

Children's haematology

Automated red cell exchange

Information for patients, relatives and carers

What is an automated red cell exchange?

An automated red cell exchange is a method of exchanging your blood for donor blood using an apheresis machine. This machine separates the red blood cells from the rest of your blood, removes them and then gives you back red cells from a donor.

During the exchange, blood will be taken out of a large vein in your arm (or through a central line) into the apheresis machine. Inside the machine, the blood is spun very quickly so that it separates into layers. The red cells travel up into a collection bag, while the separated plasma and other blood cells are returned with the donated red cells.

There will only be about 180mls (less than a glass) of blood outside of your child's body at any one time.

The team who do the procedure are specially trained nurses for apheresis.

Why have an automated red cell exchange?

The medical and nursing teams treating you have recommended that your child has an automated red cell exchange. This may be for one of the following reasons:

- Their current transfusion regimen is causing iron overload, or is not working as well as we would have hoped (for example they need the blood too often or we cannot keep their sickle cell levels low enough).
- They need a 'one-off' exchange; this could be before an operation, or if they are normally very well and suddenly get sick.
- They need to be on a long-term exchange transfusion programme because of ongoing problems with sickle cell disease or to prevent further complications.

If you are unsure why your child needs an automated red cell exchange, please talk to the care team.

What are the benefits of an automated red cell exchange?

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 sickle cell disease

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- Preventing other problems, for example if risk of stroke.

However, the automated exchanges are faster and more effective than top up transfusions. This means that:

- The levels of Haemoglobin S (sickle percent) are lower
- The time between transfusions is longer as levels remain lower for longer
- Iron overload is much less of a problem, or may not be a problem at all. This is because the exchange swaps red cells for the donor red cells very effectively.

What are the disadvantages?

One difficult challenge of an automated exchange is finding good veins for the procedure. Usually, we put cannulas into your child's X to take out and put back their blood. Even though we check where the veins are before starting, there are lots of things that can stop us from being able to get the right access using cannulas. One thing that helps with this is making sure your child drinks lots of fluids after their blood test and on the morning of the procedure.

If your child doesn't have good veins, we might need to:

- Either put a temporary catheter (a long flexible tube called a central venous access device) into a vein in your child's neck or groin,

Or

- Insert a special device called a double lumen Vortex® port under your skin, usually just below your child's 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 transfusion usually takes up to two hours but you should allow three to six hours for your appointment. This is because after the exchange we will need to:

- Give your child fluids
- Remove the catheter if needed
- Do more observations and blood tests.

How often will I need to have an automated red cell exchange?

This varies from patient to patient. If your child is just having a 'one-off' exchange, they might never have one again. If they are starting an exchange transfusion programme, you can expect to have exchanges every four to six weeks; most people have exchanges every five weeks.

It sometimes takes a while to achieve the best frequency of red cell exchanges for your child. The nursing team and haematology consultants meet to look at the results of everyone on the programme. They think about how they are doing and any problems they are having. If you have any questions or concerns, you can talk to nursing team or your haematology consultant.

What happens before the procedure?

Your child will need to come to the hospital for blood tests, weight and height 48 to 72 hours before the planned exchange. Your apheresis nurse will tell you when this should be.

Consent

We involve you in all decisions made with regards to your child's care, and you both have the freedom to talk to us about any questions you may have. This includes the reason for exchange, what the procedure involves, and any possible side effects. If you decide your child will have the procedure, you will need to sign a consent form. This is to confirm that you agree to us doing the procedure or to be part of the program and understand what it involves.

On the day of the exchange

- Please dress in loose clothing or bring something loose and comfortable to change into, for example tracksuit bottoms. Feel free to bring any comforters/electronics/games/entertainment
- Bring any regular medication your child will need to take
- Your child will be able to eat and drink as normal before and after the exchange.

The procedure will happen in the Apheresis Bay on Grand Union Ward the 7th floor of The Queen Elizabeth Queen Mother Building. As this is a busy area with several patients treated at once, you are only allowed one visitor per bed. Please be respectful of other patients at all times.

Please note: Your child can get up from the bed to go to the toilet after the procedure but for at least an hour, you must help them. You'll need to go inside the toilet with them in case they become faint/dizzy/unwell. This is rare but sometimes happens because of the large fluid shift after the exchange.

What happens after the procedure?

We will give your child fluid directly into their vein (intravenous fluid) over one hour and carry out some blood tests after that.

If they had a femoral line inserted for the exchange, we'll remove this one hour after the procedure. You will also have to stay on the ward for 30 minutes after it has been removed to make sure that any bleeding has stopped.

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

Your child's vital signs will be checked again and bloods taken to check how effective the procedure has been.

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 your child 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 anticoagulant citrate dextrose solution-A (ACD-A) during the exchange. ACD-A removes calcium 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 your child a medication to replace 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 will need to tell us immediately if these symptoms develop (contact details are at the end 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 can still form an antibody to the blood. Your body usually makes antibodies to fight bacteria or viruses, but it can also make antibodies when you get blood transfusions. If this happens, we need to give you a kind of blood that your body doesn't react to next time you have a transfusion. Your child's body is more likely to make an antibody if they get transfusions occasionally when being unwell. It's less likely to make a red cell antibody if you have transfusions regularly while you're well.

- **Low platelet count:** Your child's platelet count will be lowered by the exchange but it should still remain within the normal range. This will naturally increase back to their 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. Your child shouldn't get up until the nurses have checked their blood pressure.

How can my child be part of the automated red cell exchange programme?

Your child will be referred to the Imperial College Healthcare paediatric haemoglobinopathies clinic where they will see a consultant and a clinical nurse specialist. They will check if they're suitable for the programme and assess their veins and advise whether you might need a central line for your exchanges.

They will explain the process to you and show you around the department. It's important that your child and 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 do the procedure, we will take an informed consent. This is to confirm that you agree to be part of the programme and understand what it involves.

Our programme at St Mary's is the largest paediatric programme in England and is 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 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 and swabs your child will need before the exchange,

And

- The day and time of the exchange.

It's important that you check that you can both 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.

Contact details

Haemoglobinopathies admin team: 0203 312 6157

Haemoglobinopathies clinical nurse specialist team (09.00 to 17.00): 07795651153, imperial.paediatricaemoglobinopathies@nhs.net

Paediatric haematology day unit (PHDU): 0203 312 5080/5081

Paediatric site practitioner: 07824625419

The team

- Dr Kirstin Lund, consultant paediatric haematologist,
- Professor Josu de la Fuente, consultant paediatric haematologist
- Dr Adam Gassas, consultant paediatric haematologist
- Dr Toni Petterson, consultant paediatric haematologist
- Dr Leena Karnik, consultant paediatric haematologist
- Miss Catherine Mkandawire, matron (Haemoglobinopathies and apheresis children and young people)
- Miss Kajal Rai, clinical nurse specialist (Haemoglobinopathies children and young people)
- Ms Nancy Huntley, clinical nurse specialist (Apheresis children and young people)
- Miss Ristell Fernandes, clinical nurse specialist (Apheresis children and young people)
- Mr Renzo Tiong, clinical nurse specialist (Apheresis children and young people)

Further information

<https://www.imperial.nhs.uk/our-services/adolescent-and-young-adult-healthcare---11to25>

<https://www.readysteadygo.net/>

Sickle Cell Society

020 8861 7795

sicklecellsociety.org

UK Thalassaemia Society

020 8882 0011

office@ukts.org Website: ukts.org

Sickle Cell and Young Stroke Survivors (SCYSS)

0800 084 2809 or 0207 277 2777

info@scyss.org

scyss.org

Contact

The charity for families with disabled children

<https://contact.org.uk/>

Family Fund

<https://www.familyfund.org.uk/>

Grants are available for families raising a child or young person with a long-term disability, disabling condition or life-limiting illness, and living on a low income.

The Hope Project Scotland

07756 266691

Website: thehopeprojectscotland.org.uk

Citizens Advice Bureau

<https://www.citizensadvice.org.uk/>

The Care Information Exchange (CIE)

CIE gives secure online access to information from the hospital such as test results, appointments and letters. Young people and their parents can also add things like symptoms the young person is experiencing to give a more complete record. To register and access the record QR code below to download the application.

Everyone registering will need to complete a form, show proof of identification, and have an email address. The email address will be the login name, and the address for notifications when something new is added to the record. Go to www.careinformationexchange-nwl.nhs.uk/ or scan this QR code with your phone camera to find out more and register:



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 / 1349**

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

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