Evelina London

NHS
Guy's and St Thomas'
NHS Foundation Trust

Having an exchange blood transfusion

Information for parents or carers of a child with sickle cell disease (SCD) and thalassaemia

showing we care

Contents

This leaflet will answer some of the questions you have about your child having an exchange blood transfusion as a treatment for SCD. If you have any questions or concerns, please speak to the sickle cell doctors or specialist nurses, Snow Fox nurses, or the child and adolescent mental health services (CAMHS) practitioner.

What is blood?

Blood is the liquid in the vessels of the body. It is made up of different types of blood cells and plasma (a straw-coloured liquid that carries the blood cells around your body). The different types of blood cells are:

- red cells, which contain haemoglobin (the red pigment that carries oxygen and carbon dioxide from the tissues of the body)
- white cells (which fight infection)
- platelets (which are clotting cells).

Normally, red cells last about 120 days (four months) in the blood (although they last for a shorter time in people with SCD). They are then removed by the body, which means that the body always needs to replace them.

What is a blood transfusion?

A blood transfusion is a procedure that puts red cells into the body. This could be a planned procedure, or be performed in an emergency situation.

The two main types of blood transfusions are:

A simple transfusion (top-up)

A few units (bags) of blood are given through a small tube (drip), usually placed in a vein in your child's arm. For more information, please speak to the Snow Fox nurses or ask for a copy of the leaflet **Having a simple (top-up) blood transfusion: Information for parents or carers of a child with SCD**.

An exchange blood transfusion

This is a procedure that replaces sickle blood with non-sickle blood (from a donor who does not have SCD).

Why would my child need an exchange blood transfusion?

This might be needed in an **emergency**, such as for:

- a complicated sickle cell crisis, such as a stroke
- a chest crisis – sickling in the lungs causing breathing problems
- a very painful crisis.

A **routine or planned** exchange transfusion may also be done in the following situations.

- If your child has had a stroke, long-term repeated exchange transfusions, every 3-6 weeks, as a part of the transfusion programme can help reduce the risk of further strokes.
- If your child has had abnormal Transcranial Doppler scan results, long-term repeated exchange transfusions, every 3 to 6 weeks, as a part of the transfusion can help reduce the risk of them having strokes.
- If your child's SCD is very severe, repeated exchange transfusions (every 3 to 6 weeks as part of the long-term transfusion programme) can help reduce the number of crises.
- If your child is going to have a major operation, a single exchange transfusion reduces the risk of complications from general anaesthetic and surgery.
- If your child has leg ulcers, exchange transfusions may help healing.
- An exchange transfusion may help in cases of severe priapism (painful erections) that have not responded to other forms of treatment or surgery.

Asking for your consent

We want to involve you in all the decisions about your child’s care and treatment. It is entirely your choice whether your child has the transfusion programme (transfusions every 3 to 6 weeks) or not. We will give you relevant information to help you come to a decision with the sickle cell team. It is important that you understand the information and have the time to ask questions and to make your decision.

If you agree to the transfusion for your child, you will be asked to sign a consent form. This confirms that you understand what the treatment involves, and agree for your child to have it. If you would like more information about our consent process, please speak to a member of staff caring for your child.

Is it safe to have a blood transfusion?

In the United Kingdom, we take many precautions to make sure any blood given is as safe as possible. You can find out more from the NHS Blood and Transplant leaflet **Will I need a blood transfusion?**

The main risk from a transfusion is that the wrong blood could be given by accident. To make sure that the right blood is given, the clinical staff must make careful identification checks. They will ask you to state your child’s full name and date of birth and will check the details on their name band, to make sure they receive the correct blood.

They will also regularly monitor your child during the transfusion (check their blood pressure, temperature, pulse and breathing rate) and ask your child how they are feeling.

The risk of contracting a disease, such as hepatitis or human immunodeficiency virus (HIV), is extremely low.

- The risk of getting hepatitis B is less than one in 1.3 million, and one in 28 million for hepatitis C.
- The chance of getting HIV from a blood transfusion is one in 6.5 million.
- The possibility getting variant Creutzfeldt-Jakob disease (vCJD – a rare, incurable brain disease) is extremely small and a number of precautions are taken to reduce this risk.

We now strongly advise that all patients on a transfusion programme are routinely vaccinated against hepatitis B. During the transfusion programme, your child’s immunity to hepatitis B and other viral infections will be regularly reviewed.

Although the risk of contracting an infection from blood is very low, we recommend that we check your child for HIV and hepatitis C infection once a year.

What are the possible complications of blood transfusions?

Minor reactions

Your child may get a skin rash or a minor fever, for example. These can be treated easily with paracetamol and antihistamines.

Antibodies

Your child's blood is matched very closely with the blood of the donor (the person who donated the blood). However, it is possible to develop antibodies against the donor blood, so you need to make the clinical staff aware of any symptoms your child may be having after the transfusion (see the section on delayed transfusion reactions). These antibodies can mean that matched blood is harder to find and can take longer to prepare.

Iron overload (iron build-up)

This is common in people who receive repeated blood transfusions. When necessary, excess iron can be removed by taking medication (iron chelation) which can be in the form of injections, tablets or liquid. This is much less likely when using the exchange machine, rather than when it is done by hand.

If your child has developed antibodies you will be sent an alert card that says 'I need special blood'. This is to help make sure that anyone treating your child knows that their blood needs to be matched against them. Please make sure you show this to clinical staff before your child receives a transfusion and, in any hospital, where they are treated.

Why does my child need iron chelation?

Regular blood transfusions can cause a build-up of iron in the body, which, over time, can cause harm. Our bodies can only remove small amounts of iron and cannot get rid of the build-up of iron from transfusions. Iron chelators are medicines that bind to the excess iron in the blood and help remove it from the body. This stops problems associated with iron build-up. Once the ferritin level (a measure of iron stores) approaches 1,000 you will be offered chelation medicines.

There are three different types of iron chelation medicines. Deferasirox (also known as Exjade®), is a tablet that is taken orally once a day. Deferiprone (also known as Ferriprox®), is a tablet or liquid that is taken orally three times a day. Deferoxamine (also known as Desferal®), is an injectable medicine that is given over several (usually 8-12) hours, several times a week.

An appropriate leaflet will be given to you when your child starts iron chelation

Delayed transfusion reactions

Sometimes a patient experiences a delayed transfusion reaction (where the body abnormally breaks down the blood that has been transfused), which may happen within two weeks the transfusion.

This may cause:

- severe generalised sickle cell pain/crisis
- blood in the urine (red or cola colour)
- tiredness
- shortness of breath
- fever
- localised loin/back pain.

If your child experiences these symptoms you must take them to hospital immediately for assessment, and you must tell medical staff that they have been transfused recently.

Possible complications specific to exchange transfusions

Your child may:

- experience light-headedness and fainting.
- experience a tingling sensation on their lips and fingers. This is due to the anticoagulant used, which lowers calcium levels in the blood. We may give your child fluid to correct this.
- feel tired for a day or two after the transfusion.

Is any preparation needed before the transfusion?

Your child will need to have a blood test before each transfusion. Once the transfusion date is agreed, your child will be given an appointment card from Snow Fox Ward with the dates for their blood test (this is normally the day before the transfusion date). If they require ‘special blood’ (because of antibodies) it is essential that you bring them for blood tests a few days before, or blood may not be available from the transfusion service and their transfusion may be cancelled or delayed.

You can bring your child to the Blood Test Centre on the date on the appointment card, 9am-5pm. Your child needs to be accompanied by an adult for all tests.

If your child is unable to make their appointment, please call Snow Fox Ward or the clinical nurse specialist as soon as possible (contact details at the end of this leaflet).

A blood sample is taken so we know your child’s blood group and if they have developed any antibodies. Each time your child has a transfusion, we test their blood against the donated blood, so they are transfused with blood that closely matches their own.

It is important to attend this appointment, so we have time to order the blood that your child needs.

Where does the transfusion happen?

The transfusion takes place on Snow Fox Ward, first floor, staircase D, South Wing, St Thomas' Hospital, unless you are told otherwise. Please arrive before 9am if your child has been offered a morning session for the transfusion. If your child has been scheduled for the afternoon session, you must arrive on the ward by 12:30pm.

Does my child need to bring anything with them?

Your child might want to bring a book, laptop, or a handheld computer game with them to keep them occupied, as they will need to keep still during the procedure. They should bring their regular daytime medication, including painkillers, as we may not have them on Snow Fox Ward. They should wear loose-fitting clothing.

What happens during the transfusion?

Exchange transfusions are given through a Port-a-Cath (a type of central line). The Port-a-Cath is situated under the skin and uses a large vein in the chest. Cream is normally applied to the port site to numb the area. The exchange transfusion is done manually or with a machine.

The specialist nurse will access your child's port and attach the line to the blood exchange machine. The bag of blood that has your child's details (name, date of birth and hospital number) will be checked carefully and the exchange will start. The nurses will continually monitor your child.

During the exchange, the nurse will check your child’s blood pressure, pulse, temperature, and oxygen level regularly.

Your child can sit up or lie down. If they need to go to the bathroom, we can disconnect them for a short while.

Your child can read and write, and also eat and drink if they want to.

Will my child feel anything during the exchange transfusion?

Sometimes people feel a tingling sensation around their mouth or fingers during the exchange. This is caused by a drop in their calcium level (explained on page 10). Your child should tell the nurses if they experience this.

How long will the transfusion take?

The process takes about four hours. This will depend on your child’s clinical history and how much blood is used during the procedure.

What happens after the transfusion?

When the exchange is finished, a blood test is taken so we can see how much of the sickle haemoglobin is left in your child’s blood.

Your child will be assessed by a nurse and, if everything is fine, you will be able to take them home. We will give you the date for your child’s next exchange transfusion before you leave.

After the exchange, we recommend you take your child home and that they rest for the evening.

Why does my child need repeat exchanges?

Normal red blood cells only last 120 days in the body. Repeat exchanges are needed to keep the sickle cells in your child’s blood to a low level. The frequency of the exchanges depends on the reason for exchange.

Can I cancel or change the date of my child’s exchange transfusion?

You must contact the sickle cell nurses or Snow Fox Ward as soon as possible so that they can arrange an alternative date (contact details at the end of this leaflet).

Does it always work?

Most patients selected for a long-term transfusion programme have severe SCD. The exchange transfusion tries to reduce the number of sickle cells in the blood as much as possible, but it can’t make them disappear. It also can’t suddenly make some of the complications of SCD disappear – like stroke, bone damage or visual loss. This means that problems can happen to people even though they are on an exchange transfusion programme. Your child will still have an increased risk of infection. It is not a perfect treatment, but it does reduce the chances of new serious problems happening.

Contact us

Lead consultant for haemoglobin disorders, and consultant in haematology, **phone:** 020 7188 6203 (secretary), **email:** Dudhma.Banu@gstt.nhs.uk

Lead nurse, **phone:** 020 7188 9432 or 07918 338730 **email:** HaemoglobinopathyCNS@gstt.nhs.uk

Nurse specialist, **phone:** 07771 345847 or 07517 592436 **email:** HaemoglobinopathyCNS@gstt.nhs.uk

Research nurse, **phone:** 020 7188 6637 or 07517 592436

Specialist nurse – community,
phone: 020 3049 5993 or 07880 781545

Therapy and psychology team, **phone:** 020 7188 9125 or 07817 905844

Snow Fox Ward
t: 020 7188 4670, Monday to Friday, 7.30am-8pm

Help and advice will always be available if you have any questions or concerns. Out of hours, please call the hospital switchboard, **phone:** 020 7188 7188 and ask them to bleep the haematology registrar.

If you need to come to emergency department (A&E) at St Thomas' Hospital, please telephone the department before you arrive, **phone:** 020 7188 2111 and let them know about you child's condition. This will help to improve your child's care when you arrive.

Further information

The Sickle Cell Society, provides advice, information and support to people with SCD and their families, and raises funds for the education of carers and health professionals, **phone:** 020 8961 7795 **website:** www.sicklecellsociety.org

ERIC, education and resources for improving Childhood continence. This charity provides support and help through their website and helpline, **website:** www.eric.org.uk

Evelina London Medicines Helpline
If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.
phone: 020 7188 3003, Monday to Friday, 10am to 5pm
email: letstalkmedicines@gstt.nhs.uk

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone** 020 7188 3514 **email** complaints2@gstt.nhs.uk

Language and accessible support services
If you need an interpreter or information about your care in a different language or format, please contact the department your appointment is with.

Leaflet number: 4116/VER4
Date published: October 2023
Review date: October 2026

A list of sources is available on request