

Patient's Guide to Being Told You Have Heart Failure

Help from people like you



Authored by patients like you



HELPING PEOPLE LIVE BETTER WITH HEART FAILURE

WELCOME TO THE PUMPING MARVELLOUS FOUNDATION

Heart failure affects close to 1,000,000 people in the UK, so you are not alone.

This is the last time we will refer to heart failure as such; we all like to call it an inefficient heart because that's what it is. Sufferers and their families are at the heart of what we do. All the information we produce, just like this booklet, is developed by people who have an inefficient heart.

The Pumping Marvellous Foundation gives sufferers and their families **HOPE**.

HOPE that one day there will be a cure.

HOPE that they can manage their condition better.

HOPE people managing their heart failure get access to NICE guideline treatments and care.

HOPE that we can help you live better with heart failure.

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

Patients helping patients...

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

Angela Graves – Chair and Consultant Nurse in Heart Failure



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Point 1 – So what is an inefficient heart?

The heart is a complicated muscle working via a series of electrical impulses and valves. Like a well-tuned motor, it only takes one of the many components to malfunction and the heart won't work as efficiently as it should, just like a car's engine. Like any muscle in the body, the heart must receive oxygen and nutrients to function properly. Reasons for an inefficient heart can be:

- Coronary heart disease – like a heart attack or angina
- Untreated long-standing hypertension (high blood pressure)
- Cardiomyopathy (your heart muscle weakens)
- Heart rhythm disturbance (like atrial fibrillation)
- Damaged heart valves
- Myocarditis (inflammation of the heart muscle may be caused by a virus)
- Prolonged alcohol consumption
- The use of recreational drugs
- Chemotherapy treatment
- Pregnancy

Whatever has caused your heart to be inefficient, your Cardiologist will suggest a series of tests and treatments. You may have a blood test, an

ECG (Electrocardiogram, which looks at your heart's electrical activity) and an echo (Echocardiogram, which is a scan that looks inside your heart). Some of the options your Clinician will discuss with you will be:

- Lifestyle changes
- Medications
- Implantable devices
- Certain types of heart surgery

Self-managing your inefficient heart is very important. In most cases, if you take your medication as prescribed by your healthcare team in conjunction with making lifestyle changes, this can help your heart work as efficiently as it can and help manage your symptoms.

(The heart's inability to pump blood effectively can cause many symptoms. Some of the symptoms people may experience are chest pain, breathlessness during exertion, struggling to breathe at night and swelling of the feet and legs. If you experience any of these symptoms talk to your heart failure team).

Patient

Point 2 – Listen to your body

Your life won't stop, it will just be different. You have to think about the consequences that you will suffer if you overdo things. You could have a great day and keep busy all day, but then be prepared for the next day to be a day where you will need rest. Break up your journeys or duties or tasks by taking mini rests – you'll soon learn to know your own capabilities.

Having an inefficient heart affects people in different ways; what way is yours?

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Point 3 – A positive mind means positive results

Being diagnosed with heart failure may bring a variety of emotional responses. There may be several mental adjustments to make in order to continue enjoying life, taking into consideration the lifestyle changes involved. Practising positivity can be done by using a 'self-help toolkit'. Find ways to appreciate the pleasures in life and focus on the 'can do' moments. Looking after your mental health is so important; healthy diet, suitable exercise, hobbies, laughter and love are a sensible recipe for happiness. Talk to your Heart Failure Nurse, Cardiologist, GP, Pharmacist or Cardiac Rehabilitation Team.

Patient



Point 4 – Don't believe the "hype"

Perhaps the aforementioned flies above the heads of many – by "hype", what we mean to describe is the urge to consult the great oracle, Google, to foretell when one's untimely passing may come after being diagnosed (broadly speaking) with heart failure. As a result, many will surmise that they have an even chance of lasting five years – that's 50/50 for those not into gambling!

The truth is simply that the age range of people diagnosed with heart failure is actually broad, very broad. In fact Heart Failure impacts all generations. From the Greatest Generation through to the Silent Generation, Baby Boomers, Generation X, Millennials, Generation Z through to GEN Alpha. Don't believe everything you read.

Thus, we may halt in negative thought, for never the twain shall meet: most, if not all, do not succumb to what these outdated statistics suggest. In fact, the only way to respond to this flaky spiel is to stick two fingers up and proudly proclaim defiance in the face of adversity – do it now, sing it loud; as loud as your fluid-filled lungs will allow you to bellow.

You are now in an exclusive club among kindred spirits. Find a path of communication, whether that be through the internet, group therapy, stamp collecting – tell someone what is happening inside – and remember: we are legion.

The greatest kick in the tail for many, are the comments from well-meaning loved ones, such as "You are looking so well!" and "Are you still taking the tablets?" Although said with the best of intentions, we must fly in the face of the doom and gloom one finds after research.

Yep, bit of a melon twister is this condition, so reach out to those who understand. Come and join our community, search "Help for Hearts" on Facebook to access the Pumping Marvellous Foundation community.

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Point 5 – Important people you need to know

You: As the patient, you are the most important person. You are the one who has an inefficient heart. You are entitled to ask questions of anyone who is involved in your care and you should expect answers that you understand. So never be afraid to ask questions, no matter how silly you think they may sound.

Family and Friends: Your family and friends will be just as shocked as you are. You will not only be trying to understand it yourself but they will want to know, so be open with them. They are the ones who will support you if the going gets tough. Be honest about how you feel, as without them knowing they will not understand, therefore, not being able to help will make them feel even more vulnerable.

Doctors (GP): Your GP is the key to the door; they will be the ones doing the everyday checks of blood pressures and blood tests; they will be able to contact your Cardiologist. If you are worried, they are the person who you will speak to first, unless you are having serious problems when you should call 999.

Heart Failure Specialist Nurse: You may have a Heart Failure Specialist Nurse who is either based at your GP surgery, hospital, or who works out in the community. They are Nurses who specialise in helping people who have an inefficient heart and can help you self-manage your condition. They have a wealth of knowledge which you can tap into.

Heart Failure Rehabilitation: There are many forms of rehabilitation, but for people with an inefficient heart, exercise is a key one in managing your symptoms. It is important to keep the blood circulating, so ask your Heart Failure Specialist Nurse or GP what is available in your area. They will probably refer you initially as you need to be eased into it.

Cardiologist with a special interest in heart failure: This is the main person overlooking your care and diagnosis. They will arrange and interpret tests at the hospital and arrange regular appointments to discuss how you are progressing. You may ask them anything you like and again you should expect an honest answer. If you don't understand then tell them and get them to explain it to you again.

Pharmacist: Sometimes a forgotten resource but very much an important resource. An expert in your medication and usually, if based on the high street or in a supermarket, a lot more quickly accessible than others. Certainly a member of your team who can help you better manage your wider condition.

BIG TIP – Make sure you build up a strong relationship with all the people above. A strong relationship means that both parties get the best results. Remember they are all human and you must ensure that they realise that as well.

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Point 6 – Life-changing but manageable

Heart failure! What a strange medical term, a term that seems to come out of the 'Dark Ages' of medicine. I was diagnosed with heart failure in November 2011. The news was not delivered by a Cardiologist or a learned Clinician, but by a Specialist Cardiac Nurse at my bedside, a pleasant woman, who no doubt had delivered this kind of news many times in her career. Clinical, straightforward and to the point. "You will have to adjust your life from now on," she said, handing me literature from the Pumping Marvellous Foundation.

After she had gone I tried to get my head around the term 'heart failure'; I thought long and hard about the word 'failure' and wracked my brains as to when the last time I had 'failed' at anything, where I had made mistakes and things had gone wrong and not turned out the way they should. I always associated 'failure' with a plane losing power at 30,000 feet and plunging into the earth, killing everyone on board.

I was hospitalised for five weeks until my body adjusted to a heart that was only functioning at 29%. I was a fairly fit 65 year old, who liked to walk and led a fairly healthy lifestyle.

My life was changing dramatically. I became short of breath with swelling in the ankles. I was readmitted to hospital five times before they stabilised me and fitted an Implantable Cardiac Defibrillator (ICD) because I was in great danger of sudden death. I look upon my ICD as an on-board paramedic, ready to shock me when needs be.

We all need to be aware of the advances of medical science and trust the Doctors, Nurses, Technicians and Scientists who work tirelessly for a cure for this condition we have. We have to work alongside these professionals who are striving for the next device, the next medicine to make our lives more tolerable.

I have always said that the person who is treating me is not necessarily a nice person,

but one who is competent in the job he/she does. 'Nice' is when we are all down the pub and congratulating each other on the good work we have just done. I want a medical ally to get me through this period in life and most of all, I want us all to work together to achieve that goal.

It may not come in our lifetime, but a cure will come for the good of our children and the generations who come after them because that's how medical science works, it always has and always will do.

Having an inefficient heart is manageable but like all things you need to work on it.

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Point 7 – South of the Watford Gap - Pie and Mash North of the Watford Gap - Sausage and Mash

Along with a diagnosis of heart failure come possible changes to your income, depending on whether you are deemed fit enough to return to work or not. If you are fit enough to work, you may have to make a few minor or major changes as to what your job is. Unfortunately, we haven't got the space on this page to really demonstrate to you how to deal with this, but one tip is – make sure you keep in contact with your employer rather than them phoning you to find out how you are. You may find you can't return to work, or your employer is not very flexible, which means you will need to access the benefits system either on a short or long-term basis. We understand your concerns as we have all been there and that you may never have had to be supported before, but we give you this piece of advice, pride before a fall.

This is a lot to take in when you are already dealing with a life-changing diagnosis but help is out there. The Pumping Marvellous Foundation can point you in the right direction for help and assistance; please contact us using any of the following ways:

Telephone: 01772 796542

Website: www.pumpingmarvellous.org

Email: hearts@pumpingmarvellous.org

Remember, you do not have to go through this alone – if you are unsure about anything, we are here to help.

Patients helping patients.

Point 8 – Set your Sat Nav

Being told you have an inefficient heart sets your head racing as to where your condition will take you. It is important to know some basics before you set your goals on how you're going to conquer and effectively self-manage your condition. Before you set your Sat Nav, take these points into account.

Belief – If you don't believe in yourself then nobody else will.

Attitude – You need a lot of this, an attitude to win.

Knowledge – When you have an inefficient heart some of the right knowledge is powerful.

Heart failure symptoms are classified in a standard way which is called the NYHA (New York Heart Association) heart failure classification.

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	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 is increased.

Ask your Clinician which NYHA level you are and couple that with knowledge from the Pumping Marvellous Foundation, with a sprinkle of belief and attitude, then you will know what to do.



Point 9 – Now for the family briefing

It is hard enough to be told you have an inefficient heart and that you will have to manage your condition going forward, but spare a thought for the family/carers who have to carry on with their life and also worry about you when they are not there; just an unanswered call to a telephone to check on you can send a family member into panic with their imagination going into overdrive.

The support of the family is vital, especially in the early days so brief them on your condition as you would want to be briefed. An example of this is, "My heart is not pumping as effectively as it was ..." instead of saying, "I have heart FAILURE". Just little changes in words make such a difference. Good luck and remain calm, your calmness will help them deal with it.

Patient and their family

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Point 10 – Patients’ one-liners

"Don't be afraid to ask for help, we all struggle."

"Embrace the new you."

"From the start, take heart. Be positive."

"I found the friendship and peer support from everyone at Pumping Marvellous to be so special, those with heart failure understand you when no one does."

"It's OK to grieve for your old life, but then embrace the new you, it does get easier."

"Don't be afraid to live your life."

"Life may have to slow down but it doesn't have to stop."

"Don't let it rule your life."

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NOTES:

Other “Marvellous Guides” available in the series

You can find other resources written by patients like you, for patients like you, on our website, plus many more publications designed to help you out with managing your heart failure. You can acquire all these guides from your healthcare team.

My Marvellous Guide to Caring for Heart Failure Patients

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

My Marvellous Guide to Having a Cardiac Device Fitted

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

My Marvellous Guide to Having an Echo

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

My Marvellous Guide to Medicines for Heart Failure

Our guide that explains how the various medicines work that you are likely to be prescribed with heart failure

My Marvellous Guide to PPCM (Peripartum Cardiomyopathy)

Designed for mums diagnosed with PPCM

My Marvellous Guide to Travelling with Heart Failure

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

My Marvellous Big Pocket Guide to Heart Failure

All you need to know about managing your heart failure better

My Marvellous Guide to Using GTN

A simple guide to helping you take GTN spray or tablets

My Marvellous Guide to ‘Walking a Day in My Shoes’

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

My Marvellous Symptom Checker

A great tool to help you manage your symptoms

My Appointment Diary

Help in managing your heart failure

If you are looking for support, why not join our Facebook Group, where you'll find great peer-to-peer support. Search for “Help for Hearts” on Facebook.

Pumping Marvellous Help for Hearts



All guides are written by patients and clinically validated for accuracy by leading UK heart failure specialists.

If you have any concerns then take this booklet to your
GP, Heart Failure Nurse or Cardiologist.



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

Acknowledgements and thank yous

Angela Graves Chair of the Pumping Marvellous Foundation

Nick Hartshorne-Evans Chief Executive (Founder), Pumping Marvellous Foundation

Our Patient Community who helped to create this guide

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Contact Us



01772 796542

Twitter - @pumpinghearts

Web - www.pumpingmarvellous.org

Facebook - Search "Heart Failure Aware"

Email - hearts@pumpingmarvellous.org

Facebook Support Group - Search "Help for Hearts"

YouTube - Pumping Marvellous



Interested in getting involved in medical research in heart failure go to [CardioTrials.org](https://www.CardioTrials.org)

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