North East & Yorkshire Haemoglobinopathy Coordinating Centre

Chelation Therapy for Iron Overload

Information and advice for adults with sickle cell disorder, thalassaemia or rare inherited anaemia

Information for patients, families and carers

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What is iron overload?

Patients who have regular blood transfusions to treat their thalassaemia, sickle cell disease or rare inherited anaemia will get more iron than their body needs. This excess iron can cause damage to different parts of the body.

Treatment for excess iron is known as chelation therapy and is usually started around a year after regular transfusions begin. Some people also develop iron overload without having received regular transfusion, because their body absorbs more iron than usual from their diet.

What are the symptoms of iron overload?

Symptoms of iron overload depend upon where the excess iron is deposited in your body. Often no symptoms are felt until the iron overload is severe. The excess iron can damage:

- **The Heart:** Iron in the heart can lead to heart failure and irregular heart rhythms.
- **The Liver**: Iron in the liver can cause scarring of the liver known as cirrhosis. Symptoms of cirrhosis include loss of appetite, tiredness, very itchy skin, jaundice (yellowing of the skin and eyes) as well as others.
- **The Pancreas**: Iron in the pancreas can lead to diabetes. Some of the symptoms of diabetes include increased urination, feeling thirstier, feeling very tired and unexplained weight loss.
- **Hormone glands:** The thyroid may slow down which can cause tiredness. The sex hormone glands can also be affected, causing problems with fertility and developing secondary sexual characteristics (these are features you develop during puberty such as for females enlarged breasts and for males, facial hair).

It is important iron overload is treated as early as possible to reduce and prevent damage from the excess iron building up.

Measuring iron overload

There are different types of tests that can be performed to measure the level of iron in your blood and within certain organs. These include:

- blood test that you may have measures an iron storage protein called ferritin. If the ferritin amount is constantly raised it indicates that a build-up of iron has occurred. The ferritin level can be reduced with medication.
- a special type of MRI scan of your liver, and maybe also of your heart, to measure how much iron is in your body. These scans do not expose you to radiation and do not hurt.
- blood tests can also be performed to detect how other organs are functioning and to see if a build-up of iron has occurred in them. These tests may be for thyroid function, liver function, sex hormone level, certain vitamin and mineral levels as well as screening tests for diabetes (glucose tolerance test) and adrenal glands.

We will give you information about any tests you will have.

How is iron overload treated?

Chelation therapy is the term used to describe the process of removing extra iron from the body. The iron-removing medicine (the iron chelator) works by binding to the extra iron so that it can be removed from the body.

What are the benefits of chelation?

The benefit of using chelation therapy to get rid of excess iron will help to prevent damage to organs (including the heart, liver, pancreas and different glands).

What are the risks and side-effects of chelation?

There are different types of iron chelation medications and their risks and side-effects vary.

Please read the whole leaflet for risks of each medication.

What are the risks of not having the treatment?

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.

You are likely to develop the complications described above. These can get worse and can become irreversible and life-threatening. There are no alternatives to iron chelation.

What are the different medications available for chelation therapy?

There are 3 types of iron-removing medication which can be used in chelation therapy:

- **Desferrioxamine** (also called Desferal®)
- **Deferiprone**
- **Deferasirox** (also called Exjade®)

Your doctor will decide which type of therapy is best for you depending on where the excess iron has built up in your body and what organs it is affecting.

It is important that you use only the dose prescribed and check the expiry date.

You might need to take more than one type of iron chelation treatment at the same time. if this is the case your specialist team will discuss the reasons for this with you.

Iron chelation treatment and pregnancy

It is important to talk to your specialist team if you are planning a pregnancy.

If you are taking deferiprone or deferasirox, you will have to stop these 3 months before trying for a pregnancy.

If you are taking desferrioxamine, you will have to stop this as soon as you are pregnant. This is because of the effect these medications might have on the baby.

Desferrioxamine (also called Desferal®)

How to take it?

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. 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 PICC lines and Portacaths, and they need close monitoring.

You and your nurse will develop a plan of care for looking after your long-term intravenous line if you need one.

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. To remove the extra iron and reduce the problems in the body, you need to use their pump continuously for at least 10-12 hours.

Some patients with severe iron overload will need to use pumps which run over 24 hours to help clear the iron more quickly. Some people prefer a pump which runs over 7 days so that it doesn't have to be changed as often. An occasional missed dose will not cause a big problem but frequent missed doses will cause long-term problems.

Process of starting desferal

If you are required to start on desferal , this will be discussed with you first in your clinic appointment as a joint decision between you and the clinician. The dose will be discussed and frequency required. A lot of patients find it easier to start infusions overnight, whilst they are asleep however it is your choice.

There are two pharmacy homecare companies that deliver the medication and supplies to your requested address , these are called Baxter and Lloyds.

The process

- joint care decision between the clinician and yourself about starting desferal and confirmation of dose, frequency and administration method (subcutaneous or intravenous depending if you already have a long term intravenous line)
- A registration form, prescription and ancilliary (equipment) form will be completed by medical or nursing staff
- you will need to have a clear space at home to keep your equipment and also space for a fridge to keep your medication in which is supplied by the homecare companies.
- It will be then arranged for a nurse from the home care team to show you how to self administer (they will contact you to arrange this) and have a checklist they go through with you
- If you feel uncomfortable or unsure at all after this training please contact the Haemoglobinopathy clinical nurse specialist team who can support you and offer guidance

Possible side-effects

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

- 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. If you have skin irritation it can help to either use hydrocortisone cream on the area or have hydrocortisone added to your pumps – you can discuss these options with your specialist team.
- can cause complications with the hearing or vision. These can include reduced hearing, ringing of the ears (tinnitus), or reduced vision. It is important that patients on desferrioxamine have regular hearing and eye monitoring every year.
- bacteria grow on the excess iron that is removed; the most significant is a bacteria 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.

Storing desferrioxamine

- keep in fridge in the packaging
- do not freeze
- keep out of reach of children
- check on the expiry dates

Deferiprone

How to take it?

Deferiprone is taken orally (by mouth). It is especially effective in removing iron from the heart.

How often should I be using deferiprone?

It is taken three times daily. It is important to use only the dose prescribed and to check the expiry date of the medication. An occasional missed dose will not cause a big problem but frequent missed doses will cause long-term problems.

Possible side-effects

This medicine can reduce the body's ability to fight infection by lowering one of the types of white blood cells that fight infection. Your doctor will ask you to have a blood test performed every week when you start this medication to check that the cells that fight infection are not affected.

If you have a sore throat, temperature above 38°C, shakes or any symptoms suggestive of infection please contact your specialist team for urgent review, as prompt treatment with antibiotics may be needed.

Other possible side-effects include:

- brown colour of your urine, which may look alarming but will not cause you harm.
- sickness (often reduced by taking the tablets along with meals)
- increased appetite
- pain

Storing deferiprone

You should keep this out of reach of children. Keep medication stored at room temperature, below 30ºC.

Deferasirox

How to take it?

Deferasirox, also known as Exjade®, is also given by mouth (orally).

How often should I be using deferasirox?

It is usually given once a day as a tablet, but sometimes people find that by taking half of their dose earlier in the day and the other half later in the day, this reduces any stomach upset that they might experiences as a side effect. Splitting your dose like this might also make the medication even more effective. It is important to use only the dose prescribed and to check the expiry date of the medication. An occasional missed dose will not cause a big problem but frequent missed doses will cause long-term problems.

Possible side-effects

- sickness, stomach pain and indigestion, and diarrhoea; these usually improve over time. Taking your dose with food and taking half of the daily dose earlier in the day and the other half later might help.
- liver problems: Your doctor will ask you to have blood and urine tests performed regularly to check that the kidneys and your liver are working properly.
- rashes
- may be a small risk that your hearing or vision could be affected. Yearly checks of both are recommended.

If you develop any of these problems, please contact your doctor.

Storing deferasirox

You should keep the medication in its original packaging and keep it away from moisture. If the packaging has been damaged you should not use the medication.

It can be difficult to remember to take your iron chelators every single day so talk to your nurses and doctors about ways you can achieve this. We have charts that we can print off to help you, let us know if you would like one.

The information in this leaflet is intended to be a guide only. Please discuss the specific details of your treatment with your doctor and remember to ask if there is anything that you are not sure of.

Please use the QR code or link below to take you to the Patient Information Leaflet (PIL) section of the North East and Yorkshire Haemoglobinopathy Co-ordinating Centre Website

- www.ney-hcc.co.uk/patient-information/

For alternative formats please see
www.sth.nhs.uk/patients-visitor-information

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