



Haematology Department

Living with Sickle Cell Disease – Triggers

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 are trigger factors?

There are some things that are known to trigger a sickle cell crisis or that make them worse, so it is best to try to avoid them. These things are known as trigger factors. Sometimes a crisis can develop for no known reason.

What are the trigger factors and how should I help my child avoid them?

The most common trigger factors are:

Infections

It is difficult to avoid catching infections but they are known to start a crisis. There are some things that you can do to reduce your child catching an infection:

- Ensure that your child takes their penicillin (erythromycin)
- Check that your child is up-to-date with their immunisations
- Make sure you wash your hands regularly
- Ensure that your child takes malaria medication if they are going to a country that has malaria.



Dehydration

A lack of fluids (dehydration) can start a crisis. When your child's body doesn't have enough fluid their blood cells flow slower and become stickier. To ensure that your child doesn't become dehydrated make sure:

- Your child has plenty to drink throughout the day.
- That your child isn't too warm

If your child is unable to tolerate fluids or is not able to drink the amount they should then you should bring them to the hospital for review.

Cold and hot temperatures

Being too hot or too cold can bring on a crisis. Hot temperatures can **cause** your child's body to dehydrate. Cold temperatures cause your child's veins to constrict and slow down their blood flow causing the sickle cells to get stuck.

In hot temperatures it is important that your child doesn't have too many layers of clothing on and has plenty of fluids to drink.

In cold temperatures it is important that your child is warm enough. Your child shouldn't go swimming in cold water. If your child goes swimming make sure they are dried and dressed as quickly as possible.

If your child has a crisis it is okay to apply warm packs to the area but don't apply cold packs as this can make the crisis worse.

Stress and anxiety

Some people are affected by stress and this can trigger a crisis. The exact mechanism to this is unclear. If stress and anxiety is a trigger for your child, try to minimise stressful situations. Relaxation techniques may be a good way of doing this.

Trauma

Sometimes an injury can bring on a crisis. It is important to monitor your child after an injury to see if signs of a crisis are developing.

Tiredness / Exhaustion

Making sure that your child gets plenty of rest, particularly when they have been very active, will help reduce a crisis being triggered. You shouldn't stop your child from playing or doing any activity, you just need to make sure that they rest when tired, are dressed appropriately and have extra fluids.

Flying

At high altitudes there is a reduction in oxygen, this can trigger a crisis. If you are planning to fly with your child you should:

- Get advice from the hospital the week before you fly. They will check your child's blood count to ensure that they don't need a transfusion.
- Give your child plenty of drinks in the 24hrs before, during and after the flight.
- It may be recommended that your child receive oxygen during the flight. This is arranged through the airline at a cost.
- Make sure that your child regularly walks around during the flight. Sitting down for long periods of time slows the blood flow in your child's legs.
- Read the "Travelling with Sickle Cell" information leaflet.

Anaesthetic

An anaesthetic will reduce the amount of oxygen in the body and if the procedure is not correctly managed then it could start a crisis. To prevent this happening you should:

- Tell the Haematology Team of any proposed operations – including dental work.
- Never let your child have any operations in hospitals or clinics that don't look after patients with sickle cell disease.

Smoking

Smoking lowers the amount of oxygen in your body, so when your child is older, encourage them not to start smoking.

Second-hand Smoke

Children who are exposed to second-hand smoke (the smoke they breath from others smoking around them) have twice as many painful crises. Keep your child out of smoky environments.

Alcohol

Alcohol causes the body to dehydrate quickly. Tell your teenager about the risks of alcohol and encourage them to avoid it. If they do drink alcohol, tell them to drink plenty of water.

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



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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.

Alder Hey Children's NHS Foundation Trust
Alder Hey
Eaton Road
Liverpool
L12 2AP

Tel: 0151 228 4811
www.alderhey.nhs.uk

