

# My Marvellous Guide to Heart Failure

*Be a 'marvellous'  
heart failure patient*

“The end to *those* questions”

Endorsed by the the patient board of the  
Pumping Marvellous Foundation.

 **Pumping  
Marvellous**  
The heart failure charity

# **Welcome to your Marvellous Guide to Heart Failure.**

*We hope that it helps to answer some of  
the questions you have about heart failure.*

In memory of Les Simmons

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# HOW TO BE A MARVELLOUS HEART FAILURE PATIENT

1.1

## The End To All Those Questions

Wouldn't it be great to find an end to all those questions about how to have a better life whilst living with heart failure? To discover how to be a 'marvellous' heart failure patient whilst knowing why and how to get to grips with your condition?

As authors of this publication, we believe we have put together a comprehensive guide that will help you to become a 'marvellous manager of your heart failure'.



**The Marvellous Guide is designed to smooth out the ups and downs of managing your heart failure.**

# AN INTRODUCTION

1.2

## Welcome

This 'Marvellous Guide' to heart failure (don't you just hate that word failure?) has been created by our patient community both locally to the University Hospitals of North Midlands, nationally by our patient community in the UK and internationally by our wider community all over the globe. They believe that if they had had a resource like this, it would have been a lot easier to manage their condition.

The way the guide is constructed and the information it contains has all been at the direction of the people who know about living well with heart failure, the patients and their carers.

You may wish to work your way through the whole guide or read the parts that you want to learn about. Not everything in the 'Marvellous Guide' will relate to everybody, however, we are willing to bet that there will be parts for everyone.

**Please note: This booklet should not replace and/or substitute the interactions with and advice you get from your healthcare professional, and if you have any concerns about your condition you should discuss these with your healthcare professional at the earliest opportunity.**

# ACKNOWLEDGEMENTS

1.3

## Our Acknowledgements

We would especially like to thank those patients and carers, wherever they are, for their input into what sometimes can be a real roller coaster of an experience. We would like to specifically thank the patients and carers of Stoke and the surrounding area who helped us design and pioneer how heart failure patients and their families live a better life with their condition.

Our thanks also go to the marvellous team led by Dr Dargoi Satchi, Ash Patwala and Diane Barke from the Royal Stoke University Hospital who have been open-minded enough and marvellously passionate about improving the quality of life of heart failure patients and those affected by heart failure. As soon as we met Dr Satchi, we knew he would be up for it!

We would also like to thank Novartis for their support in supplying us with a philanthropic grant to enable us to produce this guide.

# WHO ARE PUMPING MARVELLOUS?

1.4

## Pumping Marvellous

The Pumping Marvellous Foundation (PMF) is the UK's heart failure charity. It was founded by a heart failure patient whose experiences whilst rehabilitating have shaped the Foundation's goals and principles of a patient-centric charity focused on improving patients' lives.

The beneficiaries are all people who suffer from heart failure together with their family and friends. The Pumping Marvellous Foundation's goal is to deliver HOPE to its beneficiaries through the facilitation of better outcomes by cross-working and advocating the beneficiaries at a local, regional, national and international level; working hand in hand with commissioners and clinicians to deliver better pathways and be the patient voice of progression. Our services include patient driven solutions, created by patients, guided but not policed by the Foundation, available in printed and online format. The Pumping Marvellous Foundation is funded through donations and fundraising by individuals, support from the NHS and charitable organisations together with corporate sponsorship.

All of the nearly 900,000 heart failure sufferers, their families and carers in the UK qualify for assistance. The Foundation has no bias towards specific sub groups. Heart failure is an umbrella of individual conditions and spans across all socio-economic groups therefore our support is varied and tailored to the specific needs and requests. The Foundation is headquartered in Lancashire and has a network of regional volunteers across the country who deliver the core messages and actively participate in campaigns, publications, distribution of literature and local relationship building. We have a strong online presence which enables the Foundation to reach out and catalyse progression in heart failure care with stronger engagement with clinicians and sufferers and their families.

## The Four Objectives

- ♥ Help heart failure patients, their carers and families to manage their condition on a daily basis. If you know what you are supposed to be doing then doing it doesn't seem to be so challenging.
- ♥ Raise awareness to the general public and primary care functions like A&E and GPs to the symptoms of heart failure. The quicker the diagnosis, the better.
- ♥ Optimise the team of people who surround the patient's care (Multi Disciplinary Team).
- ♥ Conduct innovative and engaging methods to get people to think about heart failure differently.

# WHAT WE GET INVOLVED IN

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1.5

## ♥ Awareness

Drive awareness of heart failure through the general public, healthcare professionals, politicians, policymakers, commissioners and academia.

## ♥ Support

We offer support to sufferers of heart failure, their carers and family.

## ♥ Advocacy

We represent the opinions and needs of heart failure patients across the UK. We give the patient a voice where representation is needed, at the top table.

## ♥ Self-management

We offer patients and families the help to self-manage their condition through coaching and developing them through the peaks and troughs of managing heart failure.

## ♥ Partnership

We work with clinicians and decision makers as to how the patient voice can improve care to people suffering with heart failure.

## ♥ Access

We work with all stakeholders in heart failure to ensure that the patient's need to access the latest therapies is heard.

# GET IN TOUCH

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1.6



Landline: 0800 9788 133



International: +44 1772 796542



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



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



[heartfailureaware](https://www.facebook.com/heartfailureaware) (open)



[helpforhearts](https://www.facebook.com/helpforhearts) (closed support group)



[@pumpinghearts](https://twitter.com/pumpinghearts)



[www.travelinsuranceforhearts.org.uk](http://www.travelinsuranceforhearts.org.uk)



**MEDICAL  
STUFF**

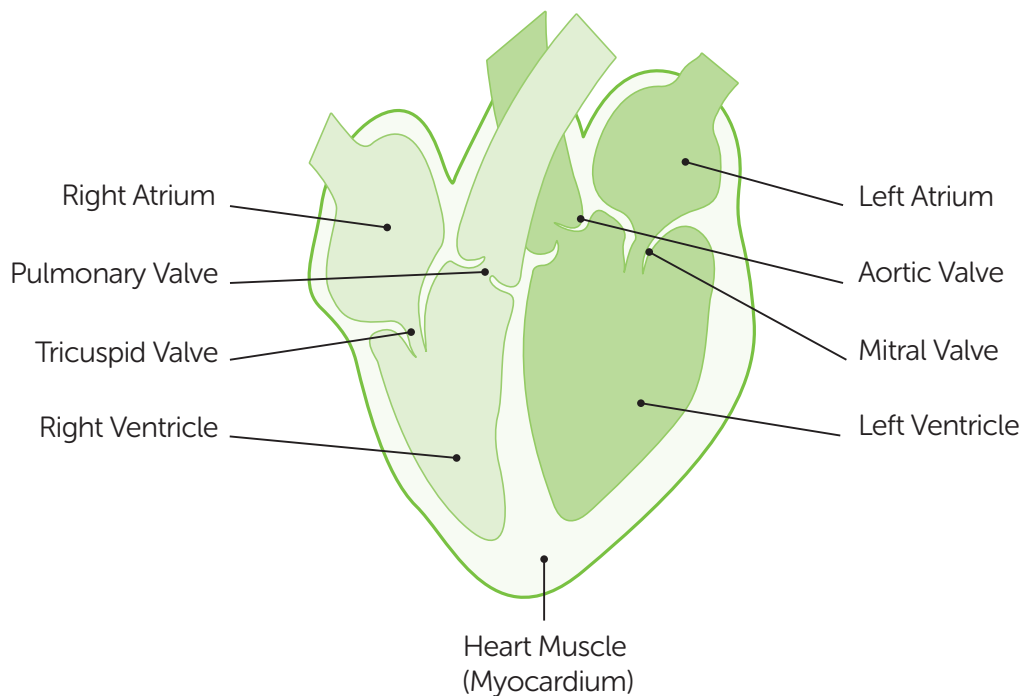
# WHAT IS A HEART?

2.1

## The Basics

You may recall learning about the heart at school (a distant memory perhaps of your teacher going on about the cardiovascular system). If you are going to understand what has happened to your heart, it's good to know how it should work in the first place.

Simple answer: it's 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 down to your left hand side. It has different layers, one of which is made of muscle. For the heart to squeeze the blood out, it needs a muscle. It is told when to pump by a nerve that triggers the heart's electric system.



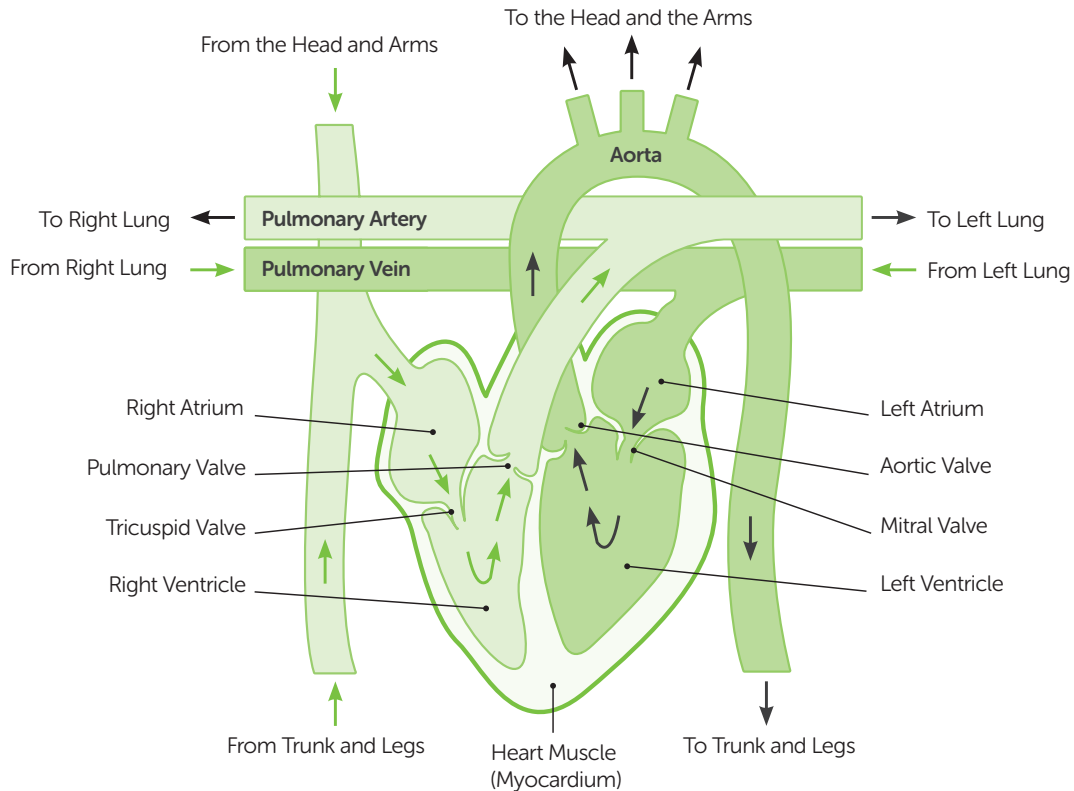
## How does it work?

To understand how the circulatory system works, think of a motorway. The diagram shows the inside of the heart. It is made up of four chambers: on the right-hand side, blood returns from having delivered oxygen around the body through the veins (a motorway), the heart then sends the blood to the lungs (petrol station), picks up oxygen and returns to the left side of the heart which then delivers the blood to the body via arteries (another motorway).

The heart itself is made up of a muscle which is split into four chambers - two at the top (the atria) and two at the bottom (the ventricles). These chambers are split by little gates letting the blood move from one chamber to another; these are called valves.

The heart has its own electrical system (the conduction system) that allows all of these structures to co-ordinate to allow passage of blood into and out of the heart. A heart beat is one cycle of blood entering and leaving the heart.

The atria (top chambers) squeeze and then the ventricles (bottom chambers) squeeze to produce the 'thump, thump' you'll know as a heartbeat. It will do this anything from 60 to 80 times a minute, but will go more quickly if the heart has more work to do.



## Looking after your heart

As with a car, your heart needs to be maintained and be looked after. If we don't look after this most vital of organs, you can have trouble with its electrics, pump, valves, and most importantly, the muscle layer. The muscle layer has its own fine arteries in order to receive the oxygen and nutrients it needs. Many problems occur with the heart if it hasn't been looked after properly. As it's a muscle, it needs exercise, otherwise the fine arteries by which it receives its oxygen and nutrients can become blocked with bad fats and sugar. We know that having to pump at high pressure (high blood pressure or hypertension) can cause the heart long-term damage. Wear and tear to the valves can also occur as we get older. As with a car, if it's not been put together properly, it does not function well, or it can be hit with a problem out of the blue. Its inability to work properly has a knock on effect on other parts of the body, for example the kidneys and lungs.

As with a car, it may need to be repaired or have parts replaced to function more efficiently. Visiting your GP for an MOT is important to see what state the heart is in and if it needs any support.

This is a very basic explanation of the heart and you can explore the heart in greater detail via the Pumping Marvellous website. If you have been told you have heart failure, then it helps to understand what part of your heart is the problem.

### **ACTION POINT**

**NOW IS THE TIME TO LOOK AT THE MODULE YOU'VE BEEN GIVEN.**

## Amazing Facts

- **Your heart is the size of your two fists clenched, and weighs approximately 11 oz or 312 grams.**
- **The heart begins to beat by the fourth week of pregnancy.**
- **It beats over 100,000 times a day, that's 2.5 billion times a lifetime.**
- **Each minute, it pumps 1.5 gallons of blood. That's 1.5 million barrels of blood during your lifetime.**
- **75 trillion cells receive blood from the heart, only the cornea doesn't.**
- **The 'thump, thump' sound of your heart is the four valves opening and closing.**
- **Grab a tennis ball and squeeze it tightly; that's how hard the heart beats to pump blood.**
- **It's the organ that has inspired numerous poems, love songs, plays and work of art, as it is seen as the centre of our emotions (which is not true), but it does respond to the chemicals that our brain issues as a result of our intense emotions.**

# WHAT IS HEART FAILURE?

2.2

## Understanding Heart Failure

Heart failure is a clinical syndrome. A syndrome is a collection of symptoms. In heart failure, you may experience breathing difficulties, gathering of fluid in your lower limbs or stomach and extreme lethargy or tiredness.

The heart's job is to pump blood around the body. Oxygen and nutrients are found in the blood; these are necessary for the body to function properly. When the heart either fails to pump efficiently or it fails to relax and fill efficiently, this is called heart failure.

The question that always needs answering is why the heart is failing to pump efficiently; what is the underlying cause that has caused the problem? Specific cases of heart failure can be broken down to conditions that affect the individual building blocks that make up the heart or things that the heart interacts with e.g.

- **The heart muscle itself - due to many conditions such as genetic causes, environmental causes such as alcohol and powerful medications, conditions where the heart is working too hard such as high blood pressure or hormone problems such as thyroid disease, etc.**
- **The motorways or blood vessels supplying the heart**
- **The gates separating blood from the two heart chambers - the heart valves**
- **The electrical wiring of the heart**
- **The protective lining around the heart - the pericardium**
- **Everything else that the heart comes into contact with such as toxins (alcohol, etc.), hormones (thyroid, etc.), powerful drugs (such as some anti-cancer drugs), difficult working conditions (such as anaemia, high blood pressure, etc.)**

When you are given your guide, do read the 'Your Information' section which describes the reason that your heart is not functioning efficiently.

## In a little more detail...

As you have seen in the previous section, there is a description of the heart and its ability to pump, focusing especially on the left ventricle chamber. It is this particular chamber that has to pump the blood out of the heart and send it around the body. When you have a scan conducted of your heart, clinicians like to measure how effectively the heart is doing this. This is called the ejection fraction, or left ventricular ejection fraction (LVEF). Usually, there is approximately 50% to 55% of blood being pumped out of the chamber. In heart failure, the heart is failing to pump less than approximately 45%. Clinicians now call this heart failure with reduced ejection fraction (HeFREF). When the heart is able to pump efficiently but not able to relax and fill the chambers, this is called heart failure with preserved ejection fraction (HeFPEF).

# SYMPTOMS OF HEART FAILURE

2.3

## Recognising Symptoms

Symptoms of heart failure may occur very quickly, or may have developed over a number of weeks or even months. Occasionally, it is by only looking back do they now appreciate how the symptoms of heart failure have been developing.

Clinicians talk of acute heart failure, whereby you have sudden symptoms requiring immediate treatment which may lead to hospital admission. They may also talk about chronic heart failure which is when patients live with heart failure on a constant basis. The symptoms of chronic heart failure will vary from one individual to another and will depend on how effective the treatment prescribed is working. People may find that they were initially in acute heart failure and whilst this was effectively treated and the heart has recovered, for many patients they may be left with chronic heart failure. The lines between acute and chronic heart failure can blur if chronic heart failure symptoms worsen and are untreated for some time.

- **Breathing difficulties - this is one of the most common symptoms of heart failure. It may be that you have noticed that you are no longer able to carry out routine activities without getting breathless, including climbing the stairs, getting washed and dressed, walking up hills.**
- **Waking up suddenly breathless, unable to feel that you can get air into your lungs, or even that you feel that you are drowning, hearing your breathing as a gurgling and coughing up pink, frothy sputum. This is due to having fluid in your lungs as a result of your heart not pumping efficiently.**
- **You are unable to lie flat in bed due to being unable to breathe and you find that you need pillows in order to help you, or even that you have taken to sleeping upright in a chair to help your breathing.**
- **You have found that your feet and ankles are swollen. This may be quite severe and extends to your thighs, or you may have noticed that your stomach is particularly swollen. Again, this is as a result of fluid building up.**
- **Patients will talk of extreme lethargy and tiredness as a result of their heart failure.**
- **Dizziness and light headiness may be a problem for some patients.**
- **Palpitations, a sensation and feeling of the heart pounding.**

You may have experienced and continue to experience some of these symptoms. See the 'Your Information' section in the guide in relation to monitoring and measuring your symptoms.

**The aim of treatment for heart failure is to reduce these symptoms and thereby stabilise your condition, providing you with the best quality of life possible.**

# TESTS & INVESTIGATIONS

2.4

## Getting Diagnosed

There are a number of examinations, tests and investigations that you will have had in order for a diagnosis of heart failure to be made. In this section of the guide, you will find an explanation of the most common types utilised by your team of healthcare professionals.

Here are our top tips from our patient educators in preparation for your test.

## Top Tips

**"Shower and go with the flow. Having tests has never bothered me."**

Liz

**"I don't get nervous as it has to be done and it's not painful or bothersome to me."**

Gail

**"I always try to view them as a means to an end... the quicker they are over with the quicker I can stop imagining what is wrong or can go wrong, after a while you just get used to having them."**

Annette

**"Prepare your evening meal before you go then you just need to put it in the oven when you get home."**

Susan

**"Preparation is the key!"**

Debs

**"After 7 years I no longer stress about tests. What will be will be and may just save my life."**

Bill

**"My echo is always around 1pm so I always remember to eat before or else everyone has to put up with my grumbling stomach sounds! I just try to relax and do as asked."**

Janey

**"Preparation, preparation, preparation is everything. Follow the instructions, sit back and relax."**

Nick

## History Taking

Your Doctor will ask you questions in regards to your past health and ask you to describe the signs and symptoms that you have been experiencing. These questions enable the Doctor to build up a picture of the various problems you have been experiencing. It is excellent medical practice to obtain a good history as this will lead the Doctor to decide which tests and investigations you will require.

## Physical Examination

Again, this is a cornerstone of good medical practice. The Doctor may just observe how you look, walk and feel. Many parts of the body can give clues to problems with the heart, so expect the Doctor to examine your hands, eyes, and stomach, as well as taking your pulse, blood pressure and importantly listening to your lungs and the heart with a stethoscope.

## Blood Tests

Your Doctor will perform routine tests that may sound like a general MOT, but these are useful to your medical team when making decisions about your treatment. These tests could include tests for: kidney function, anaemia, thyroid tests, liver function, etc.

One test that your doctor is likely to request is one that reflects the amount of a heart 'stress' hormone that is present in your blood. The commonest names for these tests are BNP or NT-ProBNP.

## Chest X-Ray

When a patient is acutely ill with symptoms of heart failure, a chest X-ray is often performed. This will not indicate if you have heart failure, but will indicate if the heart is enlarged or if there is any fluid which has gathered in the lungs as a result of the heart failure condition.

## Electrocardiogram - ECG

This is a tracing of the electrical activity of your heart. It is a painless test. Six stickers are placed on your chest and one on each arm and leg. Electrodes or pegs are then attached to the ECG machine in order to record the tracing of the electrical activity of your heart, recording them both on a screen and paper. To the patient, these may appear as just a collection of scribbles, but to the Clinician the ECG can provide vital information such as how fast your heart is beating and whether the rhythm it beats is normal.



## Remote ECG

When an ECG is performed, it gives a snapshot of what is happening to the heart at that moment in time. Your Doctor may wish to obtain a recording over a longer period of time in order to gauge if you are having any rhythm problems that appear to come and go. Therefore, they may request that you be fitted with a recording device (sometimes called a Holter monitor) which you will be able to wear and return home whilst still undertaking your normal day to day life. You will be fitted with electrodes similar to that of an ECG; these are attached to a device the size of a smartphone which will be attached to a belt worn around your waist. This will record your heart's electrical activity. You may be asked to wear this for a period of 24, 48 or 72 hours.

Occasionally, in order to obtain a much more in-depth picture, a recording device may be implanted in the chest wall. This is often used when a patient has experienced a collapse called a syncope. A small incision is made in the chest wall, and the device (which is the size of a USB stick) is inserted. This may stay in place a number of weeks; it can recall activity or some devices can be triggered by the patient when experiencing any symptoms.

## Transthoracic Echocardiogram - Echo

Commonly referred to as an echo, this is a scan of the heart and is the commonest investigation to look at the heart structure and its function. It works on the same principle as baby scans in pregnant women.

It uses an ultrasound, which is a high frequency sound that you cannot hear. The ultrasound is produced by a cool gel covered probe that will be placed on various parts of your chest and sometimes upper abdomen.

The ultrasound produces pictures that help the medical team assess your heart in more detail.

You will need to expose the front of your chest for the test, but the test is conducted in private and there are special gowns you can wear if you wish to keep the back of your chest covered.

You will be asked to recline on a couch usually rolled onto your left-hand side with your right arm at your side and your left arm bent with your hand on the left side of your face.

Once you are in position the light will be dimmed so that the pictures can be seen better by your technician (or echocardiographer).

The test requires no preparation at all, so you can eat, drink and take your medication as usual. You may have regular echos in order for your Cardiologist to monitor the functioning of your heart. The echo is important, but it does not always reflect how you are actually feeling. This is why we recommend you use the New York Heart Association Classification. See **section 3.3.1** of this guide 'Where are you in New York?'

## Transesophageal Echo

Some patients may require a much more in-depth picture of the heart, particularly if your Doctor wishes to see the back or the valves of your heart. If that is the case, they may ask to perform a transoesophageal echo. You will be asked to refrain from eating and drinking for four hours before the procedure. You will swallow a probe which is attached to the echo machine. This provides pictures that your Doctor will need to give to provide the possible evidence to understand what is going on with your heart. The probe goes into the oesophagus which is used to swallow food. You will be asked to lie down on a couch and given a sedative via a needle into the vein in your arm; this will ensure that you are very relaxed and some patients advise that they recall little of the procedure. A spray is also given to the back of your throat which will numb it. The Doctor will then ask you to swallow the probe. Once you have swallowed the probe, the procedure will only take 5 to 10 minutes. It is a little uncomfortable when the probe is withdrawn and you may have a sore throat for a couple of hours. Throughout the procedure, the Doctor will explain what is happening and will be able to explain to you what they have found once you have recovered from the procedure.

## Magnetic Resonance Imaging - MRI

MRI scanners use strong magnetic fields and radio waves to produce detailed images of the inside of the body. This enables us to see the shape and structure of your heart and see how efficiently it is working.

An MRI scanner is a large tube that contains a series of powerful magnets. You lie inside the tube during an MRI scan on a flatbed which is moved into the scanning tube. Depending on the part of the body that is being scanned, you will be moved into the scanner head first or feet first.

The scanner is controlled in another room by a radiographer. You will be able to speak to them by an intercom system. The scanner can be noisy and you will be given a pair of ear plugs or headphones, which will let you play your own music.

The test is completely pain free but if you are claustrophobic, then please tell your Doctor who will be able to prescribe medication in order for you to relax.

You may be given a dye, which is called a contrasting agent. This is given via an injection in your arm. It is able to give a clearer picture of what is happening in your heart.

You may also be given a stress MRI. This involves having two MRI tests. The first one involves having an injection of a substance called Adenosine. This puts the heart under stress, just as if the heart is having to undertake an increase in workload, such as doing exercise. You may involve feel a little warm and a little breathless. A further MRI will be performed without Adenosine, so your Doctor can compare how your heart performs normally at rest. You will be given full instructions by your clinical team prior to the tests taking place.

# CORE MEDICATION

2.5.1

One of the cornerstones to support proper functioning of your heart is medication. The drugs that are recommended for heart failure are proven to help your symptoms and improve your outlook and life expectancy.

Some general tips on taking medication:

- **Be in charge of your own medication. Know exactly what you're taking and how often, and understand why you are taking it.**
- **Medication can sometimes make you feel worse before it makes you feel better, so don't give up or suddenly stop taking your medication without first discussing it with your healthcare professional.**
- **It can be a slow process to get to the dose of a medication that works best for you. Sometimes some tablets have to be started at low doses and gradually increased, so don't get discouraged - you will get there in the end.**
- **You may need to take a lot of tablets - they've all got a role to play.**
- **Try not to miss taking your medication and make sure you take each one on time and as recommended. A daily tablet organiser could help.**
- **Remember, this is a partnership between you and your healthcare professional, so discuss how your medications are making you feel with them and if you have any questions or need any help, just ask.**

## The HeFREF/HeFPEF conversation

The medications listed below are for when your heart is not pumping efficiently which is called HeFREF (Heart Failure with Reduced Ejection Fraction). If you have been informed that your heart doesn't fill and relax properly 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 HeFPEF (Heart Failure with Preserved Ejection Fraction).

## ACE Inhibitor (Angiotensin Converting Enzyme Inhibitor)

Ramipril, Lisinopril, Enalapril, Captopril, usually ending in -pril

### What do they do?

These drugs are one of the major drugs that are used in heart failure. Their role is to reduce the workload of the heart by reducing the amount of fluid pumped around the body. They also help the heart by relaxing blood vessels, which then reduces the amount of force needed to pump blood from the heart.

### How do I take them?

They are usually taken once a day however do ensure you discuss with your healthcare professional how often you to take your ace inhibitor. When you first start on ACE inhibitors you will be started on a small dose which is gradually increased until you are on the maximum dose or a dose that your body is happy with.

### Any issues with taking them?

Be prepared to have your blood pressure checked as the dose is increased as ACE inhibitors can reduce your blood pressure, which is sometimes a good thing. However, your healthcare team will not want your blood pressure falling too low, especially if they are making you feel dizzy and unsteady. Always check things out with your health team if that is happening. You will also have regular blood tests to ensure your kidney function is not being affected by the medication. Occasionally you may get a dry, irritable cough when you first start taking the drugs, however, this often settles. If this persists you can always be switched to a similar drug, which should prevent these side effects.

## ARB Angiotensin Receptor Blockers

Candesartan, Losartan, Valsartan often ending in -rtan

### What do they do?

These drugs work very similarly to ACE inhibitors, and tend to be given if a patient can't tolerate those drugs.

### How do I take them?

These may be taken in one dose or split dosages. The same principles apply, start low and build up gradually.

### Any issues with taking them?

As with ACE inhibitors you may experience a drop in your blood pressure, so you will have it checked regularly and you will also have regular blood tests to check your kidney function.

**With ACE/ARB and Beta Blocker drugs these will all have the dose increased slowly to a target dose. The closer to this target you can get to, the more protection they provide you with. Find out from your healthcare professional what your target dose is for your particular drugs.**

# Beta Blockers

**Bisoprolol, Carvediolol, Nebivolol, usually ending in -olol**

## What do they do?

Beta Blockers are again one of our foundations in the treatment of heart failure. Their job is to make the heart beat slower but stronger, and can also be helpful in arrhythmia problems and angina symptoms.

## How do I take them?

Beta Blockers may be taken once a day however do ensure you discuss with your healthcare professional how often you to take your Beta Blocker. Again, these drugs are started very slowly and gradually increased.

## Any issues with taking them?

They may reduce your heart rate and possibly your blood pressure, therefore you will be monitored whilst you are having these drugs introduced or increased. They can make you feel worse before they make you feel better, so hang in there. However, if you are concerned, if your breathing worsens, or you are getting extremely dizzy and unsteady then do speak to your healthcare professional.

# Diuretics/Water Tablets

These medications reduce the symptoms of fluid building up. Their dose can vary over time.

## What do they do?

Patients often complain about their water tablets (officially named Diuretics) as they have to visit the toilet much more frequently. This is a good thing even if it can be very difficult to manage. The water tablet is getting rid of any excess fluid you may have in your body via the kidneys hence passing out more urine. The fluid can especially gather in your legs, stomach or even in your lungs, which can make you breathless. These tablets will make you feel better.

## How do I take them?

You may be taking many water tablets, and perhaps more than one kind but this depends on your symptoms. Remember where you are in New York (see **section 3.3.2**)! You will usually take them in the mornings.

Here is a list of the water tablets you may be on, they all help to get rid of the surplus fluid that may gather in your body, but work on different parts of your kidneys.

## Aldosterone Antagonists/Mineralocorticoid Receptor Antagonists (MRA)/Potassium Sparing Diuretics

Three names, same family of drugs.

**e.g. Spironolactone or Eplerone**

These are another form of water tablet and can be very effective, but they tend to be more important for the heart than just by removing fluid.

### Any issues with taking them?

You will need the toilet much more frequently. They may make you feel dizzy as they can reduce your blood pressure. You may experience muscle cramps. With Spironolactone you may get enlarged or tender breasts so discuss this with your Clinician if it becomes a problem. Expect to have frequent blood tests which will assess how well your kidneys are working, as water tablets can affect their ability to work efficiently.

## Entresto (Sacubitril Valsartan)

This is a new drug from a class called an 'ARNI' - it is a mixture of an ARA (the 'AR' bit) and a Nephrolysin Inhibitor (the 'NI' bit). It helps if you have left ventricular systolic dysfunction with an ejection fraction of less than 35% after you have been on the above drugs initially. It should never be taken with an ACEI (drugs ending in 'pril') as it can lead to allergic reactions in some people.

## Ivabradine

### What do they do?

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

# OTHER MEDICATIONS 2.5.2

## FOR YOUR HEART

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There are many other tablets that you may take for your heart and other medical conditions. It is important that your Doctor, Nurse or Pharmacist has explained;

- **What they are for**
- **What the common side effects to look out for are**
- **The method of monitoring the effect or side effects of these drugs (if needed)**
- **Whether they interact with any of the other medications you take**

## Digoxin

### What does it do?

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

### Any issues with taking them?

Side effects include dizziness, blurred or yellow vision, feeling sick, diarrhoea, skin rash.

## Amiodarone

### What does it do?

Amiodarone is used to treat an irregular heart rhythm.

### Any issues with taking them?

Amiodarone is a very useful drug but may have unpleasant side effects. The skin may become photo sensitive; 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 healthcare professional will also ensure that you have routine blood tests to ensure your liver function is 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.

## What happens when I am at my target doses?

Your Doctor will reassess how you are feeling if you require a further echo and if other treatment options would be suitable for you.

### Option 1 - Revised Medications

Ensuring that you are on the correct medication at the correct dose can be a long process. Drugs may have to be introduced slowly and one at a time, some may be dropped and alternatives introduced. In part this may depend on how your body reacts to a drug, and how your condition has improved or deteriorated. It can be a tedious process and the drugs may make you feel worse at first. Remember they all have a role to play, if you have any concerns about your medication do discuss with your healthcare professional.



### Option 2 - Cardiac Device

Your suitability for a device will depend on your clinical condition. This may change over a period of time. Your Clinician will be monitoring you and may suggest that as a result of any changes you are now suitable for a device. Do discuss with them their recommendations for you, likewise if they have not referred you for a device you may wish to discuss with them why they feel that this is not a suitable option for you at this time.





## 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 and heart attacks.

A blood clot is a seal created by the blood to stop bleeding from wounds. While they are useful in stopping bleeding, they can block blood vessels and stop blood flowing to organs such as the brain, heart or lungs if they form in the wrong place.

Anticoagulants work by reducing the clotting ability of your blood. They are sometimes called blood thinners but they don't actually thin your blood. You may be taking an anticoagulant for DVT or AF amongst other conditions.

It is important to note that although they're used for similar purposes, anticoagulants are different to anti-platelet medicines, such as low-dose Aspirin and Clopidogrel.

Below you will find two types of anticoagulant, Warfarin and a newer type of anti-coagulant called an NOAC. Please note that not everybody can have the newer NOACs and your Doctor or Nurse will put you on the most appropriate therapy. The major difference is that NOACs don't require testing and monitoring all the time like Warfarin.

## 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. Many patients with atrial fibrillation or heart valve disease are recommended to take Warfarin to reduce their risk of forming clots, which may then lead to a patient experiencing a stroke.

Warfarin is an anticoagulant. It is sometimes described as rat poison. This is true to some extent as this is how it was used many years ago. However, Warfarin has now been used safely for many years, resulting in patients not experiencing strokes and losses of life. 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 only 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. This is called the therapeutic range. When first commencing 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 (NOAC's)

Recently new drugs have been developed as alternatives to Warfarin, Dabigatrin, Rivaroxaban, or Apixaban, are all anti-coagulants, but work in a slightly different way than Warfarin. The advantage to these drugs are that you do not require regular blood tests.

# Things that affect Warfarin

## Other medicines

Warfarin is affected by many other medicines. This includes prescription and non-prescription medicines, vitamins and herbal supplements. Do ask your anticoagulant staff before you stop or start any new medicines.

## Diet

Some foods interact with Warfarin and affect your treatment. One nutrient that can lessen Warfarin's effectiveness is vitamin K. It is important to be consistent in how much vitamin K you get daily. You must recognise that you can eat leafy green vegetables which are rich in vitamin K as long as you eat them as part of a balanced, healthy diet. Root vegetables, fruits, and cereals tend to be low in vitamin K. What you don't want to do is have lots of green vegetables on one day of the week. The message is - be consistent with what you eat.

## Drinks

Certain drinks can increase the effect of Warfarin leading to bleeding problems. Avoid cranberry juice. Alcohol can also affect your INR levels so do be careful, one or two drinks should be OK.

## Pregnancy

If you plan to become pregnant or think you are pregnant, you must speak to the team who are monitoring your anticoagulant therapy.

## New alternative therapies to Warfarin

Recently new drugs have been developed as alternatives to Warfarin. Dabigatrin, Rivaroxaban 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.

## Top Tips

**It is important that if you are on an anticoagulant therapy and you have any signs of bleeding that you inform your GP or the anticoagulant clinic immediately. Do inform your Doctor or Dentist if you are taking anticoagulants before any procedure. If you are taking Warfarin, you are usually given a booklet or card which has the results of your blood tests and the dosage.**

## Chest Pain Management

Due to the underlying cause of your heart failure, you may be prescribed medication to be used should you experience chest pain or discomfort. You may find the following information useful.

### Tips for using GTN Tablets (Glyceryl Trinitrate 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 open 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.

- **Do not swallow tablets.**
- **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.**
- **GTN tablets expire 8 weeks after opening the bottle.**
- **If your mouth is dry, a sip of water helps the tablets dissolve better.**

It is wise to always carry the details of your next of kin should you experience any difficulties.

## Tips for using GTN Spray (Glyceryl Trinitrate Spray or Nitrate Spray)

### 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 open 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.

- **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).**

## General Pain Management

If you require general pain relief, then consider Paracetamol as prescribed on the packet. Avoid anti-inflammatories such as Ibuprofen or Diclofenac as they do not interact well with your cardiac condition. For some heart failure patients, other long-term conditions (such as arthritis or peripheral vascular disease) may be painful so always consult with your healthcare professional if you require any further intervention to treat your symptoms.

If you suffer from chest pain and discomfort like angina, please discuss this with your healthcare professional, especially if your symptoms are changing, increasing in frequency or becoming more painful.

As a result of heart failure symptoms, many patients will express feelings of pain and discomfort, particularly if their symptoms are severe. Do discuss your pain symptoms with your healthcare professional as there are a wide range of medications, therapies and interventions that can provide you with effective pain relief.

On occasion, a patient may be suitable for a cardiac device to improve their symptoms and prevent further problems occurring. To be a suitable candidate for a device will depend on your individual symptoms, and the clinical picture of your heart failure. Your Cardiologist will instigate a number of tests and investigations in order to ascertain if a device is a right treatment option for you.

There are two main type of devices that heart failure patients may be suitable for which are explained below. If you require further details then visit the Pumping Marvellous website and look under Academies, Patient Academy and then Heart Failure Toolkits where suitability will be explained in the yellow booklet called 'The Marvellous Guide to Having a Cardiac Device Fitted'.

## Cardiac Resynchronisation Therapy (CRT)/ Biventricular Device

A CRT/biventricular device may be suitable for some people with heart failure. These devices send tiny electrical signals to the heart to help it beat in a more synchronised way and ultimately help the heart to pump more efficiently. However, these devices may only be suitable for around one third of people with heart failure.

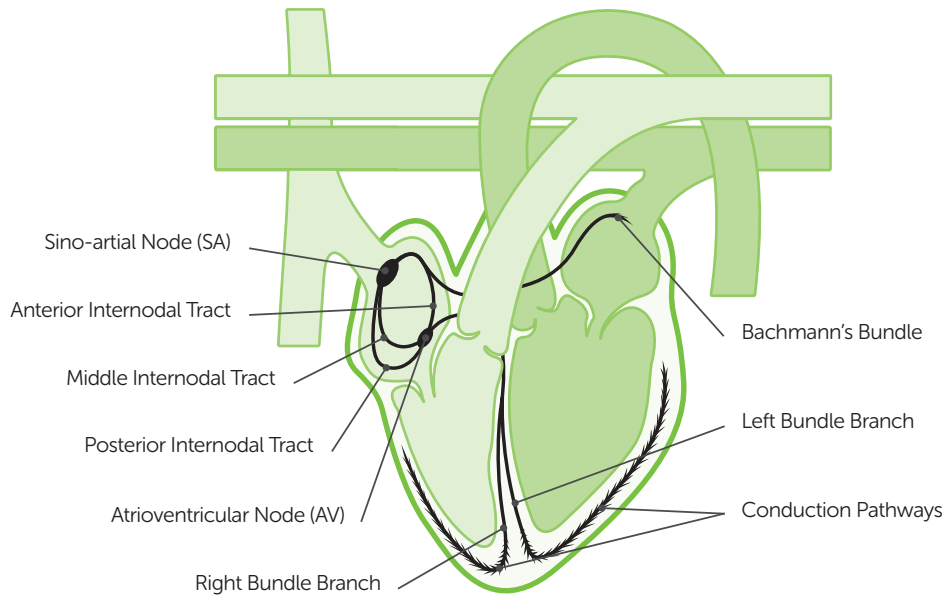
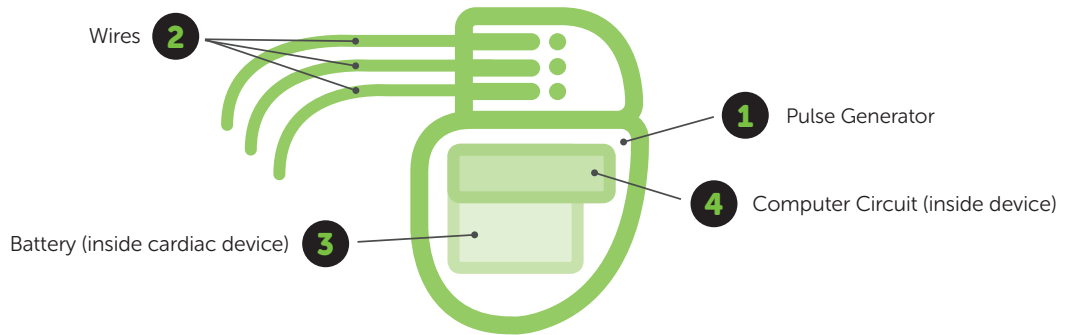
## Implantable Cardiac Defibrillator (ICD)

Not only does the heart have a beat, but also a rhythm. Sometimes there is a problem with the rhythm which may have serious consequences. In these cases an ICD may be recommended. This requires implantation of a small box under the skin in the top of the chest - wires are attached to the muscle of the heart on one end and the box at the other end. This provides a means of dealing with any would-be-fatal heart rhythm problems.

Occasionally a CRT and an ICD may be combined together into one device.

A cardiac device contains four elements:

- 1 A pulse generator.
- 2 The wires which will run from the cardiac device into your heart.
- 3 A battery, which will last anywhere up to 6 to 10 years depending how much your cardiac device has to do and which type you are given. Your battery life will be assessed on a regular basis so that your Clinician knows when you may require another one.
- 4 A minute computer circuit converts energy produced by the battery, which travels down the wires and thus stimulates your heart to beat.



You can see what it looks like to fit a cardiac device on our website;  
[www.pumpingmarvellous.org/heart-failure-guide/crt-devices](http://www.pumpingmarvellous.org/heart-failure-guide/crt-devices)  
 or scan this code for instant access.

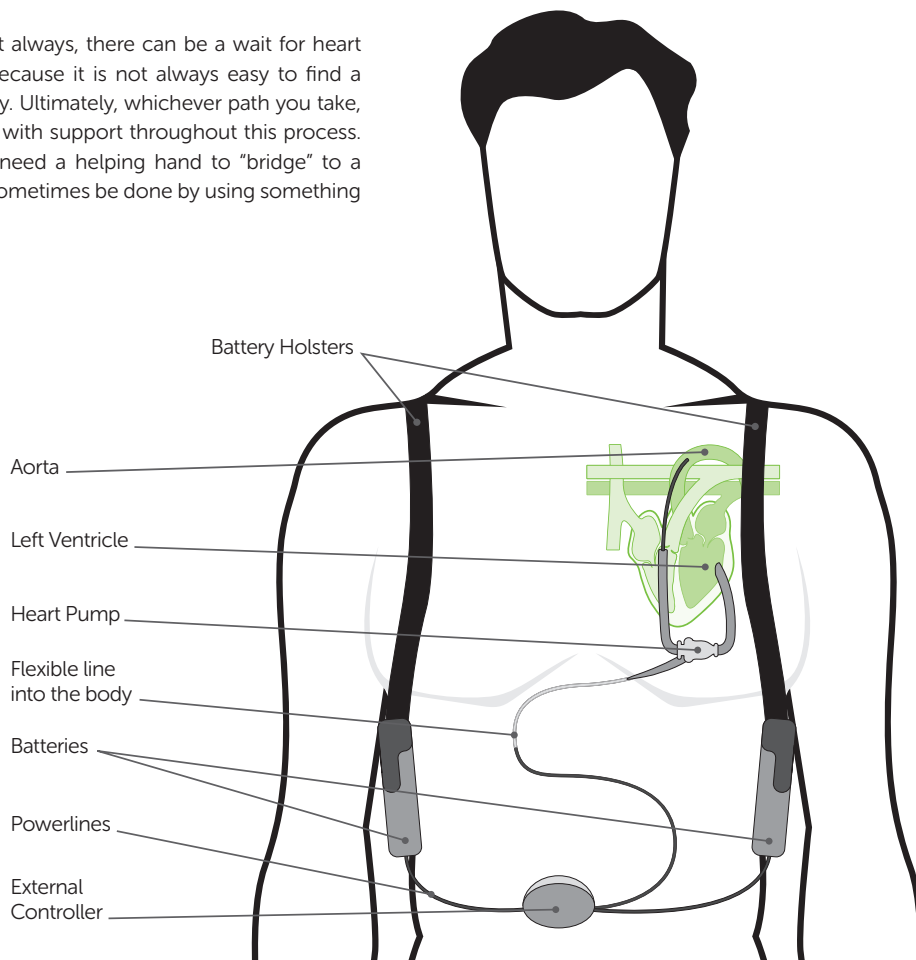


# LEFT VENTRICULAR ASSIST DEVICES (LVAD)

2.8

## LVAD

Occasionally, but not always, there can be a wait for heart transplants. This is because it is not always easy to find a suitable donor quickly. Ultimately, whichever path you take, you will be provided with support throughout this process. Sometimes patients need a helping hand to “bridge” to a transplant. This can sometimes be done by using something called an LVAD.



Left Ventricular Assist Devices are mechanical pumps that can provide this support. The latest LVAD models are a truly remarkable success of 21st century engineering. Patients can go home with them and lead a near normal life, returning to many activities they were used to. It must be stated that open heart surgery is required to implant them and they also may come with some ongoing burden. However, the success of improving a patient's condition (reducing shortness of breath, and prolonging survival) is now recognised worldwide.

The device is powered using externally worn batteries and a controller. A flexible line enters the abdomen and connects to the heart pump. The pump circulates blood from the left ventricle into the aorta.

Indeed, in many countries across the world, LVADs are now offered as an individual treatment, irrespective of plans for transplant. There are already reports of patients surviving many years with LVADs. However, given that the cost of an LVAD is substantial, the NHS can only currently offer these for transplant eligible patients.

## Benefits of a LVAD

- **Significantly improved chances of survival, as you will be able to wait longer for a transplant.**
- **Improvement of shortness of breath symptoms. Most patients can return to moderate levels of physical activity.**
- **Overall quality of life has been shown to improve.**

## Burdens of a LVAD

- **It is major open heart surgery (which carries risk) and patients can expect to be kept in hospital for a few weeks afterwards.**
- **The LVAD needs power and this is supplied from a lead that exists out of the side of the abdomen (connecting to an external battery powered computer at all times). It must never be disconnected from the power supply once it has been implanted.**
- **Patients must take blood thinning medication (Aspirin and Warfarin) to prevent clots forming in the pump.**
- **Patients cannot immerse themselves in water. This is to ensure that infection does not enter the lead exit site.**

Dr Steven Shaw, Consultant Cardiologist  
Wythenshawe Hospital, University Hospital South Manchester



## Heart Transplants

Sometimes, despite having the best treatments and care, you may be referred for heart transplant assessment.

Consultant Cardiologist Dr Steven Shaw is part of the heart transplant assessment team at Wythenshawe Hospital in South Manchester and has provided the following to help you in this stage of managing your heart failure.

**“Transplantation is championed as one of the most miraculous achievements of modern day medicine. However, it does come with its own risk as it is a major open heart surgery and it is not a treatment without some ongoing burden to it. Because of this, it is only offered to patients whose lives are at real danger from heart failure, and in these circumstances it can offer a hugely improved quality and quantity of life.**

**Heart transplant requires assessment at one of the six specialist advanced heart failure centres in the UK, to determine whether this is a treatment that should be offered to you. They have special expertise to work out how much risk you are currently under from your condition and whether the risk of considering a transplant in your individual circumstances is justified.**

**Strict eligibility criteria must be adhered to which have been agreed on a national level. Although there is no specific age cut off, most patients are aged under 65 years old. Patients should be non-smokers for at least six months, have a body mass index under 30 and have no other life-threatening medical illnesses”,** explains Dr Steven Shaw, Consultant Cardiologist.

## Benefits of a Heart Transplant

- If successful, it offers a realistic chance of surviving many years - at times when otherwise things may appear very bleak.
- It can offer a tremendous improvement in quality of life. According to the International Society of Heart and Lung Transplant, analysis of several thousands of transplant patients report that 90% have no activity limitations up to seven years after transplant.

## Burdens of a Heart Transplant

- It is a major open heart surgery which carries risk and patients can expect to be kept in hospital for a few weeks afterwards.
- Immunosuppression tablets are required every day for the rest of your life to prevent rejection. These can pose a risk to patients (including infection).
- Frequent outpatient follow-up is necessary, including the biopsies in the first two years.
- It cannot guarantee normal life expectancy, even if everything goes well initially.

Dr Steven Shaw, Consultant Cardiologist  
Wythenshawe Hospital  
University Hospital South Manchester

# CARDIAC REHABILITATION

2.10

There is evidence that people with heart failure gain significant improvement as a result of attending cardiac rehabilitation. These are usually formal exercise classes which are designed for patients with heart failure. Our patients tell us that how significant cardiac rehabilitation has been to them. If you have not yet been referred to cardiac rehabilitation, then please ask your heart failure team.

Cardiac rehabilitation will help you to understand your condition and how to live well with heart failure. The programmes are designed to help your heart to function better, and also all the other muscles in your body. Patients also say that it makes them feel more positive and they are able to share their experiences with other patients with heart failure.

Many centres offer a variety of services, some are based in the hospital, but others are out in the community. Talk to the rehabilitation team, if you do not wish to attend a formal class they may be able to provide an activity programme that you can do at home, or give you general advice on how to manage your activity levels.



# OTHER MEDICAL PROBLEMS

2.11

Many people with heart failure suffer with other medical problems. It may not surprise you to know that worsening heart failure can worsen these conditions will worsen your heart failure . Some common ones are listed below:

- **Hypertension - Having high blood pressure makes your heart work harder than it needs to. It is important to make sure your Doctor is happy with your blood pressure readings and treats you if they are not.**
- **Diabetes - It is important to make sure your Doctor or Diabetic Nurse are happy with your diabetes control and that you know what you can do to help manage your own condition.**
- **Obesity - This can make your heart function and breathing worse. It is important to maintain as near an ideal weight as possible and remain as active as you can.**
- **COPD (or Emphysema) - Ensure that your inhaler technique is correct and that your GP is happy that your breathing and oxygen requirements are as good as they can get them. It is important to understand from your COPD Nurse or Doctor what steps you can take to improve your breathing if your COPD gets worse - be aware of any 'rescue' plan if your COPD worsens.**
- **Anaemia - Ensure the cause for this has been determined and that your GP is happy with your blood counts - bad anaemia can cause or worsen heart failure symptoms.**
- **Kidney disease - Ensure your doctor is happy that your kidney function is the best they can get it and that you do not need ongoing blood test monitoring for it.**
- **AF - Atrial fibrillation is a type of irregular heartbeat. It is important :**
  - 1. as your heartbeat may be too fast or too slow with it - both of which can affect heart function**
  - 2. it can increase your risk of strokes. It is therefore important to discuss whether your Doctor needs to start blood thinning tablets to reduce this risk further**
- **Depression - A lot of people with heart failure experience depression. It is important to discuss your mood with your GP or Heart Failure Nurse.**
- **Obstructive Sleep Apnoea - Many people with heart failure have abnormal breathing when they are asleep. Your partner or carer may notice you snore or stop breathing at night. You may find that you are more exhausted in the daytime or sleep easily. If these symptoms are happening to you then it is important to see your Doctor to make sure you haven't got this treatable problem that can make your heart failure symptoms and other conditions worse.**

## What is an infection?

Infections are illnesses caused by organisms like viruses or bacteria. Antibiotics help bacterial infections, but do not help viral infections. Preventative strategies like flu vaccinations are one of the way of trying to avoid getting some viral infections.

Significant infections can worsen your heart failure and heart failure can make it more likely to develop significant infections.

## How do I know if I have a significant infection?

It is because these can be associated with:

- **Temperatures**
- **Sweats**
- **A new or worsening cough**
- **A change in your sputum colour**
- **Pain on passing water**
- **Diarrhoea or vomiting for more than 24 hours**
- **Increasing falls or loss of balance**
- **Worsening confusion**

If you have these symptoms and are concerned about them then please discuss these symptoms with your Heart Failure Nurse/Community Nurse or GP.

# COMPLEMENTARY/ ALTERNATIVE THERAPIES

2.13

## Different Techniques

Different people will approach the management of their condition in different ways. Some will look to discover different 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.

# END OF SECTION CHECKLIST

2.14

## Question 1

How big is your heart?

- A A beach ball
- B Two clenched fists
- C A grape

## Question 2

How many times a day does it beat approximately?

- A 1000 times
- B 10,000 times
- C 100,000 times

## Question 3

Can you name three causes of heart failure?

- 1 .....
- 2 .....
- 3 .....

## Question 4

What is heart failure?

- A Your heart just stops.
- B Your heart doesn't pump blood around your body well.
- C It's a heart attack.

## Question 5

Can you name common symptoms of heart failure?

- 1 .....
- 2 .....
- 3 .....

## Question 6

What does an ECG measure?

- A Electrical activity
- B Oxygen levels
- C Breaths per minute

## Question 7

What machine produces an ultrasound picture of your heart?

- A MRI
- B Echo
- C X-ray

## Question 8

What does a diuretic tablet do?

- A It adds water into my body.
- B It helps take fluid out of my body.
- C None of the above.

## Question 9

How does an ACE inhibitor or ARB medicine help people with heart failure?

- A They widen your arteries and blood vessels to help the heart pump better.
- B They make the heartbeat stronger.
- C They take fluid from my body.

## Question 10

What does CRT stand for?

- A Cardiac Regurgitation Treatment
- B Cardiac Recycling Treatment
- C Cardiac Resynchronisation Therapy

Get your Heart Failure Nurse to help you check your answers with you.

**ME & MY  
HEART FAILURE**



# THINGS I CAN DO

3.1

Our patient community believe that taking control of your condition is the most influential way to manage your heart failure on a daily basis.

Before we move on, a crucial question you need to ask yourself is, "do I want to self-manage?"

If you're still reading then you are curious or you've said yes to the previous question.

As a large patient community, this aspect of care is something we have discussed long and hard and whilst not always based on evidence, it is based on patients' everyday life experiences of managing their heart failure and then finding out what works for them.

What follows is the result of our community's thought processes and experiences in their management of heart failure.

## Insights from patients

**"Learn your limits and find the new you!"**

Deborah

**"Rest when you need to but you still need to live your life. Rule it, don't let it rule you!"**

Jacqui

**"Take control of your own recovery."**

Lorna

**"Recognise the symptoms and act accordingly."**

Victoria

**"Be honest with yourself and listen to what your body is telling you."**

Lorna

**"Trust your instincts - if you feel something is not quite right, get it checked out."**

Tracey

**"Don't be afraid to seek advice."**

Dawn

**"Self-management means knowing your own body on both good days and bad."**

Susan

# MY APPOINTMENT DIARY

3.2

## Your Appointments

Appointments with your Cardiologist, Heart Failure Nurse and GP are very important. It is an opportunity for you to have a conversation about how you feel. Below is a list of reasons why the appointment is important for you and your team.

- **It's your time to discuss your condition and any challenges you may be experiencing.**
- **It can also be reassuring to know that things are under control, both with you and with your Clinician.**
- **It's also a time when you get feedback after previous tests and investigations and what that next step looks like for you.**
- **It's an opportunity for the next step in your treatment plan.**
- **Surprisingly enough, it's a good opportunity to find out about new members of your team e.g. cardiac rehabilitation.**
- **It's time for your Clinician to find out how you are feeling. At this point you can use the NYHA scale which you will see when you read on.**
- **It's a time for you to ask questions and get the answers you may have been storing up since the last appointment. In your 'My Appointment Diary' tool you will find a section to write down any questions before your appointment.**

## Questions to ask

**"What will these tablets do for me?"**

Donna

**"What can I do to improve my quality of life?"**

Sam

**"Can I still exercise?"**

Liana

**"What over the counter medicines can I not take now?"**

Nick

**"How do I know if my heart failure is getting worse... What signs or symptoms should I look out for?"**

Bronnach

# THE NYHA SCALE - A USEFUL TOOL

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3.3.1

## What is it?

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.

## Conserving your energy

People with this condition often find they have a certain amount of energy - like a battery - to get them through each day. How much energy is in your battery generally depends on how your condition is assessed on the NYHA scale. Just as you would think about how to get the most out of a battery, it's good to think about the amount of energy you have and to try and plan out how you will use it throughout the day to prioritise the activities that are most important to you.

## What you need to consider

Depending on your NYHA level, things that you may need to think about are:

- **Your work**
- **Driving**
- **Your social activities**
- **Your sex life**

Talk to your healthcare professional about any changes you may need to make to your day-to-day life to make sure you can manage your energy levels and get the most out of each day.

# USING THE NYHA SCALE

3.3.2

## How to use the NYHA Scale

Carefully read through the different classes on the NYHA Scale, and determine where you feel you are. You can then discuss this with your Clinician.

## The NYHA Scale

NYHA Class	Symptoms
NYHA Class 1	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations, or shortness of breath.
NYHA Class 2	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations, or shortness of breath.
NYHA Class 3	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes tiredness, palpitations or shortness of breath.
NYHA 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.

## So where are you in New York?

A strange question perhaps, but patients and healthcare professionals often find the New York Heart Association (NYHA) classification scale useful in assessing this condition based on the symptoms you are experiencing.

So where are you on this scale today? We should let you know that you may move around on the scale as your condition and treatments change.

# Where are you on the scale?



## CLASS 1

"I can perform all physical activity without getting overly 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".

# DEALING WITH NYHA LEVEL 4

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3.4

## Quality of life

Many heart failure patients have an excellent quality of life and their life expectancy is very good. We have discussed how the NYHA is a good tool to reflect how you are feeling. For some people with heart failure, despite all the very best of therapies and care, their overall condition may deteriorate. Their NYHA may remain at NYHA III/IV and, if desired, an open conversation with a healthcare professional on life expectancy and a palliative approach to care can occur.

In many areas of the country, palliative and hospice care is now provided for long-term conditions such as heart failure. Organisations such as Macmillan, Marie Curie and the hospice movement now look to support heart failure patients.

No matter what your NYHA status is, if you or your carer have any concerns, feelings or desires to discuss or explore either your condition or end of life care, do not be afraid to raise the issue with your healthcare professional. They will also be able to provide you with a list of services in your area.

If you require any further information, please contact the Pumping Marvellous Foundation where we can help signpost you to local help.

# LOOKING AFTER MY UPS AND DOWNS

3.5

## Using the Heart Failure Lights

Keeping an eye on your symptoms in heart failure is a key skill for you to be able to help yourself. It gives you and your carer an easy way to spot either improving or worsening symptoms.

## Your Daily Routine

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

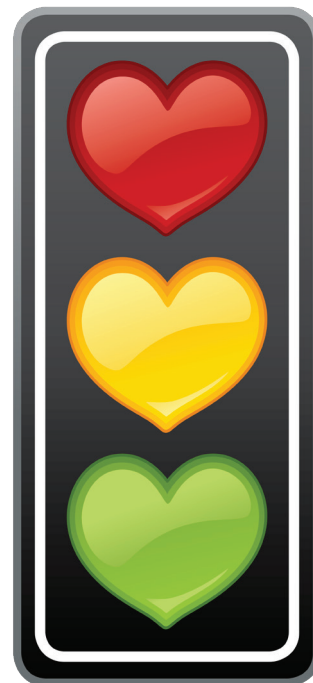
When you get up in the morning, **weigh yourself** after going to the toilet for the first time. Write this down and **compare it to yesterday's weight. If there is a change, look at the traffic lights.**

Eat a balanced diet and don't add salt. Don't use low salt alternatives - see **section 3.10.**

**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.**



## IMPORTANT NUMBERS

### Community Heart Failure Team

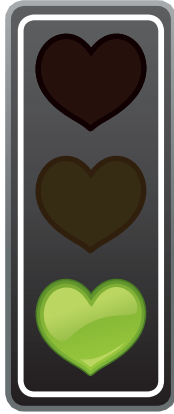
Monday - Friday  
**0300 123 0 979**  
Ext.4183

### UHNM Heart Failure Team

Monday - Friday **01782 672800**  
or page via switch **01782 715444**  
(pager number **07623611301**)

### Out of Hours

**111**  
or  
**0300 123 0 989**



## 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.

## HOW ARE YOU?

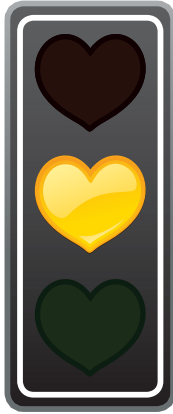
Your weight has not increased or your weight had increased by 4lb/2kg over 3 days but you agree with the statements below;

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.





## AMBER - STAY ALERT

Your weight has increased/has increased by 4lb/2kg over 3 days and/or and 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.

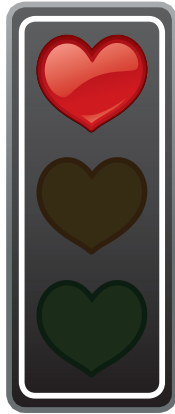
## HOW ARE YOU?

Your weight has increased or your weight 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 is necessary.



## RED - TAKE ACTION

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



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



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



You have worsening or new angina.



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



Your medication has been reduced but not by your heart failure team.



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



Any of your other medical conditions are continuing to worsen.



You have blacked out.



You have become confused about your medications.

## 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 had diarrhoea or vomiting for more than 24 hours.
2. Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.
3. You have worsening or new angina.
4. You have worsening breathlessness or leg swelling or are unable to be as active as usual.
5. If your medication has been reduced but not by the heart failure team.
6. You have symptoms of an infection and/or you feel very unwell.
7. Any of your other medical conditions are continuing to worsen.
8. You have blacked out.
9. You have become confused about your medications.

## WHAT SHOULD YOU DO?

Consider urgent advice from GP, or heart failure service. If you feel very unwell, call **999**.

When patients were asked, “who is the most important person in supporting you in the management of your heart failure?”, they told us it was their carer and family. So first, a big thank you to all those carers out there fulfilling such an important role. Please pass on the carer booklet that you will have been given with the ‘Marvellous Guide’. You will no doubt build your own team around you and every team is different; it depends on who you think is your best team from your squad and who you are going to play at certain times. Having the right team to tap into is something that Pumping Marvellous feels is vital in helping you self-care. See **section 3.7** for how to form your team.

So who are the people who can support you? Number two in the list is the Heart Failure Specialist Nurse. Our patients and carers felt that having access to one enabled a connection to all the other members of the team.

## Heart Failure Specialist Nurse

In the UK, we are lucky to have Heart Failure Specialist Nurses. Unfortunately, not every patient will have a Specialist Nurse and it does depend on where you live and the type of services offered. Heart Failure Specialist Nurses will be found in both the hospital and community setting. The Nurses will generally have a strong background in cardiology. They are often Nurses who can prescribe, so they can review and prescribe your tablets ensuring you are on the best of drugs and at the right dose. They can also arrange for tests and investigations and interpret the results so they can tell you what they say. The Heart Failure Specialist Nurse is also a good link for the patient to have access to both your Consultant Cardiologist and GP. They can act as an advocate, the go-between that enables patients and their carers to link the different services provided. This is useful as the health system can be quite complicated when looking from the outside in; your Heart Failure Specialist Nurse can help to ‘join the dots’.

They are also able to give physical, social, and psychological support and can bring in any additional professionals and agencies to support you in managing both your heart failure and other conditions or issues you may have.

## Your GP Practice

Having a good rapport with your GP 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 will identify and send their findings to a specialist service if needed.

## 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 Practice Nurse. They are an important cog in your team and are generally more accessible than your GP.

## Cardiologist

Cardiologists are highly qualified and experienced Doctors in cardiology. Recently, Cardiologists have begun to specialise in specific areas of cardiology, e.g. heart failure. You are usually under one Cardiologist who will manage your care and it will depend on your clinical picture both when and how often you will be reviewed by them.

## Pharmacist

Your Pharmacist is a great place to go to ask questions about the medications you take and find help with what you can take when you have other issues (like a cold or other common conditions). They generally complete a medicine review with you periodically. They are definitely a friendly face in a world where appointments are a norm as generally you don't need an appointment. Ask them some questions next time you go and collect your prescription medicines.

## Patient Groups

We know the power of talking to somebody in a similar situation is a powerful and valuable way to learn about your condition. At the end of the day, that's how the Pumping Marvellous Foundation helps by providing appropriate support when needed by patients and their carers through peer to peer support. Ask a member of your team to put you in touch with your local support group or, if you haven't got one, then please feel free to engage with us. We have a national patient community and are constantly helping people like you and your carer live better with heart failure. There are various ways to talk to us, please see below:



**0800 9 788133**



**hearts@pumpingmarvellous.org**



**heartfailureaware (open)**



**helpforhearts (closed)**



**@pumpinghearts**



**www.pumpingmarvellous.org**

## Other Team Players

We would say the above players are the essential team members everybody should have access to, but there are others that you can select or may find it useful to engage with. These could include the following which your main team players could refer or signpost you to:

- **Heart Failure Rehabilitation Practitioner**
- **Hospice**
- **Psychological Support**
- **Dietetics**

# WHO IS MY TEAM?

3.7

## Identify your core team

Our patient community tells us that there are a number of key players who you need to know to support you. It is important to realise that these key players help you to form your squad. By engaging and building a relationship with them you will quickly form an idea of who you need in your squad.

Spend some time filling out who is in your team. Remember, you can have substitutes.



# Who is my team?

Write their names in here!



**SUBS  
BENCH**

# GETTING THE MOST FROM YOUR GENERAL PRACTICE

3.8

## Forming a relationship

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

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

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

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

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

Choose the right Doctor for you within the practice. This is a bit like an interview process, but really you know who the good ones are from, well, the not so good ones. The one you feel best about, I don't mean the one who you know, the one you can get to agree with whatever you are saying, but the one who will work to do their best to maintain and improve your condition and at times push and encourage you.

If you are lucky enough to have a Heart Failure 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 Nurse a ring just to get their thoughts on it, which he had no objection to as he felt more informed and valued advice from a specialised Heart Failure Nurse would be great. I fed back the information and didn't stop Spironolactone. My Doctor was very pleased as he recognised that, as a team, the correct decision was made for the patient."

## Pierre's Key Tips

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



# GETTING THE MOST OUT OF YOUR CARDIOLOGIST

3.9

Your Cardiologist is your heart doctor and you may rarely see them or see them only once. Other members of your heart team such as your GP or your Specialist Heart Failure Nurses may be in contact with them on your behalf at other times.

It is important that you get the most out of your consultation and ask all of the questions you want or need to know.

## The Heart Failure Checklist

This is your chance to ask the Doctor about your diagnosis.

- **What the impact of this condition is on your life**
- **Whether it will impact on your life expectancy**
- **Whether it will improve**

## What part of your heart isn't working?

The question is, have I got HeFREF or HeFPEF? This is because , depending on which one you have, your Doctor needs to consider different medications and potentially special devices (see **section 2.5.1**).

## What has led to you having heart failure?

This may be one or many things, but this is your chance to ask your Doctor.

- **It is important in your case to know what actually caused the heart to fail. Whether there is something more specific that can and should be done to improve your heart function.**
- **What are the risks and benefits of these more specific treatment?**

# TECHNOLOGY: AN ALTERNATIVE TEAM MEMBER

3.10

There are now various technology solutions to assist patients and carers in the management of their condition. Some areas may have invested in telemonitoring, this may involve patients downloading readings of their blood pressure, pulse and weight for example. You may find some health apps that will help you with your goals e.g. Apple Watch, NIKI, and Fitbit. However, before embarking on a purchase we suggest you check with your health professional if this would be a suitable investment for yourself.

Pumping Marvellous have a very active and successful Facebook community, where peer to peer support is offered in a safe environment. NHS Heart Failure Nurses refer patients and their carers to this facility to help with some of those issues that are faced on daily basis by patients and their carers.

For regular news information around heart failure we also run the world's largest patient led information page, you can find all that latest developments and research that our patient community find positive and hopeful.



[heartfailureaware \(open\)](#)



[helpforhearts \(closed support group\)](#)



[@pumpinghearts](#)

## What are the treatment options for my heart failure?

Remember the treatment can be:

- **Lifestyle changes**
- **Medications**
- **Non-tablet treatments like cardiac devices.**

This is your opportunity to discuss all of these with your Cardiologist.

## What is the aim of treatment for my heart?

The aim of all medical treatment is either:

- **To keep you living for as long as possible**
- **Keeping you symptom free**
- **A combination of both of the above**

However sometimes you can only treat the symptoms. When treatment options are aimed at symptoms only the medical term is 'palliation' or palliative care. This can be confused sometimes with care right at the end of life.

Although palliative care specialists are involved with end of life care, they also have a big role to play, for some people to help alleviate symptoms such as:

- **Pain**
- **Breathlessness**
- **Worry and stress**
- **Fear**

The whole concept of discussing life expectancy can be a difficult thing to think about for some people. Your Doctor will always have a full and frank discussion about this if this is what you want them to do. If it is, make sure:

- **You are happy for them to discuss these issues with you in the clinic - if not choose another location or time where you will be more receptive to this discussion**
- **You take whoever you want in with you if you are discussing serious issues**
- **You take notes if you need to**
- **Arrange another time to see your Cardiologist or Specialist Nurse again if this is too much to take in one go and you need to mull it over and discuss it at another time.**

## Other conditions and your heart failure

Your Cardiologist may not be able to help improve the other medical conditions you suffer with, but they may be able to suggest who to see to investigate or improve some of these conditions over and above your GP.

Giving you the information you need to manage your condition and what to expect in the short, medium and sometimes the long-term.

This is an area that has been identified as one that is poorly addressed between heart failure sufferers and their Cardiologists. It is difficult because you can see from this checklist the potential amount of information that is involved in just one consultation.

Your Doctor should tell you:

- **What tests are coming next - if any**
- **What they entail and what the risks and benefits are of each**
- **When they will see you next - if at all**
- **What the warning signs are for you to see them sooner or to contact your Heart Failure Nurse sooner (see heart failure in lights)**
- **Who else from the heart failure team will be seeing you (this is often the cardiac rehabilitation and Heart Failure Nurse teams)**
- **What treatments are likely to be started today and at other times in the community for your heart failure**

Make sure you are happy you have all the information that you need at the end of your consultation. However if this is all too much to take in remember:

- **A letter with all of this in should go to your GP - so you can chat it through with them (see Pierre's tips)**
- **Heart Failure Nurses will have access to these letters and can chat any concerns through with you**
- **You can always arrange to see your Cardiologist again if there were things you feel were not clear when you left the clinic or once you got home**

**Our patients tell us of the marvellous benefits of heart failure rehabilitation. There are structured programmes available which have a variety of activities to suit all ages, capabilities, tastes and community localities. Remember, physical activity isn't just about the gym.**

Ask your Heart Failure Nurse, GP or other Healthcare Professional for the services that are available to you and the ones that meet your capabilities and needs. Attending a formal exercise class may be something that you have never done before, but visit your team and consider giving it a try. Some heart failure patients feel that undertaking a planned exercise programme changes and enhances their life.

There are many benefits to your health and well-being from being physically active (this is when you move your body and utilise more energy than you would at rest) or participating in a structured exercise session (where you perform planned movements aiming to specifically improve your level of cardiovascular fitness or muscular strength/endurance).

## Benefits

- **Improved breathing**
- **Weight loss**
- **Blood pressure and diabetes control**
- **Improved general well-being**

Examples of physical activity include leisurely activities such as walking, cycling, gardening and dancing when performed at a low to moderate intensity.

Examples of exercise can include the physical activities previously mentioned but carried out at a higher intensity. Other activities comprise of organised sport, circuit training or the use of cardiovascular and resistance equipment commonly found in fitness studios.

## Taking Part

Prior to participation in an exercise programme you will need to ensure that your medical professional has agreed with your choice of exercise. This may initially involve participating in physical activities in and around the home prior to your progression into structured exercise. Regardless of your choice and stage of progression, remember that your body is designed to move and should be encouraged to do so, preferably in a fun and enjoyable manner.

It is important to begin slowly; as you continue your physical activity, you can increase the size and speed of your movements progressing gradually.

## Intensity Whilst Participating

Whenever you are participating in your physical activity, it is important that you monitor how hard you are working or your 'intensity' which will be specific to you. You will become aware of changes taking place: your breathing will get deeper and quicker, you may feel your heart start to beat faster and you will feel your body become warmer. All these changes are perfectly normal reactions to exercise. When exercising, you should always be able to hold a conversation so if you start beginning to gasp, you need to slow down a little until you are no longer gasping for air.

Remember if you feel that what you are doing is too hard, then it probably is so slow down!

## Frequency/Duration/Programmes of Activity

The NHS Choices web site has a variety of information for the recommended levels and duration of activity. You will also find a variety of programmes with regard to activity programmes that meets all ages and levels.

[www.nhs.uk/livewell/fitness/pages/physical-activity-guidelines-for-adults.aspx](http://www.nhs.uk/livewell/fitness/pages/physical-activity-guidelines-for-adults.aspx)

If you are someone that experiences angina and have pain when exercising, do not attempt to work through the pain. See **section 2.6** on chest pain management in 'Medical Stuff'.

**Ask your Healthcare Professional on the services and programmes that are available for you in your area.**

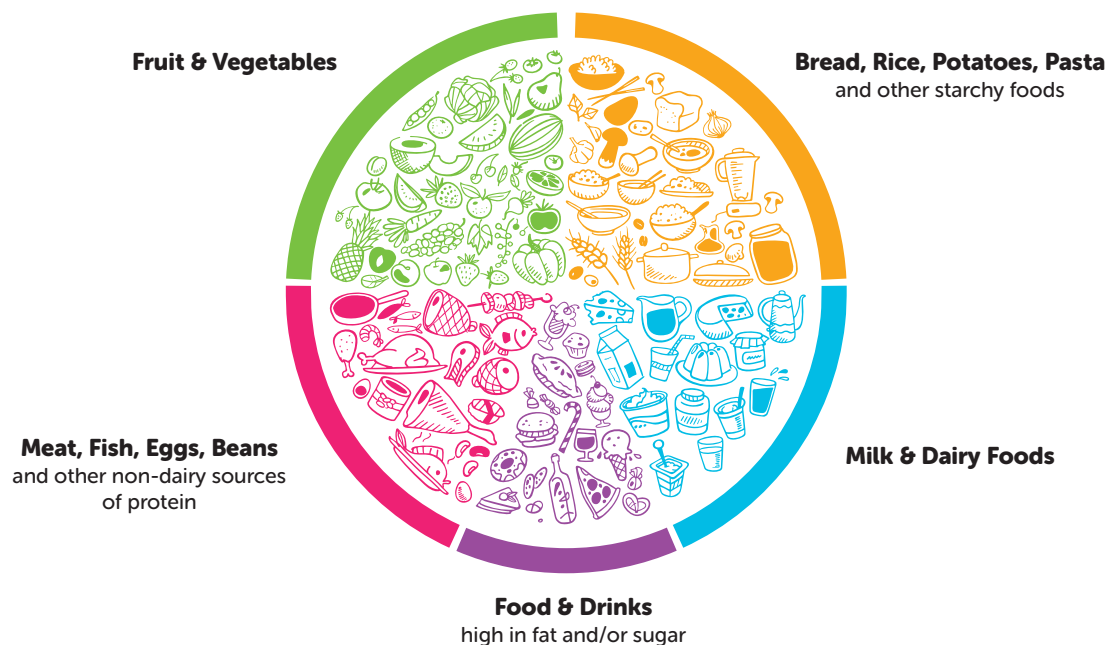
## Top Tips

- **Set yourself a goal which will provide something for you to work towards and when you reach that goal, reward yourself for your achievement.**
- **Choose an activity that you enjoy and have fun doing. Try out new physical activities as you never know what you may be missing.**
- **Do you know someone that may be interested in taking part with you? You will be able to encourage and support each other.**
- **Be sure to wear appropriate clothing which is loose fitting and comfortable. For outdoor activities, consider how the weather impacts upon you as you perform your physical activities.**
- **When possible, try to reduce the amount of time you spend sitting and try to and move more often (even if it's getting up to change the TV channel).**

# WHAT IS HEALTHY EATING FOR ME?

3.12

All foods can be included in a healthy diet. You just need to make sure you get the right balance.



The Eatwell plate shows the proportions of how much of what you eat should come from each food group. This includes everything you eat during the day, including snacks. So, try to eat:

- **Plenty of fruit and vegetables**
- **Plenty of bread, rice, potatoes, pasta and other starchy foods - choose wholegrain varieties whenever you can**
- **Include some milk and dairy foods**
- **Include meat, fish, eggs, beans and other non-dairy sources of protein**
- **Just a small amount of foods and drinks high in fat and/or sugar**

## Why should I focus on healthy eating?

It's the old saying "you are what you eat" and it's true; how else does your body grow, replenish and maintain itself?

Healthy eating can help protect your heart from further heart disease and can also help you to maintain a healthy weight and reduce your risk of:

- **Diabetes**
- **High Blood Pressure**
- **High Cholesterol**

## The Main Dietary Messages

### Eat less saturated fats

Cut down on full fat dairy products, butter, lard, ghee, pies, pastry, biscuits, cakes and processed meats, e.g. sausages, burgers. Vegetable oils such as coconut oil and palm oil are also high in saturated fat and should be limited.

Choose low fat dairy foods, e.g. low fat milk, low fat yoghurt and trim visible fat from red meats and remove skin from poultry.

Swap to olive oil or rapeseed oil. Avoid frying foods: grill, steam or oven bake instead.

### Eat more oily fish (Omega-3 fats)

Omega-3 fats help the heart to beat more regularly and reduce the stickiness of the blood, making it less likely to clot.

For comprehensive advice and information on a healthy diet (including how you can reduce weight safely and successfully), visit the following link:

[www.nhs.uk/livewell/goodfood/pages/goodfoodhome.aspx](http://www.nhs.uk/livewell/goodfood/pages/goodfoodhome.aspx)



## How much fluid should I take?

Your healthcare professional may advise you to monitor your fluid intake. The heart does not like extra fluid in the system as it results in it having to work harder. Indeed if the heart is struggling, you may find that extra fluid builds up in your body in the form of swelling, either to the legs or stomach for example, or even in your lungs which causes breathlessness. That is why you may be prescribed water tablets in order to get rid of it.

Your healthcare professional may recommend that in order to help your heart, you restrict how much fluid you take in. They will discuss the amount they recommend reducing your fluid intake to e.g. 2 litres a day is just over 4 pints. If you do have to restrict your fluid intake, and you experience a dry mouth or feel very thirsty, the following tips may help.

## Top Tips

- **Try using a smaller cup or mug for your hot drinks.**
- **Chewing gum or sucking a sugar free sweet may also help.**
- **Freeze grapes or wedges of orange or lemons to suck on. Slices of pineapple or watermelon are also thirst relieving.**
- **An ice lolly is also a good way of keeping your mouth moist and relieving thirst without cutting into your fluid allowance.**

If your skin becomes dry, try using a moisturiser cream. It does not have to be an expensive one, but applied regularly will stop your skin becoming dry and itchy.

## How much salt should I have?

We know that excessive salt/sodium is not good for your heart. It helps to retain fluid in your body and increases blood pressure. We need no more than 2-3 grams of salt a day in our diet, and yet the average adult in Britain consumes more than 9 grams. Many food products are now colour coded, so avoid those products that list salt as red, and watch out for the amber products too, as these will indicate high amounts of salt in the product, processed foods are particularly high in salt. Try and avoid adding salt at the table, and cooking vegetables in salt. It is a matter of getting used to this so do it gradually, and swapping salt for herbs, spices or lemon juice on your food may be an alternative.

Do not use LoSalt as this is high in potassium which can interfere in the function of your kidneys, and the rhythm of your heart.

## Smoking Cessation

Stopping smoking is the single most important thing that you can do to help your heart. Smoking means your heart has to work harder than a smoke free heart. It has to be faster using more energy that could be put to better use. If you stop smoking your circulation will improve within a few weeks, your lungs will gradually start to work better. The cells in your body will receive more oxygen, which in turn should help you to feel more energised and healthier.

For help, and support in regards to stopping smoking, than do visit the following NHS website:

**[quitnow.smokefree.nhs.uk](http://quitnow.smokefree.nhs.uk)**

Discuss with your GP, Practice Nurse or any other healthcare professional who will be happy to direct you to your local services.

There is now considerable information with regard to the potential risks of drinking of alcohol and its detrimental effect on the heart and the circulatory system. To put this into context, heart and circulatory diseases are the UK's biggest killers with an annual death rate in excess of 191,000 men and women. Evidence shows that excessive drinking has a direct effect on the heart.

## Potential risks of drinking

Long-term drinking and heavy alcohol consumption are linked with weakness of the heart muscle. This is known as alcohol induced cardiomyopathy. It results in the heart not pumping efficiently (in other words, heart failure).

Sporadic heavy drinking (binge drinking) increases the risk of developing coronary heart disease, which is the most common form of heart disease. Department of Health figures show that men nearly double their chances of developing coronary heart disease by drinking more than eight alcohol units a day. Women have 1.3 times greater risk of developing coronary heart disease when they drink more than six units a day.

In January 2016, the government issued new guidance on drinking safely, for all the details please visit;

[www.drinkaware.co.uk/check-the-facts/what-is-alcohol/new-government-alcohol-unit-guidelines](http://www.drinkaware.co.uk/check-the-facts/what-is-alcohol/new-government-alcohol-unit-guidelines)

## Any Benefits?

There is evidence to suggest that a regular pattern of drinking relatively small amounts of alcohol (one or two drinks a few times a week) reduces the risk of heart disease in men over the age of 40 and post-menopausal women.

For any additional information please visit:

[www.drinkaware.co.uk](http://www.drinkaware.co.uk)

# How does drinking too much alcohol affect my heart?

## 'Holiday Heart' Syndrome

Binge drinking or a period of heavy alcohol consumption can cause a sudden, irregular rhythm of the heart in otherwise apparently healthy people. The result is shortness of breath, changes in blood pressure, an increase in the risk of heart attack and even sudden death.

## An increased risk of high blood pressure

According to the Department of Health, men who regularly consume more than eight alcohol units a day are four times more likely to develop high blood pressure. Women who regularly consume more than six alcohol units a day double their risk of developing high blood pressure. People who have had a heart attack may be at greater risk of developing high blood pressure or further damaging the heart muscle as a result of drinking alcohol.

## An increased risk of thrombosis (blood clotting)

Alcohol can affect levels of a substance in the blood called homocysteine. High homocysteine levels increase the risk of blood vessel blockages.

## Alcohol Induced Cardiomyopathy

Regular heavy drinking may lead to an enlargement or damage of the heart muscle, resulting in the heart failing to pump efficiently (heart failure).

# WHAT ABOUT TRAVELLING?

3.16.1

As you know, holidays are an important time to rest and relax. Many of us look forward to our annual holiday and over the last few decades, taking a holiday abroad has become a reality for many of us. If you have retired or are planning to retire, travelling is perhaps something that you have planned and saved for. The question is, how will being diagnosed with heart failure affect your ability to travel?

Firstly, it's important to discuss the holiday you have planned with your GP, Cardiologist and or Heart Failure Nurse to ensure that you are fit to travel. It could be that previous holidays may now not be suitable for you. Don't worry; there will still be holidays that you will be able to take.

Having being diagnosed with and living with heart failure, you may find your confidence has been knocked and you are a little apprehensive about what you can and cannot do when going on holiday or travelling. We know that it may take time to build our confidence up and, by doing this gradually, you will learn what you feel comfortable doing. You could start with a weekend away and see how you get on. You'll learn a lot about yourself and then you can work out what will work for you going forward. This is an important element of self-management and will give you the confidence to do the things you are capable of doing.

## Altitude

If you intend to travel to high altitudes, please check with your Doctor to make sure you will be able to cope. Altitude forces the heart to work harder. Where a healthy heart can respond to the demands of high altitude, someone with a heart condition may therefore struggle.

## Depth

If you are contemplating diving, it is essential that you have a thorough check-up with your healthcare professional and discuss if you are fit to dive. Diving courses require you to have a medical statement to state if you are fit to dive.

## Increasing your fluids

High temperatures will obviously make you perspire more, leading to a loss of body fluid. This results in your heart having to pump harder to get the smaller amount of fluid to your working muscles, skin and other parts of your body. Therefore, you will need to increase your fluid consumption (choose water). Mention to your Heart Failure Nurse that you are going to a hot country and he/she will help you with adjusting your fluid intake.

Although it's not easy when you are on holiday, try to avoid caffeinated drinks and alcohol which exacerbates the problem. Wear light clothing and keep in the shade with a hat and sunglasses. If you look cool, you'll be cool!

## Tips for travelling

- Prepare for your trip well in advance and choose a destination where you are confident in medical facilities and access to medical treatment.
- Check that your accommodation and the local facilities are suitable. Avoid staying at a hotel situated at the top of a steep hill, miles away from the nearest town.
- It is generally not advisable to use the spa facilities (e.g. baths, saunas, Jacuzzis or steam rooms) if you have high blood pressure, a heart condition, angina or have had a heart attack.
- Do not use facilities that involve a sudden change of temperature (e.g. a sauna) followed by plunging into cold water. If you are planning to use such facilities, please ask your Doctor first.
- Do not overexert yourself. When travelling, use lightweight luggage (preferably on wheels) and make use of porters.
- Plan your journeys carefully, allowing plenty of time. Don't rush!
- Take out adequate travel insurance to cover your condition (see section 3.16.2 for advice on travel insurance).
- Take sufficient medication for your entire trip (and a little more!)
- Take a list of your medications and their dosages. If you can, depending on your relationship with your GP or Cardiologist, ask them to provide a letter explaining the simple facts around your condition. You could give this to a local healthcare provider along with your list of medications.
- Avoid hectic itineraries and don't exert yourself.

Remember, if you have any concerns then do discuss your plans with your team.

For advice on travelling, visit the following website which provides good and specific advice on travelling to various climates and destinations:

[www.fitfortravel.nhs.uk/advice/general-travel-health-advice/air-travel.aspx](http://www.fitfortravel.nhs.uk/advice/general-travel-health-advice/air-travel.aspx)

# TRAVEL INSURANCE

3.16.2

Travel insurance is an important part of going on holiday. Sometimes, heart failure is assumed as a barrier to going on a holiday abroad as there is generally a lack of signposting to those insurers who can help.

Firstly, there is distinct difference between travelling in Europe and outside of Europe. We recommend you get travel insurance wherever you are going and get signed off by your GP or Cardiologist, preferably in a letter you can keep.

If you are travelling in the EEA (European Economic Area) or Switzerland, you can obtain reduced healthcare costs, or sometimes free healthcare, if you have a European Health Insurance Card. Visit the following web site to apply:

**[www.gov.uk/european-health-insurance-card](http://www.gov.uk/european-health-insurance-card)**

If you are travelling outside the EEA, we highly recommend you get travel insurance. In some areas of the world, if you need treatment of any kind, this can become extremely expensive where the cost may have consequences outside of your control. As an example, this is evident in North America.

We realise one of the biggest obstacles for both heart patients and all patients with long-term conditions is to get back to normality. In terms of travel, this is achieved by acquiring excellent insurance when you go on holiday. One of the most frequently asked questions we hear is 'where can I get good travel insurance?' Believe us; you don't want to travel abroad without it.

**For further information please visit our website  
[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org).**

**Please note with the UK leaving the EU this may affect the way healthcare works across the EU for UK citizens.**

## Fluid

Your Clinician may have advised you to restrict your fluid to two litres a day. However, there is a move away from this due to a lack of evidence. Take advice from your Clinician; however, in summer it will be necessary to increase your fluid intake (especially water) and avoid excess alcohol intake.

## Medication

If you are taking the drug Amiodarone, stay out of the sun as much as possible. If you have to go in the sun, cover up as it will make your skin photosensitive, which means it will burn no matter what you do. GPs will often provide a high factor sun block for you to use.

If you are taking Beta Blockers such as Bisoprolol or Carvedilol, you will generally be more susceptible to changes in the heat. Therefore, stay out of the heat where you can.

## Sunburn

To avoid sunburn, the most important thing you can do is protect your skin. You can enjoy the sun safely by using a minimum sun protection factor of SPF 15. Spend some time in the shade and wear a t-shirt and hat. Apply plenty of sun cream around your shoulders, neck and arms and then move onto your body and legs. Always follow the instructions on the back of the product and, if you swim, reapply regularly. Don't forget your eyes so always wear 100% UVA protection sunglasses.



Your heart failure will no doubt be affected by the weather. If it is cold, your heart has to work harder to keep you warm and if the weather is hot, your heart works harder in order to keep you cool. Here is some general advice to help support you in with the extremes of the weather.

## Winter

Winter seasons will bring cooler temperature and, for some, ice and snow. It's important to know how cold weather can affect you as a heart failure patient. In cold weather, you should avoid sudden exertion, like lifting a heavy shovel full of snow. Even walking through heavy, wet snow or snow drifts can strain a person's heart.

Many people aren't conditioned to the physical stress of outdoor activities and don't know the dangers of being outdoors in cold weather. Winter sports enthusiasts who don't take certain precautions can suffer accidental hypothermia.

## Hypothermia

Hypothermia means the body temperature has fallen below 35°C. It occurs when your body can't produce enough energy to keep the internal body temperature warm enough. Heart failure causes most deaths in hypothermia. Symptoms include lack of co-ordination, mental confusion, slowed reactions, shivering and sleepiness.

Children, the elderly and those with heart disease are at special risks. As people age, their ability to maintain a normal internal body temperature often decreases. Because elderly people seem to be relatively insensitive to moderately cold conditions, they can suffer hypothermia without knowing they are in danger.

## Angina

People with coronary heart disease often suffer angina (chest pain or discomfort) when they are in cold weather. Some studies suggest that harsh winter weather may increase a person's risk of heart attack due to overexertion.

## High Winds

Besides cold temperatures and high winds, snow and rain can also steal body heat. Wind can be especially dangerous, because it removes the layer of heated air from around your body. At  $-1^{\circ}\text{C}$  in a 30 mile per hour wind, the cooling effect is equal to  $-9^{\circ}\text{C}$ . Similarly, dampness causes the body to lose heat faster than it would at the same temperature in drier conditions.

## Alcohol

Don't drink alcoholic beverages before going outdoors or when outside. Alcohol gives an initial feeling of warmth, because blood vessels in the skin expand. Heat is then drawn away from the body's vital organs.

## Top Tip

**To keep warm, wear layers of clothing. This traps air between layers, forming a protective insulation. Also, wear a hat or a head scarf. Heat can be lost through your head. Your ears are especially prone to frostbite. Keep your hands and feet warm too, as they tend to lose heat rapidly.**

## The heart failure patient's winter survival kit

As you may be aware, cold weather is not good news for heart failure patients. We thought you may find the "toolkit" useful as it is important to look after yourself during the cold weather and winter months. Firstly, before we give you advice, you have to realise that you are more vulnerable than others. Understand and accept it. When you have done this, carry on.

- **Make sure you have had your regular seasonal flu jab at the doctors; you should also ensure that you have had a pneumonia vaccination as well.**
- **Hat, scarf, and gloves - always carry these as they prevent you losing heat but also, if you are on Beta Blockers, you can be more susceptible to the cold.**
- **Always have a fully charged mobile phone with you when you go out. If you don't have one, then tell your carer or perhaps inform a friend of where you are going and what time you expect to be back.**
- **If bad weather is expected and you have to make a car journey, make sure you take your tablets with you and a bottle of water to take them with.**
- **Consider investing in equipment for car journeys in the snow (e.g. a snow shovel, body warming packs, snow socks for car tyres) in case you get into any difficulties.**
- **Have a list of your medications and your diagnosis just in case.**
- **Make sure if you are going out in the car that you take your coat, hat and gloves (no matter how short your journey).**
- **If you are susceptible to the cold air and get breathless, wrap a scarf around your face.**

- **If there is bad weather forecasted, make sure that you have a sufficient supply of medicines in case you cannot get to your GP's or pharmacy.**
- **Make sure your car is prepared for the winter months. Visit the RAC, AA or similar bodies for general advice.**
- **We know this is a tough one to explain but if you are worrying about the cost of heating your house due to the ever rising fuel bills, go somewhere where you can keep warm. This could involve simply going to a pub, bar, café or supermarket for a mug of coffee or tea. We know that it is not always easy, but it does make sense. If this is not possible, don't heat the whole of the house/flat; just heat the rooms you need.**
- **Wrap up warm in your house. Fashion doesn't make sense in the house; nobody can see you so wear thick jumpers, a double layer of socks and thermal underwear. A lot of the discount clothing retailers are touting for your business at the moment and there are some really good deals on clothing. Stores include Asda George, Primark, Matalan, Tesco, Sainsbury's and TK Maxx.**

## Keep a good store cupboard

Make sure you have some of the basics in your kitchen cupboard. Here are the Pumping Marvellous Top 10 essential items to have in:

- **Long life milk**
- **Low salt baked beans**
- **Low salt tinned soup**
- **Tinned tomatoes**
- **Eggs**
- **Part baked bread rolls**
- **Tinned fruit, in juice not syrup**
- **Frozen vegetables or tinned vegetables in water**
- **10 litres of drinking water if your pipes freeze**
- **Packets of rice or pasta with a good selection of spices**

## Getting a common cold

Having a cold can make you feel pretty lousy, even for people without heart failure. It can really set you back and recovering from it may take a little longer. Prevention is better than cure, so if you can avoid people or situations which may leave you vulnerable to catching a cold then do so; basic hand hygiene also goes a long way. Other factors which help are a healthy diet and physical activity to keep the body's immune system at its best.

The prevention of flu and pneumonia is vital and we strongly recommend that you have the seasonal flu vaccination. The pneumonia vaccination should last you for a number of years.

## So what should you do if you have a cold?

- **Take plenty of rest; it helps the body to recover.**
- **Avoid taking an anti-inflammatory (such as Ibuprofen and Diclofenac) as they can make your heart failure worse by causing your body to retain fluid.**
- **Avoid decongestants as they can have a detrimental effect on your blood pressure.**
- **If you have a sore throat, try gargling with warm water.**
- **A drink of lemon juice and a small amount of honey can bring some relief.**
- **If you wish to take a pain relief, Paracetamol as prescribed on the packet will help and not interfere with any of your medication.**
- **Antibiotics will not help your cold, however, if you are concerned then do consult your healthcare professional.**

# END OF SECTION CHECKLIST

3.18

## Question 1

Which city helps me know where I am with my heart failure?

- A Paris**
- B Sydney**
- C New York**

## Question 2

Can you name three things you can do to help manage your heart failure?

- 1** .....
- 2** .....
- 3** .....

## Question 3

Which traffic light colour are you at the moment and why?

.....

.....

## Question 4

Can you name three of your team?

- 1** .....
- 2** .....
- 3** .....

## Question 5

How does Pierre suggest you work with your GP?

- A In partnership with you.**
- B Just listen to what he or she says.**
- C Just tell them what he or she wants to hear.**

## Question 6

Can you name three benefits to you of staying active?

- 1** .....
- 2** .....
- 3** .....

## Question 7

How many food groups are there?

- A 4**
- B 5**
- C 6**

## Question 8

What can excessive alcohol intake produce?

- A Irregular heart rhythms**
- B High blood pressure**
- C Both of the above**

## Question 9

Can you name three ways you should go about preparing for a holiday in the sun?

- 1** .....
- 2** .....
- 3** .....

## Question 10

Can you name three ways you should go about preparing for a trip out in winter?

- 1** .....
- 2** .....
- 3** .....

Get your Heart Failure Nurse to help you check your answers with you.

**MORE HELP**



# WELFARE & BENEFITS

4.1

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

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

There are a range of benefits heart failure patients may be entitled to claim. These include ESA (employment support allowance), DLA (disability living allowance) for under 16s, PIP (personal independence payment) for working age adults aged between 16 and 64 years old and AA (attendance allowance) for over 65s.

For further information, please visit the government website:

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

The Citizens Advice Bureau may also provide advice:

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

Please contact the Pumping Marvellous Foundation if you require any further advice.

# PENSIONS

4.2

Being diagnosed with heart failure may cause you to think about reviewing your pension arrangements. Recently, there have been significant changes to pension regulation. Information appears to be changing regularly in this field, so have a look at the following links for information on the topic.

For advice and information on your state pension entitlements, visit the following website:

[www.gov.uk/pensions-advisory-service](http://www.gov.uk/pensions-advisory-service)

The Citizens Advice Bureau also covers the subject:

[www.citizensadvice.org.uk/debt-and-money/pensions/](http://www.citizensadvice.org.uk/debt-and-money/pensions/)

The Pensions Advisory Service provides independent advice on the pension system:

[www.pensionsadvisoryservice.org.uk/](http://www.pensionsadvisoryservice.org.uk/)

# RELATIONSHIPS & ROMANCE

4.3

## Relationship Communication

An old TV advert said 'it's good to talk' and indeed it is. All relationships will come under pressure at some time or other, for a variety of reasons. Keeping an open channel of communication is vital. When you are diagnosed with a condition such as heart failure, you and your partner's world may be turned upside down. It is good for both of you to discuss and share your concerns and feelings. You may find that the social, financial and physical implications of your condition puts your relationship with your partner under considerable pressure. Relate provides invaluable information, support and counselling for individuals and couples of any sex or orientation.

[www.relate.org.uk/relationship-help/help-relationships](http://www.relate.org.uk/relationship-help/help-relationships)

You may find that talking to another person with heart failure (or another carer of a heart failure patient) helps considerably. There may be a local group which can help you. If not, we run a closed Facebook group where you can become a member.

[www.facebook.com/groups/helpforhearts/](http://www.facebook.com/groups/helpforhearts/)

This group has many patients who help each other on a daily basis with living with heart failure. Patients talk about their conditions and how they have overcome their challenges. It is a safe place to talk and is highly moderated just for this reason.

## Fifty shades of pink and green

Having a physical relationship is important to many people, and having heart failure should not prevent you having one. Indeed many would say that whatever form a physical relationship takes, it can bring pleasure, closeness and a feeling of normality. When first diagnosed with heart failure you may feel too unwell for a physical relationship, but once your symptoms are under control then your heart failure should not prevent you from enjoying a healthy sex life.

- **If you have any concerns, discuss these with your partner, it is important to talk about any fears or limits you may feel you have.**
- **Discuss with your GP, Doctor or Nurse any issues or difficulties you may be having. They will not be embarrassed, it's part of their job, and neither should you be.**
- **Avoid sex for the time being if you are feeling unwell, or having any pain or chest discomfort.**
- **Don't expect too much of yourself, as with any long-term condition, you may feel anxious or depressed which may be having a bearing on you wanting to having a physical relationship. Discuss with your partner or healthcare team member if this is the case.**
- **Choose a time and environment that is right for you, where you feel relaxed and comfortable.**
- **Many people feel that just holding each other, hugging and kissing is rewarding and reassuring for both partners.**

For further information, visit the European Cardiology Heart Failure Association website at [www.heartfailurematters.org](http://www.heartfailurematters.org).

# EMPLOYMENT & HEART FAILURE

4.4

## Being Employed

Being diagnosed with heart failure may have an impact on your occupation. You may be forced to have a period of time off work. Although you may find the conversation difficult, it is important to maintain contact with your employer and have an open and frank conversation and relationship on the impact of your condition. This is an area where you can really help yourself so instead of waiting for your employer to contact you, make them set up a regular schedule of telephone calls so you remain in control. If you think about it, the more you are seen to be wanting to communicate, the more your employer understands the challenges and can therefore help you when you return to work. If you haven't been referred to your occupational health department, ask for a referral. If you haven't got an occupational health department, contact your union or other professional body for information and support if you find yourself on long-term sickness.

Many people do not understand the term 'heart failure' and that applies to employers as well. You may find the following information helpful in explaining to your employer what heart failure is.

For many individuals, continuing to work is not just about the financial need. Many people actually enjoy their job, have great work colleagues and appreciate the social interaction that work provides. It is therefore important to have a frank conversation with your employer of how your symptoms will affect your capacity to work. It may require some adjustment from both you and the employer, particularly if you work a long shift pattern, or your role requires a good deal of physical activity.

We also appreciate that for some individuals there will be little support from their employers, especially in terms of sick pay. Please see **section 4.1** for further information.

## Discussing heart failure with your employer

I have an inefficient heart which results in my heart not being able to pump blood efficiently around my body. It is called heart failure; it doesn't mean 'I am failing'.

I may experience the following symptoms:

- **Breathlessness**
- **Fatigue**
- **Swelling of my legs and ankles**
- **Restriction in my physical activity**

I am managing my symptoms. I take regular medication, monitor my symptoms, lead a healthy lifestyle and attend regular check-ups with my health team. If you have any further questions please ask me or visit the **Pumping Marvellous Foundation** website which provides information on heart failure.

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

## Further Reading

The following government website provides information on employees and employers' entitlements and responsibilities:

[www.gov.uk/taking-sick-leave](http://www.gov.uk/taking-sick-leave)

The government's health and safety executive website provides information on any legal issues with regard to employment law:

[www.hse.gov.uk/sicknessabsence/legalguidance.htm](http://www.hse.gov.uk/sicknessabsence/legalguidance.htm)

ACAS promotes excellence in employment and human resources and can act as a mediation service:

[www.acas.org.uk/index.aspx?articleid=1461](http://www.acas.org.uk/index.aspx?articleid=1461)

The benefits system is frequently under review. The following link provides the latest government information of disability and sickness benefits:

[www.gov.uk/financial-help-disabled/disability-and-sickness-benefits](http://www.gov.uk/financial-help-disabled/disability-and-sickness-benefits)

The Citizens Advice Bureau also provides independent information on a range of benefits and services that may be available to you:

[www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/](http://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/)

For general advice on a range of benefits, you can visit the following government website:

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

# DRIVING WITH MY CONDITION

4.5

For information with regard to any driving restrictions as a result of your cardiac condition, please visit the following government website:

[www.gov.uk/browse/driving/disability-health-condition](http://www.gov.uk/browse/driving/disability-health-condition)

As regulations change, please visit the website for the latest information.

Making the decision to stop driving can be difficult, but if you feel that your health is affecting your ability to drive safely then you may have to make the decision to stop. You do not want to put yourself, your passengers or other road users at any sort of risk.

If your partner, family or friends are suggesting that you should stop driving, discuss the issue with them openly and listen to their concerns. It may be a difficult conversation, but they will no doubt be thinking of your well-being. The blue badge scheme allows concessions for parking your car. Please visit the following site for information regarding qualification and application for the scheme:

[www.gov.uk/apply-blue-badge](http://www.gov.uk/apply-blue-badge)

You can ask for a referral to a mobility centre who will assess you and provide information into what vehicle or aids may assist you driving with any disability. You can ask for a referral from your GP:

[www.mobility-centres.org.uk/](http://www.mobility-centres.org.uk/)

Depending on your age and circumstances, you may qualify for a Motability allowance. This is now part of the personal independent payment. Please visit the following government website for further information:

[www.gov.uk/pip/overview](http://www.gov.uk/pip/overview)

# MARVELLOUS GUIDE IN SUMMARY

4.6

To summarise what you have read so far our patient community identifies the most important points that will help you with managing your condition on a day to day basis.

Before we identify these with you we hope you've found some real golden nuggets of information which you can take away and use. We all know this isn't easy but from experience, if you learn how to achieve something difficult you can apply the way you solved one problem with solving the next.

So see these points as the starting point of your new "marvellous" journey. They are not the only skills you will need to acquire but they will give you a good foundation.

First look at the module your Nurse has given you. Knowing why you have heart failure will help you put it all into context and enable you to understand what you need to do next.

## Section 2 - Medical Stuff

The '**Medical Stuff**' section tells you in 'patient speak,' in step by step format what the investigations and therapies are for people like you with heart failure.

### Section 2.3 - Symptoms of Heart Failure

Know your symptoms. By knowing your symptoms this will help you to apply your own fixes.

### Section 2.5 - Core Medication

Know what your medicines do, know why you are taking them and know what the side effects if any look like for you. This will help you maintain their importance in your care, take them as prescribed and try not to miss them.

## Section 3 - Me & My Heart Failure

The **'Me & My Heart Failure'** section gives you tools on how you can help manage your condition. It gives you tools that whilst not under the care of Healthcare Professionals will enable you to get to grips with your condition and help you manage it more effectively. It's amazing what a little bit of knowledge and the right attitude to self-care can do.

### Section 3.2 - My Appointment Diary

Your appointment is one of the most important times for you and your Healthcare Professional to get to know how you are doing. Preparation, preparation and preparation are the three key words. As the Healthcare Professional has prepared for your appointment, make sure that if you have questions that you ask them now.

### Section 3.3.1 - The NYHA Scale - A Useful Tool

Where are you in New York? Use this as a method of telling your Healthcare Professionals where you are, they will understand you and will value your feedback.

### Section 3.5 - Looking After My Ups and Downs

Understanding your heart failure and how this relates to your symptoms will help you make decisions that will help you manage your condition.

### Section 3.6 - My Medical Team

Knowing who your team are and how they are part of your team are really important. They are referred to as your 'Multi Disciplinary Team'. Also, if you haven't got one of these team members you should ask why not.

### Section 3.8 - Getting The Most Out of Your GP

Do not underestimate the value of relationships. A good relationship will get you a lot more than if you didn't have that relationship.

### Section 3.9 - Staying Active

Exercise is one of the best self-prescribed therapies, make sure you have been signed off for this by a Healthcare Professional and do it at your own pace and most importantly feel the benefit.

### Section 3.10 - What Is Healthy Eating For Me?

Remember, you are what you eat, so eat healthily.

## Section 4 - More Help

The **'More Help'** section covers the little extras that may not be essential to every individual but do play a part in our lives.

### Section 4.3.1 - Relationships & Romance

Remember your family are part of your team, they need you as you need them. Make sure they have an opportunity to recharge their batteries as well.



# REFERENCES

## Further Reading

The next section of the 'Marvellous Guide' will provide you with a considerable amount of information across a range of subject areas. Most of the topics will include signposts to further information, as in the digital age things are changing constantly and this is the most efficient way to provide up-to-date advice. Most of the signposts relate to website or links on the internet. We also realise that not everyone has a computer or the ability to access the internet.

You may find that friends or family members (often the youngest members) will be able to obtain the information you require. If you have no one you feel may be able to help you, consider visiting your local library for access to computers and staff will assist you in finding the information. Local library services also hold computer teaching sessions.

## Patient Organisations and Related Services

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

Website to support patients with heart muscle disease.

### [www.ageuk.org.uk](http://www.ageuk.org.uk)

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

### [www.carersuk.org](http://www.carersuk.org)

Website of organisation for carers.

### [www.macmillan.org.uk](http://www.macmillan.org.uk)

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

### [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

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

### [www.gov.uk/apply-blue-badge](http://www.gov.uk/apply-blue-badge)

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

### [www.relate.org.uk](http://www.relate.org.uk)

Organisation that provides information and counselling services for couples.

### [www.nhs.uk/Pages/HomePage.aspx](http://www.nhs.uk/Pages/HomePage.aspx)

Link to various NHS services.

### [www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11](http://www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11)

Information for carers.

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

Information in regards to current information benefits.

### [www.acas.org.uk](http://www.acas.org.uk)

Information of both employers and employees for training and mediation.

### [www.gov.uk/pensions-advisory-service](http://www.gov.uk/pensions-advisory-service)

Pension advice, both state and private.

### [www.gov.uk/contact-jobcentre-plus](http://www.gov.uk/contact-jobcentre-plus)

Employment advice and opportunities.

### [www.samaritans.org](http://www.samaritans.org)

Agency providing immediate support and crisis management.

### [www.moneyadvice.service.org.uk/en](http://www.moneyadvice.service.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](http://www.gov.uk/current-medical-guidelines-dvla-guidance-for-professionals-conditions-g-to-i#advice-for-the-general-public)

Driving information from the DVLA.

## Medical Organisations and Further Information:

[www.bhf.org.uk](http://www.bhf.org.uk)

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

[www.bsh.org.uk](http://www.bsh.org.uk)

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

[www.nice.org.uk/guidance/cg126](http://www.nice.org.uk/guidance/cg126)

NICE guidance on angina.

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

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

[www.drinkaware.co.uk](http://www.drinkaware.co.uk)

Information on alcohol intake.

[www.alcoholics-anonymous.org.uk](http://www.alcoholics-anonymous.org.uk)

Support organisation for alcohol-related issues.

[www.nhs.uk/livewell/drugs/pages/drugtreatment.aspx](http://www.nhs.uk/livewell/drugs/pages/drugtreatment.aspx)

Support organisation for drug-related issues.

[www.mind.org.uk](http://www.mind.org.uk)

Mental health charity.

[www.england.nhs.uk](http://www.england.nhs.uk)

Health commissioning organisation for the NHS.

[www.cqc.org.uk](http://www.cqc.org.uk)

Regulatory body for the NHS.

# OTHER CHARITIES

5.3

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:

## Heart Charities

**Atrial Fibrillation Association**  
[www.atrialfibrillation.org.uk](http://www.atrialfibrillation.org.uk)

**British Cardiovascular Society**  
[www.bcs.com](http://www.bcs.com)

**British Heart Foundation**  
[www.bhf.org.uk](http://www.bhf.org.uk)

**British Heart Valve Society**  
[www.bhvs.org.uk](http://www.bhvs.org.uk)

**British Society of Heart Failure**  
[www.bsh.org.uk](http://www.bsh.org.uk)

**Cardiomyopathy UK**  
[www.cardiomyopathy.org](http://www.cardiomyopathy.org)

**CRY**  
[www.c-r-y.org.uk](http://www.c-r-y.org.uk)

**Heart UK**  
[heartuk.org.uk](http://heartuk.org.uk)

**Heart Failure Matters (European Society for Cardiology)**  
[www.heartfailurematters.org](http://www.heartfailurematters.org)

**SADS**  
[www.sads.org.uk](http://www.sads.org.uk)

## Government

**NHS Choices**  
[www.nhs.uk](http://www.nhs.uk)

**NICE**  
[www.nice.org.uk](http://www.nice.org.uk)

## Mental Health Charities

**Mind**  
[www.mind.org.uk](http://www.mind.org.uk)

**Rethink**  
[www.rethink.org](http://www.rethink.org)

## General Information

**Patient**  
[patient.info](http://patient.info)

**Travel insurance for people with heart failure**  
[www.travelinsuranceforhearts.org.uk](http://www.travelinsuranceforhearts.org.uk)

**Driving with a medical condition**  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/491028/aagv1.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/491028/aagv1.pdf)

# END OF SECTION CHECKLIST

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5.4

**Now go and be  
a marvellous  
person living  
with heart  
failure!**

**Skip to the back page see the cheat's guide.**



# MY LOCAL TEAM

5.6

Your Carer's Name:

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Your Carer's Telephone Number:

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Your GP's Name:

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Your GP's Telephone Number:

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Your Cardiologist's Name:

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Your Cardiologist's Telephone Number:

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Your Heart Failure Nurse's Name:

---

Your Heart Failure Nurse's Telephone Number:

---

Your Practice Nurse's Name:

---

Your Practice Nurse's Telephone Number:

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Your Pharmacy's Name:

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Your Pharmacy's Telephone Number:

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## Other Team Details:

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If you are like most people, then you'll have a glimpse at the back pages to see what the conclusion or end of the story is - and here it is!

## How to be a Marvellous Heart Failure Patient

♥ **Know why you have heart failure**

♥ **Know how to self-care**

♥ **Know how your team care**

♥ **Be marvellous**

♥ **Believe in yourself**

**Now go and be marvellous!**

**We hope that you  
have found this  
Marvellous Guide to  
Heart Failure useful.**

*If you'd like any further information, please  
visit us at [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org).*

# MY MARVELLOUS GUIDE TO HEART FAILURE



## Contact Pumping Marvellous



0800 9 788133



hearts@pumpingmarvellous.org



heartfailureaware (open)



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



@pumpinghearts



helpforhearts (closed support group)