Clinical Haematology

Automated red blood cell exchange transfer for patients with sickle cell disease Information for patients, relatives and carers

Introduction

This leaflet explains more about **automated red blood cell exchange transfusions**. If you have any further questions, please speak to a doctor or nurse caring for you.

What is an automated red cell/depletion exchange?

Blood is made up of red cells, white cells, and platelets, which are carried around in fluid, called plasma. Red cells carry oxygen to different parts of the body, and also remove waste including carbon dioxide. The red cells can be separated from the rest of your blood, removed and replaced with red cells from blood donated by blood donors. We call this process a red cell automated exchange (often called 'exchange transfusion' for short)

Depletion exchange is where saline is replaced while removing the first part of red cells to reduce high ferritin levels, reduce the numbers of red cells transfused and to reduce the likelihood of developing new red cell allo-antibodies.

Why you need a red cell exchange

Your doctor or specialist nurse will speak to you about why an exchange transfusion is recommended and answer your questions.

Sometimes we recommend just a single procedure. This might be to help prepare you for an operation or if you are very unwell due to your sickle cell disease.

For some people we recommend regular exchange transfusions (a programme) which means having a procedure every four to eight weeks. This might be for a short length of time, for example when you are pregnant, or to help leg ulcers heal. We may recommend a long-term exchange transfusion programme because of continuing problems with your sickle cell disease or to prevent certain complications such as a stroke or chest crisis.

In sickle cell disease we usually recommend exchange transfusions rather than a conventional 'top up' transfusion. Exchange transfusions are more efficient, because:

- they will be more likely to give you a lower level of sickle blood cells in your system (often referred to as a lower HbSS)
- you will need fewer procedures each year as you can go longer between transfusions
- there is less risk of iron overload because when the blood cells are exchanged the iron in the blood is exchanged too.

Exchange transfusions are also faster and the whole procedure can usually be completed within three hours.

Where does the exchange transfusion happen?

Planned exchange transfusions happen on the apheresis unit, on Constance Wood ward, second floor, Gary Weston Centre at Hammersmith Hospital. The apheresis team are medical specialists who manage the exchange transfusion process.

If you are having the transfusion as an inpatient because you are unwell, it may be done on the ward.

The side effects or risks of exchange transfusions

Though most people tolerate their exchange transfusions well, there are a few side effects to be aware of:

- The risks of blood transfusion. These are the same as for any blood transfusion and these include transfusion reactions and the very unlikely event of transmitted infections.
 Before your first exchange you will go through all the risks and benefits of the procedure with one of your doctors or your nurse and will be asked to sign a consent form. We will also offer you information leaflets on blood transfusion.
- Reduced calcium levels. During the procedure a blood thinner is used to stop the blood clotting, and this can reduce the calcium levels in your blood. Occasionally this may cause a pins and needles-like sensation in your fingertips or lips, or cause you to feel slightly sick. If that happens, we can give you an infusion of calcium to stop these feelings.
- Feeling faint or light-headed. Your blood pressure will be monitored during the
 procedure. However, some people do feel a bit light-headed at the end, especially if they
 get up too quickly. Please let the nurses know straightaway if you feel unwell. Some
 people occasionally need a drip with extra fluid to feel better.

We will give you the HSBT leaflet 'Will I Need a Blood Transfusion' which has more information. You can also visit <u>blood.co.uk</u> and the <u>National Patient Safety Agency</u> website <u>npsa.org.uk</u> for further information.

It is essential that you tell us of any symptoms you experience as soon as they occur, especially at the start of each bag of blood. If you have had a reaction to a blood transfusion in the past,

then you should inform staff before your treatment starts.

Occasionally we cannot return the blood that is in the machine back to you, which means you lose some red cells as a result. The machine only holds a relatively small amount of blood, and this loss should not cause you any problems. We will however routinely check your blood levels to ensure they remain at a safe level after the red cell exchange.

What happens before the transfusion and on the day? First exchange transfusion

Before your first exchange transfusion your doctor or nurse will discuss the process with you and answer your questions. You will be asked to sign a consent form to document this discussion with you.

Before your first exchange transfusion you will meet with the apheresis team on the unit. This will give you the opportunity to meet the team if you haven't met them before, to have your base line blood tests taken, and your height and weight measured (so that we can calculate volume of blood required). The nurses will also review your veins to ensure they know what sort of intravenous access they will need to do the procedure.

You will be given the contact details of the apheresis team and unit, so you know how to contact them.

Before each exchange transfusion

Two to three days before your transfusion you will be asked to attend our phlebotomy department or apheresis unit to have blood samples taken. This includes a cross-match; this is important because it is how we order in and match the blood to be used for your transfusion. If you do not have this blood test taken in good time, then we will not be able to do your exchange transfusion. We also do a COVID swab.

On the day of the exchange transfusion

- Please arrive on time for your appointment. Our appointment slots are nearly all fully booked, so, if you are more than 30 minutes late, we may not be able to do your exchange transfusion that day and we will need to reschedule you. This is because of the pressure on our service.
- We need access to your veins to be able to remove your blood cells and give you the transfused blood. In most patients we can use two cannulas (or drips) in your arms, one to remove the blood and one to transfuse it into you
- The apheresis nurses may use ultrasound to locate the best veins for the procedure.
 Occasionally it may be necessary to have a long line inserted into one of the bigger veins in your groin. If this is needed it will be explained to you beforehand.

- The nurses will set up the blood and the machine. They will talk you through it and answer any questions you have.
- You will have observations such as blood pressure, heart rate and oxygen levels taken during the procedure.
- At the end of the procedure a blood sample will be taken to check that the target goals in terms of percentage of sickle cells are met. You may be given fluid through your existing venous access if required before it is removed.
- Due to COVID restrictions, you are unable to bring someone with you for company and children cannot be accommodated, to ensure that the nurses can focus on your treatment.
- We offer a limited range of cold and hot drinks. We have no facilities for ordering hot food and would encourage you to use the food outlets either before or after your procedure.
- If, at the end of the exchange transfusion, you need another procedure, you will be given the appointment date and time. Please put this in your phone, or calendar at home, as you will not receive a reminder or letter confirming the next appointment.
- Due to the high demand for this service, if you miss two consecutive exchange transfusions without letting the team know we may not be able to rearrange it. In this case you would need to come to clinic to discuss with the doctors the reason for you not attending so that we can help you to attend your exchange transfusions

What you need to bring with you

Please bring any prescribed medications that you would need to take during the time you will be at the hospital. This includes any pain medications that you usually take. We do not have facilities to provide subcutaneous analgesia on the apheresis unit routinely. If possible, wear clothing with loose-fitting sleeves as the apheresis nurses will require you to expose your upper arm for cannulation.

Please note: It is important to arrive on time for your appointment as another patient may be booked for treatment after you. Please do not hesitate to ring if you have any questions or queries. We are here to help you.

Useful contact numbers

Apheresis unit: 020 3313 4735

Haemoglobinopathy clinical nurse specialist: 020 3313 8553

Out-of-hours emergency line: 020 3311 7788

This leaflet was prepared by NHS Blood and Transplant (NHSBT) in collaboration with the National Blood Transfusion Committee. NHSBT is a Special Health Authority within the NHS, and provide the blood that patients receive. To plan future blood demands, information about which patients receive blood needs to be gathered. We may ask a hospital or GP to provide limited medical information on a sample of patients who have received blood transfusions.

NHS Blood and Transplant

NHSBT saves and improves lives by providing a safe and reliable supply of blood components, organs, stem cells, tissues and related services to the NHS, and other UK health services.

For more information:

Visit nhsbt.nhs.uk Email enquiries@nhsbt.nhs.uk

Call 030 0123 2323

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: 020 3312 1337 / 134

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk