

Haematology Department

Living with Sickle Cell Disease – Siblings

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.

How can brothers and sisters react to having a sibling with sickle cell?

Having a child with sickle cell affects the whole family. If you have other children then it is important to be aware of how they might be feeling about having a sibling with sickle cell. Every child reacts differently to having a sick sibling.

Fear

They may be afraid of becoming unwell themselves or they may be scared when their sibling becomes unwell.

Rejection / feeling ignored

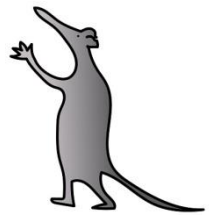
They may feel rejected as their parents have to spend so much time doing things for their sibling or that they are not being listened to.

Guilt

That they haven't got sickle cell and their sibling has

Jealousy / anger

That their sibling with sickle cell gets more attention than they do or that they get told off for things when their sibling doesn't



What can I do to help my other children?

- Share your time - ensure that you make time for all of your children. Take an interest and be part of the activities and events that they are in.
- Avoid special treatment, brothers and sisters know that their unwell sibling will be treated differently to them. Some are able to understand why this happens, others can't. Explain why you need to spend more time with your unwell child and try to involve the sibling in their care. It is important that the same disciplines and rewards are used with all of your children. Your unwell child should not be allowed to get away with something that your well child will be told off for.
- Teach them about sickle cell - teaching all your children about sickle cell can help to lessen the fears that they have about the condition. The more you encourage siblings to ask questions the more involved they will feel.
- Encourage siblings to discuss their feelings and concerns
- Let them help look after their sibling - encourage them to get involved in the care of your child with sickle cell. Encourage them to remind their sibling to take their medication. If your child with sickle cell is having a crisis, encourage their sibling to play with them, read to them, comfort them to help take their mind off the pain

Where can I get help if I am worried about how my child is coping having a brother or sister with sickle cell disease?

If you are concerned that your child is not coping with having a sibling with sickle cell, talk to your Sickle Cell Team. Your Sickle Cell Team know how sickle cell impacts on the whole family and is happy to support siblings. They can talk to your other child and answer any questions they have. They may suggest that your child is referred to the psychologist to help them cope with their feelings. Being referred to a psychologist does not mean that there is something wrong with your child or that they are mad. Psychologists are trained professionals who help people talk about their problems and find ways to deal with them.

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.

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Review Date: April 2024

PIAG: 0063

