

### Advice for a Family Member

If someone in your family (e.g. parent, offspring, sibling) is receiving medical care for haemochromatosis (pronounced hee-mo-kro-ma-TOE-sis) you may have inherited the same genes that can cause this condition.

During the early stages of haemochromatosis, many people do not feel unwell and cannot tell that they have the condition. Sometimes, but not always, they have common symptoms such as fatigue and aching joints.

Without treatment, however, iron can build up in the liver, heart, joints, pancreas, sex organs (testes and ovaries) and skin, and can cause permanent damage. Damaging levels of iron can build up before you have any symptoms.

**transferrin saturation** and **serum ferritin**  
are the tests that tell you about iron levels

The good news is that complications from haemochromatosis can be prevented if it is found and treated early.

To find out if you have this condition, have your iron levels checked by your family doctor as soon as you can.

At the same time, a simple blood test can also determine if you have the same genetic condition as your family member. This is called the HFE gene test.

**the HFE gene test** tells you if you  
have the genetic condition  
(it doesn't tell you about iron levels)

Item 73317:  
Detection of the C282Y genetic mutation of the HFE gene and, if performed, detection of other mutations for haemochromatosis where:  
(a) the patient has an elevated transferrin saturation or elevated serum ferritin on testing of repeated specimens; or  
(b) the patient has a first degree relative with haemochromatosis; or  
(c) the patient has a first degree relative with homozygosity for the C282Y genetic mutation, or with compound heterozygosity for recognised genetic mutations for haemochromatosis

It is unusual for a person under 18 years of age to have high iron, so testing is usually done over the age of 18.

If test results show that you have too much iron as well as the genetic condition, you will need to begin venesection treatment. This is a safe, simple, and very effective treatment which involves having about 500mL of blood taken from a vein in the arm, just like donating blood. Most people can give blood at the Irish Blood Transfusion Service (IBTS) and their blood is useful. To see if you are eligible to have your blood taken and used by the IBTS check [www.giveblood.ie](http://www.giveblood.ie)

If the results show that you have the genetic condition but normal iron level then you will need to have your iron levels checked every 1-2 years to see if they start to rise.

With proper treatment, people with haemochromatosis can lead long, healthy lives. **Please do not ignore this advice.** The special blood tests you need are very simple.

Remember, many people who have haemochromatosis feel fine. Discovering you have this condition EARLY is important. Be sure to ask your doctor for these blood tests and talk with your doctor about the results. Also, for more information, you can call the Irish Haemochromatosis Association information line on +353 1 8735911 or visit their website at <http://www.haemochromatosis-ir.com/>.