

Information about your Desferal[®] infusors (pump)

Why do I need to have Desferal®?

Having regular blood transfusions is a necessary part of the treatment for sickle cell disease and thalassemia major patients. This can however lead to the build up of excess iron in the major organs such as the heart or liver.

If this overload of iron is not treated then serious organ damage can occur.

Your doctor has prescribed you treatment with desferrioxamine mesylate (Desferal®). Desferrioxamine is the generic name for Desferal®. This medicine is used to help remove excess iron from the body. It does this by binding to iron in the blood to form a complex, which is then passed out in the urine.

How is Desferal® given?

Desferal® is given via a subcutaneous injection (under the skin) using a special pump called an infusor. The infusor is used to administer the medicine slowly over several hours (usually 8-12 hours). You will have the treatment between 3 and 7 times a week, depending on your level of iron overload.

Each infusor is made up for you as an individual by the hospital pharmacy. Your doctor has chosen to give you a particular strength of treatment according to the levels of ferritin (iron) in your blood.

It is important to keep your infusors in the fridge. Please check the label and make sure that the expiry date has

not passed – if it has then the treatment should not be used.

You will be given a separate infusor for each day of treatment. Each infusor is packed separately, with a separate needle, and is ready for use. There is no mixing required. We recommend that you take the infusor out of the fridge about two hours before use, so that it can reach room temperature. When you are ready to use the infusor, follow the steps below.

How to use your Desferal[®] infusor

Patients / carers will be taught how to use the Desferal[®] infusor by pharmacy before first use.

1. Please check the label and make sure that the expiry date has not passed – if it has then the treatment should not be used and the unused syringes should be returned to pharmacy or the sickle cell team.
2. Wash your hands.
3. Open the pack containing the thalaset[™] needle.
4. Remove the winged cap from the infusor and attach the needle to the opened end.
5. After about 1 minute, the infusor will fill (prime) the line and needle with a small amount of Desferal[®].
6. Pinch the skin around the injection site; see the **Guidelines** section below for the most common sites used.
7. Place the needle straight into the skin.
8. Secure it in place with the sticky pad provided.
9. Place the infusor securely under your clothing.

10. Leave in place for 8-12 hours (depending on your infusion time. See label on infusor).
11. When the infusion is finished, remove the sticky pad and needle.
12. Throw the empty infusor into the bin and needle into the sharps container that you have been given.

Rotation of injection sites

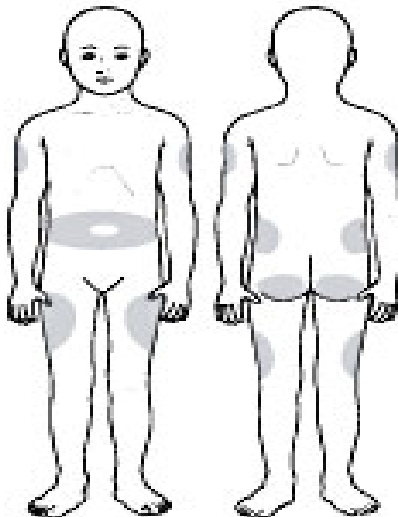
Regular rotation of the site of infusion allows proper absorption of the medication and decreases the risks of skin breakdown and scar tissue formation.

The most common sites used for infusion are the abdomen, thighs and upper arms.

Guidelines

1. Use a different infusion site each day of the month.
2. Mark the date and site on the rotation chart you have been given by pharmacy, as shown in the diagram.
3. Use a new rotation chart each month.

Diagram



How should I store the infusors?

Your infusors are to be kept in the fridge, between 2-8 degrees Celsius.

If you accidentally keep the infusors out of the fridge for a long time or outside recommended temperatures please contact the pharmacy to check if medicine is still safe to use.

What is the expiry date?

This indicates how long your infusor will be suitable for use as long as it has been kept in the fridge.

How do I get further supplies?

When you are first started on Desferal[®] by your doctor, a prescription is sent directly by your doctor to the hospital aseptic pharmacy department who will contact you to arrange a delivery. Pharmacy aseptics will then hold the prescription on file and will contact you every two weeks to arrange a delivery until that prescription runs out. You do not need to do anything as pharmacy aseptics will contact your doctor or nurse to request a new prescription if you are continuing on Desferal[®].

If you have any problems with the infusors please contact the following:

Aseptic Pharmacy
Pharmacy Department
Ground Floor
Thomas Guy House
Guy's Hospital
St. Thomas' Street
SE1 9RT

Tel. 0207 188 5048 or 5043 9am-5.30pm, Monday to Friday.

Out of hours, please contact the main switchboard on 0207 188 7188 and ask for the Paediatric Registrar on call.

Meet the Paediatric team

Consultants

Dr Baba Inusa – lead consultant for children with haemoglobin disorders

t: 020 7188 7774 (secretary Mary Abiri)

e: mary.abiri@gstt.nhs.uk

Dr Jay Alamelu – lead consultant for haemophilia and thrombosis

t: 0207 188 7545 (secretary Janet Roads)

Therapy and psychology team

Therapist **Jo Levitt** is trained to help children cope with the difficulties that can arise from having a chronic illness. She will meet you in clinic or arrange a visit if needed.

t: 020 7188 9125

Sickle cell nurse specialists

Natalee Murray sees children within the hospital, and also offers support and advice to all those caring for your child. She works with the sickle cell nurses, who are based in the community.

t: 020 7188 9432 or 07771 345 847

e: natalee.murray@gstt.nhs.uk

Sharon Ndoro – Senior Research Nurse

t: 020 7188 6637 or 07918338730

e: Sharon.ndoro@gstt.nhs.uk

Nurse Practitioner for adolescents

Luhanga Musumadi works with older children, from 13 years upwards, preparing them for the move to adult care (transition). Preparation for transition is a very important part of the paediatric service.

t: 020 7188 9821 or 07770 678 851

e: luhanga.musumadi@gstt.nhs.uk

Kemi Ajamufua – Specialist nurse (community)

t: 020 3049 5993

e: olukemi.ajamufua@gstt.nhs.uk

Where can I get further information?

Sickle Cell and Thalassaemia Conference

This international conference attracts world experts in haemoglobinopathies and occurs annually here at the Trust. If you are interested in attending, please contact Dr. Baba Inusa using the contact details given on page 3.

w: www.haemoglobin-gstt.org

w: www.score-international.org

w: www.ststn.co.uk.

Sickle Cell Society

Provide help and support for people affected by sickle cell disorders and their carers.

t: 0800 001 5660

w: www.sicklecellsociety.org

The Sickle Cell & Thalassaemia Centre

Provides information about sickle cell disease.

Thalassaemia counsellors can also offer support and information. The centre can also direct you to local services.

t: 020 7414 1363

Appointments at King's

We have teamed up with King's College Hospital in a partnership known as 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 King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Contact us

Out of hours, please contact switchboards 02071887188 ask for the Paediatric Registrar on call.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Notes

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Contact us

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.

t: 020 7188 3003 10am to 5pm, Monday to Friday

e: letstalkmedicines@gstt.nhs.uk

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 **e:** pals@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

Leaflet number: 4122/VER1

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