

Haematology Department

Living with Sickle Cell Disease – Going to School

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.

Will my child be able to attend school?

Education is important for your child. Having regular crises can mean that your child misses a lot of school. It is important to try to get your child to attend school as much as possible.

What can my child's school do to help?

There are a number of things that your child's school can do to help your child whilst they are in school. Talk to your child's teacher and Special Educational Needs Co-ordinator (SENCO) about giving your child Paracetamol and Ibuprofen in school. Many schools are happy to do this provided they are given clear instructions on when to give the medicines. This will enable your child to be able to attend school if they are having a mild crisis or recovering from one.

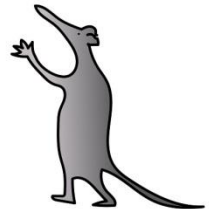
How can my child's school get more information on sickle cell disease?

Your child's sickle cell nurse will be happy to go to your child's school and explain about sickle cell disease and how to manage it in school. They will also help the school nurse develop a care plan for your child.

What information should I let my child's teacher know?

You should let your child's teacher know:

- An up to date phone number and how to contact you in an emergency.
- Hospital telephone numbers
- The medicine you are happy for the school to give (and to provide them with the medicine).
- The importance of your child drinking plenty of fluids throughout the day.
- Your child may need to go to the toilet more frequently.
- When your child has a hospital appointment.



Can my child take part in PE activities?

Keeping fit and healthy is important and your child should be encouraged to take part in PE. Your child just needs to be active in moderation and make sure that they take certain precautions. It is important that your child is allowed to drink during PE and if they feel tired that they be allowed to rest. After PE they should be encouraged to do a less energetic activity to allow them time to rest. If PE is outside then your child should be allowed to wear warm clothes if the weather is cold. Your child can go swimming as long as the pool is warm and when your child has finished their lesson they are dried (including their hair) and dressed quickly. If the lesson involves sitting on the edge of the pool, your child should be allowed to wrap up in a towel to keep warm. Sometimes swimming lessons involves children spending time underwater holding their breath. They should be discouraged from doing this as this reduces oxygen levels and may trigger a crisis.

Can my child go on school trips?

There is no reason why your child can't participate in school trips. The school should ensure that they take with them your emergency contact number and some Paracetamol. If the trip involves lots of walking your child should be encouraged to take plenty of rest stops. If your child uses a wheelchair for walking any distances then the school should use this. Make sure your child takes plenty of drinks with them and, if appropriate, warm clothing.

What can I do if my child is missing a lot of school?

If your child is missing a lot of school or is off school for a period of time ask their teacher about having some work or reading for them to do at home.

If you are concerned about the amount of school your child misses, talk to your Sickle Cell Team. They may recommend that your child tries a medication called Hydroxycarbamide to try to reduce the frequency of the crisis.

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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