

# IRON OVERLOAD

**H**aemochromatosis (*hee mo kro mah tosis*) means your body is absorbing too much iron. It can cause fatigue and joint pain and, if left untreated, can lead to cirrhosis of the liver, stroke and diabetes.

Most people will only absorb a small fraction of the iron they consume, but someone with this condition absorbs up to four times more. That builds up over time, leading to illness.

Men are affected quicker, as women lose blood through menstruation each month, but they can still be affected as they get older. Haemochromatosis (HH) is a hereditary disease, common in Celtic countries, and was once called bronze diabetes because in its later stages the person's skin can appear bronze.

The good news is that once diagnosed, with a simple ferritin level blood test, it can be treated in a straightforward way by having blood taken off (venesection or therapeutic phlebotomy) regularly. No medication is involved.

Are you rushing for iron supplements because you're always feeling tired? This could be totally wrong for you if you have haemochromatosis, writes Margaret Hawkins

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## SO WHAT IS HAEMOCHROMATOSIS?

Haemochromatosis (HH) is a genetic disorder where an excessive amount of iron is absorbed from a person's diet. This excess iron is then deposited in the liver, pancreas, heart and in the joints. The iron builds up over the years, so the person may be 30 to 40 years old before symptoms appear.

These symptoms include:

- Chronic fatigue.
- Abdominal pain.
- Joint pain.
- Impotence.
- Diabetes.
- Liver disorders.
- Cardiomyopathy (causes irregular heartbeat).
- Skin pigmentation (used to be

called "bronze" diabetes).

- Diabetes type II develops in 30% of patients with HH, as a result of pancreas damage.

Tests that may be carried out:

1. A serum iron profile test – a blood test performed after an overnight fast.
2. Transferrin saturation test. Levels above 50% suggest HH.
3. Genetic test – simple blood test that can identify the mutation in the gene. These tests have only been available since 1996.



If you have pain get checked for HH before it does serious damage

## TREATMENT

Blood is removed. This is called vene-

section or phlebotomy therapy. Every pint of blood removed contains 250mg of iron. Treatment may involve weekly phlebotomy for one to two years. Serum ferritin levels are monitored.

## LATE DIAGNOSIS CAN BE FATAL

Margaret Mullett is chair of the Irish Haemochromatosis Association. The trigger for her joining the association was the death of her husband in the year 2000 from HH.

Undiagnosed for no one knows how long, the overload of iron had caused him serious heart and liver problems as well as late onset diabetes. He was diagnosed only six weeks before his death.

"That's why I feel so strongly that awareness of haemochromatosis has to be increased," she says.

"One in 83 Irish people carries the gene, so it's out there and has to be tested for more often. The good thing is that if it is diagnosed early you will go on to have a normal life as long as you look after yourself and have blood taken off on a regular basis," she says.

One in five Irish people carries at least one gene, so it's very common that two carriers meet, she says. That's why whole families can have it.

Margaret's husband had an irregular heartbeat and used to complain of feeling tired but thought that it was

## WORDS OF LIFE

He that trusteth in his own heart is a fool, but whoso putteth his trust in the Lord shall be safe.

Proverbs ch 28 v 26 & ch 29 v 25.

## » Diagnosed with HH

### A KERRY FARMER'S STORY:

Eddie Horgan is a farmer from Gortnaskehy, Ballyunion, Co Kerry. Experiencing ankle pain eventually led to a diagnosis of haemochromatosis (HH) for him.

"I was in Cork one day and I remember I couldn't walk," he says. "My ankles were absolutely killing me. I had an X-ray and saw a rheumatologist who said that I shouldn't have that level of pain given that the X-ray was showing that my joints weren't too bad.

"He asked me then if I'd ever got my ferritin levels checked. He had obviously

come across HH before. I got the blood test done and found that my ferritin levels were nearly at 4,000-3,977 instead of around 50."

Eddie believes that donating blood regularly when he was younger kept his HH under control for many years.

"I got high blood pressure then and couldn't give blood, so my iron levels built up over the years."

He attended Kerry General as a public patient to have venesection done. "I gave 65 pints of blood over a 15-month



It's very common now, because people are getting themselves checked for it and are aware of it

period to bring the ferritin levels down." Eddie had never heard of HH when he was diagnosed.

"I knew no one that had it," he says. "It's very common now, because people are getting themselves checked for it and are aware of it. When I was diagnosed, all my five siblings were tested as well. Two of my sisters' levels were up around 2,500."

Currently, he has blood taken off, usually once a year. "I get my blood tested routinely once a year, and if I'm

## >> Lucky find

### LIMERICK FARMER'S STORY

Farmer and retired quarry owner, Bobby O'Connell from Clarina in County Limerick was diagnosed with haemochromatosis (HH) 15 years ago, in 2003, when he was 47. He had been feeling very tired and experiencing pain in his hands for several years prior to diagnosis.

"I wasn't even able to hold a glass properly," he says. "I had cramps in my hands and in the backs of my legs and pains in my shoulders as well. Doctors thought I had brucellosis for a long time."

When Bobby was finally tested for HH in 2003 his ferritin level was nearly 3,000. It should be around 50. "All my siblings were tested and it turned out that two of my brothers and two of my sisters had it as well. Both our parents must have been carriers."

Bobby had blood taken every week for the first six months and then regularly afterwards. "I went to a hospital for two years in Limerick and it was costing €720 each time on my VHI. It had cost nearly €16,000 over the two years but I came across the Irish Haemochromatosis Association stand at the Ploughing Championships at that stage, and they told me about a clinic where I could get the blood taken for more or less the normal GP charge, so I've been going there ever since."

Bobby feels well when his ferritin levels stay under 80, he says, but through



experience, he knows when he needs to have blood taken off.

"My wrists get sore every time, and my fingers start cramping. I know that if I give blood within a week I'll feel all right a week after that.

"One brother died young, so was never tested, but he could have had it as well. Generally, it affects 50% of a family. Before diagnosis one sister was told to give up drink, as her liver wasn't right, but she didn't drink! It was the HH that was causing the damage."

Bobby had several heart attacks and a stroke in 2012 and 2013 but he doesn't know if being undiagnosed with HH for so long contributed to those events.

"Years before I was diagnosed I often had chest pains and I was having angiograms and so on, and they couldn't make out what it was, but now I'm wondering was it HH was causing the heart problems. I had stents put in and they blocked. For the last two years, I've been good, though, but it was touch and go for a while."

Bobby believes he is lucky that he wasn't too badly affected by HH. "Some people died and didn't even know they had it." Bobby now has venesection every three months at a local medical centre. He advises anyone newly diagnosed with HH to contact the Irish Haemochromatosis Association for support and information.

normal enough to fall asleep on the sofa in the evenings, given that he was a busy doctor.

"I hope that talking about this will help others to get themselves checked out," Margaret says. "GPs are much more switched on to it now, I think, but there is still more to be done."

### HH CLINICS

On 28 May 2018 the Irish Blood Transfusion Service (IBTS) introduced a new programme where members of the public who have HH can attend any blood donation clinic in D'Olier Street, Dublin and St Finbar's, Cork.

The plan is to roll this out to mobile teams across the country by

going to my doctor between times for something else my GP would check the ferritin levels as well."

Eddie has had a lot of joint trouble and believes that it was HH that was partly responsible for this. He has had a hip and knee replacement already. He also wonders if HH had affected other deceased family members and they just didn't know they had it.

"My grandfather was on crutches, they tell me. My father unfortunately died at 56. HH could have been a cause. We just don't know. My mother was crippled with

the end of the year. The service was piloted in Stillorgan.

In Ireland HH is relatively common, treatment is relatively straightforward and the prognosis is excellent.

It is important to enjoy life, eat a balanced diet and avoid exclusionary iron-free diets, keep to a moderate alcohol intake and avoid iron and Vitamin C supplements, according to Dr Barry Kelleher of the Mater Hospital addressing a HH conference this spring. **CL**

The Irish Haemochromatosis Association will have a stand at this year's Ploughing Championships. See [www.haemochromatosis-ir.com](http://www.haemochromatosis-ir.com) for more information.

arthritis. I'm not saying that HH is 100% the cause of my arthritis but I think it did contribute."

Eddie's advice is to "not be a bit shy about making an issue out of it". "Ask for the blood test. If you have HH, you'll know then. I was prescribed anti-inflammatories for years, but they weren't doing me any good. I say that if you have pain get checked for HH before it does serious damage.

"Too much iron damages your organs. Your kidneys and liver – they're all in trouble trying to deal with the overload."

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