You may need to attend once a week for venesection, until your iron levels return to a normal level. Blood samples will be taken regularly to monitor your progress.

After your iron levels have returned to normal, you will need to have regular blood tests, usually every 3 months. The need for further venesection will be based on the results of your iron levels in these regular blood tests. Treatment is life long.

WHO SHOULD BE TESTED?

Relatives who are at risk should be tested. This is most important for first degree relatives, such as brothers, sisters and any children over the age of 18. Early diagnosis and treatment will prevent complications of the disease.

DO I NEED TO CHANGE MY DIET?

The common view is that a low iron diet is of little benefit and is not advised as more iron can be removed in a single venesection than in your diet. You will be given a Diet Information Leaflet at your first appointment. The following is advised:

- Modest alcohol consumption (less than 10 units per week)
- No iron medication or multivitamins containing iron
- No breads or cereals with fortified iron

CAN I DONATE THE BLOOD REMOVED IN VENESSECTION?

If you wish to donate your blood please speak to your nurse. There is a Haemochromatosis Clinic in Stillorgan run by the Irish Blood Transfusion Service where you can be referred to.

CONTACT DETAILS

A nurse is available to speak to you if you have any queries.
Tel: 01-4144182 Tuesday & Thursday
If the telephone is unattended please leave your name and contact details along with a brief message and your call will be returned as soon as possible.

LOCATION

At present we carry out the venesections in Cubicle 4, Burkitt Ward on Level 3.
Telephone 01-4144271
Monday & Friday 11.00-17.00
WHAT IS HAEMOCHROMATOSIS?

Haemochromatosis is a medical condition caused by too much iron in your body. This iron builds up in the organs in the body, mainly in the liver, pancreas, heart and joints. If left untreated this extra iron can cause damage to these organs. There are several forms of haemochromatosis, the most common being hereditary (or genetic) haemochromatosis. Haemochromatosis is more common in Irish people and people from northern Europe.

WHAT ARE THE SIGNS AND SYMPTOMS OF HAEMOCHROMATOSIS?

There are many signs and symptoms associated with haemochromatosis and these vary from person to person. As iron builds up slowly in the body, symptoms may not appear until age 30 or 40. The most common symptoms noticed by people with haemochromatosis are:

• Chronic fatigue, tiredness or lack of energy
• Joint pain - especially in the knuckles and your first two finger joints
• Abdominal pain - vague and non-specific
• Sexual dysfunction - loss of sex drive
• Skin pigmentation - a yellowing or 'bronzing' of the skin

Other signs & symptoms that your doctor can test for include:

• Irregular heart beat
• Diabetes
• Hormonal changes
• Liver damage
• Joint damage

HOW IS IT DIAGNOSED?

A simple blood test, taken when you are fasting, is the best way to test if you have too much iron in your blood. Ferritin measures the iron stored in your liver and Transferrin Saturation measures the iron circulating in your blood. If these tests are above the normal level, a genetic test (a blood test) can be carried out to confirm hereditary haemochromatosis.

Your doctor may wish to send you for other tests to check for any damage caused by the raised iron levels in your body.

These may include:

• Further blood tests
• Liver biopsy
• CT/MRI scan
• Ultrasound
• ECG

WHAT DOES THE TREATMENT INVOLVE?

Treatment of haemochromatosis is relatively simple and very effective. It involves the regular removal of blood, known as Venesection or Phlebotomy therapy, and is much the same method as is used for blood donation.

Treatment started early in the disease is best as it can prevent or stop organ damage. If there is already organ damage then treatment should stop any further damage. In a lot of cases treatment can improve symptoms.

You will be contacted by a nurse to arrange an appointment for venesection. You will be advised to eat, and drink plenty of fluids before your appointment. A nurse carries out the procedure in an outpatient setting.

To collect the blood a needle is inserted into a vein in your arm. You should only feel a pin-prick as this is done and the rest of the procedure should be painless. It is possible that you may feel a little dizzy or nauseous during or after venesection. You may be encouraged to rest for a short period following the procedure and refreshments will be offered. Over the next 24 hours it will help to rest, drink plenty of fluids and eat regularly.