell problems. The most common problems are:

Pain If your child is complaining of pain or showing symptoms of pain then you need to use their pain tool to see what their pain score is. Depending on what the score is, give them pain medicines. If the pain is manageable and there are no other symptoms then you can keep your child at home. If you are happy to do so give them their pain medicines every four to six hours (as prescribed by your doctor). If you see any other symptoms you must ring the hospital for advice.

Jaundice Red blood cells are broken down in the liver; this produces a yellow pigment called bilirubin. When the liver can't clear all the bilirubin there is a build-up and this causes the yellow pigment to appear in the eyes. Some children always have some yellowing of the eyes and some get yellow eyes when they are unwell or having a crisis. If you notice that your child has yellow eyes, particularly when it is not normal for them, you must bring them to the hospital for review

Anaemia Sickle red blood cells blood cells don't last for as long as usual red blood cells. The body tries to make more cells but it can't always keep up and this causes your child to be anaemic. Your child will be used to coping with a low haemoglobin. Their haemoglobin may fall if they are unwell or having a crisis. This may give them some symptoms – tiredness, shortness of breath, headaches and they will look pale, more noticeable on the palms of their hands. If you notice any of these symptoms then you must bring your child to hospital for review.

Enlarged spleen The spleen is an organ that is on the left hand side of the body just under the ribs. It helps to fight infections and gets rid of damaged blood cells. In sickle cell disease the spleen can be slightly enlarged and, in time, will stop working.

The spleen can trap blood in it. When this happens the spleen becomes bigger (enlarges) and is painful and causes the haemoglobin to fall making your child look pale. When this happens your child needs **to urgently come to hospital**. You will be taught how to feel your child's spleen so you will be able to tell if it is bigger than normal.

Infections You need to be checking your child for any signs of infection.

People with Sickle Cell disease are prone to infections like pneumococcal, meningitis, osteomyelitis, salmonella and septicaemia. These infections can be serious and even life-threatening. This is because the spleen (an organ in the body) functions as a filter to remove bacteria from the blood stream, helping the body fight infections.

Sickle Cells damage the spleen by blocking it so that it doesn't function normally, allowing bacteria to grow in the bloodstream. Some infections can be minor and not pose any problems to your child. Bacterial infections, particularly those caused by Pneumococcal and Haemophilus influenza bugs are serious as they can cause septicaemia and can be life-threatening or even fatal if not treated early enough. Children under the age of five years are at the highest risk.

Further information

If you have any further information please contact the Sickle Cell Team on 0151 252 5070.

Useful websites

www.alderhey.co.uk

www.sicklecellsociety.co.uk

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This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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