

Clinical haematology

Desferrioxamine (Desferal®)

Information for patients, relatives and carers

Introduction

This leaflet provides information to patients who need to take desferrioxamine (Desferal®) infusions. Frequent blood transfusions are given to patients with different blood disorders such as sickle cell disease and thalassemia. This can lead to an excess of iron building up in major organs, causing iron overload. If left untreated, this can cause complications to the heart, liver, and endocrine glands (adrenal and pancreas) and may lead to irreversible damage to these organs.

Desferal® is an iron-chelating medicine used to 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 and how often?

Desferal® is given under the skin (subcutaneously) into the fatty tissues, using a special pump called a balloon infuser. The infuser is used to administer the medicine slowly and continuously over 10 to 12 hours. Depending on the level of iron overload, your doctor will determine the dose and frequency of treatment. It is often used between two and six times a week.

Possible risks and side effects and how you can manage them

Most medicines may cause unwanted side effects, along with their benefits. Your doctor will explain the benefits and risks of taking Desferal®.

Desferal® is widely used. In some patients, it does not produce any side effects. However, side effects for some people can include:

- irritation or blisters on the skin where the needle is placed – you can avoid this by rotating the injection site. It is also important to ensure that the needle is properly positioned under the skin. Your doctor may prescribe hydrocortisone to your infusion, which will reduce the skin irritation
- ringing in the ears (tinnitus) and a decrease in night vision – it may be necessary to reduce or stop the medication if this occurs. It is important that you attend hearing and eye screening appointments every year
- abdominal pain, fever, diarrhoea, and vomiting – these may indicate an infection, which will need urgent medical attention.

If any of these symptoms occur, please contact the renal and haematology triage unit (RHTU) on **020 3311 7755** urgently for advice and assessment.

Alternatives to Desferal®

Your doctor will decide which iron chelator will be appropriate for you to take. There are other iron chelators, deferasirox (Exjade®) and deferiprone (Ferriprox®), that may be suitable alternatives. However, this depends on your overall health and any underlying issues you may have. Desferal® can be used as a single agent or in combination with other iron chelators in specific circumstances.

Regular monitoring is important

The outpatient clinic is the best place for us to monitor your health. This includes how any prescribed medicines are working. The red cell team can work with you to ensure early detection and management of potential complications. Together you can:

- see how well the treatment is working
- review and change the dose of the medication as required for maximum benefit
- manage your health and wellbeing

Ordering, collecting, and storing your Desferal® Infusion Pumps

Ordering:

- the pumps are ordered every **Wednesday** by the haematology pharmacy team
- the order is placed a week in advance before you are due for a new supply
- a 4-week supply will be ordered for you each time
- remember to place your order in time. Due to the high cost of these infusers and their short expiry date, the pharmacy does not have lots in stock.

Collection:

- the pumps are ready for collection a week after ordering, from Thursday onwards. The pharmacy is open Monday to Friday, from 09.00 to 19.00, and Saturday to Sunday, from 09.30 to 13.30.
- the haematology pharmacy team will contact you by email or phone to tell you that the pumps are ready for collection. Please keep the pharmacy updated with your contact details.
- remember to place your order. Due to the high cost of these infusers and their short expiry date, the pharmacy does not have lots in stock

Important: pick up your pumps straightaway

Infuser pumps are very expensive and have a short expiry date – they ‘go off’ after 4 to 5 weeks. They must be thrown away if not used in time, which wastes pumps and money.

So, please pick up your pumps as soon as you get a notification from the haematology pharmacy team.

Storage:

- pumps must be stored in the **fridge**, between **2°C** and **8°C** in the packaging. If the pumps are accidentally left out of the fridge for a while, please contact our medicines information helpline* to check if they are safe to use. *Medicine helpline at Hammersmith Hospital: 020 3313 1000 (open between 09.15 and 17.00, Monday to Friday).
- do not freeze
- keep a check on the expiry dates
- keep out of reach of children

Do not use your pump if:

- it has expired
- it is leaking
- the winged cap is missing

Disposal:

- seal the empty pump with the winged cap to prevent leakage and return it to the hospital or any local pharmacy for safe disposal
- do not dispose of the pumps in your bin at home
- do not throw away any medicines via waste water or household waste. Return medicines you no longer use to your pharmacist who will dispose of them correctly. These measures will help protect the environment

Precautions

If you experience symptoms that affect your vision or hearing, or you feel dizzy it is important you do not operate any machinery or drive.

Self-administration

You or your carer will need to set up and administer the infusion pump at home. The nurse will give you tubing, dressings, and a sharps disposal box. They will show you how to:

- set up the pump
- attach it to your body and remove it from your body
- dispose of the equipment safely

Setting up your subcutaneous infusion pump

You will need (we will give you these):

- a clean surface or tray
- sterile wipes
- your Desferal® infuser
- a Thalasset® needle
- tape
- a sharps disposal bin

Before you start

1. Collect everything together on a clean and dry surface.
2. Wash and dry your hands.
3. Remove the Desferal® infuser outer packaging.
4. Remove the winged cap from infuser and wait for a bubble of fluid to appear at the end of the tubing.
5. Attach the Thalasset® needle to the opened end of the infuser.
6. Open the infuser clamp and wait for the infuser to fill the tubing. When it has, close the clamp.

Setting up the infusion

1. Select the site where you are going to insert the needle.
2. Prepare the site by cleaning with sterile wipes.
3. Remove protective covering from the Thalasset® needle. Do not touch the needle.
4. Pinch skin around the injection site.
5. Insert Thalasset® needle at right angles, pressing down firmly on the sticky dressing.
6. Release the infuser clamp to begin infusion.
7. Place the infuser securely under your clothing. As the Desferal® infuses, the balloon will gradually deflate and become smaller.
8. Leave in place for 8 to 12 hours (depending on the prescription)
9. Remove sticky pad and needle once infusion has finished
10. Dispose of the Thalasset® needle in a sharps disposal box. Return the empty infuser to the pharmacy.

Rotation of infusion sites

Rotating the sites of the needle will make the subcutaneous infusion less painful and reduce skin irritation. Generally, suitable areas are those with some fat below the skin;

- the abdomen
- thighs
- upper arms

How to wear your infuser

You can choose how you want to do this. The pharmacy will give you a pump holder that you can attach to your clothing with 1 or 2 safety pins, or you can place it in a pocket. Have a practice with different clothes; you will soon find what suits you.

If you miss an infusion

- Set up the pump as soon as you remember.
- Desferal® will be more effective if you do not miss any doses.
- If you are not able to use the pump on your set day, you can set it up to run on a non-scheduled night (another night/day) during the same week.

Getting the most from your treatment

Always take your medication as instructed by your doctor. If you are unsure, you can always speak to the pharmacist, your doctor, or your clinical nurse specialist (CNS).

When you first start, you will need to have weekly blood tests to monitor your full blood count and kidney function. If you become unwell with an infection the treatment will stop until you have recovered.

You must use effective contraception while you are taking Desferal®. Discuss with your doctor which method is best for you.

It is advisable that you or your partner do not become pregnant while taking Desferal® as it can harm the baby. If you plan to become pregnant, discuss it with your doctor so that appropriate arrangements can be made.

If you do become pregnant while taking Desferal®, stop taking it and contact your CNS or your doctor. An early clinic appointment to see the doctor will be arranged. Do not use Desferal® if you are breastfeeding as the drug may be harmful to the baby.

Try to attend all your appointments for clinic and any investigations needed such as blood tests and scans. If you are unable to attend the appointment, you can call the number on your appointment letter to reschedule to a time that's convenient for you.

For further information

Call the CNS for haemoglobinopathies and iron overload on **020 3313 8553**

Or

Call the hospital switchboard on **020 3313 1000** and ask for the RHTU or red cell registrar/consultant on call.

For enquiries relating to your infusion pumps please contact the pharmacy haematology team on **020 3313 2624**.

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 complain by contacting our complaints department:

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

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

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.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk