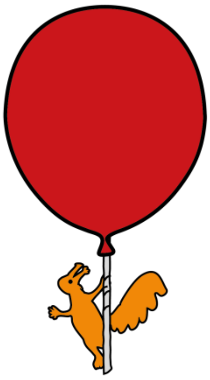

Haematology Department

Living with Sickle Cell Disease – Day to Day Care

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 should I be doing for my child on a daily basis to try to keep them well?

There are a lot of things that you can be doing for your child to keep them well. You need to ensure that you are keeping an eye on:

- Fluids.
- Prevention of infection.
- Avoiding trigger factors.
- Diet and nutrition.
- Not getting too hot or too cold.

There are fact sheets available for each of these things that provide information on what to look out for and how to prevent complications.

What symptoms should I be checking my child for on a daily basis and what should I do if I spot any of the symptoms?

The most common symptoms that your child is becoming unwell are:

Pain	The most common is pain. If your child experiences pain then you need to assess the level of pain they have and give the appropriate pain medicine for that level. Pain assessment and management is explained in the Sickle Cell Pain Booklet. If your child's pain is severe bring them to hospital for review.
Temperature	You should have a thermometer at home and if your child feels hot you should check their temperature. If their temperature is over 38°C you should take them to hospital for review.
Anaemia	Your child is anaemic due to their sickle cell disease. Their body learns to cope with their level of anaemia. If your child's haemoglobin drops below a level that is normal for them, they will start to get symptoms. The most common symptoms are: • Paleness - most noticeable in the face and palms of the hands. • Increased tiredness. • Shortness of breath following activity. • Headaches. If you notice any of these symptoms, take your child to hospital for review. The hospital will do a blood test to check your child's haemoglobin level

Jaundice

Red blood cells are broken down in the liver; this produces a yellow pigment called bilirubin. When the liver can't get rid of all the bilirubin there is a build-up and this causes a yellow pigment to appear in the whites of the eyes. Some children always have some yellowing of their 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 or if their eyes become very yellow over a short period of time, bring them to hospital for review

Enlarged Spleen

The spleen is an organ on the left hand side of the body just under the ribs. Its main job is to help fight infection and get rid of damaged red blood cells. The spleen can trap blood in it. When this happens the spleen becomes bigger (enlarges). It can be painful. It causes your child's haemoglobin to drop. You will be taught to feel your child's spleen. If you ever feel your child's spleen then you should bring them to hospital straight away for review.

What other things can I do for my child to keep them well?

Clinic

It is important to attend your child's clinic appointment even if they haven't been having any problems from their sickle cell disease. It gives the sickle cell team a chance to:

- Make sure that your child isn't developing any long term (chronic) complications.
- Check that they are growing well.
- Check that they are on the right amount of medication.
- Advise you on any current treatments that may be of benefit to your child.
- Give you information so that you are confident managing your child at home.

It also gives you and your child a chance to ask any questions that you may have.

Housing

Having the right type of housing will help to keep your child well. Houses need to be:

- Warm.
- Clean.
- Free from draughts.
- Free from damp and mould.
- Free from mice and rats.

If your house doesn't have these things then your child is at a higher risk of having a crisis or catching an infection.

Diet and Nutrition

Having a good balanced diet is necessary for everyone to keep well.
The body needs nutrients to help it work properly.

Folic Acid

Folic acid is a vitamin that helps the body make red blood cells. Your child should take folic acid supplements once a day unless you have been instructed by your sickle cell team that it is safe not to take it.

Further information

If you have any questions or want any further information please contact your Sickle cell Team on 0151 252 5070.

Useful websites

www.alderhey.co.uk
www.sicklecellsociety.co.uk

Alder Hey Children's NHS Foundation Trust is neither liable for the contents of any external internet site listed, nor does it endorse any commercial product or service mentioned or advised on any of the sites.

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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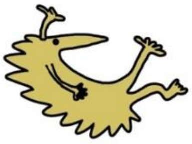

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