

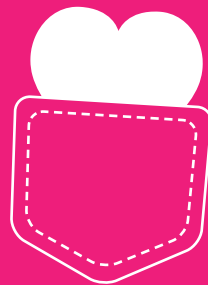
# My Marvellous Guide to Heart Failure with preserved Ejection Fraction

*A Patient's Story*



Authored by patients like you

HELPING PEOPLE LIVE BETTER WITH HEART FAILURE



# WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



If you have been given this booklet, it's because you have a diagnosis of Heart Failure. It is estimated that 50% of the 1,000,000 people living with Heart Failure across the UK have your type of Heart Failure, which is called **Heart Failure with preserved Ejection Fraction**, often referred to as HFpEF. This booklet is designed to help you understand about the condition, what treatments and care are available, who your team is, what may happen next and what you can do to help yourself.

We recommend that you explore some of the topics raised in this Marvellous Guide by visiting our website **[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)**, where you will find other Marvellous Guides or gain invaluable support from patients/carers at our closed support group on Facebook; simply tap into the Facebook search bar 'Help for Hearts' and apply to enter. If you prefer, you can also call the team on **01772 796542**.

All of 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 the 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.

**The development of this patient information has been funded by a grant from the Boehringer Ingelheim and Lilly Alliance. The Alliance had no input into the content of this booklet.**

# What Does the Heart Do?

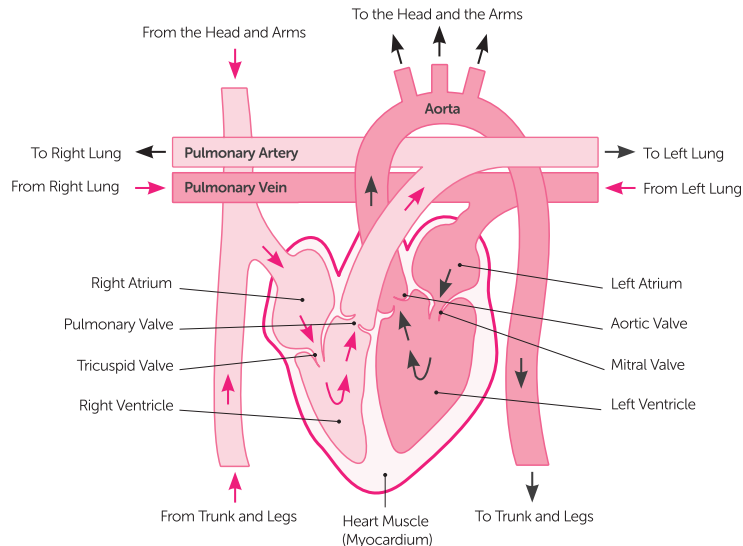
The heart is an organ that acts as a pump to send blood around the body. Your blood contains oxygen and nutrients that are needed by every part of your body in order to function. Clench your two fists together and that's about its size; it sits in the centre of your chest, tipping towards your left-hand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

The diagram (right) shows the inside of the heart, which is made up of four chambers.

Think of its layout as a motorway system. On the right-hand side, blood returns from delivering oxygen to the body via the veins (a motorway); the heart then pumps blood to the lungs (petrol station), picks up oxygen, and then returns to the left side of the heart via arteries (another motorway) to deliver blood to the body again.

The diagram shows gateways in the heart, called valves, that allow blood to move from one chamber to another. Every time this occurs, this is called a beat.

Similarly to a car, the heart also needs to be looked after in order to do its job effectively - for example, when the body's need for nutrients increases (such as when we are unwell or moving around), the heart has to be able to work harder and equally efficiently to do its job effectively.



## What is Heart Function?

Heart Function describes the amount of blood pumped out by the heart called the Ejection Fraction (EF). The Ejection Fraction refers to the amount of blood that is squeezed/ejected by the ventricle.

Preserved Ejection Fraction is normally defined as 50% or more.

This guide provides specific information about Heart Failure with preserved Ejection Fraction.

To learn more about the different types of Heart Failure, visit our booklet 'Know Your Type' in our Community Hub here: <https://qrco.de/WhatsmyTYPE> or scan the QR code.



## What is Heart Failure?

If you have been told you have Heart Failure, this means that your heart is not pumping as efficiently as it should in order to supply the body with the oxygen and nutrients that it needs. This causes the symptoms of breathlessness, fatigue and oedema that you may be experiencing.

No one likes the word failure — and neither do we. This is because the problem starts with the heart not functioning properly and is not because the heart is failing entirely.

## What Are the Types of Heart Failure?

There are 3 main types of Heart Failure:

- HFrEF - Heart Failure with reduced Ejection Fraction
- HFmrEF - Heart Failure with mid-range Ejection Fraction

- **HFpEF - Heart Failure with preserved Ejection Fraction**  
**In this guide we are talking about HFpEF specifically.**

# 1. What Is My Type of Heart Failure?

This guide is designed to help you if you have been told that your Heart Failure type is Heart Failure with preserved Ejection Fraction (HFpEF).

In some people, the left ventricle or left atrium can become abnormally stiff. This means that it can look as though the percentage of blood ejected is normal, but in reality the pressure inside the heart is higher to achieve this.

To explain, think about the difference between a thin-walled party balloon and a stiff-walled hot water bottle: to get them to be the same size, there would need to be a considerably higher amount of pressure to inflate the hot water bottle.

Similarly, HFpEF causes higher pressure not only in the left ventricle or atrium, but also in the pulmonary veins and pulmonary artery connected to the heart. Consequently, the back pressure from the pulmonary artery causes higher pressure in the right ventricle and atrium, and therefore higher pressure into the veins bringing blood back to the heart.

As a result of these back pressures, fluid is squeezed out of the blood vessels and into the various tissues they supply, where it is called oedema (fluid build-up), causing many of the symptoms experienced in Heart Failure, including:

- Pleural effusion or pulmonary oedema – fluid build-up in the lungs;
- Ascites – fluid build-up in the abdomen;
- Oedema – fluid build-up in the legs.

It is important to remember that the heart pumps blood to the entire body, meaning that Heart Failure can affect the body comprehensively; including the kidneys, liver, muscles, brain, and more. It is the combination of heart inefficiencies and their effect on the whole body that leads to the symptoms of Heart Failure. This is why it is important to look after your body as a whole to help you live better with Heart Failure.



# What Can Lead to a Stiffening of the Heart and an Inefficient Heart Pump?

## Causes arising from the heart itself

Abnormalities in any of the parts of the heart can lead to stiffening of the heart, including:

- Ischaemic heart disease – disease of the blood vessels which supply the heart muscle;
- Cardiomyopathies (diseases of the heart muscle) or myocarditis (inflammation of the heart muscle);
- Disease of the heart valves;
- Arrhythmias – a problem with the heart's rhythm. The most common type is Atrial Fibrillation (AF);
- Abnormalities in the pericardium (the lining of the heart).

**Visit our Community Hub**  
<https://qrco.de/CommunityHub>



## Causes arising from the rest of the body

Abnormalities in the heart's relationship with the rest of the body include:

- Abnormalities in the blood vessels. The most common is hypertension (high blood pressure in the aorta);
- Comorbidities (other illnesses) such as:
  - Diabetes
  - Lung diseases
  - Thyroid dysfunction
  - Being overweight – with the additional weight in the chest often increasing heart pressures;
- Kidney disease;
- Conditions that may cause deposits in the heart (for example amyloidosis, caused by the build-up of abnormal protein in organs and tissues);
- Drug treatments such as chemotherapy.

## 2. Education and Living with Your Heart Failure

### Why Has This Happened?

This is a question to ask your Doctor or Nurse. The most common causes are:

- A single or a combination of illnesses you may already have, such as: the narrowing or blockage of the arteries connected to your heart (caused by ischaemic heart disease), high blood pressure, diabetes, obesity and many others;
- Heart rhythm disturbances (arrhythmias). The commonest type of heart rhythm disturbance results in the heart chambers on the top of the heart (the atrium) beating abnormally. One of these abnormal rhythms is called Atrial Fibrillation (AF). If your heart beats too quickly or too slowly, it can result in or be associated with worsening Heart Failure. Your heart team will ensure that you have the appropriate treatments to optimise your heart rate in Atrial Fibrillation, and work with you to reduce risks associated with Atrial Fibrillation, such as having a stroke;
- Heart valves are one-way valves that let blood flow from one area of your heart to the other. Diseases of these valves can lead to a stiffening of the heart and Heart Failure with preserved Ejection Fraction;
- Cardiomyopathies (diseases of the heart muscle) can be genetic and alter the shape/function of the heart muscle. The commonest types of cardiomyopathies include dilated cardiomyopathy (the stretching of the heart muscle) or hypertrophic cardiomyopathy (thickening of the heart muscle);
- Amyloidosis – the build-up of an abnormal protein (amyloid) in the heart or other organs/tissues, causing the heart to work harder;
- Diseases of the pericardium (the lining of the heart), which can cause it to thicken or stiffen and stop the heart from filling;
- Sometimes we do not know the cause.

# Can the Causes of my Heart Failure be Treated?

This is a question you will need to discuss with your Doctor or Specialist Nurse.

It is important to remember that there are various treatments to support your heart to work more effectively, which can ensure that you live well with minimal symptoms. Understanding your Heart Failure and being actively involved in self-management is important for improving your quality of life.

## The 10 Pillars of Heart Failure with preserved Ejection Fraction

The 10 Pillars of Care below have been developed to support you to live as well as possible following your diagnosis of Heart Failure with preserved Ejection Fraction.





# 3. Self-Care Strategies

## Keep Moving (Exercise)

It is essential to keep moving. This can be exercise in any form, whether walking to the shops or getting up to make yourself a cup of tea. Keeping moving, no matter how big or small, may help improve and keep on top of your daily symptoms. Knowing your limits and setting manageable goals is the key to mental and physical well-being.

Exercise is just a part of the overall strategy for living well with your condition. As you read through this section, you can digest how you can better self-care. You can utilise all the information in this section or pick and choose what works for you.

The choice is crucial when it comes to self-care as you commit to embracing how you live your life in the future.

Search for Pumping Marvellous on YouTube where you'll find many videos produced by patients to help you.

<https://qrco.de/KeepMoving>



## General Tips and Advice

- Try and keep active; ask your health team if there are Heart Failure rehabilitation classes in your area. Every muscle responds well to exercise and your heart muscle is no different. It also ensures that your body generally works more efficiently, thereby easing the workload of the heart. Why not hear from our patient community on the benefits of attending cardiac rehabilitation?
- Eat a healthy diet and seek out support from your health team around any specific needs you have regarding weight management, etc.
- Give up smoking. There is a wealth of information and support provided by the NHS and charities.
- If your Heart Failure is due to excess alcohol intake then you must stop. The general recommendations are to drink within the recommended safe limits. The NHS and charities provide lots of information on managing alcohol consumption.
- You may be given instructions by your Doctor or Nurse on restricting your fluid intake; you will need to discuss this with them.
- Peer-to-peer support has helped many people with Heart Failure because sharing experiences has enhanced their ability to better look after themselves. Come and join the Pumping Marvellous Foundation's community for vibrant discussions about living with Heart Failure. All you need to do is go to Facebook and search for the 'Help for Hearts' private group, where you'll have to complete a few short questions to gain entry. We do this because it keeps our conversations private, safe and relevant to the community.

To join our community of people living with Heart Failure, scan here.

<https://qrco.de/OurCommunity>



## Welfare Rights, Benefits and Travel

We understand this can be a tricky part of managing your life going forward. We know that being comfortable and knowledgeable about some of the challenges you may face can be helpful in living with Heart Failure. Access to the benefits system is one of the most discussed topics in our community; as the benefits landscape is ever-changing, this page will direct you to all the correct websites and resources that will update this information.

For information about travelling, please visit the link at the bottom of this page.

For further information, please visit the government website:

[www.gov.uk/browse/benefits](https://www.gov.uk/browse/benefits)

The Citizens Advice Organisation may also provide information:

[www.citizensadvice.org.uk/benefits/](https://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](https://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.

You may wish to travel on holiday or for business. For advice specific to this, please visit our guide here:

<https://qrco.de/PatientGuides> or scan this QR code.



## The Art of Self-Management

Thus far, we have talked about how others can help you. However, this next section, arguably the most important, is about self-management: how you can help yourself to feel better.

We believe the key to self-management is a determined, positive attitude: a resilient, can-do approach to the ups and downs of living with Heart Failure.

It's understandable to feel overwhelmed. Our patients tell us of a range of emotional responses to their diagnoses, such as loneliness and even relief – that although they have felt very ill, at least they can now explore the care and support available. It may even be some time before you can come to terms with and vocalise your own feelings. Being diagnosed with Heart Failure is difficult enough to get your head around, and we understand that navigating the question of what care and support you can expect is another challenge entirely. Take your time, and take information in at your own pace.

For helpful reading material, visit the Support Guides section of our website's Community Hub, where you can read our **'HOPE'** and **'Walking a Day in My Shoes'** guides.

## The New York Heart Association Classification Scale

Another way of describing your symptoms that patients and Healthcare Professionals find useful is through the New York Heart Association (NYHA) Classification Scale. Think of your heart as a battery that supplies you with your day's energy: you have to use it wisely to get you through the day. How much energy you have in your battery is assessed on the New York Heart Association Scale, so you can gauge where you are in New York each day.

## So, Where Are You in New York?

Where are you on this scale today? Be aware that you may move around on the scale as your condition 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

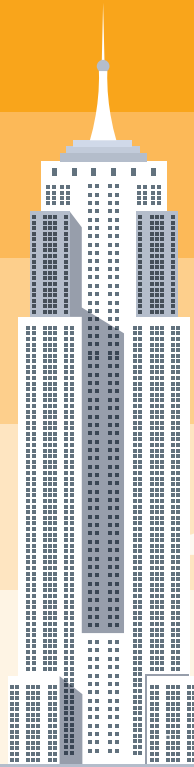
**"I get short of breath, tired, or have palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps."**

## 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 Marvellous Symptom Checker 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 Marvellous Symptom Checker has been put together by the Pumping Marvellous Foundation and developed with NHS Heart Failure teams 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:



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.

## 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.



## AMBER - STAY ALERT

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



You are feeling more breathless than usual.



Your 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.



## RED - TAKE ACTION

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



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.

## WHAT SHOULD YOU DO?

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



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



## What Tests Have I Had, Or Will Have to Undergo?

At this stage, it's important to work with your Doctor to give them the whole picture of your experiences and symptoms: think of it as a jigsaw that needs to be completed. In our experience, telling them everything will complete the picture more quickly.

Remember: being able to have open and honest conversations with your Doctor or Nurse, before diagnosis and throughout your treatment, is essential to self-managing your condition.

When discussing your tests and investigations, you may or may not encounter the following:

- 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 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 NTproBNP or BNP. The blood test may also assess your kidney or liver function, 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 an electrocardiogram (ECG) – a tracing of the heart, which can give a great deal information about your heart rate and whether your heart rhythm is unusual (arrhythmias).

- Echo (echocardiogram) - a scan using ultrasound to show how your heart is working. The ultrasound beams are similar to what is used in pregnancy ultrasounds. The echo scan is the most common test used to find out what your Ejection Fraction is. It is also a test that can show the team how other parts of your heart may contribute to your symptoms - such as whether your heart valves are normal.

You may have further complex investigations as you go along. Please visit the **Pumping Marvellous website** for more details.

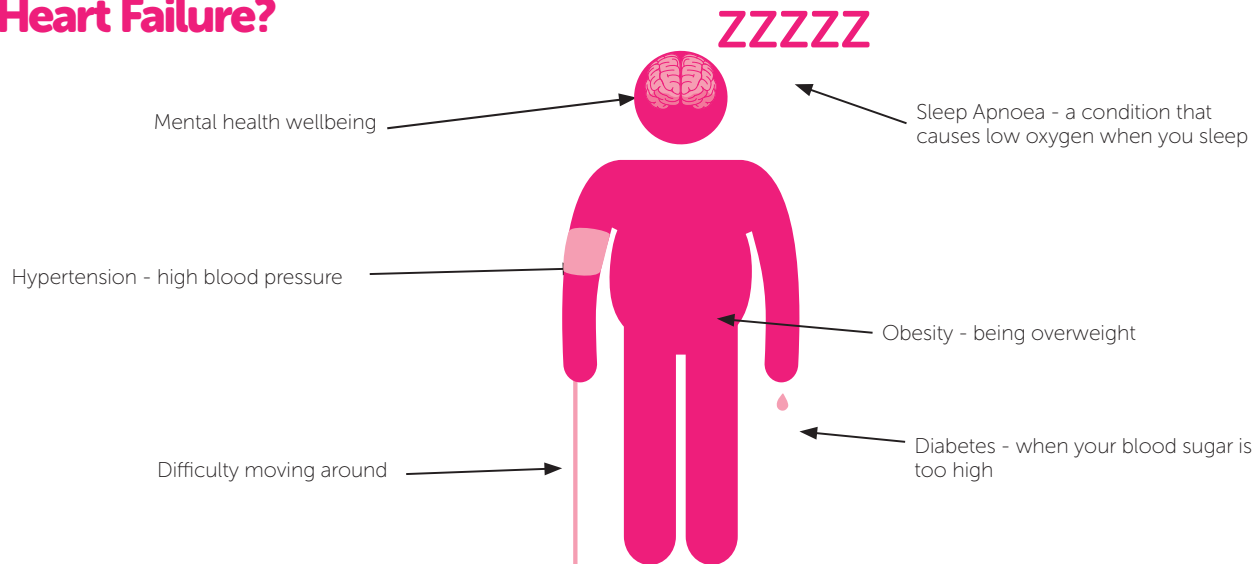
## Tips – Your Relationship with Your Tablets

If you are taking tablets, it is important that you understand what all of your treatments are for.

- 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;
- They all have a job to do, so don't worry if you have to take a number at once, the body can handle it;
- You are in charge of your tablets, so get into a routine that works for you. Understand what they are and how they are going to help you;
- A number of your medications may require adjustment and you will have your blood pressure checked and blood tests taken between each increase. It can be a tedious process, but stick with it, you will see the positive benefits;
- Try not to miss taking them and never stop taking them. Remember that your treatment is a partnership between you and your Doctor or Nurse. 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 Other Symptoms/Illnesses Can I Seek Support for When Trying to Improve My Overall Health and Live Better with Heart Failure?



Speak to your GP practice if you have any of these conditions and make sure you get help.

## Management of Your Other Conditions

If you have other illnesses (comorbidities), then you may be able to help your overall health by making sure these are as well treated as they can be. Get your other clinical teams to tell you more about your other conditions, and discuss if your treatments for these are the best they can be and who to contact if you need help. Alternatively, talk to your GP if you are not sure and ask whether all your treatments are the best they can be. They will also make sure that all the medications that you currently take, at the doses you are taking, are right for you.

## Understand, Monitor and Manage Your Heart Failure

You can help yourself by managing your Heart Failure. This section describes things you can do to help yourself and therefore is a bit more detailed than the other sections. It is important to monitor the main symptoms of Heart Failure to know if they are improving, staying the same or getting worse. The most common symptoms and what to do about them are easily remembered by the **BEAT** method:

- B** BREATHLESS
- E** EXHAUSTION
- A** ANKLE SWELLING
- T** TELL YOUR GP OR NURSE

For more information about the commonest symptoms and what to do about them, see our 'Marvellous Symptom Checker' available from your healthcare team or via our website: [www.pumpingmarvellous.org/community-hub/support-guides/](http://www.pumpingmarvellous.org/community-hub/support-guides/)

# 4. Peer and Social Support

## Getting the Most Out of Your Healthcare Team

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. You can apply his thoughts to all of your healthcare team relationships.

**"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 team (consisting of GP/DN/Pharmacist and HFSN if appropriate) 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."**

**\*Access to Heart Failure Specialist Nurses is variable across the UK.**

## 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.

Living with Heart Failure is a long-term project. If you have other conditions, it can sometimes become overwhelming. Below, you will find some of our knowledge to help you tap into support.

1. As Pierre indicated above, building a relationship with your healthcare team is essential. If you wish to find out what is important, please visit our Patient Charter through this <https://qrco.de/OurCommunity> or scan the QR code:
2. Equally important is having someone to talk to who understands what it's like to live with Heart Failure. This is called peer-to-peer support, a powerful and sometimes emotional experience. Generally, this can happen either as a one-to-one or in a group community setting, either online through something like Facebook or as a face-to-face patient group set up by a charity or healthcare professionals. Peer-to-peer support has transformed many thousands of people who live with the condition you do.
3. Due to Heart Failure symptoms sometimes being typically disabling, you may need to access the benefits system, which may be utterly alien to you. We get many questions about the benefits system and sometimes it can be confusing. We always signpost people to the Citizens Advice Bureau, which offers a fantastic and knowledgeable service. All you need to do is go to their website, which is very easy to use: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)
4. Never be afraid to ask questions or ask for help. Try always to communicate your feelings, try not to bottle anything up, and talk to someone; if they can't help, they may know somebody who can.
5. Learn to understand your conditions. Try to learn what makes them easier to live with and how to manage your symptoms. This is why you should endeavour to have a good relationship with your healthcare team, carer and, if possible, your peer-to-peer support, whether one-on-one or as a group. What is very satisfying is when you have talked about a problem, and the knowledge you gain is also passed on to other members of the support group.



# 5. Cardiac Rehabilitation

Heart Failure affects more than just the heart; it affects all of you. Regular exercise improves your fitness and helps to improve the way your muscles and heart work. Remember that exercise can be as simple as regular walks or as part of a cardiac rehabilitation programme.

## What is Cardiac Rehabilitation?

Your cardiac rehabilitation team can offer you numerous ways to support your journey to recovery (back to normality), one of which is an 8-week progressive exercise program, usually within a gym, community setting or maybe through your smart device. Alongside this, you will be supported with nutritional advice and guidance to help you to better understand how certain foods affect the body, empower you to achieve your long-term goals and best manage your overall health.

## What Can I Expect?

Your program will be a personalised exercise plan considering your medication, fitness levels and comorbidities. The team will use different approaches to your exercise sessions, such as cardiovascular, muscle conditioning and functional training. These are extremely important and tailored specifically to your goals and abilities.

## How Can I Access Cardiac Rehabilitation?

Cardiac rehabilitation is essential to helping you to live better with Heart Failure alongside medications used to manage your symptoms; when used together, evidence shows that cardiac rehabilitation can impact your quality of life/wellbeing. It would be beneficial to request a referral to a cardiac rehabilitation programme via your healthcare team (e.g. your Consultant, GP, or Heart Failure Specialist Nurse). Do consider self-referral if it is an option in your area. Scan the QR code to access videos from the University Hospitals of North Midlands' (UHNM) cardiac rehabilitation team.

Remember: exercise can be done even if you can't get up and walk around. Ask your cardiac rehabilitation team or gym about these exercise programmes; if your local cardiac rehabilitation team does not have an exercise programme for your HFpEF, talk to your Cardiologist or GP.

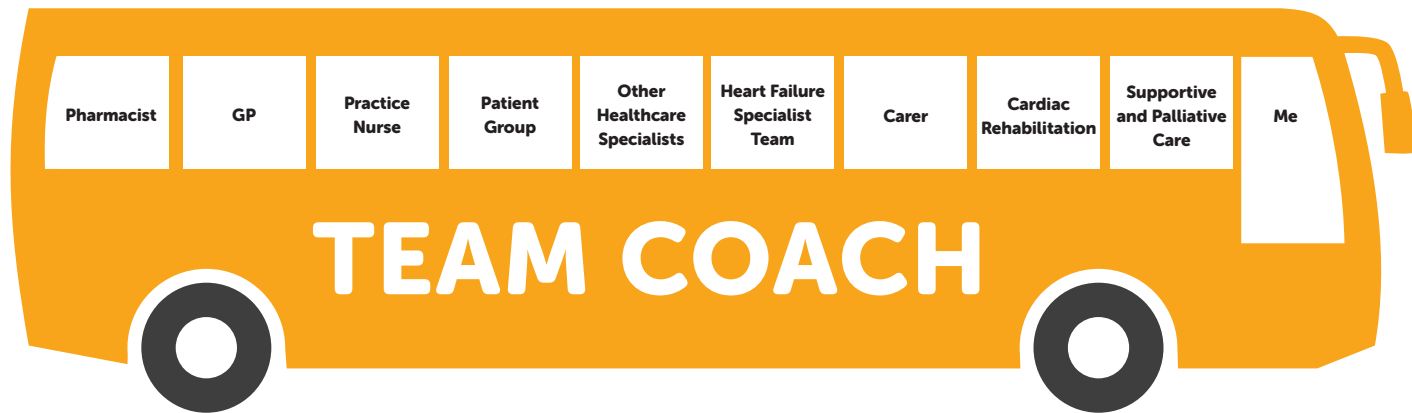
Cardiac rehabilitation is an essential part of NICE/SIGN guidelines, which show how care and treatments for people living with Heart Failure across the UK should be offered.



## 6. Access To Multi-Disciplinary Team

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

It's also important to know who and how to contact when your symptoms are worsening and your self-management isn't working—fill out your team's details nearer the back of the book.





## Cardiac Rehabilitation

Cardiac rehabilitation is a programme you may be referred to which helps you to learn about living better with Heart Failure. It includes a structured exercise programme and advice on your nutrition, self-management and lifestyle.

## Carer

A carer is defined by the NHS as: 'Anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction, and cannot cope without their support'. A carer can also be a paid carer. Carers are a significant part of supporting you to live better with your condition. It is important to remember that this is a partnership approach where there is give and take between both parties. Carers also have needs and require a good quality of life: respecting this is essential.

## GP

It is important you have a good relationship with your GP and their team in the surgery. They are responsible for your overall care and probably play a really big part in how all your care is coordinated. They are usually the first call for tests and investigations and refer on to other more specialised services if you need them. They are also responsible for prescribing all your medications.

## Heart Failure Specialist Team

Your Heart Failure team may include a number of different professionals such as a Consultant Cardiologist, GP, Care of Elderly Consultant, Specialist Nurses, Allied Health Professionals, etc. Their role is to help optimise your treatments and care.

## Me

You are the most important person. Never forget this is about you and your family. The decisions that are made for you or with you are about you. Therefore, never forget this is your health and you have a responsibility for this. It is in your best interest to have your whole team bus work like a well-oiled machine. Read our Patient Charter <https://qrco.de/PatientCharter>, to help put all of this into context.



## Other Healthcare Specialists

If you have other conditions e.g. diabetes, high blood pressure, or podiatric, your GP or specialist teams (consisting of multi-disciplinary specialists) may need to monitor you. It is important that you unite these professionals, ensuring you are able to receive optimised care/advice to aid your self-management.

## Patient Groups

Patient groups are necessary to help with essential peer-to-peer support. The Pumping Marvellous Foundation runs its community through Facebook here: <https://qrco.de/OurCommunity> or scan the QR code. There may also be local patient support groups available that are probably face-to-face. Ask your healthcare team for advice on this.



## Pharmacist

Pharmacists are experts in medicines and can explain why you may have been prescribed a particular medication; they can support monitoring and regular review to ensure the right dose is prescribed to avoid predisposing to harm. The Pharmacist will ensure the person gets the best from their medications without experiencing side effects; they can also support longer-term adherence to medication regimes and can address questions a person might have about their medicines.

Pharmacists optimise medication therapy; they are experts in drug interactions and dosages, patient educators, and work collaboratively with other members of your healthcare team to prevent medication errors and improve how you live with your conditions.

## Practice Nurse

A crucial team member who is usually the first line of treatment and is somebody who may have invaluable local knowledge to signpost or refer to services that may help you. It is very important to communicate with your Practice Nurse whether your symptoms are getting better, staying the same or getting worse. Use our **BEAT** method (**B**reathless, **E**xhaustion, **A**nkle Swelling, **T**ime), indicating when to notify your GP/Nurse regarding changes in your symptoms.

## Supportive and Palliative Care

Supportive and Palliative Care is a multi-professional approach that aims to enable people to live well following a lifelong diagnosis such as a Heart Failure. It should be considered alongside the very effective treatments we now have for Heart Failure, to support minimising any ongoing unmet physical, psychological, psychosocial and/or carer needs. Read the section about Supportive and Palliative Care further on in this booklet.

## 7. Address Reversible Causes

We explained in section 1 'Education and Living with your Heart Failure' what the potential causes for your HFpEF may be. Your Cardiologist or Specialist Nurse will tell you whether there is a specific cause that has led to your HFpEF or (as in most cases) whether there may be many causes and many potential treatments including all of those in the other 10 Pillars of Care.

## 8. Non-Medicine Management

The management of Heart Failure is not just about taking medicines: it involves a whole view of you as a person. You may find this daunting at first, but as you start managing your life you may find it becomes less daunting as you get used to living with Heart Failure. There is no single solution to living well with Heart Failure; however, each little step goes a long way to benefiting and impacting you positively.

### Typical aspects you many need to think about:

- If you have heart valve disease;
- If you need a pacemaker;
- If you need corrective surgery.

Remember: optimising good diet, exercise and good mental health whilst making sure all of your other conditions are managed well is very important. Good self-care and knowledge of red flag symptoms is important because when you feel out of control it alerts the healthcare team that you are in need of help.

Red flag symptoms are symptoms where it is time to seek help or advice. These can be the symptoms in BEAT HF, explained on page 19 and also in the red section of your symptom checker on page 15.

## 9. Medicine Management

### Diuretics (Water Tablets) to Reduce Symptoms and Fluid Retention

Diuretics (water tablets) can help if you show evidence of fluid retention caused by a 'stiff' heart; the most common are furosemide, bumetanide or bendroflumethiazide. Diuretics are useful at the lowest dose that your Doctor feels that you need to control symptoms caused by fluid build-up in areas such as the lungs, tummy, legs and ankles. Your team will monitor you closely to ensure:

- Your dose is tailored to you and your symptoms. Over time, this may require ongoing adjustments to your dosage in response to changing symptoms;
- Any changes to your water tablets are monitored by blood tests to measure the impact of these tablets on minerals including potassium or sodium, along with your kidney function.

### SGLT2i Medications

SGLT2 inhibitors are an important addition to the treatment of symptomatic chronic Heart Failure with preserved Ejection Fraction. They are:

- Well tolerated by patients;
- Usually prescribed by a Doctor (Cardiologist), Heart Failure Specialist Nurse or Pharmacist.

SGLT2 inhibitors are a group of medicines used to treat Heart Failure, as well as other diseases such as diabetes, and now symptomatic chronic Heart Failure with preserved Ejection Fraction. They may also be called sodium-glucose co-transporter 2 inhibitors or simply ‘-gliflozins’.

### What do they do?

SGLT2 inhibitors have shown to benefit patients with Heart Failure caused by a pumping problem with their heart. If a patient is experiencing Heart Failure symptoms despite being on optimised therapy, a GP may, on the advice of a Heart Failure specialist, prescribe an SGLT2 inhibitor as an additional medication to their standard treatment. In addition to improving symptoms, clinical trials of SGLT2 inhibitors have shown a reduced possibility of being admitted to hospital with Heart Failure, alongside an improved length of life.

### Other reasons for being prescribed

In insufficiently controlled type 2 diabetes, SGLT2 inhibitors are prescribed to reduce blood sugar levels. Clinical trials of SGLT2 inhibitors have shown reduced admissions to hospital with Heart Failure, and in more recent trials have also shown to benefit patients with symptomatic chronic Heart Failure with preserved Ejection Fraction, despite being optimised on standard Heart Failure medication.

### What are the most common side effects?

SGLT2 inhibitors are well tolerated. Common side effects 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.

## How do I take them?

You may need blood tests to monitor how you react to the medication, mainly concerning kidney function and blood sugar levels. If you already have diabetes, some adjustment to your usual diabetic medicines may be necessary to ensure that your blood sugar levels do not go too low. Dapagliflozin and empagliflozin, for example, are both one-tablet-per-day medicines and you may take them any time of the day, but it is best if you take them at a regular time each day. Dapagliflozin and empagliflozin can be part of your Sick Day Rules. Please discuss this with your healthcare professional. You can access our Sick Day Rules guide here: <https://qrco.de/SickDayRules> or scan the QR code.

**Acknowledgement – We would like to thank Dr Jim Moore, GPSI Gloucestershire Heart Failure Service and President of the Primary Care Cardiovascular Society for his review of this section about SGLT2 inhibitors.**

# 10. Supportive Palliative and End-Of-Life Care

## What is Supportive Palliative Care?

Palliative Care is a multi-professional approach that aims to enable people to live well following a lifelong diagnosis such as Heart Failure. It should be considered alongside the very effective treatments we now have for Heart Failure, to support minimising any ongoing unmet physical, psychological, psychosocial and/or carer needs.

Contrary to existing belief, Palliative Care can be considered at any time following a diagnosis of Heart Failure, and may include end-of-life care as appropriate. It is important to know that Palliative Care has much more to offer throughout. Your Heart Failure and primary care teams will address most of your Palliative Care needs.

Care for people who are approaching the end of their life is only one component of Palliative Care. Being offered Palliative Care does not mean



end-of-life is approaching soon; rather, Palliative Care is something much broader and can last years.

Palliative Care may be considered alongside active Heart Failure treatments; as Heart Failure is a lifelong chronic condition, you will require medications and other treatments throughout. As with all long-term conditions, you are likely to experience periods where you feel as if nothing has changed, and at other times you may have periods where you feel less well. Most people are likely to need adjustments to their treatment plan in response to changes in their condition. This may include Palliative Care therapies to support any changing unmet needs. Palliative Care may also be considered alongside more advanced treatments such as mechanical support or cardiac transplant.

For further reading, please visit <https://qrco.de/Palliative> or scan this code to read our booklet 'Supportive Palliative Care in Heart Failure — What May Matter to You'.



# One Step at a Time

We hope that our Marvellous Guide to HFpEF has triggered thoughts around some of the questions you may have. We know this is not a position you want to be in but it's about taking small steps, which is a good thing. You may never have had to deal with something like this but if you so wish, then self-management can be the key to a better life and enable you to find your normal again.

This may be the start of your journey so if you need help do seek out further advice from your Healthcare Professional or visit our website:  
[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)

## Other Marvellous Guides in the Series

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

**Please scan this  
QR code with  
your smartphone:**



**Or visit  
[pumpingmarvellous.org](http://pumpingmarvellous.org)**



# The Wonders of Social Media

At Pumping Marvellous, we know how important it is for patients to get support from other people who have Heart Failure, to share experiences, knowledge, feelings and emotions, the negatives and positives of Heart Failure - and yes, there are positives. People find successes in Heart Failure as they learn to manage the challenges of Heart Failure. Pumping Marvellous has looked at new and exciting ways of providing patient-to-patient support. Why don't you give some of them a try? Search 'Help for Hearts' on Facebook or search 'Pumping Marvellous' on YouTube, as well as visiting the Pumping Marvellous website. In everything we do, you will find rich channels of support to help you manage your Heart Failure better.

**Good luck, good health and keep those positive pants on!**

## Important Pumping Marvellous Contacts



Website - [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)



Office Tel - 01772 796542



Facebook Support Community - Search 'Help for Hearts'



Email - [hearts@pumpingmarvellous.org](mailto:hearts@pumpingmarvellous.org)



X (Twitter) - @pumpinghearts



YouTube - Search 'Pumping Marvellous'

# My Team

**Your Carer's Name:**

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**Your GP's Name:**

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**Your Cardiologist's Name:**

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**Your Specialist Nurse's Name:**

---

**Your Practice Nurse's Name:**

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**Your Pharmacy's Name:**

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**Your Carer's Telephone Number:**

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**Your GP's Telephone Number:**

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**Your Cardiologist's Telephone Number:**

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**Your Specialist Nurse's Telephone Number:**

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**Your Practice Nurse's Telephone Number:**

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**Your Pharmacy's Telephone Number:**

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## Other Team Details

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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.*

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**Craig Gilchrist**, Exercise Physiologist and Nutritionist, University Hospitals of North Midlands Cardiac Rehabilitation Team

**Yvonne Millerick**, Heart Failure Palliative Care Nurse Consultant, NHS Greater Glasgow & Clyde, Glasgow Caledonian University, Scotland

**Georgina Newnham**, Heart Failure Advanced Nurse Practitioner, Isle of Wight

**Nick Hartshorne-Evans**, CEO and Founder of the Pumping Marvellous Foundation

**All the patients living with HFpEF who have helped**

# Contact Us



01772 796542



[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)



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Search 'Help for Hearts' for our support community group



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