

A Marvellous Guide to Medicines for Heart Failure

A Patient's Story...



WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



Welcome to the “Marvellous Guide for Medicines for Heart Failure”. Over the last twenty years there have been significant developments in the treatment for heart failure, and these have been shown to improve your quality of life and extend your life expectancy. There has also been tremendous development in care and services that will support you going forward to live well with heart failure.

We would like to start off and thank our team of patient educators who have helped create this guide. They have given their insights into a positive life they have achieved because of heart failure medication. Thank you also to the wider patient community on our closed Facebook group who, on a daily basis, give peer to peer support and share their experiences of what it is like to live with heart failure and the role that their medicines play. If you search “Help for Hearts” in Facebook you too can join the community. Finally, thank you to the members of our Clinical Board who have ensured the clinical information contained in the guide is correct.

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PLEASE NOTE: This booklet should not replace and/or substitute the interactions with and advice you are given from your Healthcare Professional. If you have any concerns about your condition then do discuss them with your Healthcare Professional at the earliest opportunity.

Your Journey

From the moment you're diagnosed with heart failure you're opened up to a whole new world. Changes seem to come at you all at once. You will experience new terminology, tests, scans, lifestyle changes and a bewildering array of medication. You'll also hear many people's opinions on what you should be doing so as you can see there's a lot to take on board and it's easy to feel overwhelmed. At the Pumping Marvellous Foundation we believe that everyone needs a hand getting onto this first step on your journey to help you live well with heart failure.

Our patient educators have shared with us their experiences of being told that they had heart failure. Some received little or no information on their condition or how it was to be treated. Others say they just couldn't take in what was being said, due to shock or because they were so unwell. You may wish to know everything right from the beginning, for others the bare minimum of information is all they feel they can cope with.

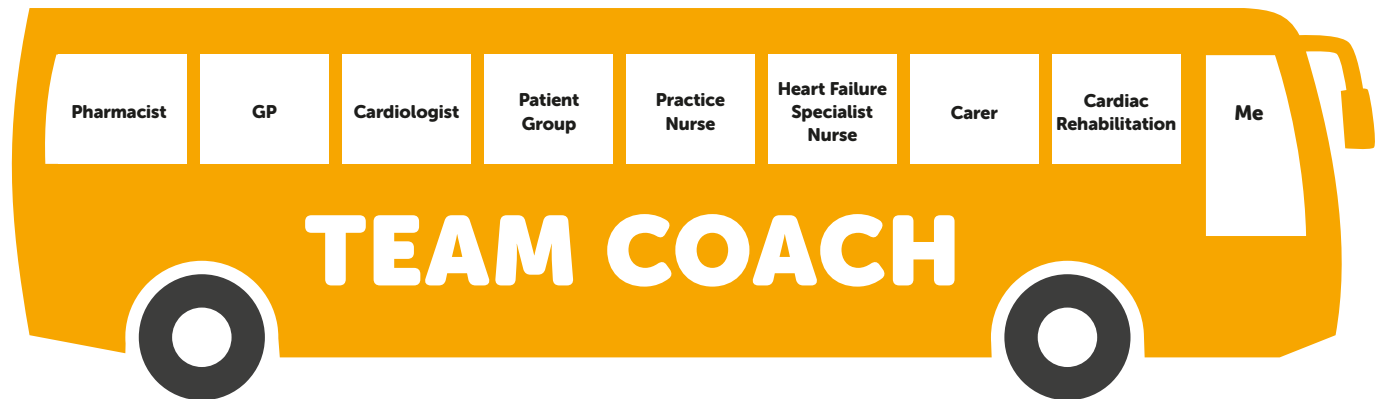
At the Pumping Marvellous Foundation we appreciate everyone approaches their diagnosis and management of their condition differently. This guide is here to support you in understanding the array of medication that may have been given to treat your heart failure. Our community of patients often tell of the shock they get on receiving 'a bag full of pills'. Use the guide as an initial introduction to your medicines, or an ongoing resource to support you with managing your heart failure. Managing your heart failure is important and our 'Marvellous Pocket Guide to Heart Failure' is a great way of grasping some ways you can live well with heart failure and our 'Marvellous Map of Heart Failure', which explains the care and treatment you should expect on your journey with heart failure. Ask your heart failure team for a copy.



See our Marvellous Map to Heart Failure to explain the care and treatment of heart failure in the UK

Your Marvellous Support Team

Our community of people living with heart failure tell us of the marvellous care and support that they receive from a host of people that make living with heart failure a positive experience. Knowing who is in your team can make this a winning experience for you. To know who they are and the role they play is important. Individual members of your team may differ from someone else's, but it is your team to build a partnership with. You also have a whole community of patients like you who have similar challenges and concerns that you may be experiencing. Search "Help for Hearts" on Facebook to find our group and join.



The core of your “Marvellous Team”

Taking your medication is not a one-way thing. Being told what you must take, and just taking it, is not great. If somebody told you to put your hand in the fire, would you not want to know why before you did? Taking your medications is a partnership with whoever is prescribing your medication. Developing that relationship with your heart failure team is key and will lead to you gaining confidence in the medication.

Cardiologist with a special interest in heart failure

You are likely to have a Consultant who specialises in the heart, they are called a Cardiologist. Your Cardiologist should also be specialised in heart failure.

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. Many Specialist Nurses will be able to examine you, prescribe your medication, order and interpret investigations, support you with some of the challenges of your condition and direct you to other services you may need. If you have not got a Heart Failure Specialist Nurse, ask your GP or Consultant if you can be referred to one.

Practice Nurse

Your Practice Nurse is often someone with whom you may already have a strong relationship. The Practice Nurse role is to support, monitor and treat you for any long-term conditions that you may have. If your heart failure treatment has been optimised and your condition is stable, then you may be discharged to the care of your GP practice. The Practice Nurse is an important member of your team and generally more accessible than your GP. They can monitor your condition and see you for regular reviews.

GP

Having a good rapport with your GP and practice is vital. Having a regular GP who knows and understands you and your condition is valuable as they tend to be more accessible than Cardiologists in hospitals. Your GP is often your first point of call; although your GP may not specialise in your condition, they can usually manage aspects of your care and refer you to a specialist service if needed.

Pharmacist (medicines expert)

An often overlooked key member of your team will be your Pharmacist, some of whom may work within the heart failure team that supports you. These Pharmacists may also be qualified to prescribe your medication. Pharmacists may also work within your GP practice. Your Community Pharmacist is an invaluable team member who will give you advice about your medication and advice on every day routine illnesses and what you can and can't take with regards to over the counter and off the shelf medications for colds and minor ailments.

Top tips from the people in the know!

Kindly put together by our marvellous patient educators

- If it's possible, have someone with you when you are first given your heart failure medicines, it helps if you can check back with someone who was there.
- Keep a list of your medicines with you all the time, your green slip form from your GP is often the best. Stick it on the outside of your fridge door.
- Learn the name of your drugs and what they do.
- Always talk with your heart failure team as to how your tablets are making you feel. If you are struggling they may have alternatives or different ways to take your existing medicines.
- Develop a routine for taking your medicines. Include a reminder system for taking your medicines that works for you, this may be an alarm on your phone, a tablet dispensing box or you can even get apps that will help you.
- Make sure you know what to do if you forget to take your medicines.
- Know what to do if you are having a 'sick day'.
- Understand and know the people in your team who are supporting you.
- Find a good local Pharmacist you can obtain your medicines from on a regular basis. They will get to know you and your treatment plan and can provide invaluable support and advice.
- Try not to Google your tablets, ask a member of your heart failure team if you have any concerns or things you wish to know. Revisit this guide to see if it has the answers you need.
- Give your medicines a chance to work, they may make you feel worse before they make you feel better.
- If it helps keep a diary of what you are taking and note any changes that are made.
- The responsibility for taking your tablets is down to you. You may need help from your carer but try and take charge of your medicines yourself, if your partner is unwell you need to know what to do.
- If you have to pay prescription charges then obtain a 'season ticket'. Details are in your pharmacy or if you enter "NHS prepayment certificate" on Google you will find how to apply. It's easy and it works out considerably cheaper if you have to take a number of medicines a day.
- Get support from the Pumping Marvellous Foundations, online community. Search "Help for Hearts" on Facebook.

Another helpful section from our Marvellous Patient Educators

- Don't forget to reorder medicines, develop a system that works for you.
- Don't forget medicines come in assorted colours and shapes. They may change from month to month as it often depends on who has manufactured your medicines. If you have any concerns, contact your Pharmacist.
- Don't share your medicines with your partner or friends, it is not safe to do so.
- Don't rely on others to manage your medicines, know how to do them yourself.
- Don't double your dose, if you have any problems then speak to a member of your heart failure team.
- Don't self-medicate, always discuss any issues with your heart failure team.
- Don't be frightened to ask or query any concerns with your heart failure team, they are there to support you and after all this is a partnership between you and them.
- Don't suddenly stop taking your medicines, it can be dangerous. If you have a problem speak to your heart failure team.
- Don't get disheartened at the number of medicines you have to take they are there to help. You should soon get use to them.
- Remember that the medicines you are taking have been shown to improve your quality of life and life expectancy.
- Ensure you have the contact details for your heart failure team handy in case you need to speak to them urgently.
- If your medicines are altered by a Doctor, Nurse or Pharmacist who aren't a member of your heart failure team, make sure you inform your heart failure team at your earliest convenience that your heart failure medicines have been altered.
- Store your tablets in a safe place.
- Check the label on the front of the packet of your tablet to make sure that they are the correct ones you have been prescribed. Count the tablets to make sure you have received the correct amount. If you have any problems speak to your Pharmacist.
- Make sure you know the name of the tablets you are on. This is called the generic name, not the brand name which is the manufacturer of the tablet.



The marvellous heart failure medicines

Here are the medicines that you are most likely to be prescribed according to NICE (National Institute of Health and Care Excellence) Guidelines. NICE produce guidelines for how you should be treated when you have heart failure. We have described what they do and the role they play in your care. We have included the most common side effects; however, you will find a comprehensive list of side effects in the leaflet that is found in all packets of your prescribed medications. People often react differently to medicines and some are able to cope with higher dosages of a specific medicine when others are unable to do so. With heart failure medication you may find that other medicines will change in order to get you on appropriate dosages of a particular medicine, or your heart failure team will alter the dose of your medicines either up or down if your symptoms alter. It sounds complex, and yes, it is, but as our patients say 'keep your positive pants on' as they are there to help.

The medications listed below are for when your heart is not pumping efficiently which is called **HF_rEF (Heart Failure with Reduced Ejection Fraction)**. If you have been informed that your heart doesn't fill and relax properly (**HF_pEF (Heart Failure with Preserved Ejection Fraction)**) then you may be prescribed water tablets which are called diuretics and other medications that will support your heart as a result of why your heart is failing to relax and fill adequately.

If you are not on any of the medications or a combination of them then discuss with your heart failure team, there may be very valid reasons why you are not on certain medication(s) but do ask if you have any queries or concerns.



ACE Inhibitors

These tablets are easy to remember as they usually end in 'pril' such as **Ramipril, Lisinopril, Perindopril, Enalapril**.

What do they do?

ACE Inhibitors ease the workload of the heart by relaxing the blood vessels around the body thus easing the strain on the heart. They have been shown to stop your heart failure getting worse, consequently they will improve your quality of life and help you to live longer.

Other reasons ACE Inhibitors are prescribed

They may be prescribed to reduce blood pressure and protect you from having a heart attack as they improve blood supply to the muscle of your heart.

What are the most common side effects?

You may experience a dry and irritable cough, this often settles down, however if it does fail to settle and is keeping you awake at night then tell a member of your heart failure team as they may be able to prescribe an alternative. They can make you feel dizzy, especially when you stand up as the medication does lower your blood pressure. Again, this often settles, take your time standing up as this often helps.

More unusual side-effects

If they cause your lips, mouth or face to swell, then contact a member of your heart failure team straight away. It may mean you are having a reaction to the medication, although it is rare you will need to get medical help. Other side effects are a rash or itching.

How do I take them?

You will have a blood test before you start the medication and each time your tablets are increased. Occasionally they may disturb your kidney function. They will always be prescribed at a low dose at first, with the aim to get you on the top dose which is the optimal dose for you. Usually you will be seen approximately two weeks after you are first prescribed them, have a blood test to check your kidney function and have your blood pressure checked just to make sure it hasn't dropped significantly. It can be a long process in order to get you on the top dose of ACE Inhibitor that your body can cope with. You may be advised to take them before you go to bed, as the reason is that if your blood pressure drops you will not notice it during the night. Alternatively, they may advise you to take them in split dosages as your body is able to cope with them better this way. As always do discuss with your heart failure team any concerns you may have.

ARBs - Angiotensin Receptor Blockers

These drugs work very similarly to ACE Inhibitors. They can be remembered as they often end in 'artan' for example **Candesartan**, **Losartan**. They have all the same aims, side effects and ways to be taken just like ACE Inhibitors, however the trial evidence is not so strong for them, but they may help prevent you getting a dry, irritable cough that some experience with the ACE Inhibitors.

Beta Blockers

These drugs are easy to remember as they usually end in 'lol' such as **Bisoprolol**, **Carvedilol**, **Nebivolol**, **Metoprolol**.

What do they do?

Beta Blockers help your heart to beat slower but stronger by the blocking of certain hormones such as adrenaline. They have been shown to increase your chances of living longer if you have heart failure.

Other reasons Beta Blockers are prescribed

They are also able to control your heart rate and help keep any rhythm problems of your heart under control. You may also have them prescribed if you have angina symptoms.

What are the most common side effects?

When you first start to take Beta Blockers they may make you feel tired and weary, but usually this settles down over a few days. They can make your heart rate slow down too much therefore you are usually checked over by your heart failure team after approximately two weeks to see how you are settling down taking them. If you begin to feel more breathless or feel as though you may faint, arrange to see a member of your heart failure team as soon as you can. They can make you feel dizzy and experience cold hands and feet. More rarely they can cause vomiting and diarrhoea, sleep disturbance or impotence. Do speak to your Clinician to discuss any concerns you may have. Remind your Clinician if you have asthma as occasionally Beta-Blockers may make your asthma worse.

How do I take them?

As with ACE Inhibitors, you will start off with a low dose of the drug and gradually have it increased until you are on the top dose, or a dose that you are comfortable with. It can be a lengthy process for some patients as they can feel a little worse until their body gets use to the Beta Blocker. So be prepared to give the drug a chance as we know that they are very beneficial to patients who have heart failure. You will have your heart rate and blood pressure checked each time you have your dose increased just to make sure that they haven't been adversely affected.

Diuretics or Water Tablets

You are likely to find yourself on water tablets or its formal name diuretics, and you may find you have to take more than one type of water tablet.

Mineralcorticoid Antagonists - MRAs

What do they do?

Spirolactone or **Eplerenone** are the drugs that fall into this class. They help prevent water and salt building up in the body and lower your blood pressure so protecting the heart. They also keep potassium levels in your blood at good levels. These drugs are prescribed to improve your symptoms particularly any swelling you may have in your feet, legs, stomach or fluid in your lungs. You are usually prescribed a low dose of MRA, however this may be increased if a large amount of fluid has built up.

Other reasons MRAs are prescribed

They may also be prescribed if there is congestion of the liver or low potassium levels because of hormonal problems in the adrenal gland.

What are the most common side effects?

Too high potassium levels and the function of the kidneys being affected. They may give you diarrhoea and Spirolactone may cause slightly enlarged and tender breasts in men, a condition called gynecomastia.

How do I take them?

When you first start to take these drugs, you will need to have a blood test every one to four weeks in order to check that your potassium levels and kidney function are not being adversely affected. Indeed, your Clinician will arrange for this blood test to be taken on a regular basis approximately every three to six months.

ACE Inhibitors/ARBs, Beta Blockers and MRAs are called “triple therapy” and are the cornerstone of treatment for people with HFrEF (Heart Failure with Reduced Ejection Fraction).

Other water tablets (Diuretics)

There are several other groups of water tablets that are prescribed in heart failure. Commonly prescribed are **Furosemide** or **Bumetanide (loops)**, and as an add on **Bendroflumethiazide** or **Metolazone** (thiazide). If you are prescribed a 'thiazide' then check with your heart failure team if they are to be a temporary or regular part of your medicines.

What do they do?

They are water tablets that help get rid of fluid that has built up in your body, but they do this in a different way. They work by helping the kidneys get rid of the fluid. They may make you pass more water, but they do make you feel better by getting rid of the fluid that is causing your feet, legs, and stomach to swell. They may help your breathing by getting rid of any fluid in your lungs.

What are the main side effects?

You will go to the toilet a lot more as you get rid of any extra fluid you may have, this is a good thing as it improves your symptoms. However, you may find it very troublesome so it is good to talk with your heart failure team on how you can take your tablets and how they can fit in with your lifestyle, for example, going shopping or having meals out. You may experience some lightheadedness or dizziness, experience cramp, particularly at night, or more rarely gout. If you experience any of these symptoms do discuss with your heart failure team.

How do I take them?

Your Clinician should discuss with you when it is best for you to take your water tablets, usually they are prescribed to take first thing in the morning. If your symptoms are becoming worse, they may suggest that you go into hospital and have the medication delivered via a drip, either as an inpatient, a day patient or in some areas, they are able to provide this treatment in your home. Ask what services are available in your area.

ARNI - Angiotensin Receptor Neprilysin Inhibitor

Sacubitril Valsartan (Entresto)

What do they do?

More recently, **Sacubitril Valsartan** has been given to heart failure patients. It works in two ways, by increasing the body's defences against heart failure and by blocking the body's natural systems which have a harmful effect on the heart. They are then able to relax your blood vessels, get rid of extra salt and fluid meaning the heart has less to do.

What are the main side effects?

The main side effects are very similar to **ACE Inhibitors** and **ARBs**. They do lower your blood pressure, so you may experience some dizziness. If you experience any swelling to the face, lips or tongue, any breathing or swallowing problems then seek medical help.

How do I take them?

Generally, you will have already been on **ACE Inhibitors** or **ARBs** before your Clinician switches you onto **Sacubitril Valsartan**. Again, it is a medicine that you will start on a low dose and then have it gradually increased. You will have a blood test before you start the drug and each time you have the drug increased just to check it hasn't affected your kidney function and potassium levels.

N.B. Entresto will replace an ACE or an ARB so you would need to stop taking these tablets before starting Entresto as they can't be taken together.

Ivabradine

What do they do?

Having the correct heart rate in heart failure is important. To do this, your team may introduce a medicine called **Ivabradine**. By slowing the heart rate, the heart needs to do less work to pump blood around the body, so that it can beat slower and stronger. If Beta Blockers have not controlled your heart rate sufficiently well, **Ivabradine** may be added, or if you haven't been able to tolerate a Beta Blocker then your heart failure team may prescribe **Ivabradine** instead.

What are the main side effects?

Your heart rate may slow down too much so you will be monitored closely when you start the medicine. You may get a headache or a feeling of dizziness. On rare occasions, patients have experienced some light or blurred vision. Discuss any issues or concerns with your Clinician.

Other medicines used in heart failure

We have discussed the most likely medicines you will find yourself on, however, here are some other medicines that you may find are recommended to you.

Amiodarone - This is used to treat an irregular heart rhythm. It is a very useful medicine but can have unpleasant side effects. Your skin may become photosensitive; therefore, you will need to use a high factor sun block, even on a cloudy day. Blue or grey marks may also appear on areas exposed to the sun, particularly the face. Nausea and lethargy may be an issue, as well as blurred vision. Your heart failure team will also ensure that you have routine blood tests to ensure your liver and thyroid functions are not affected. They may even request a chest X-ray as deposits have been known to build up in the lungs. Patients have also noted a metallic taste or have experienced difficulties in sleeping, occasionally due to nightmares.

Digoxin - If you have a normal heart rate and heart rhythm, and despite treatment, you still experience symptoms of heart failure you may be prescribed **Digoxin**. **Digoxin** improves the contractility (squeezing) of your heart and slows your heart rate. Common side effects include a heart rate that is too slow, nausea, vomiting or loss of appetite.

Hydralazine and Isosorbide Dinitrate (H-ISDN) - If you are not able to tolerate an **ACE Inhibitor** or **ARB** then you may be prescribed this drug, and although it works in the same way it is not as effective. It may cause some dizziness or lightheadedness.

Glyceryl Trinitrate Tablets and Spray

Glyceryl Trinitrate (GTN) is prescribed to relieve angina. Angina is pain, discomfort or tightness in the chest due to narrowing of the arteries supplying the heart muscle with blood (coronary heart disease).

GTN comes in tablet and spray formulations that can be put on or under the tongue for quick onset. They are used to provide rapid relief from angina symptoms. They can also be used for when angina pain is expected to happen, such as before exercise that is likely to cause chest pain (for example, before climbing stairs). GTN works in two ways. It mainly relaxes blood vessels in your body (causing them to widen) and this reduces the strain on your heart, making it easier for your heart to pump blood around your body. It also, to a lesser extent, relaxes and widens blood vessels in your heart (coronary arteries), which increases the flow of blood to your heart muscle. The following tips for using GTN are adopted with permission from the 'GTN Card Project' by Dr Rani Khatib and the Cardiac Rehab Team at Leeds Teaching Hospitals NHS Trust.

GTN Tablets

10 Minute Rule: If you experience chest pain (angina), chest ache or chest discomfort, you should: Stop what you are doing, sit down and rest. If the pain persists, place one tablet under your tongue and wait 5 minutes. If the pain is still present, use another tablet and wait 5 minutes. If the pain is still present, ring 999 and unlock your door. If your pain gets severe at any stage, or if you feel unwell (e.g. dizzy, short of breath, sweaty) call 999 immediately. It is wise to always carry the details of a next of kin should you experience any difficulties.

GTN Spray

GTN should be sprayed under or on your tongue. Sit down before using as GTN may make you feel lightheaded. Carry your GTN at all times and don't hesitate to use it. Keep several GTN bottles, e.g. at home, at work, in a bag. Your healthcare team may advise two sprays per dose. If the spray was not used for a long time, spray it in the air a few times before using. (Check expiry date.)

10 Minute Rule: If you experience chest pain (angina), chest ache or chest discomfort, you should: Stop what you are doing, sit down and rest. If the pain persists, use one spray under your tongue and wait 5 minutes. If the pain is still present, use another spray and wait 5 minutes. If the pain is still present, ring 999 and unlock your door. If your pain gets severe at any stage, or if you feel unwell (e.g. dizzy, short of breath, sweaty) call 999 immediately. It is wise to always carry the details of a next of kin should you experience any difficulties.

Anticoagulant Therapy

Anticoagulants help prevent blood clots. They are given to people who have a high risk of developing blood clots, in order to reduce their chances of developing a stroke. Anticoagulants work by reducing the clotting ability of your blood. They are sometimes called blood thinners but they don't actually thin your blood.

Warfarin

Warfarin lowers the risk of blood clots forming in your body or treats existing clots that have formed. Certain conditions may result in you having a higher risk of forming clots like **AF (Atrial Fibrillation)**. Many patients with atrial fibrillation or a heart valve condition are recommended to take **Warfarin** to reduce their risk of forming clots, which may then lead to a patient experiencing a stroke. It needs to be given to you in a very precise manner. Therefore, you will need to have regular blood tests to ensure that your blood becomes neither too thin (so that you will bleed excessively) or not thin enough (so that it does not prevent clots forming). If you are prescribed **Warfarin**, you will have regular blood tests to ensure the clotting factor in your blood is at the correct level. This is called your INR. You may be asked to attend the clinic at your hospital, GP's, or at special clinics in the community. The blood test involves a small prick to your finger and the result will then dictate how much Warfarin you need to take on a daily basis to ensure your INR level is at the right target, called the therapeutic range. When first starting on Warfarin, it can take some time to achieve this and you may require your blood to be checked weekly. However, as everything stabilises, it may be a number of weeks before you have a further check.

Alternative therapies to Warfarin (DOACs)

Recently new medicines have been developed as alternatives to **Warfarin**. **Dabigatran, Rivaroxaban, Edoxaban** or **Apixaban** are all anticoagulants, but work in a slightly different way than Warfarin. The advantage to these drugs is that you do not require regular blood tests, however, you will need your kidney function testing one or twice a year.

Statins

Statins are a group of medicines that aim to lower the level of low-density lipoprotein - LDL (bad cholesterol) in the blood. They do this by reducing the production of it in the liver. You will be prescribed Statins if you have high levels of LDL, as it can lead to hardening and narrowing of the arteries.

For further information on the above drugs or any drugs that have been prescribed to you, we advise you visiting NHS Choices at <https://www.nhs.uk/pages/home.aspx>

We know that it can be a challenge to take so many different medicines, but your treatment is a partnership between you and your heart failure team. Remember if you have any concerns about your medicines then do discuss them with your heart failure team, it may be that they are able to adjust, provide an alternative or gave some broad support about your therapy.

What patients and Clinicians do know is that they are a very important part of you living well with heart failure.



Heart Failure in Hospital

Our patient community tell us about how challenging it can be if they need to be admitted into hospital due to their heart failure. Hospital may be the place when you are first given a diagnosis of heart failure or you may have to be re-admitted to manage and improve your symptoms. Most people wish to avoid being admitted into hospital, however it may be the best place to be in order to get the care and treatment you need. It can be a traumatic and anxious time for a patient and distressing for their families like any hospital admission.

When most patients are admitted into hospital it is often because of acute heart failure, whereby the heart is struggling to pump efficiently and has led to severe symptoms such as breathlessness due to fluid in the lungs, considerable swelling to the feet, legs, stomach, and other organs such as the kidneys and the liver struggling to do their job as a knock-on effect of the heart not working adequately. The aim of treatment is to treat any underlying causes that have put pressure on the heart such as a heart attack or a rhythm problem with the heart. Ultimately, it's important to get rid of the excess fluid that is giving you such distressing symptoms.

To get the best care, we recommend that you ask to be looked after in a cardiology/heart ward.

It is important if you have a Heart Failure Nurse or a heart failure specialist team, to ask the hospital staff to let them know you have been admitted into hospital. If you have somebody with you like a carer they can inform them as well on your behalf.

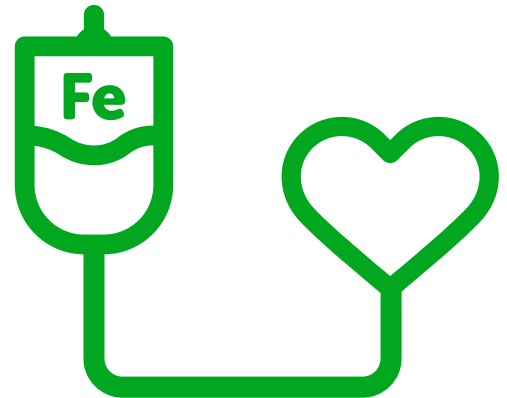
The hospital team may first give you some drugs in your vein to relax you and to relax your heart, this is likely to be **Morphine**, it can make you feel a little woozy, and also something to prevent any feelings of nausea that it can give you. Your heart failure specialist team in hospital will look to Diuretics (water tablets) to get rid of the excess fluid. If you have had heart failure for some time they may need to increase your normal dose of Diuretics or add in a different type of Diuretic. This may be in the form of tablets, or a drip which delivers the Diuretics via a needle that is placed into a vein in your arm or a very fine needle that is placed just under your skin, usually in the stomach. You may find yourself on a mixture of a drip and Diuretic tablets. It is likely that you will pass considerable amounts of urine as you get rid of the excess fluid, so speak to the team to work out the best way for you to cope with this. Expect to have many blood tests during this time, as your team will want to know how your treatment is affecting your kidneys. You should expect to have your tablets reviewed, possibly stopped or changed if you have had heart failure for some time. If you are newly diagnosed, expect to be started on an array of tablets that will tackle your symptoms. Look up the tablets that are prescribed to you in hospital in our section in this guide on heart failure medication.

Iron Deficiency in Heart Failure

Iron is used to make red blood cells which help store and transport oxygen in the blood to all parts of your body. Iron deficiency is a lack of iron and can lead to Anaemia. It is beginning to be understood that iron deficiency is often present in heart failure.

We have now begun to realise that some patients with heart failure are unable to use iron correctly, either being unable to absorb it or being unable to use it for what the body intended. This may make the symptoms of heart failure worse. Looking at the link between iron deficiency and heart failure is part of ongoing research. You may find that your Clinician will check your iron levels particularly your ferritin levels. Ferritin is the protein that stores iron in the body. If your ferritin levels are found to be low, your healthcare professionals may arrange for you to receive iron therapy treatment. This involves having an intravenous infusion (drip), possibly over a number of sessions either in hospital or day clinic.

N.B. Normal Ferritin levels in patients with heart failure are different to those without heart failure. This is one of the reasons why Healthcare Professionals may not spot iron deficiency in heart failure patients because they look at the wrong reference range.



What to ask before you are discharged from hospital

Patients tell us how they have left hospital with little idea of their condition, and little understanding of their medication. You may still be feeling unwell and find it difficult to concentrate and take things in or feel you are not ready to take on more than the basic details. Our patient community found getting the answers to the following questions before you leave hospital helpful in order to take the positive steps forward to live well with heart failure. We suggest asking the following questions.

- Before you leave hospital, ask if you can have a member of your family or your carer with you when they explain to you what will happen once you are discharged, two heads are better than one!
- Before you get discharged, ensure you know who your heart failure team are.
- Don't feel too daunted by the number of tablets you may be discharged on, a member of the nursing staff should explain to you what they are, what role they play and what the side effects are. Question anything you don't understand and use this tool kit to fill in any gaps.
- Ask how your GP will know about the medication you have been prescribed or if there are any changes to your medication.
- Ask how you will get a repeat prescription of the drugs you have been discharged on.
- Ensure that you know if any of the medication is to be taken for a short or indefinite period. This is most important for Diuretics due to the potential dosage frequency.
- Make sure you know what your follow-up appointments are and any blood test you may need and when and where to have them done.
- Find out a contact number in case you have any difficulties.
- If they have not been informed, then do let your heart failure team know that you have been in hospital and are about to be discharged and remember it is important to tell them if your heart failure medication have changed or even been stopped by anybody else other than a heart failure specialist.
- If you have been taking regular medicines before admission - always ask to be provided the contact details of your Community Pharmacist and ask the ward to send them a copy of changes to your medicines.

What to do if you are generally unwell

Everyone experiences the occasional cough, cold or upset stomach. However, for heart failure patients getting such everyday illnesses can make throwing off these conditions much harder and can even make their symptoms of heart failure feel worse. Your local Pharmacist is an invaluable resource to advise you on what you can take and what to avoid to ease your symptoms. Acting early can prevent complications, therefore do consult your heart failure team if you feel your heart failure symptoms are deteriorating. Ask your heart failure team to give you a copy of our symptom checker to help monitor your symptoms. You can also download this in our patient academy section on our website.

Always follow the guidance on any tablets you purchase over the counter and read the enclosed patient information. The list below is advice only and does not supersede information from your heart failure team. **Seek advice from your local Pharmacist** before purchasing any over the counter medication, herbal medicines or supplements. Bring to their attention the medication you are taking for heart failure.

Coughs and colds, infections and general pain relief

Paracetamol can be taken to bring down a temperature and bring general pain relief to aching joints. Avoid taking non-steroidal anti-inflammatory (NSAIDs) such as **Ibuprofen** and **Diclofenac**, as they are known to make heart failure worse. Make sure to rest, and take your usual medication and look at our symptom checker for further guidance.

Be careful with decongestants and always check before buying decongestant remedies as many are not suitable.



Heart Failure in Lights

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.**



HOW ARE YOU?

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

1. You are no more breathless than usual.
2. Your ankles are no more swollen than usual.
3. You are as active and mobile as you normally are.
4. 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.

HOW ARE YOU?

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

1. You are feeling more breathless than usual.
2. Your legs are more swollen than before.
3. You are breathless at night or need more pillows to sleep on.
4. You are unable to be as active as usual/you are a bit more muddled than usual.
5. Any of your other conditions are worsening.
6. 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 necessary.

HOW ARE YOU?

If over 3 days your symptoms continue to worsen, or if you have other symptoms below consider phoning your GP or the urgent contact numbers below.

1. You have worsening breathlessness or leg swelling or are unable to be as active as usual.
2. You have worsening or new angina.
3. You have blacked out.
4. Any of your other medical conditions are continuing to worsen.
5. You have had diarrhoea or vomiting for more than 24 hours.
6. You have symptoms of an infection and/or you feel very unwell.
7. Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.
8. You have become confused about your medications.

WHAT SHOULD YOU DO?

Consider phoning **999** if you feel very unwell.

Complementary/Supportive Therapies

Different people will approach the management of their condition in different ways. Some will look to discover alternative approaches, techniques and therapies. For some, relaxation techniques such as meditation or yoga are helpful; we do know that relaxation helps to reduce blood pressure. Supportive therapy may take many forms. For some people, it may be physical activity, hobbies, keeping a reflective diary, or social interaction including social media. For others, it's a spiritual thing, as they see their religious faith being supportive, enriching and providing a valuable coping strategy. Some will investigate alternative medicine, but a word of caution: there is little or no clinical evidence behind many forms of alternative or complementary medicine. Indeed, there are potentially serious consequences when taking such therapies with cardiac medication. These also include over the counter medication (particularly St John's Wort). With the popularity of Chinese medicine, the following all have potential to interfere with your medication for heart failure: liquorice, hawthorn, motherwort, ginseng and ginkgo. Before taking any complementary medicine or considering alternative medicine, it is important to discuss it with your GP, Cardiologist, Heart Failure Nurse or Pharmacist.

And so.....

We hope that we have provided answers to the many questions you may have. Heart failure medication can be complex, but with support from your heart failure team, it is possible to adapt to a life that involves these marvellous medicines.

We should perhaps end with a thank you to all those companies, Scientists, Doctors, Nurses, Pharmacists and individuals who lead the way on developing therapies that have transformed heart failure care over the last twenty years. We would also like to thank all the patients that have participated in clinical trials to ensure we have effective and safe medicines for people with heart failure. At Pumping Marvellous we will play our role in continuing that challenge.

You will find further information on a range of topics related to heart failure on our website at www.pumpingmarvellous.org.

One step at a time

We hope that our Marvellous Guide to Medicines for Heart Failure 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 self-management can be the key to a better life enabling 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

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 using 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 visit PMTVLive on YouTube as well as the Pumping Marvellous website. In everything we do you will find rich veins of support to help you manage your heart failure better.

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

Important Pumping Marvellous Contacts



Office Tel - 01772 796542



Facebook Support Community - Search 'Help for Hearts'



Email - hearts@pumpingmarvellous.org



Twitter - @pumpinghearts



Website - www.pumpingmarvellous.org



Youtube - PMTVLive

Useful Contacts - Patient Organisations and Related Services

www.pumpingmarvellous.org

The UK patient led heart failure charity, the go-to-site for both patients with heart failure and carers looking after them.

www.cardiomyopathy.org

Website to support patients with heart muscle disease.

www.ageuk.org.uk

Website with a range of information and services for the older person.

www.carersuk.org

Website of organisation for carers.

www.macmillan.org.uk

Organisation website that supports not just those with cancer but for those requiring palliative care services.

www.citizensadvice.org.uk

Information on a wide range of issues and details of local branches for appointments.

www.gov.uk/apply-blue-badge

Details as to how to apply for a blue badge, enabling free parking.

www.relate.org.uk

Organisation that provides information and counselling services for couples.

www.nhs.uk/Pages/HomePage.aspx

Link to various NHS services.

www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11

Information for carers.

www.gov.uk/browse/benefits

Information in regards to current information benefits.

www.acas.org.uk

Information for both employers and employees for training and mediation.

www.gov.uk/pensions-advisory-service

Pension advice, both state and private.

www.gov.uk/contact-jobcentre-plus

Employment advice and opportunities.

www.samaritans.org

Agency providing immediate support and crisis management.

www.moneyadviceservice.org.uk/en

This is an independent body set up by government to provide information and support on a range of financial matters.

www.gov.uk/current-medical-guidelines-dvla-guidance-for-professionals-conditions-g-to-i#advice-for-the-general-public

Driving information from the DVLA.

Useful Contacts - Medical Organisations and Further Information

www.bhf.org.uk

Website to support those with a range of conditions in relation to heart disease.

www.bsh.org.uk

The Clinicians' organisation for those who specialise in heart failure.

www.nice.org.uk

NICE (National Institute for Health and Care Excellence)

NICE's role is to improve outcomes for people using the NHS and other public services. They do this by:

1. Producing evidence based guidance and advice for health and public health and social care practitioners
2. Developing quality standards for health, public health and social services
3. Providing a range of informational services across the spectrum of health and public health services

NICE Chronic Heart Failure Guidelines (under review)

www.nice.org.uk/guidance/cg108

NICE Acute Heart Failure Guidelines

www.nice.org.uk/guidance/cg187

www.heartfailurematters.org

European Society of Cardiology website, Clinician organisation but does have patient information.

www.drinkaware.co.uk

Information on alcohol intake.

www.alcoholics-anonymous.org.uk

Support organisation for alcohol-related issues.

www.nhs.uk/livewell/drugs/pages/drugtreatment.aspx

Support organisation for drug-related issues.

www.mind.org.uk

Mental health charity.

www.england.nhs.uk

Health commissioning organisation for the NHS.

www.cqc.org.uk

Regulatory body for the NHS.

Useful Contacts - Other Charities and Nonprofit Groups

Here at Pumping Marvellous we are enthusiastic about working with other charities who, like us, are aiming to help individuals and their carers by providing information and support to manage their health and general well-being. Please find the list below:

Atrial Fibrillation Association

www.atrialfibrillation.org.uk

British Cardiovascular Society

www.bcs.com

British Heart Foundation

www.bhf.org.uk

British Heart Valve Society

www.bhvs.org.uk

British Society for Heart Failure

www.bsh.org.uk

Cardiomyopathy UK

www.cardiomyopathy.org

CRY

www.c-r-y.org.uk

Heart UK

heartuk.org.uk

Heart Failure Matters (European Society for Cardiology)

www.heartfailurematters.org

SADS

www.sads.org.uk

Government Information

NHS Choices

www.nhs.uk

NICE

www.nice.org.uk

Mental Health Charities

Mind

www.mind.org.uk

Rethink

www.rethink.org

General Information

Patient

www.patient.info

Travel insurance for people with heart failure

www.travelinsuranceforhearts.org.uk

Driving with a medical condition

www.gov.uk/government/uploads/system/uploads/attachment_data/file/491028/aagv1.pdf

Other 'Marvellous Guides' available in the series:

Hope

Designed for newly diagnosed people with heart failure

PPCM awareness

Designed for pregnant mums

PPCM toolkit

Designed for mums diagnosed with PPCM

CRT and ICD pre-implant toolkit

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

Heart Failure in Lights

A great tool to help you manage your symptoms

Guide to GTN

A simple guide to helping you take GTN spray or tablets

The Complete Marvellous Guide to Heart Failure

Toolkit for Carers

A marvellous guide to help people who care for people managing heart failure

Heart Failure and Holidays

Ideal for people wanting some help with going on holiday with heart failure

Walking a day in my shoes

Marvellous guide for people wishing to inform their families about heart failure

My Appointment Diary

You can record your appointments, weights and medicines in this useful diary

My Marvellous Guide to having an ECHO

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

Marvellous tools to help manage your heart failure with your doctor or nurse

So why have I got heart failure

A comprehensive set of marvellous guides to the reasons why you may have heart failure

Marvellous Map of Heart Failure

A map of how to navigate your way around the NHS with heart failure

All guides are written by patients and clinically validated for accuracy by leading UK heart failure specialists. To access go this link; <http://pumpingmarvellous.org/heart-failure-patient-academy/heart-failure-toolkit>

My Team:

Your Carer's Name:

Your Carer's Telephone Number:

Your GP's Name:

Your GP's Telephone Number:

Your Cardiologist's Name:

Your Cardiologist's Telephone Number:

Your Heart Failure Nurse's Name (if applicable):

Your Heart Failure Nurse's Telephone Number (if applicable):

Your Practice Nurse's Name:

Your Practice Nurse's Telephone Number:

Your Pharmacy's Name:

Your Pharmacy's Telephone Number:

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



*Another Midi Toolkit by The Pumping Marvellous Foundation
Crowdsourced information from REAL patients.*

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Honorary Research Fellow University of Bradford

Nick and the patients who helped to create this guide

Contact Us



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www.pumpingmarvellous.org



hearts@pumpingmarvellous.org



PMTVLive



@pumpinghearts



heart failure aware



help for hearts (closed support group)



Can you help us by donating or fundraising?

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