NHS SCOTLAND

SPAH
SCOTTISH PAEDIATRIC AND ADULT HAEMOGLOBINOPATHIES NETWORK

Patient Information

Managing Iron Overload

This document has been prepared by Public Services Delivery Scotland (PSD Scotland) on behalf of the Scottish Paediatric and Adult Haemoglobinopathies Network (SPAH). Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. The SPAH Network is a collaboration of stakeholders involved in care of patients with haemoglobinopathies, who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

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What is iron overload?

Regular blood transfusions can cause iron overload because each red blood cell contains iron. The body has no natural way of removing all the extra iron, so the iron is stored in cells. Iron overload is a build-up of iron in the body, which can cause harm over time.

How is iron overload measured?

A simple blood test to measure the level of ferritin (a protein that stores iron inside your cells) can give an idea of the iron stored in the body. This test can be carried out when your child has a blood sample taken before a planned transfusion.

When your child is old enough, they may have an MRI scan of their liver and heart called a FerriScan. This is painless and is usually only carried out once a year.

Why is iron overload harmful?

The liver is the main place where extra iron is stored, but once the liver is full the body starts to store iron in other organs, such as the heart, and hormone glands.

Too much iron in the body can be harmful to the tissues where it collects. It may cause the liver or heart not to work as it should. It may also cause problems with your child's growth.

Iron overload will start to happen when your child is young, but the problems may not be seen until your child is much older.

What are iron chelators?

Iron chelators are medicines that bind to the extra iron in the blood and help to remove it from the body. This stops many of the problems linked to iron overload. Your doctor or nurse will talk to you about when your child will start an iron chelator, but this usually happens once your child's ferritin level approaches 1,000 or after about a year on transfusions.

Your doctor or nurse will also talk to you about which iron chelator drug is best for your child.

There are three different types of iron chelators.

- Desferrioxamine (also known as Desferal) is given as an injection over several hours (usually eight to 12), several times a week.
- Deferiprone (also known as Ferriprox, L1) is a tablet or liquid that is taken by mouth three times a day.
- Deferasirox (also known as Exjade) is a tablet that is taken by mouth once a day.

It is important for children on iron chelators to be monitored regularly. This is to avoid giving them too much or not enough medicine and to spot any side effects.

Side effects can happen with any drug given to your child. However, it's important to know that all these medicines, with time, usually work well (even though they can take a bit of getting used to).

Desferrioxamine (Desferal)

Desferal is given under the skin (subcutaneously) into the fatty tissue. It is given using a small infusion needle (sometimes called a Thalaset or neria guard) and a special pump.

The infusion usually lasts around 10 hours, and your child will need several infusions a week, depending on the level of iron in their blood. Your doctor or nurse will talk to you about how often your child will need to have this infusion.

You will be taught how to prepare the drug and how to use the pump correctly so that, when you are able, you can provide this treatment at home. Some families find it easier to do the infusions overnight, while their child is asleep.

Side effects

The most common side effect of Desferal is irritation of the skin where it was given. You can avoid this by regularly swapping between the arms, legs and abdomen, and moisturising the areas regularly.

Desferal may cause your child to be at risk of an infection called yersinia. If your child has tummy pain, diarrhoea or a fever, you should stop giving Desferal and contact your haematology nurse or doctor for advice. Your child may need to take antibiotics for a short time. They can start Desferal again when the infection has cleared.

Other less common side effects are:

- disturbed vision and hearing; and
- reduced growth

However, these are usually only seen in patients who have very large doses of Desferal.

Monitoring

There are some important monitoring tests that need to be done for patients taking Desferal.

- Monthly liver function test (LFT): Liver function is monitored by taking a blood sample and is usually only done when a sample is taken for a crossmatch.
- Hearing and eye and growth tests: These tests are carried out at separate clinic appointments (in the relevant department – audiology, ophthalmology or endocrinology) every one to two years by doctors who specialise in these areas.

Deferiprone (Ferriprox)

Deferiprone is available as tablets or as an oral solution (liquid). It is taken by mouth three times a day and can be taken with or without food.

If your child misses a dose, give it as soon as you remember. If it is almost time for their next dose, skip the missed dose and then continue with their regular schedule. Do not try to catch up or give two doses at the same time to make up for a missed dose

Deferiprone can be used alone or is sometimes used with Desferrioxamine. Your doctor will discuss this with you if they feel this may be necessary.

Side effects

Deferiprone can cause a low neutrophil level in the blood. This is called neutropenia. Neutrophils are white blood cells which help the body to fight infections.

Neutropenia does not happen to every child who takes Deferiprone. However, if it does happen, you will be advised to stop giving Deferiprone. Your child's blood count should return to normal soon after.

Deferiprone can cause other side effects which are usually mild and do not last long. These include:

- nausea or vomiting
- joint pain; and
- red urine. This is a very common side effect which most patients will get and is caused by the action of the drug

Monitoring

There are some important monitoring tests that need to be done for patients taking Deferiprone.

- It is very important that your child has weekly thumb-prick tests to check their neutrophil count while taking Deferiprone.
- If your child has a fever (a temperature of 38ºC or above) while taking Deferiprone, you should contact your nurse or doctor. They may want to do a thumb-prick test to check the neutrophil level, or they may advise you to stop giving the Deferiprone for a short time.
- Kidney and liver function: This is monitored by taking a blood sample. This test is usually only done when a sample is taken for a crossmatch.
- Eye and ear tests: These tests are carried out at separate clinic appointments (in the relevant department – ophthalmology or audiology) every one to two years by doctors who specialise in these areas.

Deferasirox (Exjade)

Exjade is only prescribed for children who are two years and above. It is taken once a day (seven days a week) and we suggest that your child takes it at the same time each day.

Exjade is only available in tablet form and can be taken on an empty stomach or after a light meal. If your child cannot swallow tablets, Exjade can be crushed and mixed with a small amount of soft food (for example, yoghurt).

The dose of Exjade your child is prescribed may need to be adjusted from time to time by your doctor or nurse. The dose will depend on the level of iron overload and the results of any monitoring tests.

Side effects

Common side effects include:

- skin rashes
- constipation, diarrhoea and tummy pain
- headaches; and

- nausea and vomiting

If your child is suffering from any of these side effects, or anything else that you think may be related to their medication, please let your haematology doctor or nurse know.

Exjade can also alter the function of the kidneys or the liver. To try to lessen any effect on the kidneys, it is important to encourage your child to drink enough fluids. The amount your child should drink will depend on their age and weight. Your nurse or doctor will discuss this with you.

Monitoring for side effects of Exjade

There are some important monitoring tests that need to be done for patients taking Exjade.

- Kidney and liver function: This is monitored by taking a blood sample. This test needs to be done every week when the treatment is first started or if the dose is increased. A urine sample will also be taken at these visits. After this, the blood and urine tests are usually only done when a sample is taken for a crossmatch.

- Eye and ear tests: These tests are carried out at separate clinic appointments (in the relevant department – ophthalmology or audiology) every one to two years, by doctors who specialise in these areas.

Giving your child these medicines as instructed is important in reducing the amount of iron overload they have and, in turn, improves their health and well-being. Also, it can improve their life expectancy as an adult and protect their fertility.

It is normal for this to seem like quite a lot to manage, but your doctor and nurses will support you. We are always happy to talk about any concerns about these treatments.

If you have any questions, it may be helpful to write them down so you can remember them when your child is seen at clinic.

For more information about SPAH and other helpful resources:

SPAH Website: www.spah.scot.nhs.uk
Email: nss.spah@nhs.scot

If you need this leaflet in another format (such as large print), please:

- Email: psd.contact-us@nhs.scot
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