

Patient information

Chelation therapy for iron overload

Haematology Department

What is iron overload?

Some patients with thalassaemia, sickle cell disease or other long standing severe anaemias may have higher than normal iron levels. Patients who have regular blood transfusions to treat their condition will get more iron than their body needs however some patients may develop iron overload even without transfusion due to increased iron absorption in the gut. 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 a year after regular transfusions or when iron levels are persistently high.

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 for cirrhosis include loss of appetite, tiredness, very itchy skin, jaundice (yellowing of the skin) 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 enlarged breasts for females and facial hair for males).

It is important that iron overload is treated as early as possible to reduce or 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:

Ferritin – this is a measure of iron storage in the body. If the ferritin amount is constantly raised it indicates that a build-up of iron has occurred. The ferritin level can be reduced to normal with medication.

Other blood tests can 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.

Occasionally, it is necessary to perform a liver biopsy. This is where a piece of liver tissue is used to measure the iron content.

In certain cases, special scans of your heart may be required to assess whether a build-up of iron has occurred and to see how your heart is functioning. The best way of looking for iron in the heart is by MRI scans which measures the amount of iron in the heart and liver.

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.

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:

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.

The liver:

Iron overload in the liver can result in scarring of the liver 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 or irregular or stop. Later, 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 treatment?

There are no alternatives to iron chelation.

What are the different medications available for chelation therapy?

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

- Deferisarox (also called Exjade).
- Desferrioxamine (also called Desferal).
- Deferiprone.

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.

Desferasirox

Desferasirox, also known as Exjade®, is particularly good at removing iron from the liver.

How often should I be using desferasirox?

It is given once a day as a film coated tablet. 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 problem, but frequent missed doses will cause long-term problems. If you take more than you should, you should contact your doctor immediately.

Possible side-effects

- Nausea, sickness and diarrhoea; these usually improve over time.
- Stomach pain and indigestion
- Kidney problems: Your doctor will ask you to have a blood test performed regularly to check that the kidneys are working properly.
- Skin rashes
- Blurred vision
- Hearing problems

If you develop these problems, please contact your doctor. Please attend your appointments for your blood tests as these are to check whether the medicines are causing any problems with your liver or kidney.

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.

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 their pump continuously for at least 10-12 hours. Some patients prefer to be attached to their pump until it finishes; this takes 48 hours. An occasional missed dose will not cause a problem, but frequent missed doses will cause long-term problems.

Possible side-effects

Desferrioxamine 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 desferrioxamine have regular hearing and eye monitoring every year.
- Certain 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.

Deferiprone

Deferiprone 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 problem, but frequent missed doses will cause long-term problems. If you take more than you should, you should contact your doctor immediately.

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 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 either your doctor, (within working hours) or the Emergency Department (ED) if out of hours as prompt treatment with antibiotics may be needed.

Other possible side-effects include:

- Reddish brown colour of your urine, which may look alarming but will not cause long-term problem.
- Nausea and sickness (often reduced by taking the tablets along with meals)
- Increased appetite.
- Stomach pain.
- Joint pain.

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Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

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Review Date: June 2028

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