******

Haematology Department

**Sickle Cell Disease – Chronic Complications**

**Blood Transfusion Programme**

Information for parents and carers

**Introduction**

This leaflet is designed to explain about the long term (chronic) complications of sickle cell disease. The information does not cover everything. If you are ever worried about your child then please contact your Sickle Cell Team or take your child to Accident and Emergency Department

**Why does my child need regular blood transfusions?**

Your sickle cell team has recommended that your child receives regular blood transfusions. Approximately once a month they will come to the hospital for a blood transfusion. We call this a blood transfusion programme. This treatment has been recommended for your child as they either have had a stroke, are at risk of a stroke, have had a life-threatening complication from sickle cell disease or have chronic organ damage.

**What will a blood transfusion programme do for my child?**

The purpose of having regular blood transfusions is to reduce the amount of sickle red blood cells that your child has. This will stop or reduce the risk of them having a sickle cell crisis and the risk of sickle cell complications.

**Are blood transfusions safe?**

We aim to make blood transfusions as safe as possible for your child. The most common thing that people worry about from blood transfusions is catching an infection. In the UK the risk of catching an infection is low. All blood is screened for HIV, Hepatitis B and C and syphilis.

Recent data puts the risk of catching an infection as:

* Less than one person per 1.2 million people receiving blood transfusions for hepatitis B,
* Less than 1 person per 28 million people for hepatitis C
* 1 person per 7 million for HIV.

(Handbook of Transfusion Medicine, 2013)

****The most common reported risk of having a blood transfusion is receiving the wrong blood. There are processes in place to ensure that this does not happen to your child. Your child should be given a name band when they are admitted for transfusion. This will be checked against the unit of blood that is given to your child. Hospitals have implemented a policy of “right blood, right patient, right time.”

**What are the side effects of my child receiving regular blood transfusions?**

The most common side effects of blood transfusions are:

* Reactions - these are usually mild and are often skin rashes and temperatures.
* Antibodies - your child's blood is matched closely with the unit of blood that they are receiving but sometimes they can develop antibodies. Antibodies are part of the body's immune system and are a natural defence against anything which is different. If your child develops antibodies, the blood given to them will need to be matched more closely. Sometimes having antibodies means that it becomes hard to find exactly matched blood, making it more difficult to have a blood transfusion.
* Iron overload - each unit of blood contains 200mg of iron, the body naturally loses 1-2mg of iron daily. The body has no mechanism for getting rid of excess iron so the iron builds up when someone receives regular blood transfusions. People on regular transfusions need medication to get rid of the excess iron. For further information, see the Chelation Therapy leaflet.

**Can I donate blood to be given to my child?**

No. There is an increased risk of serious reactions if blood is given from a relative.

**How are blood transfusions given?**

Blood transfusions are given through a drip (IV). Your child will have a tiny tube (cannula) inserted into a vein so that the blood can be given. For some children it can be difficult to find veins to insert the cannula. For those children we may advise having a long term access device inserted. These are known as port-a-cath's.

****Port-a-caths are implanted intravenous access devices that sit under the skin. It is a catheter that is inserted into a major vein. This catheter is attached to a chamber that sits under the skin. When the port-a-cath needs to be used, a needle (gripper) is inserted into the chamber. The needle is removed at the end of the blood transfusion.

**Where will my child receive their blood transfusions?**

Your child will be admitted to a day-case ward for their transfusion.

**What will happen when my child comes to hospital for their blood transfusion?**

When your child comes to the day case ward the nurses will either insert a cannula or access their port-a-cath and take blood tests. The blood tests will be to match your child's blood against the donor unit, check their Hb, kidney function, liver function and iron levels. It takes approximately one hour to match your child's blood against the donors. The nurses will also do a set of observations - check your child's blood pressure, pulse rate and temperature.

Once the unit of blood is ready it will be given to your child, it usually takes between two to four hours to have the blood transfusion. The nurses will perform checks before it is given to make sure it is the right blood that your child is receiving. During the transfusion your child will have more observations done to check that they are not having a reaction to the blood. Once the blood transfusion is finished your child's gripper needle or cannula will be removed.

**How long will they need to stay in hospital?**

Your child will only need to stay in hospital for the duration of their transfusion. If your child is having their blood tests on the same day, then they will usually need to spend the full day on the ward. Blood tests can be done the day before your child's blood transfusion is due. This will reduce the amount of time they need to be on the day case ward. It is your decision whether to have the blood tests done the day before the transfusion or on the day of the transfusion.

**What should I bring with me to the hospital?**

Your child will be on the day-case unit for most of the day. They will be given lunch and water / juice but you may want to bring in additional snacks. You may also want to bring in things to entertain your child such as books, colouring etc. The day case ward does have television and some DVD players. You are welcome to bring in your own DVD player or laptop, small electronic games etc. If your child is at school you could ask their teacher for some work or reading that they do.

**Are there any other treatment options?**

At the moment blood transfusions are the best option for the treatment and prevention of strokes.

**Further information**

If you need any further information please contact the Sickle Cell Nurse Specialist on

0151 252 5070

**Reference**

United Kingdom Blood Services, 2013, Handbook of Transfusion Medicine. 5th Edition. TSO information and publishing solutions.



**Useful websites**

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

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

www.blood.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.

Alder Hey Children’s NHS Foundation Trust

****Alder Hey

****Eaton Road

Liverpool

L12 2AP

Tel: 0151 228 4811

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

**© Alder Hey Review Date: April 2024 PIAG: 0080**