

Having an exchange 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. For more information, please speak to the day unit nurses or ask for a copy of the leaflet, **Having a simple (top-up) blood transfusion** and the National Blood Service leaflet.
- **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).

Why would I need an exchange blood transfusion?

This procedure might be needed in an emergency, such as for:

- a complicated sickle cell crisis, such as a stroke
- a chest crisis – sickling in the lungs causing breathing problems
- a very painful crisis.

A routine or planned exchange transfusion may also be done in the following situations:

- If you have had a stroke, repeated exchange transfusions can help reduce the risk of further strokes happening.
- If your sickle cell disease is very severe, repeated exchange transfusions can help reduce the number of crises.
- In pregnancy an exchange transfusion may prevent complications to you and your baby.
- If you are going to have a major operation such as a hip replacement, a single exchange transfusion reduces the risk of complications from the general anaesthetic and surgery.
- If you have leg ulcers exchange transfusions may aid healing.
- An exchange transfusion may help in cases of severe priapism (painful erections) that have not responded to other forms of treatment or surgery.

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 National Blood Service 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.

Possible complications specific to exchange blood transfusions

- You may experience light-headedness and fainting.
- There may be a tingling sensation on your lips and fingers. This is due to the anticoagulant used, which lowers calcium levels in your blood. We may give you calcium tablets or an injection during the procedure to prevent this.
- Some patients feel tired for a day or two after the transfusion.

Is any preparation needed before the transfusion?

You will need to have a blood test before the transfusion. Once the transfusion date is agreed, you will be sent a letter from the haematology day unit with the dates for your blood test (this is normally a few days before the transfusion date). If you require 'special blood' (because of antibodies) it is essential that you attend for blood tests a few days or blood may not be available from the transfusion service and your exchange may be cancelled or delayed.

You can come to the Haematology Day Unit for your blood test on the date given in the letter, between 9am and 6pm.

If you are unable to make your appointment, please call the day unit as soon as possible, so that your appointment and the blood allocated for you can be given to someone else who needs it.

Why do I need a blood test?

A blood sample is taken so that we know your blood group, and whether you have developed any antibodies. Each time you have a transfusion, the laboratory will test your blood against the donated blood, so you are transfused with blood that closely matches your own.

It is important to attend this appointment, so we have time to order the blood that you need.

Where does the exchange transfusion take place?

The exchange transfusion takes place in the haematology day unit on the 4th floor of the Southwark Wing at Guy's Hospital, unless you are told otherwise. Please arrive before 9am if you have been offered a morning session for exchange. However, if you have been scheduled for afternoon session you must arrive on the unit by 12.30pm. **It is important you arrive on time to avoid a cancellation or the need to stay in hospital overnight to complete the exchange the following day.**

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, 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.

Having a femoral line inserted

A femoral line is a cannula (tube), which is inserted into the femoral vein near the groin to give you the donor blood. It is larger than a cannula for your arm we often need to use a femoral line because we need to use a large vein for an exchange blood transfusion, especially if the blood exchange machine is used. This is called an automated exchange transfusion

The femoral line is inserted by the advanced nurse practitioner or by one of the medical or specially trained nursing staff on the day unit at Guy's Hospital. You will initially attend the haematology day unit and a cannula will be inserted. If you are having sedation, you will also need to change into a theatre gown.

You will be given the choice to have medication (sedation) to help you relax when the femoral line is inserted. If you choose this, then a member of staff in the day unit will insert a needle into your veins so this medication can be given at the time of the femoral line insertion. If you choose to have sedation you will need to organise for someone to collect you to accompany you home. In addition if you have sedation you must not eat or drink anything for 6 hours before the procedure, as it is important to have an empty stomach to reduce the risk of complications. For your safety, if you fail to organise for someone to collect you from hospital to take you home or you eat or drink before the procedure, we will have to insert the femoral line under a local anaesthetic.

The majority of people do not have sedation for their femoral line insertion. Some people say it hurts when the femoral line is inserted, while others say that it does not hurt at all. You are given an injection of local anaesthetic to your groin, which is a medication used to numb the area so it is less painful. For more information, please ask us for a copy of the leaflet, **Having an anaesthetic**.

It takes about half an hour to prepare for the insertion of the femoral line, but it only takes fifteen minutes to put the line in. The line will need to be secured by a **strong dressing or stitched in** to stop it falling or being pulled out.

What happens after the femoral line has been put in?

After you have had the femoral line inserted and you have had sedation your vital signs will be monitored. Once you are fully recovered you will be accompanied by a nurse back to the haematology day unit and your exchange blood transfusion procedure will be started.

What happens in the haematology day unit?

A member of staff in the day unit will attach the femoral line to the blood exchange machine. Connecting the femoral line to the machine line is not painful. The bag of blood that has your details (name, date of birth and hospital number) will be checked carefully and the exchange will begin. The nurses continually monitor you and the machine.

During the exchange you can expect the following:

- Your nurse will check your blood pressure, pulse, temperature and oxygen level regularly.
- You can sit up or lie down, but you cannot move off the bed. This is because the lines attached to you are not long enough for you to move around and because you may become light-headed.
- You can use a bed pan or a bottle if you need to go to the toilet.
- You will be able to read and write and also eat and drink if you wish.

Can I have an exchange transfusion without the femoral line?

If your veins are large enough, the exchange transfusion might be done through a vein in each arm. It is also possible to do a manual exchange, which does not involve the use of the blood exchange machine. This process is longer and takes all day to complete. A cannula (tube) is inserted into the vein in your arm, the blood is drawn out and then replaced through the cannula. This is an old-fashioned way of doing an exchange blood transfusion: the results are not as good at reducing the amount of sickle cell haemoglobin in your body as using the blood exchange machine.

Is there an alternative to femoral line insertion?

For some patients who have had a lot of femoral lines the sites become scarred and are more painful. Therefore the sickle cell service uses a permanent access device (Portacath) in a small number of patients who are not able to tolerate femoral lines. The Portacath is situated under the skin and uses a large vein in the chest.

Will I feel anything during the transfusion?

Sometimes people feel a tingling sensation around their mouth during the exchange - you should inform the nurses if you experience this. This is caused by a drop in your calcium level (explained on page 4). It can be quickly corrected with calcium tablets or injection. Calcium tablets may be given routinely after the third or fourth unit (bag) of blood.

How long will the transfusion take?

The exchange blood transfusion process can take from one to four hours on the machine. This will depend on your clinical history and how much blood will be used during the procedure. However, you should expect to be in the day unit for the whole day (10am to 5pm). This is because the femoral insertion takes about 45 minutes and you should allow another hour and a half after the machine has stopped before you can leave the hospital.

Sometimes the exchange transfusion will start late. This is usually because a patient has had difficulty getting to Guy's Hospital in time or the machine is being used for an emergency procedure. This may mean that your exchange is scheduled to finish late. Unfortunately, the day unit is not normally able to open beyond 6pm, as there is no emergency medical cover. In this case, you would be asked to stay in hospital overnight to complete the exchange the next day.

What happens after the transfusion?

When the exchange is finished, blood is taken from the femoral line so we can see how much of the sickle haemoglobin is left in your blood.

The femoral line is then taken out and the nurse will apply pressure with their thumb to the area for about five minutes. You will be asked to lie flat for half an hour. This is to prevent bleeding. You will finally be assessed by a nurse and, if everything is fine, you will be able to go home.

We will give you the date for your next exchange transfusion before you leave and send you a letter about two weeks before the appointment to remind you.

If you have received sedation, you must not drive home and will also need someone to pick you up from the haematology day unit.

Why do I need repeat exchanges?

Normal red blood cells only last 120 days in your body. Repeat exchanges are needed to keep the sickle cells in your blood to a low level. The frequency of the exchanges depends on the reason for exchange but can range between four and 14 weeks.

After the exchange

We recommend that you go home and rest for the evening. You can return to work the next day if you feel up to it.

What happens if I want to cancel my exchange or change the date of my procedure?

You must contact the sickle cell nurses and they may be able to offer you an alternative date. However if you fail to attend without notifying the sickle cell clinical nurse specialist you may be referred to the clinic for assessment with the consultant haematologist before any other dates are re-scheduled.

Does it always work?

Most patients selected for a long-term transfusion programme have severe sickle cell disease. The exchange 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 an exchange transfusion programme. You 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.

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