Top tips for managing your red cell exchange

Information for patients, parents, and carers

This leaflet is designed to help you be well prepared for your red cell exchange. It also outlines who you should contact if you have concerns. This leaflet applies to people having red cell exchange procedures in hospitals across the Wessex and Thames Valley region.

Preparing for your exchange appointment



1. Things that can help make it easier to get the lines in:
    a. Being well hydrated:
        i. Drink plenty of water the day before, in the morning and on the way to your appointment
    b. Being warm:



        i. Keeping warm means your veins stay closer to the surface of your skin and they can be more dilated
        ii. If it's a cold day you can keep your coat on and gloves on in the department to make sure you stay warm
2. Eat breakfast preferably something with calcium in it such as milk, diary free milk alternatives (have the same amount of calcium as diary) yoghurt, cheese, smoothy, milky coffee and consider calcium rich foods 24-48 hours before your appointment. This link takes you to information about calcium rich foods:

https://www.bda.uk.com/resource/calcium.html	

3. If you need time to settle before you are assessed and the lines go in, then arrive earlier, you can sit, wait, and eat in the department if you wish
4. Bring things to entertain yourself, e.g. laptop, book, phone, college or school reading! etc
5. You may want to bring lunch, most units will only provide snacks, hot and cold drinks.
6. Go to the toilet before your procedure starts.
7. Bring any drugs or pain relief you may need, as not all units will be able to prescribe medication.

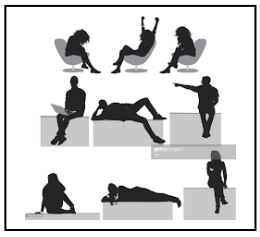
During your exchange

1. You can eat and drink whilst on the machine.
2. If you feel odd or unwell in anyway, tell the nurse straight away
3. A low calcium can make you: yawn excessively, have tingly fingers lips, metallic taste, feel dizzy, faint, nauseous; please tell the nurse if you experience any of these symptoms
4. Let the nurses know if you need the bathroom, they can help you. Rushing off to the loo straight after an exchange can make people feel faint or cause line sites to bleed.

After your exchange

1. Plan to rest for the rest of the day, some people need to rest for a day or two afterwards
2. Stay well hydrated, drink plenty of water
3. Consider Calcium rich foods:

https://www.bda.uk.com/resource/calcium.html	



4. Many patients feel completely exhausted for 1-3 days after their exchanges. Please do rest. Please mention this to the staff when you go back for your next exchange.

Things to report 24-48 hours after your exchange

1. Excessive bruising or pain or new tingling on or around the site of your line(s).
2. Bleeding from your line site(s) that won't stop after pressure has been applied for 5 mins.
3. Feeling unwell in anyway.
4. Fever.

Post Exchange Transfusion reactions

Blood transfusion reactions are rare. The reaction relates to your immune system reacting to the blood received during the exchange. Reactions can be 'acute' within a few hours of the exchange or 'delayed' up to 10 days after the exchange.

Symptoms may include:

Acute:

- New rash or itching
- Dark urine

- Feeling achy and shivery, like when you have a high temperature
- Temperature
- Lower back pain around the kidneys

Delayed:

- Very dark urine
- Feeling achy and shivery, like when you have a high temperature
- Temperature
- Yellow eyes (if this is not usual for you)
- Lower back pain around the kidneys

Who to contact?

Oxford patients - please contact your usual team for any acute problems or concerns - all this information will be in your service information leaflet.

Southampton patients - Apheresis Unit – Tel: 0238 1203 728
During out of hours please attend the Emergency Department.

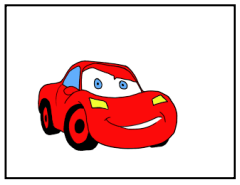
What do I tell the team?

You must say:

- you have sickle cell disease
- you have had a red cell exchange
- the date of the exchange, where you had the exchange
- if you know, how many units of blood
- you are concerned you are having a transfusion reaction and ask them to contact the haematologist on call.

Planning your next exchange

1. Make sure you know the date of your next exchange before you leave the hospital
2. If accessing your veins is becoming challenging or difficult and or painful for you, let your specialist nurse know or speak to the NHSBT team



Transport

We suggest that for your first exchange you have someone bring you as it is a new experience and you may feel very tired afterwards.

Following that you may drive yourself if you think this is appropriate.

If you do not drive, cannot get someone to bring you or feel unwell after your exchanges you can arrange transport via the SCAS patient transport system, this is for the southeast only. You can register online or via the telephone. You will be asked some questions and in some areas, you are asked to justify your need for transport each time you book. We cannot change the local policies but are happy to provide a letter if this helps. Register and book using this link or you can telephone.

https://managemybooking.scas.nhs.uk/patientzone/frmPatLogin.aspx	

Buckinghamshire, Berkshire West, Oxfordshire and Frimley patients
Contact Centre is open 7am-7pm
Telephone: 0300 777 3333 – Patient eligibility line

Milton Keynes patients can access transport by calling the SCAS Contact Centre or via PTS Patient Zone. **Contact Centre is open 8am – 8pm, 7 days a week.**
Telephone: 0300 100 0015

Hampshire patients accessing transport for the first time need to call the SCAS Contact Centre to create a master record and book your initial appointment. You can then use the PTS Patient Zone to book subsequent journeys, manage your bookings and check your journey status. Telephone: 0300 777 4444

Dorset Contact Centre is open 8:30am – 6.30pm, Monday to Friday (not bank holidays). Telephone: 012787 27457

Sussex - relay users can book their transport using the **Relay app** or can dial **18001** followed by our booking number from a textphone. Telephone: 0300 777 6666

Authors:

Specialist nurses, Thames Valley Haemoglobinopathy Network

Specialist nurses, Wessex Haemoglobinopathy Network