

The side effects of Desferal

Please check with your doctor as soon as possible if you feel any of the following side effects.

Most common side effects. Pain, swelling, reddening, itching of the skin at the site of the infusion. Sometimes this pain, swelling and reddening occur together with symptoms such as fever, watery eyes, sneezing, aching joints, aching muscles, headaches and nausea.

Less common side effects. Dizziness, visual disturbances, hearing disturbances. For this reason, patients receiving Desferal have annual Audiology (hearing tests) and Ophthalmology (eye check ups) assessments.

Very rare side effects. Shortness of breath, skin rash and weakness of the muscles and a loss of sensation (for example numbness) If you develop abdominal pain, vomiting and diarrhoea, it may be due to an infection called Yersinia. If this happens please stop your Desferal infusion and contact your doctor immediately.

We have shared care across the Whittington and University College London hospitals and your haematology consultants are: Professor John Porter, Dr Andrew Robins, Dr Bernard Davis, Dr Farrukh Shah, Dr Sara Trompeter and Dr Ali Rismani

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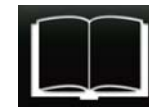
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Desferal at home for red cell patients

A patient's guide



.... caring for you

Introduction

Regular blood transfusions are used to treat people with lots of different blood disorders including sickle cell disease (SCD) and thalassaemia. However these blood transfusions can mean that too much iron accumulates in the heart, liver and other major organs. If this is not treated, serious organ damage will eventually occur.

Desferrioxamine (Desferal) is a medication which removes the excess iron from the body. Desferal binds together with the iron and then they both leave the body in urine and faeces.

Your doctor will discuss your Desferal treatment with you. Your dose will be adjusted to your particular needs and the best method of giving you the Desferal will be decided.

There are three ways of taking Desferal:

- by a slow infusion into a vein, or
- through a permanent (in-dwelling) catheter, or
- by slow infusion under the skin (subcutaneously) using a portable infusion pump or Baxter Infusor

The first method can only be used when you visit the hospital or haematology day care unit for blood transfusion. The second and third methods can be used at home. Depending on the level of iron in your blood, you will need one - seven infusions a week, which you can arrange at times to suit you. Some people find it most convenient to have night-time infusions, which take place while they sleep.

What is a Baxter Infusor?

The Baxter Infusor (also called the Baxter pump) is a lightweight, disposable device containing Desferal. We use it to give a slow, continuous infusion into your subcutaneous tissue via a thalasset needle.

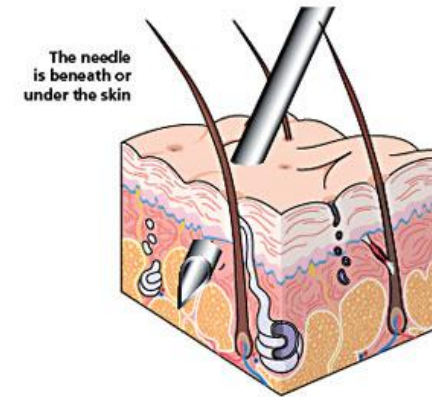


Image from Great Ormond Street Hospital for sick children booklet on subcutaneous infusions

The Butterfly needle should go into a fold of skin up to the wings. The tip of the needle should move freely when the needle is waggled. If it doesn't the tip of the needle may be too close to the skin surface. If the needle is too close to the skin surface, withdraw it, clean a new site on your skin with an alcohol wipe and try again.

Steady/secure the needle and infusion line with tape or a dressing

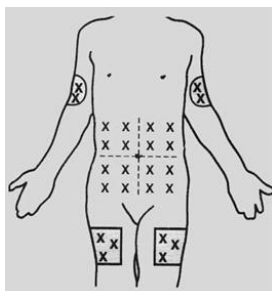
When you fix the infusion line with tape or dressing, the best way is to make a small loop to allow for movement. When making the loop, ensure there are no kinks as this will stop the drug from flowing.

Check the insertion site periodically. From time to time check the insertion site for redness and fluid leakage, and to make sure the needle hasn't dislodged.

Discard the needle and tubing. When the infusion is complete carefully remove the dressing and withdraw the needle. Place the used needle and tubing in the special needle container (sharps bin). When the bin is full return the bin to the Thalassaemia Unit or you can arrange with your local pharmacy for disposal.

Select the skin site for needle insertion

The places under your skin which are best for needle insertion are the abdomen, thighs and upper arms. Study the diagram below to show you exactly where these places are. Choose a different place on your body each day. By rotating the site of your infusion in this way, the medication will be absorbed properly. Rotation also lowers the risk of skin irritation and scar tissue developing.



Sites where infusions can be set up

Prepare the site for needle insertion. Using an alcohol wipe, clean the skin in a circular motion starting at the middle and moving outward

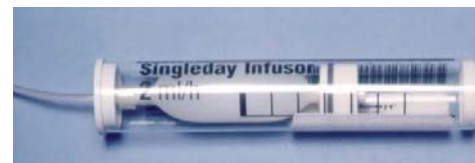
Remove the protective covering from the needle. When you do this, make sure you do not touch the needle.

Pinch the skin around the insertion site.

Insert the needle. A thalaset needle inserted at a 90° degree angle. Butterfly needles are inserted into the skin at a 45 degree angle.



This allows the Desferal treatment to be given over 12 or 24 hours using an infusor for home treatment. The Desferal is contained in a balloon reservoir, inside a casing. No batteries are needed.



Baxter balloon infuser has

- winged cap
- connector attaches the infusor to your thalaset line
- flow Restrictor controls how fast your Desferal is given
- delivery Tubing carries the Desferal
- balloon holds the Desferal
- infusion Scale shows how much of your Desferal has been given
- end cap seals and protects the infusor system

In general parents or a carer the patient puts in and changes the infusor, we will teach you how to do this when you start the treatment.

Equipment

- thalaset needles
- alcohol swabs (for skin)
- sharp container
- cleaning solution for hands
- cleaning solution for hard surfaces (may not require)
- clear plastic dressing e.g. Tegadrem (may not require)
- any extra equipment can be discussed with the nursing staff in haematology day care.

As the Desferal is infused the balloon deflates and slowly pushes the drug up through the thalaset at a fixed rate. As this happens, the balloon gradually becomes smaller and moves down the scale on the side of the outer casing.

What are the benefits of the infusor?

You can have your treatment at home. This allows you to continue with your daily activities.

How do you store your infusors?

Your spare infusors should be stored in the refrigerator and sealed in its outer wrapping. Please keep your infusors in a clean place, away from direct sunlight, radiators, fires and out of the reach of children.

Do not store the infusors in the freezer.

How do you dispose of your empty infusor?

Seal the empty infusor with the winged cap connected to prevent leakage and return to the hospital for safe incineration. Do not put the infusor in your refuse bin at home. When HealthCare@Home start delivering to your home they will collect your empty infusors

How do you monitor your infusor?

You should look at the balloon or scale on the side of the infusor every morning to make sure the infusor is working correctly.

How do you change your infusor?

Please do not attempt to change your pump without previous training from nursing staff. If you or your carer will be changing your infusor, you need to follow steps one - ten carefully.

Steps:

- collect together the equipment and place on a clean dry surface
- check name, hospital number and expiry date on the new infusor
- prepare clean surface
- wash and dry your hands.
- open infusor onto clean surface

- wash and dry hands
- wipe the end of your thalaset line with the alcohol wipe
- remove the winged cap from the infusor and wait for a bubble of fluid to appear at the end of the pump tubing
- attach the infusor by twisting in a clockwise direction onto the thalaset line
- unclamp your thalaset line (if it has a clamp)
- place the infusor in its carrying sock and pin it to your clothing

Checklist

Do not use your infusor if:

- the name on the label is incorrect
- the balloon has burst
- there is any sign of leakage from the infusor or tubing
- the winged cap is missing

The bubble does not appear

- ignore small air bubbles within the infusor tubing. They are not harmful.
- if for any reason the infusor has to be disconnected before it is completely empty, a winged cap should always be placed on the end of its tubing to prevent leakage.

How do I wear my infusor?

You can choose the best way to wear your infusor. The infusor is supplied with a sock which you can attach to the inside of a shirt, cardigan or jacket, or you may prefer to use the belt/sling. Some people adapt their clothing by sewing in pockets for the infusor to sit in.

What do I do if I want to go away for a holiday?

You should discuss this with your doctor. Your choice of holiday destination may be restricted, depending on the availability of medical care.