

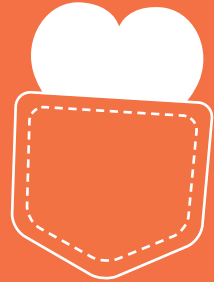
My Big Pocket Guide to Heart Failure

A Patient's Story



Authored by patients like you

HELPING PEOPLE LIVE BETTER WITH HEART FAILURE



WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



They say good things come in small packages, and we think that this is a marvellous example.

This Big Pocket Guide will provide you with some initial information, answers, support, and give examples of how you can live well with a diagnosis of Heart Failure. This guide is a result of the experience gained by our marvellous team of patients at the Pumping Marvellous Foundation who started just like you – with a diagnosis of Heart Failure.

To explore some of the topics raised in this guide, visit www.pumpingmarvellous.org where you can access more information guides, and gain invaluable support from fellow patients and carers at our closed support group on Facebook – search '**Help for Hearts**' to apply to enter. If preferred, you can also call the team on **01772 796542**.

All our patients and carers have been where you are, at the start of their new journey – but never forget you are not alone.

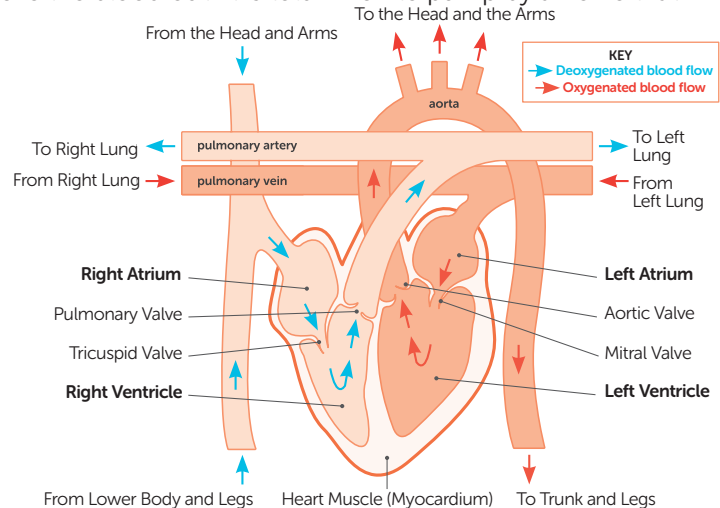
Please note: this booklet should not replace/substitute interactions with and advice from your healthcare professional. If you have any concerns about your condition, then do discuss them with your healthcare professional at the earliest opportunity.

What Does the Heart Do?

The heart is an organ that acts as a pump to send blood around the body. The left side of the heart delivers blood to the rest of the body via arteries, which is returned by the veins to the right side of the heart. Your blood contains oxygen and nutrients that are needed by every part of your body in order to function. Clench your two fists together and that's about its size; it sits in the centre of your chest tipping down to your left-hand side. It has different layers (one of which is made of muscle), so the heart can squeeze the blood out. It is told when to pump by a nerve that triggers the heart's own electric system.

The heart delivers the blood via arteries and it is then returned via veins. Think of it as a motorway system. The diagram shows the inside of the heart. It is made up of four chambers: on the right-hand side, blood returns from delivering oxygen around the body by the veins (a motorway), the heart then sends the blood to the lungs (petrol station), picks up oxygen and returns to the left side of the heart which then delivers the blood to the body via arteries (another motorway). Note from the diagram the little gates letting the blood move from one chamber to another; these are called valves. Every time this occurs, it is called a beat.

As with a car, the heart needs to be looked after in order for it to do its job effectively.



Why Have I Got Heart Failure?

No one likes the word failure. The Pumping Marvellous Foundation was founded around the mantra to be positive around Heart Failure, so let's start by assuring that you are not a failure.

Heart Failure means that your heart is failing to pump as efficiently as it should, in order to supply the body with the oxygen and nutrients it needs.

Why is my heart not working efficiently?

The question to ask your Doctor or Nurse is, "**What type of Heart Failure do I have?**"

You may hear technical terms to describe the different Heart Failure types, such as Heart Failure with mildly reduced or reduced Ejection

Fraction (HFmrEF or HFrEF) or another common type, Heart Failure with preserved Ejection Fraction (HFpEF).

HFpEF means that the heart fails to relax and fill efficiently. **If you have HFpEF, ask your Doctor or Nurse for our Guide to Heart Failure with preserved Ejection Fraction**, as treatments differ between Heart Failure types. You can also download it from the Community Hub/Support Guides section on our website.

There is generally a reason why the heart is not pumping correctly. The most common reason is that the heart muscle has been damaged by a poor blood supply such as after a heart attack. Other causes include:

- High blood pressure

- Type 2 diabetes
- A virus that has affected the muscle of the heart
- Abnormal heart rhythm, e.g. atrial fibrillation (AF)
- A genetic condition which may have affected the muscle of the heart as in cardiomyopathy
- Excessive alcohol intake or recreational drug use
- Obesity
- The valves of the heart being damaged
- Some types of chemotherapy
- In rare cases, a form of Heart Failure in pregnancy or just after delivery called peripartum cardiomyopathy

On very rare occasions, the cause is undetermined (idiopathic). However, your Heart Failure team will be doing their best to find out the cause.

Your treatment will consist of therapy in order to correct or modify the underlying causes of your Heart Failure, as well as improve the efficiency of your heart. This could be medication or a cardiac device.

To understand what treatments and care you may be offered, please visit our Patient Charter: pumpingmarvellous.org/community-hub/patient-charter

How Do Doctors Know I Have Heart Failure?

You may have had a number of symptoms, including:

- Breathlessness, particularly on activity, or lying down, resulting in you waking up at night gasping for breath
- Exhaustion, feeling tired and lethargic
- Ankle swelling and/or swelling in your feet, legs and tummy
- A cough, particularly at night
- Feeling dizzy, lightheaded and maybe a little confused

Symptoms often develop gradually, but you may have had a sudden onset of symptoms, causing a rapid deterioration in your health. These symptoms may also have been severe, resulting in a hospital admission, where you are perhaps reading this guide.

So How Bad Are Things?

We are aware that Heart Failure is a serious condition, however the important thing to remember is that there is now a good understanding of it, and that there are a number of treatment options available, from medication to cardiac devices, to help manage it. Like many other conditions the relentless challenge of discovering newer treatments is always on the horizon.



What Tests Have I Had, or Will Have to Undergo?

Think of it as jigsaw pieces being put together to reveal a picture of what has been going on. At this stage it's very important you help give the Doctor the whole picture. You may feel uncomfortable discussing what's been going on if you feel negatively about it. In our experience telling them everything will lead to the picture being built up quicker.

This is a very important part of self-managing your condition; being able to have an open and honest conversation with your Doctor or Nurse (whether before diagnosis or all the way through your treatment) is so important. If this is the only thing you pull from this guide then this is crucial to understand.



These are some of the tests and investigations you may encounter:

- Your Doctor will have asked you a number of questions about what has been happening to you now and in the past.
- Your Doctor will have given you a physical examination.
- You may well have had a number of blood tests to show if your heart is perhaps struggling by measuring 'natriuretic peptides'. These are proteins released by the heart when it is under strain, sometimes referred to as NT-proBNP or BNP. The blood test will also be checking if your kidneys or liver are functioning well, ensuring you are not iron deficient or anaemic, and that your thyroid gland is working well. You may have had these done on a number of occasions and your health team will no doubt be repeating them to make sure everything is going well.
- You will have had a tracing of the heart (an ECG). This can provide a great deal of information; it can show if your heart is going too fast or too slow, if it is in an unusual rhythm, and what has happened to the heart in the past.
- Echo (echocardiogram) – this is a scan of the heart and is vital to show how your heart is pumping, if the heart's structure has been affected in any way and how the valves are working. It is able to measure your Ejection Fraction, meaning how much blood your heart is pumping to the rest of the body. A normal Ejection Fraction is 55%-70%; normal is never 100%. Heart Failure with reduced Ejection Fraction (HFrEF) generally means your ejection fraction is 40% and below, while Heart Failure with mildly reduced Ejection Fraction is 41-49%. What matters is how you are feeling, not just the numbers. To learn more about having an Echo, visit our website and download our Guide to Having an Echo from the support guides section.

You may have further complex investigations as you go along, more details can be found on the Pumping Marvellous website.

Can They Cure My Heart Failure? How Will They Treat Me?

This is a question you will need to discuss with your Doctor or Specialist Nurse, as it depends on what has caused your Heart Failure. What is important to remember is that there are various treatments to support your heart to work more effectively, which can ensure you live your life well. **You have a big role to play in that process.** This guide will give you some tips and will share some of our tried and tested self-management tools that will ensure you get the best from your treatment and that you find your new normal as soon as you can. Remember, Heart Failure is treatable.

Tablets, Tablets and a Few More Tablets!

Yes, you will be asked to take a number of tablets – but remember they are there to do a job, and have a positive role in improving your health and wellbeing. The tablets you may take for Heart Failure are sometimes referred to as the 4 Pillars; these are evidence-based to show benefit in potentially lengthening your life, improving the quality of your life and reducing risks of being admitted to hospital with worsening Heart Failure. Remember, your medications and their dosages are unique, like you, and work with you as an individual.



Top Tips: Your Relationship with Your Tablets

- They may take some getting used to, and you may feel worse before you feel the benefits, stick with it and discuss any concerns with your health team.
- You are in charge of your tablets, get into a routine that works for you. Understand what they are and how they are going to help you.
- When you're living with Heart Failure, getting your medication right isn't a one-off moment — it's a journey. Your tablets may need to be increased over time to reach the level that's right for you. This is called optimisation, meaning finding the balance where your heart is best supported and you feel as well as possible. For some people, this happens quite quickly. For others, it takes a bit more time. There's no "one size fits all"— your body will guide the pace, and your healthcare team will work with you to get it right. You might notice changes as your doses increase. That's normal. These medications are powerful because they're doing an important job — helping your

heart work better and protecting you for the future. Sometimes it takes a little while for your body to adjust. The most important thing? Stick with it. Even on the days when it feels uncertain, these treatments are proven to help you live better and longer. You're not just taking tablets — you're investing in your future. And remember — you're not alone in this. If something doesn't feel right, speak up. Your voice matters in shaping your care.

- Try not to miss taking your medications as prescribed and never stop taking them. Do discuss with your Doctor or Nurse any problems when you see them, but don't hesitate to contact them at any time with any concerns you may have.



What Tablets Will I Be On?

Different people will be on different tablets at different dosages, but below are some of the key medications you are likely to find yourself on. The following is not a complete list of any side effects with your tablets but serves as a general guide. If you have any concerns do speak to your health team.

Beta Blockers - often ending in 'lol' -
e.g. Bisoprolol, Carvedilol

These tablets make your heart beat slower but stronger. You are started on a dose that is specific to you and then increased to the optimum dose that you are comfortable with. They may make you feel weary at first; occasionally they can slow down your heart too much and make you feel lightheaded.

ACE Inhibitors - often ending in 'pril' - e.g. Ramipril, Lisinopril, **or ARBs** (often end in 'sartan')

These tablets ease the workload of the heart by relaxing the blood vessels around the body, which reduces the strain on the heart. Occasionally they may give you a dry, irritable cough at first which often settles, however if this persists, particularly during the night, mention it to your

Doctor or Nurse. They do lower your blood pressure so that will be checked as the tablet is increased and may affect how your kidneys work, so a blood test will be taken again as the tablet is increased. You are started on a dose that is specific to you and then increased to the optimum dose that you are comfortable with.

Should the ACE Inhibitor give you persistent problems with a cough then an alternative can be prescribed called an ARB (Angiotensin Receptor Blocker), these often end in 'sartan', e.g. Losartan, Candesartan. They work very similarly to an ACE Inhibitor but should avoid any problems with a dry cough.

Diuretics (water tablets)

- Mineralocorticoid Receptor Antagonist (MRA) Spironolactone/Eplerenone. These are evidence-based and typically have less diuretic effect but have other actions which protect the heart.
- Diuretics (like Furosemide, Bumetanide, and Torsemide). Diuretics are used specifically for fluid retention and frequently for Heart Failure. Doses vary depending on symptoms and weight.

These tablets help the body to get rid of any extra fluid that may have built up (in your lungs, feet, legs or stomach) which will ensure that there is less fluid for your heart to deal with. You may be on one or more different types of water tablets as they work in different ways on the kidneys, e.g. Furosemide, Bumetanide, Spironolactone, Eplerenone. The difficulty is that they will make you have to pass more water, so be prepared for frequent trips to the toilet, but they will ease your symptoms. If you are admitted to hospital due to fluid that has built up in your body, then you will be given diuretics via a drip. They can make your skin dry, and upset your kidneys, so again expect frequent blood tests.

Sacubitril Valsartan (also known as Entresto)

Sacubitril Valsartan may be prescribed to replace the ACE or ARB you may already be on; however, it may be considered without first prescribing an ACE or an ARB. If your heart muscle remains significantly impaired despite ACE or ARB, your specialist may recommend a switch to Entresto. Sacubitril Valsartan blocks certain enzymes which may strain your heart and enhances the protective systems that support your heart. It can lower your blood pressure and affect your kidneys, so frequent blood pressure checks and blood tests are required as the drug is increased.

Digoxin

Digoxin is occasionally used in Heart Failure, but may also be used to control the rhythm of the heart.

Ivabradine (also known as Procoralan or Corlanor)

This drug is used on top of, or instead of, a Beta Blocker if you have a normal heart rhythm, but a heart rate that is greater than expected when you are at rest.

SGLT2 Inhibitors (Sodium-Glucose Co-Transporter 2 Inhibitors often ending in "gliflozin", e.g. Dapagliflozin, Empagliflozin)

- Are well tolerated by patients
- Can be prescribed by your GP or Heart Failure specialist

SGLT2 Inhibitors are a group of medicines used to treat insufficiently controlled type 2 diabetes and now symptomatic chronic Heart Failure. They may also be called "Sodium-glucose co-transporter 2 inhibitors" or just "gliflozins".

Dapagliflozin and Empagliflozin are currently approved for use in symptomatic chronic Heart Failure, whether you have type 2 diabetes or not.

What do they do?

SGLT2 Inhibitors have shown benefit to patients with Heart Failure. They improve symptoms, length of life and reduce the possibility of being admitted to hospital with Heart Failure.

What are the most common side effects?

SGLT2 Inhibitors are well tolerated. Common side effects may include dizziness, rash, back pain and increased frequency of passing urine. If the patient has diabetes then thrush (candidal genital infection), urinary tract infection and a more unusual side effect known as diabetic ketoacidosis (DKA) may also occur.

Patients with DKA are unwell and may experience excessive thirst, sickness, tummy pain and a sweet smell on their breath in addition to feeling tired or confused. Consult your Heart Failure team or GP if you are concerned with any side effects you may be experiencing.

NICE First Line Treatment Options

NICE (National Institute for Health and Care Excellence) is an independent UK organisation that provides evidence-based guidance and standards to improve health and social care. National Institute for Health and Care Excellence is important to patients because it helps ensure people receive safe, effective, evidence-based care and fair access to the best available treatments across the NHS.

These are the NICE Guidelines first line treatments for people with an Ejection Fraction of the less than 50%. This is designed to tell you what may be available to you. Notice the word "**offer**", which in NICE language means you should offer, and the word "**consider**", which in NICE language means you should consider offering.

HFrEF - Where EF is less than 40%	HFmrEF - Where EF is between 41% to 49%
OFFER	CONSIDER
ACE Inhibitors*	ACE Inhibitors
Beta Blockers	Beta Blockers
MRA (Mineralocorticoid Antagonists)	MRA (Mineralocorticoid Antagonists)
SGLT2-I (Sodium-Glucose Cotransporter-2 Inhibitors)	SGLT2-I (Sodium-Glucose Cotransporter-2 Inhibitors)

*Replace ACE-I for ARNi (Angiotensin Receptor Neprilysin Inhibitor) if symptoms persist

Treatment Table

Highlighted sections represent the four pillar medications: Beta Blockers, RAAS Inhibitors (ACE or ARNI or ARB), Mineralocorticoid Antagonists (MRA), SGLT2 Inhibitors Receptor. Please note you will be only on one type of ACE, ARNI or ARB.

Treatment Name	Maybe called	Prescribed by	What it does
ACE Inhibitor ends in "pril or ARB* ends in "sartan" *ARB only offered if ACE or ARNI not tolerated	Ramipril, Enalapril, Lisinopril, Candesartan, Losartan	GP or Heart Failure Specialist	Relax blood vessels to reduce strain on the heart
ARNI (Angiotensin-Receptor-Neprilysin Inhibitor)	Sacubitril Valsartan (Entresto)	GP or Heart Failure Specialist	Enhances protective systems that protect your heart. Lowers blood pressure
Beta Blocker ends in "lol"	Bisoprolol, Carvedilol	GP or Heart Failure Specialist	Make your heart beat slower and stronger
Mineralocorticoid Receptor Antagonist - MRA	Spironolactone, Eplerenone	GP or Heart Failure Specialist	Reduce excess fluid 3 build-up
SGLT2 Sodium-Glucose Co-Transporter 2 Inhibitor or ending in "gliflozins"	Dapagliflozin Empagliflozin	GP or Heart Failure Specialist	Decreases absorption of sugar in the kidneys and reduces fluid build-up
Diuretics	Furosemide, Bumetanide, Torsemide	GP or Heart Failure Specialist	Reduce excess fluid build-up
Hyperpolarisation-activated Cyclic Nucleotide-gated (HCN) Channel Blockers	Ivabradine	Heart Failure Specialist	Reduces heart rate when rate is more than expected when in normal rhythm
Internal Cardiac Defibrillator	ICD	Heart Failure Specialist	See next page
Cardiac Resynchronisation Therapy	CRT-D or CRT-P	Heart Failure Specialist	See next page

These are the most common tablets that will be prescribed, however depending on why you have Heart Failure, other tablets may be prescribed. A good resource for patients and their families to look at medicines is the NHS website.

Will I Need Any Surgery or Pacemakers to Help with My Heart Failure?

Your Doctor or Nurse will discuss your suitability for any other options open to you, but specialised pacemakers may be recommended. They are likely to be the following:

Cardiac Resynchronisation Therapy – CRT

Depending on the results of your ECG, echo and your symptoms then you may be recommended for this form of cardiac device, which is a type of pacemaker. A small incision is made in the skin, making a pocket in the fat below the skin, usually above the left breast, for the device to sit into. This specialised pacemaker sends tiny electrical signals to the heart to help it beat in a more synchronised way, ultimately ensuring that the heart pumps more efficiently and hopefully making you feel better with less symptoms.

Implantable Cardiac Defibrillators – ICD

Not only does the heart have a beat but also a rhythm. Occasionally the heart can go into dangerous and even fatal rhythm which requires the ICD to deliver a small electrical shot or shock to the heart in order to restore a normal heart rhythm. An ICD is implanted in a similar way to a CRT device. **On occasions the two devices (a specialised pacemaker and defibrillator) are combined together which are called CRT-D.**

See our Guide to Having a Cardiac Device Fitted. Ask a member of your health team for a copy or visit www.pumpingmarvellous.org and download it from the Community Hub support guides section.



The Art of Self-Management

We understand this is a lot of information to take on board. The information you have read so far mainly concerns what others need to do to help you. This next section is about self-management: how you can help yourself and, most importantly, how you can help yourself feel better.

The key to self-management is getting yourself into a can-do positive attitude by being determined and resilient to what sometimes feels like a roller coaster ride of ups and downs.

You may be feeling overwhelmed at this time. Our patients tell us of a range of emotions they experience upon being diagnosed; from feelings of loneliness to even a sense of relief – that although they have been feeling so ill, at least they now know what has been causing it and can begin to get it sorted.

Firstly, you are not alone. Being told you have Heart Failure can be distressing and it can take time to accept and share your emotions. Take your time and take in information at your pace. We believe you'd agree that being diagnosed with Heart Failure is difficult enough to get your head around, but having to navigate your way through what care and support you should expect is a completely new problem.

Visit www.pumpingmarvellous.org for more helpful information in our Community Hub support guides section.



Scan the QR code to access useful resources on self-management

Is There Anything I Can Do to Help My Condition?

Yes: we believe in the concept of self-management. This is not simply education about Heart Failure and the goals of treatment – this is about how you can successfully monitor/manage your symptoms and address the psychological/social implications of your condition. Successful self-management helps you to be in control and achieve a quality of life that suits you.

There is a lot of understanding and treatment out there to help you – including the **New York Heart Association Classification Scale**.

The New York Heart Association (NYHA) Classification Scale

Patients and Healthcare Professionals often find the New York Heart Association Classification Scale useful in assessing your condition, based on the symptoms you are experiencing.

One common symptom of Heart Failure is a lack of energy caused by breathlessness, exhaustion and fatigue. Think of your energy as a battery that you must use wisely to get you through the day.

The New York Heart Association (NYHA) Scale can assess how much energy you have in your battery by categorising your symptoms from class 1-4 – so you can gauge 'where you are in New York'.

So, Where Are You in New York?

See the next page to find out where you are in New York.

Note: you may move around on the scale as your conditions and treatments change.

The NYHA Scale

The NYHA scale is usually used by Clinicians to assess you. However as you are the only one who knows how you feel, it's a great tool to help you explain to Clinicians what's been going on whilst they aren't there.

NYHA Class Symptoms

Class 1 No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations, or shortness of breath.

Class 2 Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations, or shortness of breath.

Class 3 Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes tiredness, palpitations, or shortness of breath.

Class 4 Unable to carry out any physical activity without discomfort and tired and short of breath even at rest. If any physical activity is undertaken, discomfort increases.

CLASS 1

"I can perform all physical activity without getting short of breath, tired, or having palpitations."

CLASS 2

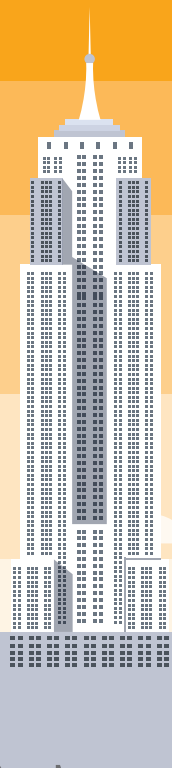
"I get short of breath, tired, or have palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps."

CLASS 3

"I get short of breath, tired, or have palpitations when performing day-to-day activities (for example, walking along a flat path)."

CLASS 4

"I feel breathless at rest, and am mostly housebound. I am unable to carry out any physical activity without getting short of breath, tired, or having palpitations."



Symptom Checker

Manage your symptoms by using our traffic lights system so that you know what to do if you are hitting any problems. Plan your activities around your energy levels, these may include your work, social life, or your sex life.

Pace yourself through your various activities, it's often a case of doing the same things that you were used to but at a slower pace. In time you may find your activity levels increase and you find your new normal.

Your Daily Routine

Make sure you **take the prescribed tablets for your heart.**

When you get up in the morning, **weigh yourself** after going to the toilet for the first time. Write this down and **compare it to yesterday's weight. If there is a change, look at the traffic lights.**

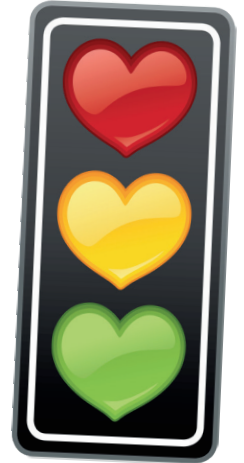
Eat a balanced diet and don't add salt. Don't use low salt alternatives.

Check for either reduced or increased swelling in your feet, ankles, legs and stomach.

Ask yourself if your **breathing pattern is the same as normal.**

Balance exercise and rest; **know your limits.**

This Symptom Checker has been put together by the Pumping Marvellous Foundation and developed with Professor Dargoi Satchi, his specialist team, and patients from Staffordshire.





GREEN - KEEP WATCH

Your weight has not increased/has increased by 4lb/2kg over 3 days but you agree with the statements below:

HOW AM I?

You are no more breathless than usual.

Your ankles are no more swollen than usual.

Any other conditions you have are no worse than usual.*

You are as active and mobile as you normally are.

Your main carer's health is unchanged.



You are no more breathless than usual.



Your ankles are no more swollen than usual.



All of your other medical conditions are OK.



You are as active and mobile as you normally are.



Your main carer's health is unchanged.



SCAN ME

JOIN OUR PATIENT AND CARER COMMUNITY - SCAN WITH YOUR DEVICE HERE

WHAT SHOULD YOU DO?

There is no need for a review by the Heart Failure specialist team/GP/Practice Nurse apart from your regular reviews. However, you should be reviewed at least twice a year. *Other conditions means other medical problems that you and your GP are already aware of and that you are already treated for.

MAKE SURE YOUR HEALTHCARE TEAM WHO GAVE YOU THIS SYMPTOM CHECKER HAVE TALKED YOU THROUGH IT TO CHECK YOUR UNDERSTANDING



AMBER - STAY ALERT

Your weight has increased/had increased by 4lb/2kg over 3 days and/or one of the statements below is true:

HOW AM I?

You are feeling more breathless than usual.

Your tummy and/or legs are more swollen than before.

You are breathless at night or need more pillows to sleep on.

You are unable to be as active as usual/you are a bit more muddled than usual.**

Any of your other conditions are worsening.

Your main carer is becoming more ill and is unable to help look after you as much as before.



You are feeling more breathless than usual.



Your tummy and/or legs are more swollen than before.



You are breathless at night or need more pillows to sleep on.



You are unable to be as active as usual/you are a bit more muddled than usual.



Any of your other conditions are worsening.

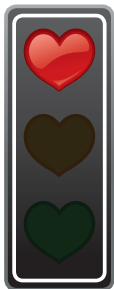


Your main carer is becoming more ill and unable to help look after you as much as before.

WHAT SHOULD YOU DO?

Try simple measures to improve your symptoms and/or consider a sooner appointment with the Heart Failure specialist team/GP/Practice Nurse if you feel it is necessary.

****This means that if you are not able to do as much as you would normally do, or are becoming a bit more confused because of; pain, unsteadiness/falls, worsening Heart Failure symptoms, worsening of another condition you have, or developing a new problem, then it is important to contact one of the medical team looking after you.**



RED - TAKE ACTION

If your symptoms continue to worsen over 3 days, or you have any of the problems below:

HOW AM I?

Over these last 3 days your breathlessness/leg swelling are worsening and/or you are far less able to be as active as normal or look after yourself.

You have symptoms of an infection and/or you feel very unwell.***

Any of your other medical conditions are continuing to worsen.

You have blacked out.

You have worsening or new angina.****

You have become confused about your medications.*****

Diarrhoea and vomiting for more than 24 hours.

Continuing to feel unwell without a clear cause - especially if you take a medicine which ends in '-flozin'.

Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.

WHAT SHOULD YOU DO?

Consider urgent advice from your GP or Heart Failure service. If you feel unwell call **111**. If you feel very unwell call **999**.



You have symptoms of an infection and/or you feel very unwell.



You have blacked out.



Any of your other medical conditions are continuing to worsen.



You have become confused about your medications.



My medication has been reduced/stopped and I am not sure why/my Heart Failure team are unaware.



You have worsening breathlessness or leg swelling or are unable to be as active as usual.



You have worsening or new angina.



Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.



You have had diarrhoea or vomiting for more than 24 hours.

***Symptoms of infection; temperatures, sweats, new cough, change in colour of your usual sputum, pain on passing water, diarrhoea/ vomiting, increasing falls or loss of balance.

****Angina is one kind of heart-related chest pain. Please discuss your chest pains with your GP if you are unclear as to whether they are angina or not.

*****Confused about medication: in terms of specific doses/why you take specific medications or whether you are uncertain you have taken today's medication correctly.

Contact your medical team if you are on a tablet ending in '-flozin' and you have had prolonged vomiting or you are feeling unwell without an obvious cause. Very rarely these drugs can cause a condition called 'ketoacidosis' that your medical team should be able to test for. It is a very rare but serious complication of this group of drugs.

General Tips and Advice

- There is evidence that people with Heart Failure gain significant improvement as a result of attending Heart Failure Cardiac Rehabilitation. These are usually formal exercise classes but can also be online and are designed for patients with Heart Failure. Our patients tell us how beneficial Cardiac Rehabilitation has been to them. If you have not been referred to Cardiac Rehabilitation, please ask your Heart Failure team.
- Eat a healthy diet, again seek out support from your health team around any specific needs you have.
- If you smoke, give up. There is a wealth of information and support, see our information page for advice and support to help you.
- If your Heart Failure is due to excess alcohol intake then you must stop, again information can be found at the end of this guide. General recommendations are drink within the recommended safe limits.
- Keep an eye on your salt intake, as high salt intake keeps fluid on board and raises blood pressure. Look out for the salt label on foods and avoid those that show as red.
- You may be given instructions by your Doctor or Nurse on restricting your fluid intake, you will need to discuss this with them.

*Scan this QR code to listen
to our educational podcasts
about Heart Failure*



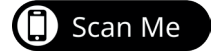
Develop Your Team

Many of our patients, carers and families tell us of the great support they get via our **Facebook group Help for Hearts**.

The carer, be that your partner, child, parent, neighbour or friend will often be the most important person in your support team. Remember they will also need help to come to terms with your condition so visit our website for information and support that will help you build your team.

Why not join us on this journey of discovery, learning and connection, and listen to our series of Podcast/YouTube discussions about Heart Failure, involving many of the team on the coach. Scan the QR code with your smart device to listen.

Learn more about Heart Failure, scan this for our YouTube channel.



The Marvellous Heart Failure Specialist Nurse

You may have been referred to a Heart Failure Specialist Nurse. Our patients and their carers tell us of the invaluable support these Nurses provide. Specialist Nurses will be able to examine you, prescribe your medication, order and interpret investigations, support you on the challenges of your condition and direct you to other services you may need. It's good to form a rapport with your GP practice as well.

If you have not got a Heart Failure Specialist Nurse, ask your GP or Consultant if you can be referred to one.

Pharmacists

Pharmacists occupy an important role in helping you manage your Heart Failure. They occupy roles within the hospital, GP surgeries and of course high street pharmacies. They are generally more accessible than your GP and if you need help with medications or you feel you need a review of your current medications, a pharmacist can help. They are also instantly accessible when you have questions about over the counter medications and if they are safe to take with your current medications.

Cardiac Rehabilitation

Cardiac Rehabilitation is an important part of helping you live well with Heart Failure. It can make a real difference to how you feel day-to-day, improving your confidence, wellbeing, and quality of life.

You are not alone — many people with Heart Failure find that having the right support and guidance helps them feel more in control and more confident about the future.

Cardiac Rehab supports you with things like safe and tailored exercise, practical nutrition advice, and skills to help you manage your condition.

Across the UK, Cardiac Rehabilitation is recommended as part of routine care for people living with Heart Failure.

To support NHS Cardiac Rehabilitation services, Pumping Marvellous has created a free, lifelong digital Cardiac Rehabilitation programme, approved for use within the NHS.

By scanning the QR code with your phone, you can go straight to our website and sign up for free.

Scan me with your smartphone to learn more about our Cardiac Rehabilitation platform



Getting the Most Out of Your GP and General Practice

We have a number of patients who are willing to support both the charity and other patients. We call these experts Patient Educators. Pierre is one of our Patient Educators; read his advice on forming a good relationship with your GP.

"I feel that where Heart Failure is concerned, it is key to have the right GP. This is vital as he/she is the main day-to-day contact any Heart Failure patient has.

Strike up a good relationship with the receptionists as they can help you a lot with prescriptions, appointments, etc.

Be an educated patient i.e. know about the condition and how it affects you. Know your medication and what it does for you and how it works to improve your condition.

Try not to come across with an attitude of 'there's nothing they could tell me about Heart Failure'. Remember, they are part of your team and are trying to help you.

Choose the right Doctor for you within the practice. This is a bit like an interview process, but really you know who the good ones are from, well, the not so good ones. The one you feel best about, I don't mean the one who you know, the one you can get to agree with whatever you are saying, but the

one who will work to do their best to maintain and improve your condition and at times push and encourage you.

If you are lucky enough to have a Heart Failure Specialist Nurse, point this out to them, as the Doctors do not know everything about your condition. This will help your Doctor as they will know that the Nurse is in partnership with them. If there are any issues, there is a good source of information and advice a patient can access. Here is an example: my kidney function was abnormally high and my Doctor said that they would stop one of my tablets, Spironolactone. I said I would give the Heart Failure Specialist Nurse a ring just to get their thoughts on it, which he had no objection to as he felt more informed and valued advice from a specialised Heart Failure Nurse would be great. I fed back the information and didn't stop Spironolactone. My Doctor was very pleased as he recognised that, as a team, the correct decision was made for the patient."

Pierre's Key Tips

1. Explain to your Doctor/practice that due to your condition you would like to see the same Doctor at all times.
2. This may be difficult in emergencies, but if it is an emergency for a Heart Failure patient, in reality the GP would not be the first port of call.
3. Discuss your current symptoms with your Doctor and how together you can both work to improve your health. Discuss access with your Doctors as seeing the same Doctor enables you to build up a good relationship. If you feel you need to see your Doctor, ask if they wouldn't mind you ringing to get a telephone appointment. Quick access can make a big difference in Heart Failure. It is very reassuring knowing you have that facility available to you.
4. Where Heart Failure is concerned, it is key to have the right GP, which in turn helps the self-management process.
5. Work with your Doctor if they have suggestions e.g. on healthy lifestyle options, different medications. Do not dismiss this as they may offer a good solution to help improve your condition.
6. Heart Failure patients are just normal people and normal people have normal problems. A good relationship with your Doctor and GP practice will no doubt be better for you.

What About Welfare Rights and Benefits?

We want you to know that we understand this can be a tricky part of managing your life going forward. We know through our own experiences that you can get what you deserve and that being comfortable and knowledgeable about the system is significantly helpful.

You will also be aware that the benefit landscape is changing all the time, therefore we will keep this page light on information whilst pointing you to the correct websites.

For further information, please visit the government website:

www.gov.uk/browse/benefits

The Citizens Advice Organisation may also provide advice:

www.citizensadvice.org.uk/benefits/

If you or your carer require additional input, support or equipment to enable you to manage, please visit the following website where you will be directed to social services in your area for a free assessment:

www.gov.uk/apply-needs-assessment-social-services

When making a claim for any benefit, it's important you give as much detail as possible as to how your ill health/ disability impacts your daily life. This includes the help and support you need to complete basic daily tasks (even if you do not get that help). You should also provide examples where you can; this should ensure the decision-maker gets a clear picture of the impact your health has upon you on a daily basis.

A Quick Pit Stop

Preparing for an appointment with your Doctor or Nurse

If you have an appointment with your Doctor or Nurse, it's important to ask questions that will help you understand your condition, treatment options, and ways to manage your health as well as informing the Doctor or Nurse how you feel with your Heart Failure. Preparing for a Doctor's or Nurse's appointment can help you make the most of your time and ensure you cover everything important. Scan the QR code to read our useful booklet.

Self-Manage Your Heart Failure Guide

Self-managing your Heart Failure is important. People find this guide insightful as to what self-management could mean for them. Scan the QR code to read our useful booklet.

My Team

Your Carer's Name:

Your GP's Name:

Your Cardiologist's Name:

Your Heart Failure Nurse's Name:

Your Carer's Telephone Number:

Your GP's Telephone Number:

Your Cardiologist's Telephone Number:

Your Heart Failure Nurse's Telephone Number:



How You Can Support the Charity

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.

Fund our educational support guides

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

Scan the code or visit: 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



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



Help Fund our Educational Podcasts

We have some superb educational podcasts on our YouTube and podcast channels. Patients and family members really find them useful. Our guests include world-leading experts in healthcare and our amazing patient volunteers talking about their experiences.

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



Consider a legacy donation 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



Other 'Marvellous Guides' in the series

All guides are written by patients and clinically validated for accuracy by leading UK Heart Failure specialists.

Scan the QR code or visit: pumpingmarvellous.org



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



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

Acknowledgements and Thank You

Professor Clare J. Taylor MBE Professor of General Practice at the University of Birmingham and a GP in the NHS

Professor Fozia Ahmed Consultant Cardiologist at Manchester University NHS Foundation Trust and NIHR CRN GM Cardiovascular Speciality Lead

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

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Search 'Pumping Marvellous Foundation' for our page



Search 'Help for Hearts' for our support community group



Can you help us by donating or fundraising?

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