



Genetic Haemochromatosis

Information for patients and carers

What is haemochromatosis?

Haemochromatosis is an inherited condition where the body absorbs too much iron from the diet. If left untreated this build-up of iron (iron overload) can eventually cause damage to tissue and organs which may lead to liver problems (including scarring of the liver), diabetes, arthritis and heart failure. If the condition is diagnosed and treated early on it is unlikely to result in serious problems.

Common symptoms of haemochromatosis

fatigue
weight loss
weakness
joint pain
loss of sex drive

How is haemochromatosis diagnosed?

Haemochromatosis is diagnosed with blood tests to check:

- the amount of iron in your blood (transferrin saturation level)
- the amount of iron stored in your body (serum ferritin)
- if you carry a faulty gene associated with the condition

How is haemochromatosis treated?

Haemochromatosis is usually treated with regular venesectiions (a procedure to remove some of your blood). This is the simplest and quickest way of reducing the iron levels in your blood and may need to be done every fortnight at first. The procedure will be fully explained to you by your doctor or specialist nurse. It usually takes about 30 minutes. Immediately following the venesection, you may feel a little dizzy; this is not unusual and can be minimised by resting before you leave the unit and by drinking water. It is advisable to rest for a few hours following the procedure. Most people carry on as normal after they have left the unit. Some people, however, do feel a little tired for a couple of days. If bruising has occurred this may be uncomfortable, and we would ask that you contact us for advice.

Diet and haemochromatosis

If you are having regular venesectiions, you do not need to make any big changes to your diet, but it is advisable to avoid:

- breakfast cereals containing iron
- Iron or vitamin C supplements
- Drinking too much alcohol

Dietary advice Link <https://www.haemochromatosis.org.uk/rcn-section-dietary-advice>



Where will the venesections be done?

Initially you will need to come to the Whittington Red Cell Day Unit which is based on level 4. Your specialist doctor will put you in touch with the nursing team to make a convenient appointment for you. Follow on appointments will be scheduled with you directly and the frequency of venesections will depend on your iron levels. Once your iron levels come down to a safe level then maintenance venesections will be needed two to four times a year, for life.

Can I donate blood?

Once your iron levels have normalised (your hospital team will let you know) and providing you meet the donor eligibility criteria you can be accepted as a blood donor. You should contact the National Contact Centre helpline directly **(0300 123 23 23)**. Once accepted you can sign up for an online account at **blood.co.uk** to manage future appointments. You will be able to donate at various agreed intervals (minimum 6 weeks to 12 plus weeks) as indicated by your hospital specialist. If you are not accepted for donation for any reason, then your venesections will continue in the hospital day unit.

Longer term follow-up

Once you are receiving maintenance venesections (either in hospital or at donation centre) you will need to have your serum ferritin level checked every six months and an annual clinic appointment with your hospital doctor.

Unit Nurses:

Emma Prescott - 020 7288 5225 - emma.prescott@nhs.net

Niamh Malone-Cooke - 020 7288 5225 - niamh.malone-cooke@nhs.net

Shirley Ellis – 020 7288 5225

Where can I get more information?

Haemochromatosis UK (Link: <https://www.haemochromatosis.org.uk/>) is a patient run charity which provides information and support for people with genetic haemochromatosis.

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.whithealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

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