

Having a simple (top-up) blood transfusion

Information for parents or carers
of a child with sickle cell disease

This information sheet has been given to you to help answer some of the questions you may have about your child having a simple (top-up) blood transfusion as a treatment for sickle cell disease. If you have any questions or concerns, please do not hesitate to speak with the sickle cell doctors, sickle cell specialist nurses, Snow Fox nurses or the child and adolescent mental health services (CAMHS) practitioner.

What is blood?

Blood is the red liquid in the vessels of the body. It is made up of different types of blood cells and plasma (a straw-coloured liquid that carries the blood cells around the body). The different types of blood cells are:

- red cells, which contain haemoglobin (the red pigment that carries oxygen to and carbon dioxide from the tissues of the body)
- white cells, which fight infection
- platelets, which are clotting cells.

Normally red cells last about 120 days in the blood (although they last for a shorter time in people with sickle cell disease). They are then removed by the body, which means that your body always needs to replace them.

What is a blood transfusion?

A blood transfusion is a procedure that puts red cells into the body. This could be a planned procedure or be performed in an emergency situation.

The two main types of blood transfusions are:

A simple transfusion (top-up) – A few units (bags) of blood are given through a small tube (drip), usually placed in a vein in your child's arm.

An exchange blood transfusion – This is a procedure that replaces sickle blood with non-sickle blood (from a donor who does not have sickle cell disease). For more information, please speak to the Snow Fox nurses or ask for a copy of the leaflet **Having an exchange blood transfusion: Information for parents or carers of a child with sickle cell disease**.

Why would my child need a simple (top-up) blood transfusion?

A simple transfusion might be needed if your child's haemoglobin level falls too low. This can happen during a sickle cell crisis, which destroys their red cells. Please contact your GP or hospital doctor immediately if:

- your child's urine is a dark colour
- your child's eyes and skin are yellow (jaundiced)
- your child feels light-headed
- your child feels weak
- your child easily becomes tired or breathless
- your child's spleen feels bigger than normal and child is unwell.

Other reasons for needing a simple transfusion are:

- to get your child ready for an operation – to reduce the risk of complications from the general anaesthetic and the surgery
- to reduce the risk of stroke.

You can find out more from the NHS Blood and Transplant service.

Asking for your consent

We want to involve you in all the decisions about your child's care and treatment. It is entirely your choice whether they have the transfusion programme (which means having transfusions every three to six weeks) or not. We will give you relevant information to help you come to a decision with the sickle cell team. It is important that you understand the information and have the time to ask questions and to make your decision.

If you agree to the transfusion for your child, you will be asked to sign a consent form. This confirms that you agree for your child to have the treatment and understand what it involves. If you would like more information about our consent process, please speak to a member of staff caring for you.

Is it safe to have a blood transfusion?

In the United Kingdom, we take many precautions to make sure any blood given is as safe as possible. You can find out more from the NHS Blood and Transplant leaflet **Will I need a blood transfusion?**

The main risk from a transfusion is that the wrong blood could be given by accident. To make sure that the right blood is given, the clinical staff must make careful identification checks. They will ask you to state your child's full name and date of birth and will check the details on their name band, to make sure they receive the correct blood.

They will also regularly monitor your child during the transfusion (check their blood pressure, temperature, pulse and breathing rate) and ask your child how they are feeling.

The risk of contracting a disease, such as hepatitis or human immunodeficiency virus (HIV), is extremely low.

- The risk of getting hepatitis B is less than one in 1.3 million and one in 28 million for hepatitis C.
- The chance of HIV infection from a blood transfusion is one in 6.5 million.
- The possibility of a blood transfusion transmitting variant Creutzfeldt-Jakob disease (vCJD – a rare, incurable brain disease) is extremely small and a number of precautions are taken to reduce this risk.

We now strongly advise that all patients on a transfusion programme are routinely vaccinated against hepatitis B. During the transfusion programme, your child's immunity to hepatitis B and other viral infections will be regularly reviewed.

Although the risk of contracting an infection from blood is very low, we recommend that we check your child for HIV and hepatitis C infection once a year.

What are the possible complications of blood transfusions?

Minor reactions

Your child may get a skin rash or a minor fever, for example. These can be treated easily with paracetamol and antihistamines.

Iron overload

This is common in people who receive repeated blood transfusions. When necessary, excess iron can be removed by taking medication (injections or tablets). This is much less likely when the exchange machine is used than when an exchange transfusion is performed manually.

Antibodies

Your child's blood is matched very closely with the blood of the donor (the person who donated the blood). However, it is possible to develop 'antibodies' against the donor blood, so you need to make the clinical staff aware of any symptoms your child may be having after the transfusion (see the section on delayed transfusion reactions). These antibodies can mean that matched blood is harder to find and can take longer to prepare.

If your child has developed antibodies you will be sent an alert card that says 'I need special blood'. This is to help ensure that anyone treating your child knows that their blood needs to be matched against them. Please ensure you show this to clinical staff before your child receives a transfusion and in any hospital where they are treated.

Delayed transfusion reactions

Occasionally a patient experiences a delayed transfusion reaction (where the body abnormally breaks down the blood that has been transfused), which may occur within the first two weeks of being transfused.

This may cause:

- severe generalised sickle cell pain/crisis
- blood in the urine (red or cola colour)
- feeling tired
- feeling short of breath
- fever
- localised loin/back pain.

If your child experiences these symptoms you must take them to hospital immediately for assessment and you must inform medical staff that they have been transfused recently.

Is any preparation needed before the transfusion?

Your child will need to have a blood test before the transfusion. Once the transfusion date is agreed, your child will be given an appointment card from the day unit with the dates for their blood test (this is normally a day before the transfusion date). If they require 'special blood' (because of antibodies) it is essential that they attend for blood tests a few days in advance or blood may not be available from the transfusion service and their transfusion may be cancelled or delayed.

You can bring your child to the phlebotomy unit for their blood test on the date given on the appointment card, between 9am and 5pm. Your child needs to be accompanied by an adult for all tests.

If you are unable to make your appointment, please call Snow Fox ward or the clinical nurse specialists as soon as possible.

A blood sample is taken so we know your child's blood group and whether they have developed any antibodies. Each time your child has a transfusion, the laboratory tests their blood against the donated blood, so they are transfused with blood that closely matches their own.

It is important to attend this appointment, so we have time to order the blood that your child needs.

Where does the transfusion take place?

The transfusion takes place on Snow Fox ward on the first floor of St Thomas' Hospital, South Wing, staircase D, unless you are told otherwise. Please arrive before 9am if you have been offered a morning session for the top-up transfusion. However, if your child has been scheduled for the afternoon session, you must arrive on the ward by 12.30pm.

What happens during the transfusion?

During a simple blood transfusion, blood is given to your child through a tube (drip), which is usually placed in a vein on their arm. This tube (drip) will be removed once the transfusion is complete.

Alternatively it may be given through a portacath (if your child has one). The portacath is situated under the skin and uses a large vein in the chest. Cream is normally applied to the port site before accessing to numb the area.

The number of units (bags) your child is given depends on how much blood is needed to correct their haemoglobin level. It is usually given in the day unit (between 9am and 7pm) and your child will usually be given two to three units (bags) of blood. You can both go home once the transfusion is finished. Occasionally, we may ask your child to stay in hospital overnight if it is very late.

How long will the transfusion take?

The blood transfusion process takes about two to four hours. This will also depend on your child's clinical history and how much blood will be used during the procedure.

Why does my child need repeat transfusions?

Normal red blood cells only last 120 days in your body. Repeat transfusions are needed to keep the sickle cells in your child's blood at a low level. The frequency depends on the reason for transfusion.

What happens if I want to cancel or change the date of my child's transfusion?

You must contact the sickle cell nurses or Snow Fox ward as soon as possible so that they can arrange an alternative date. You can find contact details at the end of this leaflet.

Does it always work?

Most patients selected for a long-term transfusion programme have severe sickle cell disease. The top-up transfusion tries to reduce the number of sickle cells in the blood as much as possible, but it can't make them disappear. It also can't suddenly make some of the complications of sickle cell disease disappear – like an old stroke, bone damage or visual loss associated with sickle cell disease. This means that sometimes problems can happen to people even though they are on a top-up transfusion programme. Your child will still have an increased risk of infection. It is not a perfect treatment, but it does reduce the chances of new serious problems happening.

Meet our team

Dr Baba Inusa (lead consultant for children with haemoglobin disorders)

t: 020 7188 7774 (secretary Mary Adeyoluwa)

e: mary.adeyoluwai@gstt.nhs.uk

Dr Maria Pelidis (consultant in paediatric haematology)

t: 020 7188 7774 (secretary Mary Adeyoluwa)

e: mary.adeyoluwai@gstt.nhs.uk

Natalee Murray (sickle cell nurse specialist)

t: 020 7188 9432 or 07771 345 847

e: natalee.murray@gstt.nhs.uk

Sharon Ndoro (senior research nurse coordinator)

t: 020 7188 6637 or 07918 338 730

e: sharon.ndoro@gstt.nhs.uk

Dr Hatel Bhatt (therapy and psychology team)

t: 020 7188 9125

Kemi Ajamufua (specialist nurse - community)

t: 020 3049 5993

e: olukemi.ajamufua@gstt.nhs.uk

Contact us

Snow Fox ward

t: 020 7188 4670, Monday to Friday, 7.30am to 8pm.

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday

e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS website

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Leaflet number: 4117/VER2

Date published: December 2018

Review date: December 2021

© 2018 Guy's and St Thomas' NHS Foundation Trust

A list of sources is available on request