My Marvellous Guide to Heart Failure

Be a 'marvellous' heart failure patient

Medical Stuff

The end to *those* questions



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

CONTENTS

1.0	My Marvellous Guide to Heart Failure How to be a Marvellous Heart Failure Patient02	3.6 3.7 3.8	My Medical Team4 Who Is My Team?4 Getting The Most Out of Your General Practice .5	8
1.2	An Introduction03	3.9	Getting The Most Out of Your Cardiologist5	
1.3	Acknowledgements03	3.10	Technology: An Alternative Team Member	
1.4	Who Are Pumping Marvellous?04	3.11	Staying Active	
1.5	What We Get Involved In05	3.12	What is Healthy Eating For Me?5	
1.6	Get In Touch06	3.13	Fluid & Salt	
2.0	Medical Stuff	3.14	Me & Smoking	_
		3.15	Me & Alcohol6	
2.1			1 What About Travelling?6	
	What is Heart Failure?10		2 Travel Insurance	
2.3	Symptoms of Heart Failure11			-
	Tests & Investigations12		3 My Summer Guide	
	1Core Medication16		4 My Winter Guide6	
2.5.		3.17		
2.6	Pain Management24	3.18	End of Section Checklist	4
2.7	Cardiac Devices26	4.0	More Help	
		4.1	Welfare & Benefits	-
	Heart Transplant30	4.1	Pensions	_
2.10	Cardiac Rehabilitation32			
2.11	Other Medical Problems33	4.3	Relationships & Romance	
2.12	2 Infections34	4.4	Employment & Heart Failure7	
2.13	Complementary/Alternative Therapies35	4.5	Driving With My Condition8	
2.14	Find of Section Checklist36	4.6	Marvellous Guide in Summary8	1
		5.0	References	
3.0	Me & My Heart Failure	5.1	Further Support8	3
3.1	Things I Can Do	5.2	Web Links8	4
3.2	My Appointment Diary38	5.3	Other Charities8	6
3.3.1	The NYHA Scale - A Useful Tool39	5.4	End of Section Checklist8	7
3.3.2	Using the NYHA Scale40	5.5	Your Notes8	8
3.4	Dealing With NYHA Level 441	5.6	My Local Team8	9
3.5	Looking After My Ups and Downs42	5.7	The One Pager9	

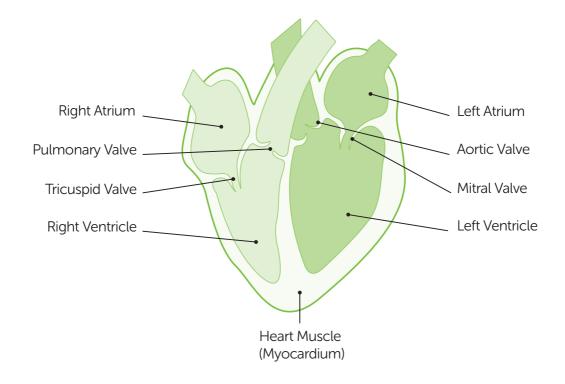
WHAT IS A HEART?



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.



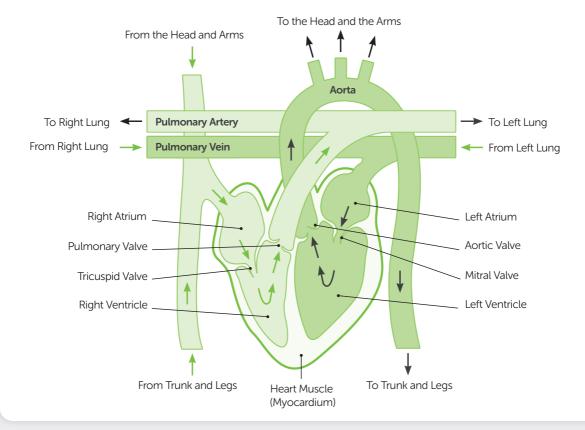
How does it work?

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 faction (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 quide 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."

"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."

"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

Candersartan, 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 Eplelerone

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 Neprolysin 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

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 have 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.

PAIN MANAGEMENT

2.6

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.

CARDIAC DEVICES

2.7

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.

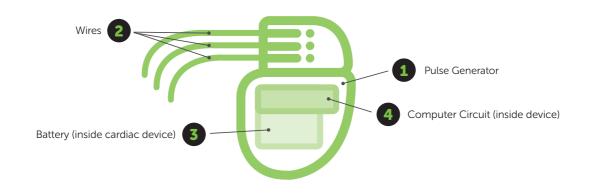
Implantable Cardiac Defibrillator (ICD)

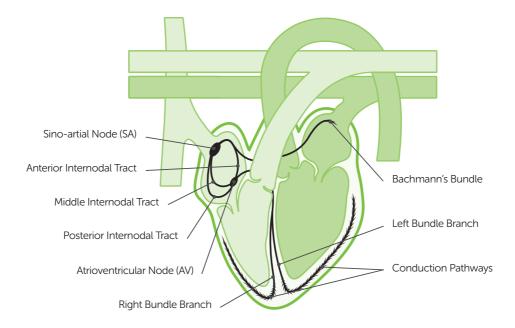
Not only does the heart have a beat, but also a rhythm. Sometimes there is a problem with the rhythm which may have serious consequences. In these cases an ICD may be recommended. This requires implantation of a small box under the skin in the top of the chest - wires are attached to the muscle of the 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.
- The wires which will run from the cardiac device into your heart.
- 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 minute computer circuit converts energy produced by the battery, which travels down the wires and thus stimulates your heart to beat.





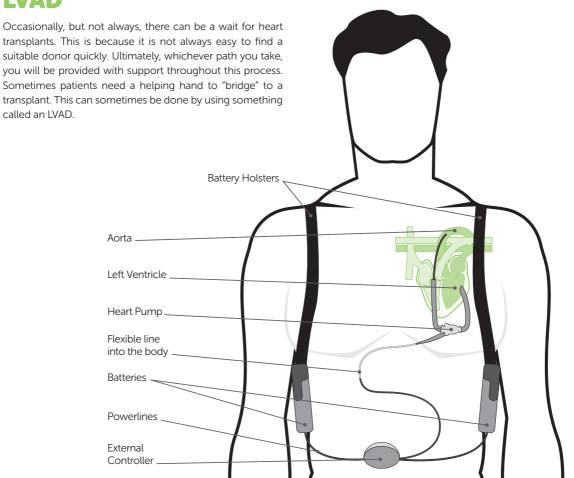
You can see what it looks like to fit a cardiac device on our website; www.pumpingmarvellous.org/heart-failure-guide/crt-devices or scan this code for instant access.



LEFT VENTRICULAR (ASSIST DEVICES (LVAD)

2.8

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 TRANSPLANT



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 it is 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.

INFECTIONS

2.12

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

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

2.14

How big is your heart?	What does an ECG measure?	
A A beach ball	A Electrical activity	
B Two clenched fists	B Oxygen levels	
C A grape	C Breaths per minute	
Question 2 How many times a day does it beat approximately?	Question 7 What machine produces an ultrasound picture of your heart?	
A 1000 times	A MRI	
B 10,000 times	B Echo	
C 100,000 times	C X-ray	
Question 3 Can you name three causes of heart failure?	Question 8 What does a diuretic tablet do?	
1	A It adds water into my body.	
2	B It helps take fluid out of my body.	
3	C None of the above.	
Question 4 What is heart failure?	Question 9 How does an ACE inhibitor or ARB medicine help people with heart failure?	
A Your heart just stops. B Your heart doesn't pump blood	A They widen your arteries and blood vessels to help the heart pump better.	
around your body well.	B They make the heartbeat stronger.	
C It's a heart attack.	C They take fluid from my body.	
Question 5 Can you name common symptoms of heart failure?	Question 10 What does CRT stand for?	
1	A Cardiac Regurgitation Treatment	
2	B Cardiac Recycling Treatment	
3	C Cardiac Resynchronisation Therapy	

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.





Contact Pumping Marvellous



0800 9 788133



hearts@pumpingmarvellous.org



heartfailureaware (open)



www.pumpingmarvellous.org



@pumpinghearts



helpforhearts (closed support group)