Introduction

This leaflet explains what desferrioxamine is and why your child needs to have it. It also provides guidance on how this medication can be given at home. Please feel free to ask our team any questions you have about the information below.

What is Desferrioxamine?

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

The treatment, called chelation therapy, 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/brown). The effect of the treatment will increase if it is given regularly, so it is important to follow the plan your child’s consultant gives you.

How is Desferrioxamine given?

Desferrioxamine can be given in a number of ways. The decision about which one is best for your child will be based on:

- the amount of iron overload identified
- 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/two-weekly basis. It is given as an infusion under the skin using the needle and tube set supplied.
Port-a-Cath®
If there is a high degree of iron overload, Desferrioxamine may be needed continuously so that iron is constantly being removed from the body. It will be supplied by an external company and delivered weekly/two-weekly in a pre-filled elastomeric device which will contain enough medicine to infuse for a week. Your child’s community nurse will change the infusion on a weekly basis.

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:
- shortness of breath
- shivering
- redness of the face
- dizziness
- headache
- skin rashes and itching

Serious reactions (requiring immediate medical attention):
- high temperature
- chest pain

Gastrointestinal infection
If your child develops a temperature and diarrhoea, please contact your nurse for advice.
What other investigations will my child need while receiving 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 carried out to monitor the ferritin level, which is used as an indicator for how well 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 on a monthly basis throughout the treatment.
- Sometimes, the effectiveness of the chelation therapy will need to be investigated. This is done by collecting urine over a 24-hour period to see how much iron is being removed. If this is necessary the process will be explained to you in full.
- We may refer your child 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, but 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 amend the dose and frequency of the medication as necessary.
- Once there is a reduction in the ferritin result from the blood test and a reduction in the iron level reported from the scans, we may perform a liver biopsy 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 at least one hour before it is given so 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 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 you are away.
Local anaesthetic cream

If you have any other questions about supplies you should contact the external company directly. If your child prefers to have a local anaesthetic cream to numb the area before injection, either LMX4, Ametop or EMLA/Denela can be used. It should be used according to the manufacturer’s instructions. It is held in place on the chosen infusion site by an adhesive plastic dressing and 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 the team). The nursing team 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 local community nursing team will provide support if the medication is to be given subcutaneously.

You will need the following equipment:

- a clean work surface
- 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
- tape
- a sharps box – a box used to dispose of needles

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 and allow the tube to fill. 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, please follow 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-degree 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 (moves)?

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 of the usual dosage time, give the dose immediately. If it is more than two hours after, 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: ...........................................................................................................

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BMT nurses:
Telephone: 020 3312 5062 or 020 3312 3345

Haematology clinical nurse specialists:
Telephone: 07795 651 156 or 07795 651 153

Grand union ward:
Telephone: 020 3312 6465

Paediatric haematology day unit:
Telephone: 020 3312 5081

How do I make a comment about my treatment?

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 pals@imperial.nhs.uk. 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:
Chief executive - complaints
Imperial College Healthcare NHS Trust
Trust Headquarters
The Bays, South Wharf Road
London W2 1NY

Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on 020 3312 5592.

We have a free and premium Wi-Fi service at each of our five hospitals. For further information please visit our website: www.imperial.nhs.uk.