NHS
Sherwood Forest Hospitals
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INFORMATION FOR PATIENTS

Living with haemochromatosis

A guide for newly diagnosed patients

What is haemochromatosis?

Haemochromatosis is an inherited (genetic) condition where iron levels in the body slowly build up over many years. Excess iron is toxic and can affect many parts of the body.

Genetic haemochromatosis (GH) affects everyone differently and whilst some people experience one or more symptoms, others don't experience any symptoms at all. Sometimes when there are no symptoms the condition is found only during a blood test or when a relative is found to have it and family members are sent for screening.

Symptoms usually appear between the ages of 30 and 60 but can occur earlier. They tend to develop earlier in men, and some women do not experience problems until after the menopause. Symptoms can include the following:
- Arthritis; this may affect any joint but is particularly common in the knuckle and first joint of the first two fingers.
- Feeling tired all the time (fatigue).
- Weight loss.
- Decrease in body hair.
- Abdominal pain; this can sometimes be in the stomach region or the upper right-hand side but is sometimes more generalised.
- Brain fog, impaired memory, mood swings, irritability or depression.
- Sexual disorders such as loss of sex drive, or impotence in men.
- Absent or scanty menstrual periods and early menopause in women.
- Bronzing of the skin giving the appearance of a permanent tan, or sometimes a grey skin tone.

Over time the iron can damage organs in the body leading to complications such as:
- Cardiomyopathy which is a disease of the heart muscle.
- Diabetes; high blood sugar levels due to damage to the pancreas.
- Pituitary or adrenal problems (e.g. Addison's disease).
- Liver disorders such as liver cirrhosis, or liver cancer.

How is haemochromatosis diagnosed

Several blood tests are needed to diagnose haemochromatosis. You'll have a:
- Full blood count test.
- Liver test.
- Transferrin saturation level test (Tsat) to check how much iron in the blood is bound to the protein transferrin. This shows if you have a high iron level in the blood.
- Serum ferritin level test to check the amount of iron stored in your body.

If your blood tests suggest haemochromatosis, you'll have a test to see if your DNA carries the gene associated with the condition.

How is haemochromatosis managed?

There's currently no cure for haemochromatosis, but there are treatments that can reduce the amount of iron in your body. This can help relieve some of the symptoms and reduce the risk of damage to organs such as the heart, liver and pancreas. Venesection is the best way of controlling the iron levels but for those who cannot manage it, chelation is an alternative although it is less effective

Venesection (phlebotomy)

The most commonly used treatment for haemochromatosis is a procedure to remove some of your blood, known as a venesection or phlebotomy.

The procedure is very similar to giving blood. You lie back in a chair, and a needle is used to drain a small amount of blood, usually about 500ml, from a vein in your arm. The removed blood includes red blood cells that contain iron, and your body will use up more iron to replace them, helping to reduce the amount of iron in your body.

There are two main stages to treatment:

- **Induction**. Blood is removed on a frequent basis (usually weekly) until your iron levels are normal; this can sometimes take up to a year or more.
- **Maintenance**. Blood is removed less often (usually two to four times a year) to keep your iron levels under control; this is usually needed for the rest of your life.

Chelation therapy

This may be used in a small number of cases where regular phlebotomies are not possible because it's difficult to remove blood regularly, for example if you have very thin or fragile veins.

It involves taking medicine that removes iron from your blood and releases it into your urine or poo. Commonly used medicines are deferasirox and desferrioxamine.

Deferasirox is unlicensed for the treatment of haemochromatosis, which means it has not undergone extensive clinical trials for this use, but your doctor may recommend it if they feel the possible benefits outweigh any risks.

Diet and alcohol

You do not need to make any big changes to your diet, such as avoiding all foods containing iron, if you have haemochromatosis. It is unlikely to be of much extra help if you're having one of the treatments above and could mean you do not get all the nutrition you need. You'll usually be advised to:

- Have a generally healthy, balanced diet.
- Avoid breakfast cereals that have been ‘fortified’ with extra iron.
- Avoid taking iron and vitamin C supplements – these may be harmful for people with high iron levels.
- Be careful not to eat raw oysters and clams – these may contain a type of bacteria that can cause serious infections in people with high iron levels.

- Avoid drinking excessive amounts of alcohol as this can increase the level of iron in your body and put extra strain on your liver.

Preparing for venesection

In the days before your venesection, it is important to stay well hydrated by drinking lots of fluids (not alcohol), and eating well. This is important as when blood is removed your blood pressure can fall.

On the day of your venesection, ensure you have had plenty of fluids and have eaten well to reduce the risk of feeling dizzy or faint during the procedure. Although it may sound strange it is helpful to keep warm, as when you are cold your blood vessels constrict (shrink) and are harder to find. Drinking coffee or tea or going for a walk can sometimes help if your blood vessels are hard to find.

If you take regular medications, you should continue to take them unless otherwise instructed. If you are taking anticoagulant medications to thin the blood such as clopidogrel, warfarin, apixaban or rivaroxaban you should tell the practitioner as they may need to apply pressure to the blood vessels for a little longer after the procedure.

If you have a history of fainting please let the practitioner know so that they can take precautions.

If you are very anxious about the procedure let us know so that we can offer support or allow somebody to accompany you for support.

Undergoing venesection

You will be sat in a chair or on a bed and made to feel comfortable. A practitioner will check your pulse and blood pressure before finding a suitable vein. They will apply a tourniquet to help the veins stand out before cleaning the area with a sterilising wipe. They will then insert a needle into the vein which is then connected via a tube to the bag in the blood will be collected.

Once the correct amount of blood has been collected the needle will be removed and pressure will be applied to the site before applying a dressing.

After venesection:

- There is a risk of fainting so if this is your first time you should avoid driving and operating machinery until you know how it affects you.
- Don’t try and stand up too quickly after venesection. Take your time, enjoy a snack and a drink afterwards.
- If you feel faint after leaving the department sit down on the floor, bend your head towards your knees and ask for help.
- The dressing can be removed after three hours if the bleeding has stopped. If there is bleeding from the site after you have left the department your should elevate your arm, apply firm pressure and if necessary, return to the department.
- Drink at least one litre of extra fluid and avoid alcohol for at least 24 hours.
- Avoid heavy lifting or strenuous exercise for 24 hours.

- Observe for bruising and notify staff if there is tingling or swelling in the arm or hand.
- Sometimes there is slight discomfort or bruising at the site which can last for a few days. You can take painkillers such as paracetamol if needed.

Risks associated with venesection

Venesection is considered a safe procedure however complications can rarely occur. These can include

- Feeling lightheaded, dizzy or faint.
- Bruising of bleeding. If you experience severe pain, swelling that is increasing in size, or persistent bleeding please inform a healthcare practitioner.
- Nerve irritation. If you experience any weakness, numbness or pins and needles during, immediately after or within one week of your venesection please notify a healthcare practitioner.
- Rarely an artery can be punctured during venesection. In that event your practitioner will remove the needle and apply pressure until bleeding stops.
- Scarring of the veins can occur and we try to alternate veins to help reduce the chances of this happening.
- Anaemia. It is possible for you to become anaemic after frequent venesections. To prevent this we will monitor your blood count along with your iron levels and may pause your venesections briefly.

Further sources of information

NHS Choices: www.nhs.uk/conditions
Our website: www.sfh-tr.nhs.uk
Hemochromatosis UK: www.haemochromatosis.org.uk

Patient Experience Team (PET)
PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service:
King’s Mill Hospital: 01623 672222
Newark Hospital: 01636 685692
Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

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