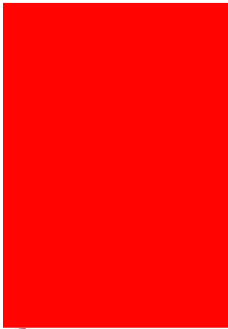


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REAL LIFE



SYMPTOMS ARE OFTEN ONES

that are common with other things

An Irish woman who has been diagnosed with haemochromatosis has encouraged people to be more aware of the symptoms of the genetic disorder.

Haemochromatosis is a genetic condition where the body overloads too much iron from the day-to-day diet into vital organs like the liver, heart, lungs and body tissue.

It is the most common genetic disorder in Ireland – and early detection is vital to avoid damage to the organs, and live a healthy life after treatment.

One in 83 people in Ireland are at risk of developing haemochromatosis – and one in five carry the gene, according

Irish woman on her genetic disorder, haemochromatosis, and her journey to getting a diagnosis after having difficulty breathing... By Keeley Ryan

to the **Irish Haemochromatosis Association**.

Research has recently found that one in ten people in Northern Ireland are at risk of having genetic haemochromatosis.

Caroline Martin was diagnosed with haemochromatosis after experiencing a few symptoms – including anxiety, headaches, fatigue and difficulty breathing.

And the Wexford-based mum told *Chic* how her doctor “suspected straight away” that she had haemochromatosis, as she opened up about the journey to her diagnosis.

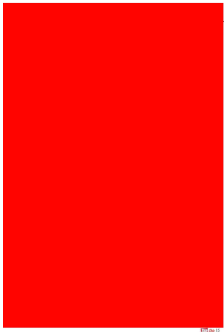
She said, “I went to the doctor, I think, five years ago – I was 27 at the time. I

went to the doctor because I was having difficulty breathing in that my heart skipped a beat, and a few small things – I was feeling tired, and all that.

“And then my doctor took blood tests, and when she came back, my ferritin levels were really high – they were 370, and I think you’re meant to have them around 50 or so – and my iron absorption was also quite elevated.

“She suspected straight away that I have haemochromatosis, so she did a genetic test. It came back that I had the two copies of the gene – it’s a C2A2Y gene, which means you have haemochromatosis.

“I got diagnosed with haemochromatosis and it went from



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there. I think I went into the hospital for my first venesection, that would have been a couple of months later.

"I have a really bad fear of needles — I actually couldn't go through with the first one, there was so much fear.

"I went back then, a few weeks later, and I had my first venesection. My blood pressure was really low and I needed oxygen. It was a bit messy, the first one.

"But then I went in every few weeks for a while, until I got the levels of the ferritin back down. I got really used to getting the needles, and it kind of cured my fear of needles as well.

"At the moment, we've got the levels OK — so I haven't been in a while. It's the kind of thing where you have to get the maintenance, and then it goes back up. So I'll probably go back within the next couple of months, anyways."

World Haemochromatosis Awareness Week takes place from June 1 until June 7. There are at least 20,000 undiagnosed cases of haemochromatosis in Ireland.

The Irish Haemochromatosis Association is hoping to raise awareness of the condition — and encourages people to get checked out to see if they may have the disorder.

Symptoms can include unexplained weakness or fatigue, abdominal pain, liver disorders, discolouration or bronzing of the skin and irregular heart rhythm.

Caroline noted that haemochromatosis symptoms can often be ones that are "quite common with loads of other things", and that it's important to get checked out.

She said, "It's one of those things where if they do a blood test and you have high ferritin, then they can do a genetic test and it's very easy to find out if you've got haemochromatosis."

The main treatment for haemochromatosis is called a venesection, which is where a unit of blood is taken from the patient until their iron levels are brought down.

Caroline praised the "lovely" nurse who looks after her when she gets the treatment, and told how she's "one of the things that really helped me".

She said, "Basically, it's done in the hospital and they put the needle in and draw the blood out. One of the things that really helped me is the nurse — I get the same nurse every time, and she's lovely.

"Imelda is her name and she always numbs my arm, so at least I can't feel the needle going in — which makes it a bit easier, anyways."

Caroline opened up about how she got involved with the Irish Haemochromatosis Association and raising awareness of genetic disorder.

She said, "I get it done in Wexford with Imelda, and she was talking to Miriam (Forde, Irish Haemochromatosis Association executive director) — and they don't have a lot of younger people who have haemochromatosis. And they want to try to encourage other young people to get checked out, because it's the best time to get diagnosed with it.

"People often think that haemochromatosis, it's only older people who have that. But it is something that you have from birth.

"I have eight siblings, so I'm the youngest. A few of them have got

checked, and none of them have haemochromatosis — but they are carriers. You can be a carrier, you can have the two genes that mean you have haemochromatosis, or you don't have it all.

"I think two or three of my siblings are a carrier, anyways."

Caroline told how haemochromatosis is something that can be "quite often overlooked and goes undiagnosed" as she opened up about her family background.

She said, "If a carrier has a baby with a carrier, they can have a child that has haemochromatosis. So most likely, each of my parents are a carrier.

"I think that — I'd say, realistically, there has to be [a family history of it]. I'd say both of my parents are a carrier and it's just so common in Ireland.

"I'd say that it was just undiagnosed to a lot of my family — diabetes and liver failure are quite common. My granny died of diabetes and liver failure, which is quite associated with haemochromatosis.

"It's something that's quite often overlooked and goes undiagnosed. I'd say there were definitely a good few people in my family who had it, anyways."

To mark this year's World Haemochromatosis Awareness Week, a number of county and city councils from around Ireland join the international initiative to 'Light Up Red'.

The buildings include Dublin's Mansion House, the Lord Mayor's residence in Dublin; the Dublin Convention Centre; Fingal Town Hall; Cork City Hall; Limerick Council Offices; Galway Town Hall and The Browne Doorway; Eyre Square, Galway; Sligo City Hall; Wexford County Hall; Donegal Public Services Centre; Cavan Town Hall; Monaghan County Council Offices; Kerry County Council

Buildings, Tralee; Princes Quay and Ashe Memorial Hall Building, Tralee; Killarney Town Hall and Kenmare Courthouse Building, Kenmare, Co. Kerry.

Caroline opened up about the importance of raising awareness of haemochromatosis — and how important and early diagnosis of the condition can be.

She explained, "I think the Irish Haemochromatosis Association wants to raise awareness of it because it's so common in Ireland — and so many people might have symptoms, particularly older people.

"I was in my 20s when we found out about it. And that's really uncommon, most people are in their 60s and all that.

"And it can do a lot of damage. It can damage your liver, or all your other organs — and if you wait too long to get a diagnosis, it can do a lot of harm.

"But if you get it early and keep on top of it, get your venesections and keep your ferritin levels at an adequate level, then it won't affect your health or your life particularly.

"I think it's important to get diagnosed early enough, if you've got any of the symptoms for haemochromatosis — just get checked out, because it's easy enough to find out if you have it and then it's easy enough to keep on top of it and keep your levels low."

And the mum shared her advice to anyone who might be experiencing symptoms of haemochromatosis or who might have recently been diagnosed.

She said, "I think that I'd say that, you know what, it's nothing to panic about really. Get into your local hospital and get to know the nurse that will usually do it — and if you've any fears, be open and honest.

"I went in the first day and I was so afraid of the needle. And when I told

them, they were so lovely and calming about it.

"Make sure to ask for numbing gel, or spray. And be open and honest if you've got a fear of needles, because once they know about it then they know what to look out for.

"Once you get into it — I think that I've had over 20 venesections now, and once you start getting a good few done then it kind of becomes normal. It's not really that big of a deal anymore. You do get used to it, and it's not really something to worry about as long as you get diagnosed early."

And Caroline said that she's a member of the Haemochromatosis Support Group on Facebook, which is a "great group" that features "people from all over the world" who have haemochromatosis.

She said, "There are people in there that have had it for years, who are giving advice to people who have only just been diagnosed — it's great."

Visit www.haemochromatosis-ir.com for more information or support and follow the IHA on Twitter, Facebook or Instagram. Text 'IRON' to 50300 to donate €4. Funds raised will be used to continue the IHA helpline, providing information and resources for patients and their families throughout the year.

IT IS IMPORTANT TO GET DIAGNOSED EARLY ENOUGH."



NOTABLE SYMPTOMS: Haemochromatosis can affect your liver, heart, lungs and body tissue; (main image) Caroline with her family