Automated red cell exchange for patients with sickle cell disease

North Central London Haemoglobinopathy Network jointly with Whittington Health, Royal Free London, and Luton and Dunstable NHS Foundation Trust

Joint Red Cell Unit
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Introduction
The medical and nursing teams treating you have recommended that you have an automated red cell exchange. This may be for one of the following reasons:

- Your current transfusion regimen is causing iron overload, or is not working as well as we would have hoped (for example you need the blood too often or we cannot keep your sickle cell levels low enough).
- You need a ‘one-off’ exchange; this could be before an operation, or if you are normally very well and suddenly get sick.
- You need the exchanges regularly for a short period of time, for example when pregnant.
- You need to be on a long-term exchange transfusion programme because of ongoing problems with your sickle cell disease or to prevent complications (for example stroke).

If you are unsure why you may need an automated red cell exchange, please talk to the team treating you.

What is an automated red cell exchange?
An automated red cell exchange, known as Auto-REX, is a method of exchanging your blood for donor blood using a special device called an apheresis machine.

The team who carry out the procedure are known as the apheresis nurses.

What are the benefits of Auto-Rex?
Some of the benefits of automated exchange are the same as the benefits of having blood transfusion therapy in general. These include:

- feeling healthier
- having fewer problems with your sickle cell disease
- preventing problems, for example if you are at risk of stroke.
However, the automated exchanges are faster and more effective than manual exchanges or top up transfusions. This means that:

- the levels of HbS are lower
- the time between transfusions is greater as your levels remain lower for longer
- iron overload is much less of a problem, or may not be a problem at all, as the exchange swaps your red cells for the donor red cells very effectively.

**What are the disadvantages?**

The automated exchange will need excellent blood flow so the apheresis machine can work. If you don’t have good veins in your arms, we may need to:

- either put a temporary catheter (a long flexible tube) called VAS-CATH® into a vein in your groin, or
- insert a special device called Vortex® port under your skin, usually just below your collar bone. This is a more permanent solution than a catheter.

Please talk to your apheresis nurse and haematology consultant to find out more about these options.

**How long does it take?**

The red cell exchange usually takes two hours but you should allow three to six hours for your appointment. This is because after the exchange we will need to:

- give you fluids
- remove the catheter if needed
- carry out blood tests and other observations, such as check your pulse and blood pressure.
How often will I need to have an automated red cell exchange?
This varies from patient to patient.

If you are just having a ‘one-off’ exchange, you may never have one again.

If you are starting a transfusion programme, you can expect to have exchanges every four to eight weeks, with most people having exchanges every five weeks. It sometimes takes a while to achieve the optimum frequency of Auto-REX.

The lead Auto-REX nurse and haematology consultants meet weekly to review the results of those on the programme in the context of how they are doing and any problems they may be having. If you have any questions or concerns about your exchanges, you can talk to the apheresis nursing team or your haematology consultant.

What happens before an automated red cell exchange?
You will need to come to the hospital for blood tests 48-72 hours before the exchange – the Auto-REX coordinator will tell you when this should be.

What happens on the day?
Please wear loose clothing or bring something loose and comfortable to change into, for example tracksuit bottoms.

You will be able to eat and drink as normal before and after the exchange.

The procedure will take place in the Apheresis Unit on the 4th floor of the University College Hospital Macmillan Cancer Centre. The Apheresis Unit is an eight-bedded bay with two side rooms, usually used for children or those with infections or particular needs. Children who are in junior school usually have their exchange on the paediatric ward T11 south.
A friend or relative will be able to stay with you. However, as this is a busy area with several patients treated at once, we have a limit of one visitor per bed. We ask that you and your visitor are respectful of your fellow patients at all times.

During the exchange, blood will be taken out of a large vein in your arm (or through a VAS-CATH® or Vortex® port if you have one) into an apheresis machine. Inside the machine, the blood will be spun very quickly so that it separates into layers. Your own red cells will then travel up into a collection bag, while the separated plasma and other blood cells will be returned to you with the donated red cells. There will only be about 180mls (less than a glass) of blood outside of your body at any one time.

**What happens after the procedure?**
We will give you intravenous fluid (fluid given directly into a vein) over one hour and carry out some blood tests after that.

If you had a VAS-CATH® inserted for the exchange, this will be removed one hour after the procedure. You will also have to stay in the Apheresis Unit or on the ward for 30 minutes after it has been removed to ensure that any bleeding has stopped.

If you are on the red cell exchange programme, we will give you a letter with the time and date of your next exchange before you leave hospital.

**Are there any side effects?**
As with any procedure, there are some side effects associated with an automated red cell exchange. Please note they don’t affect everybody and everyone reacts differently – talk to the team looking after you if you have any questions or concerns.
**Lowered calcium levels:** Calcium is essential for your blood to clot. To stop the blood from clotting while it’s going through the apheresis machine we use a blood thinner or ‘anticoagulant’ called ACD-A during the exchange. ACD-A binds to calcium and removes it from your bloodstream. Lower levels of calcium can make you feel sick or cause a tingling sensation in your nose, lips or fingertips. We will give you a drip to replace your calcium and help to relieve these side effects.

**Reaction to the donor red cells:** Even though we use the safest possible products provided by the NHS Blood and Transplant, there is always the possibility that your body may react adversely to the donated red cells. Early signs of a reaction include itching, hives (a type of rash) and wheeziness.

Signs to watch out for when you go home include:
- yellowing of skin or whites of the eyes (jaundice)
- becoming pale
- passing very dark urine.

You need to let us know immediately if these symptoms develop (contact details are on page 10 of this leaflet). Transfusion reactions vary from mild to life threatening.

**Developing a red cell antibody:** Even though we will match the donor blood to your blood according to the national guidelines, you may still form an antibody to the blood. If this happens, you will need specific blood that doesn’t react to that antibody the next time you have a transfusion. You are more likely to form an antibody if you get transfusions occasionally when being unwell, rather than if you have them regularly when being well. If you have an antibody and need a transfusion outside of UCLH, ask the hospital staff to check the details of your blood requirements with UCLH so that they give you the correct blood.
• **Low platelet count:** Your platelet count will be lowered by the exchange but it should still remain within the normal range. This will naturally increase back to your usual levels in the days after the exchange.

• **Feeling faint:** Sometimes if you get up too quickly after an exchange you can feel a bit faint. Please don’t get up until the nurses have checked your blood pressure.

**How can I be part of the red cell exchange programme?**

You will be referred to the UCLH red cell adult or paediatric clinic where you will see a consultant and the Auto-REX coordinator. They will assess your suitability for the programme and advise whether you may need a VAS-CATH® or Vortex® port for your exchanges. They will explain the process to you and show you around the department. It’s important that you feel confident that this is what you want to do so feel free to ask any questions you may have. If you decide to go ahead, you will need to sign a consent form. This is to confirm that you agree to be part of the programme and understand what it involves.

The Auto-Rex programme at UCLH is the largest in Europe and heavily subscribed. To keep it working smoothly and to allow as many people to be on the programme as possible, we need you to be very organised with your appointments.

We will schedule your next appointment before you leave the Apheresis Unit after your exchange. This will have two components:

• the day and time of the blood tests you will need before the exchange, and

• the day and time of your exchange.

It’s important that you check you can make those dates. It may also be a good idea to put them in your diary or your phone with a reminder set earlier in the week.
If you need to change the date of your appointment, you must call the Apheresis Unit at least one week in advance. This is to allow us to offer your slot to someone else. If you change your appointment with less than one week’s notice or miss your appointment twice, we will take you off the programme pending further discussion with your consultant in the red cell clinic.

It’s important that you bring your own supply of pain relief as we don’t give injectable painkillers before or during routine exchanges.

We ask all patients on the red cell exchange programme to follow the UCLH guidelines on conduct and behaviour, and treat all members of staff with respect and courtesy. Your place on the programme will be reviewed every year and will depend on whether you adhere to the guidelines. Please talk to your healthcare team if you would like more information about this.

**Where can I get more information?**

**Sickle Cell Society**
Tel: 020 8861 7795
Website: www.sicklecellsociety.org

**UK Forum on Haemoglobin Disorders**
Website: www.haemoglobin.org.uk

University College London Hospitals NHS Foundation Trust cannot accept responsibility for information provided by external organisations.
Contact details
Haematology advice line (office hours, adults and children):
020 3447 7359

Adult haematology advice line (out of hours):
07852 220 900

Paediatric helpline (out of hours):
• nurse in charge 07961 081 645
• ward T11 south 020 3456 7890 ext. 71103 or 71143

Apheresis Unit:
4th Floor, UCH Macmillan Cancer Centre
Huntley Street
London WC1E 6AG
Tel: 020 3447 8955

The Joint Red Cell Unit:
Department of Haematology
3rd Floor West, 250 Euston Rd
London NW1 2PG

Website:
www.uclh.nhs.uk/JRCU

Haematology consultants:
Professor John Porter
Dr Sara Trompeter
Dr Perla Eleftheriou
Dr Emma Drasar
Dr Bernard Davis
Dr Farrukh Shah

Specialist nurses:
Bernadette Hylton (adults)
Nancy Huntley (apheresis)
Nina Gorman (children)
Space for notes and questions