

My Marvellous Guide to Why Iron Matters

A Patient's Story



Authored by patients like you



HELPING PEOPLE LIVE BETTER WITH HEART FAILURE

WELCOME TO THE PUMPING MARVELLOUS FOUNDATION

A big welcome to "My Marvellous Guide to Why Iron Matters". Over the last twenty years there have been significant developments in the treatment of Heart Failure. These have been shown to improve your quality of life and extend your life expectancy. There has also been tremendous development in care and services that will support you going forward to live well with Heart Failure.

This guide is all about why iron matters.

Iron is critical to the production of red bloods cells that carry oxygen around your body. If you are living with Heart Failure, then you may have an increased risk of low iron levels. Without intervention, low iron levels can develop into iron deficiency anaemia which can impact your quality of life and in severe cases even be life-threatening.

This leaflet has been developed to help you understand the role that iron plays in your body and how higher levels can impact your health. We hope that this information will enable you to better manage your condition and help guide conversations with your healthcare professionals. The Foundation would like to express a huge thank you to our Patient Educators for sharing their stories and experiences with us.

Please note: this booklet should not replace and/or substitute interactions with and advice from your healthcare professional. If you have any concerns about your condition, then do discuss them with your healthcare professional at the earliest opportunity.

Nick Hartshorne-Evans Heart Failure Patient, Founder and CEO of the Pumping Marvellous Foundation

Angela Graves Chair of the Pumping Marvellous Foundation

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What is Iron and Why Does it Matter to Me?

Iron is an essential mineral that plays a critical role in heart health, muscle function and exercise capacity. It's important to have the right level of iron in the body.ⁱ

People with Heart Failure often lack iron, causing iron deficiency. People can be iron deficient, with or without anaemia, when there isn't enough iron to meet the body's needs.ⁱⁱ

When you have iron deficiency, you might experience:ⁱⁱⁱ

- More symptoms
- Worse health-related quality of life, resulting in considerable impact on your daily activities
- Changes to muscle tissue in your heart (this is known as myocardial alterations)
- Fatigue
- Reduced ability to exercise



ⁱ Beattie, J.M., et al. Iron deficiency in 78 805 people admitted with heart failure across England: a retrospective cohort study. *Open Heart* 2020;7:e001153. doi:10.1136/openhrt-2019-001153.

ⁱⁱ Brookes, M.J., et al. *Frontline Gastroenterology*. 2021;12:363–369.

ⁱⁱⁱ Comin-Colet, J., et al. Iron deficiency is a key determinant of health related quality of life in patients with chronic heart failure regardless of anaemia status. *European Journal of Heart Failure* (2013) 15, 1164–1172. doi:10.1093/eurjhf/hft083.

What is Iron Deficiency Anaemia?

Iron is one of the components of haemoglobin, the substance in your red blood cells that carries oxygen around your body. The body cannot make haemoglobin without enough iron, and this causes iron deficiency anaemia.ⁱ

People with chronic Heart Failure are at high risk of developing iron deficiency anaemia,ⁱⁱ with more than half (55%) of chronic Heart Failure patients having iron deficiency.ⁱⁱⁱ The exact cause of iron deficiency in Heart Failure remains unknownⁱⁱⁱ but it is likely a combination of factors such as poor dietary intake and malabsorption, inflammation, medication or other conditions such as renal disease.^{iv}

What's the difference between Iron Deficiency and Iron Deficiency Anaemia?

Iron deficiency refers to a decrease in the amount of iron stored in the body.^v

Anaemia refers to a drop in the number of red blood cells and/or the amount of haemoglobin within the red blood cells.^v



ⁱWong, C., Iron Deficiency Anaemia. Paediatrics and Child Health. 2017;27(11): 527-529 doi.org/10.1016/j.paed.2017.08.004.

ⁱⁱBrookes, M.J., et al. Frontline Gastroenterology. 2021;12:363–369.

ⁱⁱⁱEuropean Society of Cardiology. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. Developed by the Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). European Heart Journal (2021) 42, 3599-3726 ESC GUIDELINES doi:10.1093/eurheartj/ehab368. Van der Wal et al. Eur Heart J. 2019;40. 3616–3625.

^{iv}Van der Wal et al. Eur Heart J. 2019;40. 3616–3625.

^vLab Tests Online UK. Ferritin Test. Available at: <https://labtestsonline.org.uk/tests/ferritin-test>. [Accessed December 2022].

What's the Right Level of Iron?

There is a blood test that can diagnose iron deficiency. It is recommended that all patients with Heart Failure are regularly screened for anaemia and iron deficiency. This is done through a blood test in which the full blood count, serum ferritin concentration, and transferrin saturation (TSAT) are measured.^{vi}

- Full blood count – a general screening blood test^{vii} which measures haemoglobin and red blood cells
- Serum ferritin concentration – assesses the levels of iron stored in the body^{viii}
- Transferrin saturation (TSAT) – corresponds to circulating iron^{ix}

In patients with Heart Failure, iron deficiency is defined as either a serum ferritin concentration of less than 100 nanograms per millilitre (ng/mL) or 100-299 ng/mL with TSAT of less than 20%.^x

How to spot when your iron levels may be low

A blood test can confirm if your iron levels are low; however, there are signs that you can look out for. Symptoms of iron deficiency anaemia can include:^{xi}

- Tiredness and lack of energy
- Shortness of breath
- Noticeable heartbeats (heart palpitations)

- Pale skin
- Headaches
- Hearing ringing, buzzing or hissing noises inside your head (tinnitus)
- Food tasting strange
- Feeling itchy
- Sore tongue
- Hair loss – you may notice more hair coming out when brushing or washing it
- Wanting to eat non-food items, such as paper or ice
- Finding it hard to swallow (dysphagia)

- Painful open sores (ulcers) in the corners of your mouth
- Spoon-shaped nails
- Restless legs syndrome

If you are experiencing any of these symptoms of iron deficiency, speak to your GP or Heart Failure Nurse and ask for a blood test. They may explore options with you to manage your iron levels including diet, medication, and other interventions.

^{vi} European Society of Cardiology. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. Developed by the Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). European Heart Journal (2021) 42, 3599-3726 ESC GUIDELINES doi:10.1093/eurheartj/ehab368

^{vii} Lab Tests Online UK. Full Blood Count (FBC). Available at: <https://labtestsonline.org.uk/tests/full-blood-count-fbc>. [Accessed August 2022].

^{viii} Lab Tests Online UK. Ferritin Test. Available at: <https://labtestsonline.org.uk/tests/ferritin-test>. [Accessed December 2022].

^{ix} Wish JB. Assessing Iron Status: Beyond Serum Ferritin and Transferrin Saturation. CJASN September 2006, 1 (Supplement 1) S4-S8; DOI: <https://doi.org/10.2215/CJN.01490506>.

^x Comin-Colet, J., et al. Iron deficiency is a key determinant of health related quality of life in patients with chronic heart failure regardless of anaemia status. European Journal of Heart Failure (2013) 15, 1164-1172. doi:10.1093/eurjhf/hft083.

^{xi} NHS. Iron Deficiency Anaemia. Available at: <https://www.nhs.uk/conditions/iron-deficiency-anaemia/>. [Accessed December 2022].

Talking to your Healthcare Professional about Iron Matters

If you have Heart Failure and haven't had a blood test to check your iron levels within the last year, it's worth talking to your GP, Consultant Cardiologist or Heart Failure Nurse. We know this can sometimes be difficult, so the following points may help you to have this conversation:

- Start by letting your GP, Consultant Cardiologist or Heart Failure Nurse know that you're aware that people with chronic Heart Failure, like yourself, are at high risk of developing iron deficiency, with or without anaemia.ⁱ

If you have any symptoms, let your GP, Consultant Cardiologist or Heart Failure Nurse know about them. You can refer to page 5 of this guide.

- Let your GP, Consultant Cardiologist or Heart Failure Nurse know that you understand that people with Heart Failure with iron deficiency may have poorer health outcomes,ⁱⁱ impacting your quality of life, and this is something you're keen to avoid.
- If you have previously had your iron levels tested, let your GP, Consultant Cardiologist or Heart Failure Nurse know when this was and mention that you're keen for these to be checked regularly. Ask if they feel it's time for your iron levels to be retested.

Or, if you haven't had your iron levels checked before, let them know and ask if blood tests can be arranged.

Once you receive your test results, you can record your results in the 'Tracking your Iron Levels' section of this guide and use it to discuss any changes in iron levels and whether treatment is needed.

ⁱBrookes, M.J., et al. *Frontline Gastroenterology*. 2021;12:363–369.

ⁱⁱBeattie, J.M., et al. Iron deficiency in 78 805 people admitted with heart failure across England: a retrospective cohort study. *Open Heart* 2020;7:e001153. doi:10.1136/openhrt-2019-001153.

Management and Treatment Options for Low Iron Levels

There are a number of ways to help manage low iron levels and the right option for you will depend on a number of factors. Your doctor will look at the results of your blood tests and be able to confirm if you are iron deficient or have iron deficiency anaemia and recommend the best treatment for you.

Making changes to your diet, specifically increasing the amount of iron-rich food you eat, is one way to help improve iron levels.ⁱⁱⁱ However, diet modifications alone may not be enough to correct your iron levels, therefore you may also need to consider treatment. Treatment options include:

- Oral iron supplements. Available over the counter or on prescription, oral iron tablets are a widely used and an easily accessible option. Many factors will be taken into consideration when determining the suitability of oral iron for an individual patient, such as use of other oral medications, gastrointestinal tolerance, and iron absorption rate.^{iv}
- Intravenous (IV) iron. In cases where oral iron supplements have been ineffective, cannot be used or if there is a clinical need to deliver iron rapidly, your doctor may suggest IV iron therapy for you. This is where iron is delivered by injection or infusion directly into your bloodstream.^{iv}

Your doctor will assess your level of iron deficiency, any other medical conditions you may have and any medication you are already on, before supporting any decision on which treatment option is best for you.

ⁱⁱⁱ Alleyne M., Horne M.K., Miller J.L. Individualized treatment for iron-deficiency anemia in adults. *Am J Med.* 2008;121(11):943-8. doi:10.1016/j.amjmed.2008.07.012.

^{iv} McDonagh, T., Macdougall, I.C. Iron therapy for the treatment of iron deficiency in chronic heart failure: intravenous or oral? *Iron deficiency: a common co-morbidity in heart failure.* *Eur J Heart Fail.* 2015.


Tracking your Iron Levels

Blood test date	Full blood count	Serum ferritin concentration (Less than 100 ng/mL or 100-299 ng/mL)	Change since last test (Up or down)	Transferrin saturation – TSAT (Less than 20%)	Change since last test (Up or down)

Tracking your Iron Levels

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Patients' Stories



Day-to-day living with Heart Failure is hard enough, but I started to notice I was tired all the time, even after having a full night's sleep; I had zero energy for even the smallest of tasks like brushing my hair. I was even out of breath doing it. Small tasks were more difficult than usual and I just felt restless. My sleeping was increasing and my quality of life was decreasing. After going to the GP, I had a blood test which showed my iron levels were low, so I was put on oral ferrous sulfate. After a few days, I noticed such an improvement; my energy levels increased and simple tasks were a lot easier! Even my mood improved! - Katie

Discovering I had iron deficiency anaemia was a bit of a relief. I felt so awful that I was sure something major had happened and my heart was struggling again. I was exhausted, unable to concentrate, more breathless than usual, my joints ached and I had terrible headaches. I couldn't keep warm and I was very pale. Once I'd been lucky enough to have had the iron infusion I felt better almost immediately. Within a couple of days I had more energy and could walk further. It amazed me how much of a difference it made to my quality of life. - Sarah

Patients' Stories

Living with Heart Failure is hard, but adding in low iron made it harder. I would get really dizzy doing simple tasks and was constantly tired and so out of breath. I also felt like I was going to pass out. After some blood tests I was told I had low iron and was given oral iron tablets. I felt a difference after a few weeks; I didn't feel I was going to pass out all of the time and the dizziness settled. I have been told that I have chronic iron deficiency anaemia so will likely be on the iron meds for life, but they really do make a difference. - Donna

I have just been told I am borderline anaemic again and have low iron levels. Not sure if it's my Heart Failure or psoriatic arthritis. Nothing done as yet, but my healthcare team have mentioned an iron infusion. I feel exceptionally tired, weak, and have limited energy. It's pants, really. - Clare

Other “Marvellous Guides” available in the series:

HOPE - A Patient's Guide to Being Told You Have Heart Failure

Designed for people newly diagnosed with Heart Failure

My Marvellous Big Pocket Guide to Heart Failure

A key guide to help you manage your Heart Failure

My Marvellous Guide to Caring for Heart Failure Patients

A marvellous guide to help people who care for people managing Heart Failure

My Marvellous Guide to Having a Cardiac Device Fitted

To enable people to make an informed decision about having a cardiac device

My Marvellous Guide to Having an Echo

Everything you need to know about having an echo scan on your heart

My Marvellous Guide to Medicines for Heart Failure

Our guide that explains how the various medicines work that you are likely to be prescribed for Heart Failure

My Marvellous Guide to PPCM (Peripartum Cardiomyopathy)

Designed for mums diagnosed with PPCM

My Marvellous Guide to Travelling with Heart Failure

Ideal for people wanting some help with going on holiday with Heart Failure

My Marvellous Guide to Using GTN

A simple guide to helping you take GTN spray or tablets

My Marvellous Guide to 'Walking a Day in My Shoes'

Marvellous guide for people wishing to inform their families about Heart Failure

My Marvellous Symptom Checker

A great tool to help you manage your symptoms

My Appointment Diary

Help in managing your Heart Failure

All guides are written by patients and clinically validated for accuracy by leading UK Heart Failure Specialists. To access go to this link; www.pumpingmarvellous.org

My Team:

Your Carer's Name:

Your GP's Name:

Your Cardiologist's Name:

Your Heart Failure Nurse's Name:

Your Practice Nurse's Name:

Your Pharmacy's Name:

Other Team Details:

Contact Name:

Contact Name:

Contact Name:

Your Carer's Telephone Number:

Your GP's Telephone Number:

Your Cardiologist's Telephone Number:

Your Heart Failure Nurse's Telephone Number:

Your Practice Nurse's Telephone Number:

Your Pharmacy's Telephone Number:

Telephone Number:

Telephone Number:

Telephone Number:

How can you support us?

Your support gives the Pumping Marvellous Foundation its energy in supporting people and their families. The support received contributes significantly to the organisation's efforts to help heart failure patients.

Educational Support

Delivered to patients and their families through the NHS
Save Lives, Fund Our Guides

Scan the code or visit: [qr.pumpingmarvellous.org/
EducationGuides](https://qr.pumpingmarvellous.org/EducationGuides)



Support our National Campaign

Increase awareness of Heart Failure, get faster diagnosis, and get better support living with Heart Failure. BEAT HF, our National Campaign

Scan the code or visit: [qr.pumpingmarvellous.org/
SupportBEAT](https://qr.pumpingmarvellous.org/SupportBEAT)



Fundraise

Raise money to help people like you and your loved ones.
We can help you realise your idea.

Scan the code or visit: [qr.pumpingmarvellous.org/
FundraiseNow](https://qr.pumpingmarvellous.org/FundraiseNow)



Remember us in your Will

Gifts in your Will can make a huge difference in our ability to transform support to people with heart failure and their families.

Scan the code to place us in your Will or visit: qr.pumpingmarvellous.org/MakeAWill



Shape our ideas with your experiences

The Pumping Marvellous Foundation, driven by patients' needs living with heart failure, we never have enough ideas. Come and join our "Marvellous Patient Educators" and make positive changes.

Scan this QR code to join our Patient Educators or visit: qr.pumpingmarvellous.org/PatientEducator



If you have any concerns or questions, get in touch with the
Pumping Marvellous Foundation.



*Another Mini Toolkit by the Pumping Marvellous Foundation
Crowdsourced information from REAL patients.*

Acknowledgements and thank yous

Thank you to the **Patients** who have helped in the creation of this Marvellous guide,
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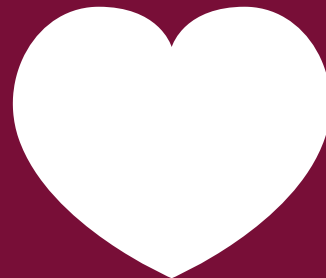
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