

Changes to your automated red blood cell exchange transfusions

Information for patients

This leaflet explains why changes are being made to automated red blood cell exchange transfusions for sickle cell patients. If you have any further questions or concerns, please do not hesitate to speak to the team caring for you.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you do not have an ID band we will also ask you to confirm your address. If we do not ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

Why are changes being made?

Red cell exchange (RCE) is a medical procedure where a patient's red blood cells are removed and replaced with donor red blood cells. The procedure is most efficiently done using a specialised apheresis machine. This is called an automated red blood cell exchange transfusion.

More people with sickle cell disease are now receiving automated red blood cell exchange transfusions. This is having a positive impact on managing the disease, but it also means that:

- the demand for donor blood has increased significantly (by around 50% over the past five years)
- there is a shortage of donors who can provide closely matched blood for people with sickle cell disease

We are making changes to ensure blood is used as carefully and effectively as possible. By carefully planning the procedure and using blood-saving techniques, we can often achieve the same treatment goal while using fewer donor blood units.

This may reduce your exposure to donor blood while still lowering the number of unhealthy red blood cells to the target level.

What is the aim?

We have a responsibility to:

- use the minimum amount of blood needed to meet your treatment targets safely
- reduce unnecessary exposure to donor blood, which may:
 - lower the chance of developing antibodies
 - reduce the risk of transfusion-related reactions

What are treatment targets in your apheresis plan?

We use two blood results to determine how much blood is needed for your procedure.

1. Sickle haemoglobin (HbS) level

- This is the percentage of your own red blood cells remaining in your blood between procedures.
- Typically, we aim to keep this number below 30% or 50%, depending on your condition.

2. Haematocrit (HCT)

- This is the total amount of red blood cells (from the donor and from yourself) in your blood.

How has the procedure been done historically?

Until now:

- the apheresis machine settings were based on body height and weight and baseline HCT
- we reviewed if patients were meeting their targets once a year
- many patients were treated using a standardised ('one-size-fits-all') approach to their HCT level after transfusion

What is changing?

Your treatment targets will not change. We are improving how we reach those targets, by reviewing your results more frequently and tailoring your treatment to you, while safely reducing blood use where possible.

We are moving to a more personalised approach, which is an improvement in your care.

- We will now review whether you are meeting your targets before every procedure.
- The apheresis machine settings may be re-programmed before each procedure.
- For some patients, the procedure will now start with an extra depletion cycle. This will make the subsequent exchange transfusion more efficient. Please see below for a further explanation.
- HCT targets may be adjusted to help prevent or reduce iron overload.

This means:

- many patients will need fewer blood units per procedure
- some patients may occasionally need more units, depending on their results

What will this mean for you?

- You may notice a change in the number of blood units you receive.
- Your treatment will be more closely tailored to your individual needs.
- Your programme may start with a depletion cycle.

What is a depletion cycle?

The depletion cycle is an extra step in the programme of the apheresis machine that lowers the patient's HCT level before the actual donor red blood cell replacement starts, using normal saline or human albumin to keep the blood volume steady.

This extra step reduces the number of donor units needed while still achieving the same target post-procedure HCT and HbS levels.

If you have the depletion cycle:

- it may make the procedure up to 30 minutes longer
- side effects are similar to the standard procedure, although you may notice they are more pronounced
- you will still be monitored closely throughout the procedure and advised to be cautious when going home as there is a risk of dizziness and fainting

Who can I speak to for more information?

- If you have any questions or concerns about these changes, please contact the Apheresis Team by calling 020 3299 2051 or 020 3299 4268 or e-mailing kch-tr.apheresis@nhs.net.
- Your treatment plan and targets can be discussed during your clinic appointment.

MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. To sign up or for help, call us on 020 3299 4618 or email kings.mychart@nhs.net. Visit www.kch.nhs.uk/mychart to find out more.

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our nursing students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

Tel: **020 3299 4618**

Email: kings.pals@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email kings.access@nhs.net