

Desferal chelation therapy

Information and advice for patients

Sickle Cell and Thalassaemia

The information in this leaflet is general and is intended to be a guide only. Please discuss the specific details of your treatment with your GP/doctor.

What is the medication?

If you have a condition that is treated by regular blood transfusions it can lead to a build-up of iron. This will need to be treated with iron-removing medication.

THIS LEAFLET FOCUSES ON DESFERAL® (Desferrioxamine)

What is the benefit of the medication?

Regular blood transfusions are used to treat Beta Thalassaemia Major and in some situations Sickle Cell Disease. Over a period of time regular blood transfusions can cause a build-up of iron. This may damage some of the organs of the body such as the heart and liver. Chelation is the term used to describe the process of removing the extra iron from the body. Therefore, taking this medication helps to prevent a build-up of iron.

What are the risks and side effects?

Desferal® is widely used and some people have no side-effects from the drug. However, some possible side-effects include:

- Irritation or blisters on the skin where the needle is placed. Rotating the site of injections can avoid these problems. It is also important to ensure that the needle is properly positioned under the skin. You will have information from your nurse about what to look for if your treatment involves a long-term intravenous line.
- Ringing of the ears (tinnitus) and a decrease in night vision. It is important that patients on Desferal® have regular hearing and sight tests every year.
- Iron is a growth factor for certain bacteria; the most significant is a bacterium called Yersinia which can cause abdominal pain, fever, diarrhoea and vomiting. If any of these symptoms occur, stop your treatment and seek medical help urgently.

What are the risks of not taking the medication?

As blood contains iron which can build up in different parts of the body, if you do not take this medication, it can cause damage to these parts:

- **The heart:** This can be mild, moderate or severe and is picked up using a special type of scan called an MRI scan. Large amounts of iron in the heart can lead to heart failure and irregular heart rhythms. Iron in the heart is dangerous but it can be removed by using strong iron-removing medications.

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- **The liver:** Iron overload in the liver can result in scarring, which is also known as cirrhosis.
- **Pancreas:** A large amount of iron in the pancreas can lead to diabetes. Diabetes is irreversible and is treated with insulin.
- **Hormone glands:**
 - Underactive thyroid which can cause tiredness.
 - **Sex hormone glands:** In women periods may be delayed, irregular or stop. Later on this can affect fertility. In men, less testosterone is made, (testosterone is needed for muscle bulk, secondary sexual characteristics such as facial hair etc.).

Are there any alternatives to this medication?

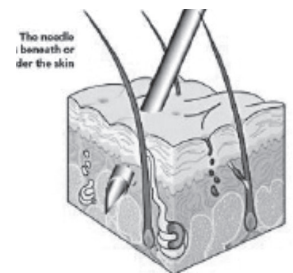
There are three types of iron-removing medication available: they are called desferrioxamine (also called Desferal®), deferiprone and deferisarox (also called Exjade®). Your doctor will decide which type of therapy is best for you depending on where the excess iron has built up and what organs it is affecting.

How to take this medication

This medicine is given either under the skin (subcutaneously) or into a vein (intravenously). When the medicine is given under the skin, special small and easy needles are used called Thalaset. If a needle into the skin is not suitable for you, then a long-term intravenous line can be used. These types of lines include Hickman lines and Groshong® lines. In addition, peripherally inserted central catheters (PICCs) and Portacaths need close monitoring. You and your nurse will develop a plan of care for looking after your long-term intravenous line.

Subcutaneous Desferal administration

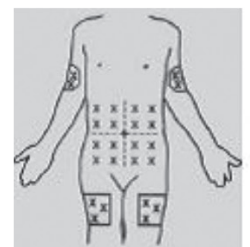
If you are using a long-term intravenous line (Hickman lines, Groshong® lines, PICCs and Portacaths) you will need extra information from your nurse, so please ask for this.



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Rotation of infusion sites

Rotating sites will make the subcutaneous infusion less painful and reduce irritation. There are several suitable areas as shown on the diagram. As a general rule suitable areas are those with some fat below the skin; the abdomen, thighs and upper arms. There are 2 sizes of Thalaset needles so make sure you have the right size for you.



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Giving a subcutaneous infusion

You will need:

- A clean surface or tray
- A sanicloth
- Your Desferal prefilled balloon infuser
- A Thalaset
- 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. Open infuser onto surface.
4. Remove cap from infuser and wait for bubble of fluid to appear at the end of tubing.
5. Attach the Thalaset to the balloon infuser, unclamp and wait for the Desferal to fill the tubing. When it has, close the clamp again.

Setting up the injection

1. Select the site.
2. Prepare site by cleaning with a sanicloth.
3. Remove protective covering from needle and then do not touch it.
4. Pinch skin around site.
5. Insert Thalaset needle 90 degrees and the sticky dressing pressed firmly down.
6. Release the clamp to begin infusion.

As the Desferal infuses the balloon will gradually deflate and become smaller.

The completed infusion and Thalaset should be disposed of in a sharps disposal box.

How should I wear my infuser?

You can choose how you wish to do this; you can place it in a pocket or use a belt or sling. Some people adapt clothing by sewing in secret pockets. Have a practice with different clothes, you will soon find what suits you.

Do not use your infuser if:

- The name on the label is incorrect
- The balloon has burst or is leaking
- The cap is missing
- It has expired

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How often should I be using Desferrioxamine?

Your doctor will determine the dose and frequency of your treatment. For treatment to be effective, you must make sure that the pump is properly connected and turned on as discussed with your doctor. To remove the extra iron and reduce the problems in the body, you need to use your pump continuously for at least 10-12 hours. Some patients prefer to use their pumps overnight. An occasional missed dose will not cause a problem but frequent missed doses will cause long-term problems.

Storage

Keep in a fridge in the packaging. Do not freeze. Keep out of reach of children. Keep a check on the expiry dates.

Ordering and collecting your desferal

You and your doctor will decide how many infusers you need over a 2 week period. You will then need to let the SCAT nurses know when your infusers need ordering. They will inform pharmacy and you will then be able to collect from the pharmacy the next day. You will need to come and collect infusers every 2 weeks. Please keep in mind the high cost of these infusers (each one costs the trust around £90) and the fact that they have short expiry dates (35 days from the day of manufacture). For these reasons pharmacy cannot carry large volumes of stock and uncollected infusers may often be wasted at significant cost to the trust.

Can I come less often to collect my infusers?

If you have to travel a long distance this may be possible. However due to the short expiry dates pharmacy can only supply enough infusers to last up to that expiry date (maximum 28 – 30 days).

Precautions

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

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Contact details

If you have any questions or concerns please contact the Sickle Cell and Thalassaemia Centre.

Sickle Cell & Thalassaemia Centre

Sandwell & West Birmingham NHS Trust

City Hospital, Dudley Road, Birmingham, B18 7QH

Tel: 0121 507 6040

Opening hours

Monday, 9am – 4pm

Tuesday, 9am – 6pm

Wednesday, Thursday and Friday, 9am – 5pm

Saturday blood transfusion service only

For further information

Birmingham Sickle Cell & Thalassaemia Service

Nineveh House, Nineveh Road, Handsworth, Birmingham, B21 0SY

Telephone: 0121 466 3667

bchc.sicklecellresults@nhs.net

Sickle Cell Society

54 Station Road, London, NW10 4UA

Tel.: 020 8961 7795

Email: info@sicklecellsociety.org

www.sicklecellsociety.org

For more information about our hospitals and services please see our website

www.swbh.nhs.uk, follow us on Twitter @SWBHnhs and like us on Facebook

www.facebook.com/SWBHnhs.

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Sources used for the information in this leaflet

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