

Having a simple (top-up) blood transfusion

Information for adult patients with sickle cell disease

This information sheet has been given to you to help answer some of the questions you may have about having an exchange 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 nurse practitioners, day unit nurses or the psychologists. Please feel free to show this leaflet to other family members and discuss it before making any decisions.

What is blood?

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

The adult human body contains about five litres (nine pints) of blood. 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 your 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 through your arm.
- **An exchange blood transfusion** – This is a procedure that replaces sickle blood with non-sickle blood. For more information, please speak to the day unit nurses or ask for a copy of our leaflet, **Having an exchange blood transfusion**.

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

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

- your urine is a dark colour
- your eyes and skin are yellow
- you feel light-headed
- you feel weak
- you easily become tired or breathless.

Other reasons for needing a simple transfusion are:

- to get you ready for an operation – to reduce the risk of complications from the general anaesthetic and the surgery
- to reduce the risk of complications to you and your baby if you are pregnant.

You can find out more from the NHS Blood and Transplant Service leaflet

Asking for your consent

We want to involve you in all the decisions about your care and treatment. It is entirely your choice whether to have the transfusion programme 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 have the transfusion, you will be asked to sign a consent form. This confirms that you agree to have the treatment and understand what it involves. You should receive the leaflet, **Helping you decide: our consent policy**, which gives you more information. If you do not, please ask us for one.

If you have agreed to repeated exchange blood transfusion (for instance, to help prevent further strokes), your consent will be reviewed at least every six months. It is up to you if you want to stop the transfusions. If you do, it is important to discuss this with your haematologist, so that you are clear about how your decision may affect you. Other suitable treatments for you can also be discussed and offered to you at this time.

Is it safe to have a blood transfusion?

In the United Kingdom, we take many precautions to make sure any blood given to you 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 you could be given the wrong blood by accident. To make sure you receive the right blood, the clinical staff must make careful identification checks. They will ask you to state your full name and date of birth and will check the details on your name band, to make sure you receive the correct blood. They will also regularly monitor you during the transfusion (check your blood pressure, temperature, pulse and breathing rate) and ask you how you 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 1 in 1.3 million (you are more likely to die in a gas fire, explosion or carbon monoxide poisoning) and 1 in 28 million for hepatitis C.
- The chance of HIV infection from a blood transfusion is 1 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 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 you for HIV and hepatitis C infection once a year.

What are the possible complications of blood transfusions?

Minor reactions

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

Delayed transfusion reactions

Occasionally a patient experiences a delayed transfusion reaction (where your body abnormally breaks down the blood you have 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 you experience these symptoms you must attend hospital immediately for assessment and you must inform medical staff you have been transfused recently.

What happens during the transfusion?

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

The number of units (bags) you are given depends on how much blood is needed to correct your haemoglobin level. It is usually given in the day unit (between 9am and 6pm) and you will usually be given two to three units (bags) of blood. Each unit will be given over two to three hours. You can go home once the transfusion is finished. Occasionally, we may ask you to stay in hospital overnight if it is very late.

Do I need to bring anything with me?

We advise you to bring something to eat (non-microwaveable), as you may be in the unit all day. You might want to bring a book, a laptop, personal stereo or a handheld computer game with you to keep you occupied as you will need to lie still during the procedure. You may bring your mobile phone if you wish, but we may ask you to turn it off during the procedure. You should bring your regular daytime medication, including your painkillers, as we may not have them on the day unit. Make sure you wear something comfortable.

Please do not bring any children with you, as the day unit is an unsafe environment for children to be in and the nurses cannot supervise the children.

Religious objections to blood transfusion

Some people decline blood transfusions because of religious objections. We would encourage you to discuss any concerns you have about blood transfusion with the sickle team, particularly if you have had severe complications of your sickle cell disease before, or are planning a pregnancy or an operation. This is to allow the haematologist looking after you to consider if there are any alternative treatments that could be offered. They will also clearly document your wishes in the medical notes and share this information and plan accordingly with other relevant medical professionals who may be involved in your care. We would also encourage that you discuss your objections or wishes with your family members, and in particular your legal next of kin, because in a situation where you become unwell they may be consulted about your wishes regarding blood transfusion.

Contact us

Main hospital switchboard

t: 020 7188 7188

Haematology Clinic

t: 020 7188 2743 / 2724

Haematology Day Unit

t: 020 7188 2745 / 2727

Consultant Haematologists

Dr Jo Howard and Dr Rachel Kesse-Adu

t: 020 7188 2741 (Secretary)

Specialty Registrar (sickle cell)

bleep: 0248(via the main switchboard)

Junior Doctor (sickle cell)

bleep: 2283(via the main switchboard)

Advanced Nurse Practitioner

Mr Neil Westerdale

t: 020 7188 2710

07770 683947 (mobile)

bleep: 1843(via the main switchboard)

Advanced Nurse Practitioner (adolescent)

Mr Luhanga Musumadi

t: 020 7188 2710

07770 678851

bleep: 2256(via the main switchboard)

Clinical Nurse-Specialist

Mrs Judith St Hilaire

t: 020 7188 8124

07920 711266 (mob)

bleep: 2868(via the main switchboard)

Psychologists

Dr Nicky Thomas, Consultant Health Psychologist

t: 020 7188 2725

Dr Heather Rawle, Clinical Health Psychologist

t: 020 7188 2718

Mina Abedian, Health Psychologist

t: 020 7188 2718

Other useful contacts

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

e: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@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 using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

Knowledge & Information Centre (KIC)

For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.

t: 020 7188 3416 **e:** kic@gstt.nhs.uk **w:** www.kic.gstt.nhs.uk