

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. However, this can lead to a build-up of excess iron in major organs such as the heart or liver. **If this overload of iron is not treated then serious organ damage can happen.**

Your doctor has prescribed treatment with desferrioxamine (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, which is then passed out in the urine.

How is Desferal® given?

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

Each infusor is made up especially for you 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, 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.

How to use your Desferal® infusor

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

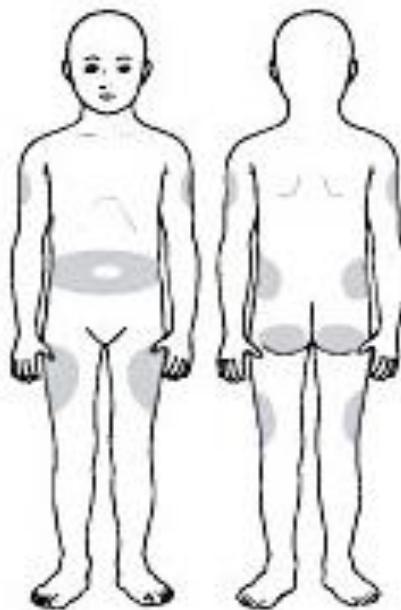
- 1 Please check the label and make sure that the expiry date has not passed – if it has, the treatment should not be used and the unused syringes should be returned to pharmacy or the sickle cell team.
- 2 Wash your hands.
- 3 Open the pack containing the Thalaset™ needle.
- 4 Remove the winged cap from the infusor and attach the needle to the opened end.
- 5 After about one minute, the infusor will prime (fill) 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 the 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. It also decreases the risks of skin breakdown and scar tissue formation. The most common sites used for infusion are the abdomen (tummy), 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 the pharmacy, as shown in the diagram.
- 3 Use a new rotation chart each month.



How should I store the infusors?

Your infusors are to be kept in the fridge, between 2 to 8C. If you accidentally keep the infusors out of the fridge for a long time or outside recommended temperatures, please contact the pharmacy (details at the end of this leaflet) to check if the 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 to the hospital aseptic pharmacy department who will contact you to arrange a delivery.

Pharmacy aseptic staff 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 aseptic staff will contact your doctor or nurse to request a new prescription if you are continuing on Desferal®.

Where can I get further information?

Sickle Cell and Thalassaemia Conference

This annual international conference is held at Guy's and St Thomas', with world experts in haemoglobinopathies. If you are interested in attending, please email Dr Baba Inusa.

w: www.scorecharity.com or **w:** www.ststn.co.uk

e: baba.inusa@gstt.nhs.uk

Sickle Cell Society

Provides 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

Notes

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

If you have any problems with the infusors, please contact the Aseptic Pharmacy, Pharmacy Department, Ground floor, Thomas Guy House, Guy's Hospital St Thomas' Street, London SE1 9RT

phone: 020 7188 5048 or 5043, Monday to Friday, 9am to 5:30pm.

Out of hours, please contact the main switchboard, **t:** 020 7188 7188 and ask for the paediatric registrar on call.

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.

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.

NHS website

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health. **w:** www.nhs.co.uk

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