

Paediatric haematology

Infusion of desferrioxamine mesilate (Desferal®)

Information for patients, relatives and carers

Introduction

The following information will explain about desferrioxamine mesilate and why your child needs to have it. It will also provide guidance on how this medication can be given at home via a balloon pump, syringe driver or continuously via a Port-a-Cath.

What is desferrioxamine?

Desferrioxamine is a medicine that removes excess iron that builds up after a period of time on regular blood transfusions. The body is unable to remove excess iron naturally. Iron overload can damage major organs, particularly the heart and liver, if it is not treated.

The treatment is designed to bind with iron in the blood stream, which is then removed from the body in urine (it is normal for the urine to be dark orange or brown). The effect of the treatment will increase if it is given regularly, so it is important to follow the treatment plan given to you by your child's consultant.

The treatment is called chelation therapy.

How is desferrioxamine given?

Desferrioxamine can be given in several ways. The decision on which one is best for your child will be based on the amount of iron overload which has been identified, based on ferritin levels in the blood, MRI T2*, FerriScan® and liver biopsy results.

Subcutaneously (under the skin): desferrioxamine is given as an infusion under the skin using a Thalaset™ needle. You may need to make the medicine up and withdraw the required amount to be infused. The needle is attached to a syringe driver which will be programmed to deliver the medication over a set period of time, usually overnight. Your child may need the infusion up to seven nights per week, depending on the degree of iron overload.

Elastomeric device (balloon pump): desferrioxamine can be given via a pre-filled syringe (balloon pump), which will be made by an external company and delivered to you on a weekly or two-weekly basis. It is given as an infusion under the skin using the needle and tube set supplied.

Port-a-Cath®: in cases where there is a high degree of iron overload, it may be necessary to give desferrioxamine continuously so that iron is constantly being removed from the body. This will be supplied by an external company and delivered weekly or two-weekly in a pre-filled elastomeric device which will contain enough medicine to infuse for a week. The infusion will be changed on a weekly basis by your child's community nurse.

What are the possible side effects?

- discoloration of urine – your child's urine may become dark orange or brown while on desferrioxamine. This means that excess iron is being removed and the medication is working
- local skin reactions – when infusing desferrioxamine under the skin, pain and swelling can appear at the site where the infusion has been given. It is important to rotate infusion sites to prevent skin breakdown. If the pain or swelling lasts for more than 24 hours, contact your nurse for advice
- mild allergic reaction – itching, watery eyes and sneezing may occur while using desferrioxamine. If these symptoms develop, contact your nurse for advice
- severe allergic reaction – developing a severe allergic reaction is rare, however, if the following symptoms develop stop the infusion immediately and seek medical advice:
 - minor reactions
 - high temperature
 - shivering
 - redness of the face
 - dizziness
 - headache
 - skin rashes and itching
 - **serious reactions — these need immediate medical attention**
 - shortness of breath
 - chest pain
- gastrointestinal infection – if your child develops a temperature and diarrhoea, please contact your nurse for advice.

What other investigations will be needed while my child is receiving treatment with desferrioxamine?

- it is important that your child's eyes and hearing are assessed before starting treatment with desferrioxamine, and at least yearly while treatment continues. This is because high levels of the drug can cause toxicity, which can cause hearing and visual disturbances
- monthly blood tests will be done to monitor the ferritin level, which is used as an indicator for how effectively the medication is removing the excess iron
- your child's liver will also be monitored by blood tests called liver function tests (LFTs). This will be done before starting treatment and every month basis throughout the course of the treatment
- sometimes, the effectiveness of the chelation therapy will need to be investigated. This is done by a 24-hour collection of urine – all urine is collected over a 24-hour period to see how much iron is being removed. If this is necessary, the process will be explained to you more fully
- your child may be referred for a bone density scan (also known as a DEXA scan) to assess the strength of their bones, as the treatment can cause bone disorders, though this is very rare
- regular MRI T2* and FerriScans will be performed (if your child has been assessed and can tolerate the scans). This will assess the effectiveness of iron reduction. Your child's consultant will then be able to change the dose and frequency of the medication as necessary
- once there is a reduction in the ferritin result from the blood test and there is a reduction in the iron level reported from the scans, a liver biopsy may be performed to assess the structure of the liver to make sure that any scarring from the treatment has resolved

Important information about storing Desferrioxamine at home

- all medication should be stored safely and out of children's reach
- follow the storage guidance from the supplying company – if you are travelling overseas to a hot country the medication should be stored in the fridge
- if the medication is stored in the fridge, it should be removed for at least one hour before it is given so that it can reach room temperature
- when treatment with desferrioxamine is stopped, all remaining medication should be returned to the supplying company

How do I arrange delivery of medicine and supplies?

Once funding has been agreed for desferrioxamine to be given via a pre-filled elastomeric device, either subcutaneously or continuously via a Port-a-Cath®, supplies will be arranged via an external supply company.

The company will speak to you directly about delivering the supplies.

If you are planning holidays you should give as much notice as possible to the supply company, so that supplies can be arranged for the entire time that you are away.

If you have any other queries about supplies, you should contact the external company directly.

Local anaesthetic cream

If your child prefers to have a local anaesthetic cream to numb the area before injection, you can use any of the following:

- Ametop
- Denela
- EMLA
- LMX4

Use the cream according to the manufacturer's instructions. It is held in place on the chosen infusion site by an adhesive plastic dressing and it will take up to one hour to be absorbed and effectively numb the area.

If you would like to use local anaesthetic cream, please let your doctor or nurse know so that this can be prescribed for you.

Receiving desferrioxamine via a Port-a-Cath®

If your child is going to receive desferrioxamine via a Port-a-Cath® your nurse at the hospital will refer you to your local community nursing team (if you are not already linked up to a community nursing team). They will arrange to connect and disconnect the desferrioxamine from your child's Port-a-Cath® on a weekly basis. This is usually done at the same time each week to avoid as much disruption to your family routine as possible.

How do I use a subcutaneous infusion?

Your nurse at the hospital will refer you to your local community nursing team (if you are not already linked up to a community nursing team) who will provide support if the medication is to be given subcutaneously.

You will need the following equipment:

- a clean worksurface
- a sterile alcohol wipe
- a pre-filled balloon pump or desferrioxamine powder for infusion (to be made up according to pharmacy instructions)
- a Thalaset™ needle

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- tape
 - sharps box – this is a box used to dispose of needles

How to give the infusion

1. Prepare the work area and clean it with an alcohol wipe.
2. Open the equipment and packages carefully.
3. Remove the local anaesthetic cream from the skin if you are using it.
4. Wash your hands thoroughly.
5. Release the clamp on the infusion set to allow the tube to fill to the end. Allow it to flow until it reaches the needle and then close the clamp. (If you are making the medication up and using a syringe driver, follow the pharmacy instructions. Attach the end of the Thalaset™ needle to the syringe and push the medication through the tube until it reaches the needle, then program the syringe driver as instructed).
6. Remove the sticky backing and protective cover from the needle.
7. Lift the skin between your thumb and index finger.
8. Insert the needle at a 90° angle and press firmly.
9. Press the dressing around the needle so that it remains in place. You may need to apply additional tape.
10. Release the clamp to begin the infusion.
11. Check the infusion site for any signs of leakage.
12. Once the infusion is complete, remove the needle and put the pump and needle into the sharps box. (If you have made the medication up yourself you should dispose of all needles, syringes and medication vials in the sharps box).

Rotating infusion sites when giving desferrioxamine subcutaneously

Subcutaneous infusions should be given in areas of the body where there is a layer of fat under the skin. The most suitable areas are the abdomen and thighs.

To make the infusions less painful and to avoid irritation and scarring, the infusion site should be rotated. If the same site is used every time, fatty deposits can develop under the skin and cause the medication to be absorbed more slowly.

What should I do if the needle becomes dislodged?

If your child is receiving desferrioxamine via an elastomeric pump and the needle becomes dislodged from the Port-a-Cath®, contact your community nurse or your local hospital for advice as soon as possible.

The needle should be completely removed and disposed of safely. The Port-a-Cath® should be flushed as soon as possible to prevent blockages. This will need to be carried out by your community nursing team or your key nurse at your local hospital. Arrangements should be made for supplies to be delivered, so the next dose can be given as soon as possible.

If your child is having desferrioxamine via a Thalaset™ needle and it becomes dislodged, remove the needle and dispose of it safely. Discard any remaining solution. Do not give another dose. Give the next dose as planned in the usual routine.

What if I forget to give a dose of desferrioxamine?

If you remember the missed dose within two hours, give the dose immediately. If it is more than two hours, do not give the dose. Wait until the next dose is due and give as you normally would. **Do not give a 'double dose' under any circumstances.**

Who do I contact for more help or information?

If you have any queries about dosage and frequency, you need further guidance on how to give desferrioxamine, or you wish to report any concerns about the treatment, please contact:

Your child's community nurse:

Name:

Telephone number:

Bone marrow transplant (BMT) nurses:

020 3312 5062
077 6699 1070
020 3312 3345

Haematology clinical nurse specialists (CNS):

Diamond Blackfan Anaemia & Bone Marrow Failure Syndromes CNS
077 9651 156 | 077 8903 4929
Haemoglobinopathy CNS – 077 9565 1153

Grand union ward:

020 3312 6465

Paediatric haematology day care unit:

020 3312 5081
020 3312 5095
020 3312 5096

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How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any suggestions or comments about your visit, please either speak to a member of staff or contact the patient advice and liaison service (PALS) on 020 3313 0088 (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or 020 3312 7777 (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net. The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to express your concerns in writing to:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille, or in alternative languages. Please email the communications team: imperial.patient.information@nhs.net

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