Hereditary Haemochromatosis (HH)

Symptoms and Treatment

This leaflet is written for people with hereditary haemochromatosis and for people with genetic test results that suggest they could develop hereditary haemochromatosis.

What is hereditary haemochromatosis?

Hereditary haemochromatosis (HH) is a treatable inherited condition where the body absorbs too much iron from the diet. When too much iron builds up in the body this is known as **iron overload**. The excess iron is stored in the liver and other organs of the body such as the pancreas, heart, endocrine (hormone producing) glands and joints.

Why is the amount of iron in the body important?

A small amount of iron is stored in the liver and is essential for health, as it is needed when new red blood cells are formed. However, when too much iron is stored in the liver, the liver may become enlarged and damaged. Excess iron may also be stored in other organs and joints, causing damage.

What are the symptoms of HH?

- Constant tiredness, weakness, lethargy
- Abdominal pain
- Joint pain (arthritis); this can affect any joint but commonly affects the knuckle and first joint of the first two fingers
- Late onset diabetes
- Cirrhosis of the liver (scarring of liver tissue that damages liver function)
- Bronzing of the skin, like a permanent tan
- Loss of libido
- Irregular heartbeat.

People with HH can have no symptoms for many years.

What age do people develop HH?

The onset of HH is normally between 30 and 60 years, as the build-up of iron takes many years. However, women tend to develop HH later in life than men. The reason for this is that before the menopause, having periods (menstruation) regularly removes blood, and therefore iron, from the body. Therefore, before the menopause, women do not accumulate so much iron in their bodies as men do.

What is the treatment for HH?

The excess iron can be removed simply and effectively by regularly removing blood. This is known as therapeutic venesection or phlebotomy and is the same process as donating blood. A pint of blood is removed, usually every week, until iron levels return to normal. This process can take up to two years. When levels are normal, venesection is only needed a few times a year. The treatment works because each pint of blood removed contains iron in red blood cells, and the body uses stored iron to make new red blood cells.

Is it possible to cure or prevent HH?

If the diagnosis is made early enough so treatment begins before the individual develops symptoms of HH then it is possible to prevent any serious complications. However, it is not possible to undo tissue damage (such as cirrhosis of the liver) if that damage has already occurred.

Should someone with HH have a low iron diet?

It is advisable for people with HH to avoid taking in too much iron. They can do this by:

- not taking multivitamins containing iron or iron tablets
- avoiding foods which are rich in iron such as red meat and red wine.

Where can I find more information?

- Haemochromatosis UK www.haemochromatosis.org.uk
- GP or hospital specialist.

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