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Haematology Department

**Sickle Cell Crisis – What to look out for in your baby**

Information for parents and carers

**Introduction**

This leaflet aims to provide you with general information about the signs and symptoms your baby may have when they are having a sickle cell crisis. If you are ever worried about your baby please contact your Sickle Cell Team or take your baby to the Accident and Emergency Department.

**What is a Sickle Cell Crisis?**

A sickle cell crisis is when the red blood cells change shape and cause a blockage in blood vessels resulting in pain. This is explained in more detail in the ‘What is Sickle Cell’ leaflet.

**When will my baby have their first crisis?**

Babies usually start having sickle cell crisis once they are over six months of age. However this is quite variable and some children are much older when they experience their first crisis. When babies are younger than six months old they have a type of haemoglobin called Foetal haemoglobin (HbF). This type of haemoglobin is what your baby is born with and will switch over to sickle haemoglobin (HbS) as your baby gets older.

By the time your baby is six months old we would expect that they will have very little HbF left. Some children do keep some HbF and these are the children that will be older when they have their first crisis as HbF gives the red blood cells protection from sickling.

**What can cause a crisis to happen?**

****Sometimes you never know what causes a crisis to happen but some things are likely to cause a crisis. These things include:

* Infection - a temperature over 38 ̊C.
* Vomiting.
* Diarrhoea.
* Poor drinking or refusal to drink.
* Getting too hot or cold.

For more information on what can cause a crisis please read “The Trigger Factors” leaflet

**How will I know when my baby is having a crisis?**

It is difficult to tell if your baby is having a crisis as they are unable to tell you. However, there are a few things that may tell you that your child is in pain or not very well.

**Swelling**

* You may notice swelling in their hands, fingers or feet. This is known as Dactylitis. It will be painful for your child if you touch it.

**Unusual/inconsolable crying**

* All babies cry but if your baby is crying more than usual and the normal comfort measures are not working then this may be a sign that they are in pain.

**Can't move an arm or leg**

* If your baby will not move their arm or leg or when you move their arm or leg they cry.

**Can’t walk or crawl**

* If your baby has been walking or crawling then suddenly stops doing so or they cry when they are walking or crawling or you notice they are limping.

**What other symptoms should I look out for?**

* Enlarged spleen.
* Signs of infection.
* Sudden yellowing of the whites of the eyes.
* Difficulty in breathing.

**What should I do if I think my baby is having a crisis?**

If you think that your baby is having a crisis give them a dose of paracetamol. **You should only give the amount recommended on the bottle or by your doctor**. If they are experiencing pain then this should help lessen that pain. You should contact your Sickle Cell Team for advice or take your baby to the Accident and Emergency Department for review. During the first few crisis you will be advised to bring your baby to the hospital to be reviewed by the doctor. Once you get used to managing a crisis you will be supported to do this at home.

**Further information**

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

**Useful websites**

[www.alderhey.co.uk](http://www.alderhey.co.uk)

[www.sicklecellsociety.co.uk](http://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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**© Alder Hey Review Date: April 2024 PIAG: 0040**