

# The Marvellous Map of Heart Failure

A decorative graphic consisting of several colored lines (purple, pink, orange, green) and three white circular nodes with black outlines. The purple line is horizontal and passes through the first two nodes. The pink line is vertical and passes through the first node. The orange line is vertical, passes through the second node, and then curves to the right to pass through the third node. The green line is vertical and passes through the third node.

*The journey*

# Navigating Heart Failure in the NHS

We believe you'd agree that being diagnosed with heart failure is difficult enough to get your head around but having to navigate your way through what care and support you should expect is a completely new problem. We believe our map will give you a good overview of what you may encounter and answer those questions you might find tough.

## The Lines

### Blue Line

Guidelines and pathways dictate the way patients interact with their heart failure services. The blue line represents this journey; you start at diagnosis and the stations indicate who you interact with whilst managing your heart failure.

### Community Line

Where do you spend most of your time? At home of course. Heart failure lives nearly all of its time in the community. This line represents what you should expect from heart failure services outside of the hospital. You may never come off the community line and that's not a bad thing!

### Unplanned Hospital Line

Sometimes you may have to visit hospital if your symptoms become difficult to manage. Hopefully you won't spend much time on this line.

### Planned Hospital Line

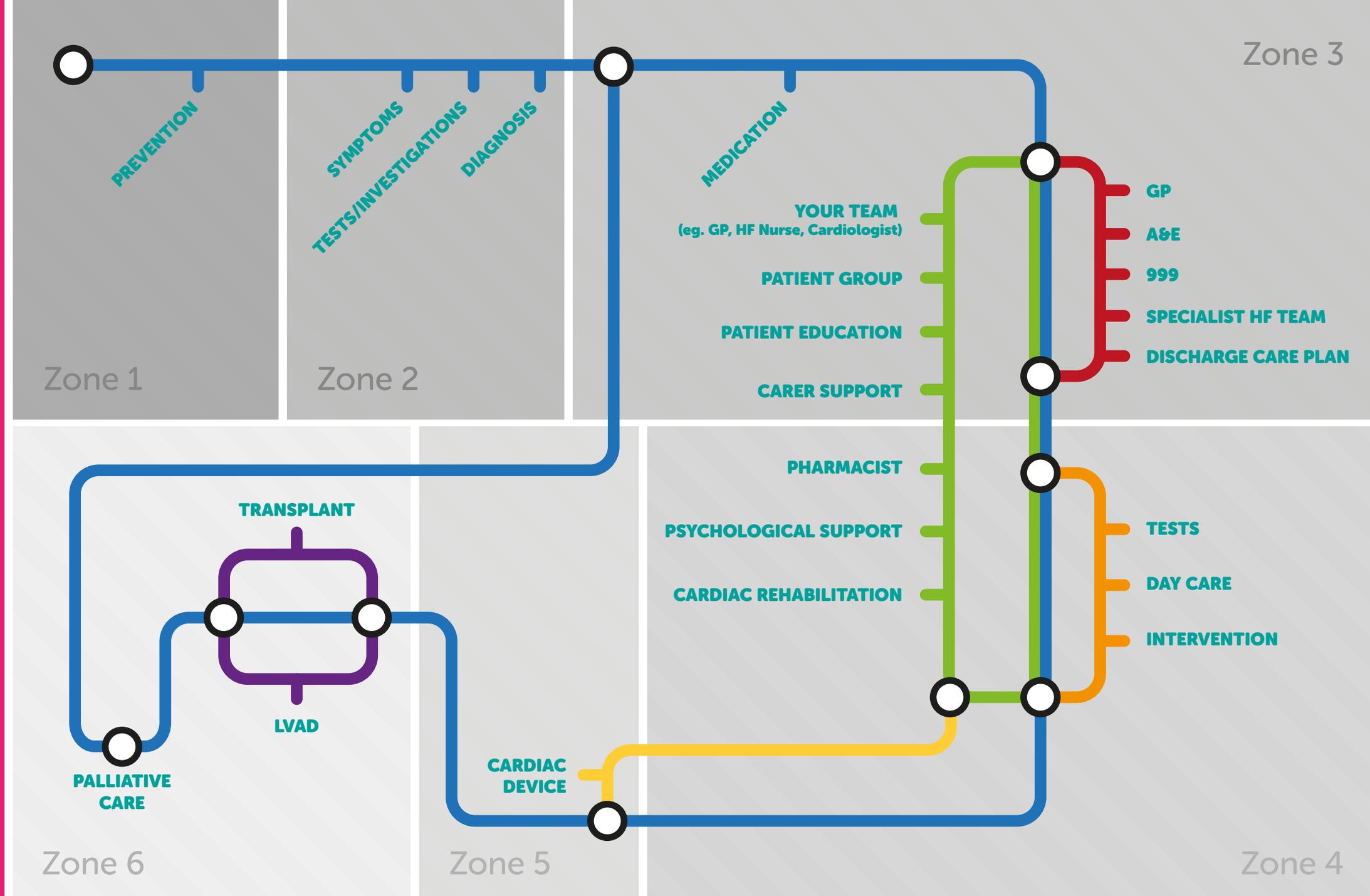
This is a bit of a hop on and off line. It's important for your heart failure team to fully understand your condition so they can ensure you are being treated to the best standards. Planned hospital visits are organised through your heart failure team, they are not unexpected.

### Cardiac Device Line

Your heart failure treatment starts off with drug therapy, however your Cardiologist may refer you to have a cardiac device. There are various types of devices that do different things. Once you have had the device you'll probably go back onto the community line. For in depth information about cardiac devices ask your heart failure team for our 'Marvellous Guide to Having a Cardiac Device Fitted.'

### Advanced Therapies Line

A heart failure journey can be very complex, and you may find that you are referred to a specialist centre for consideration for a mechanical pump and/or heart transplant.



## Key

- Journey
- Community Line
- Unplanned Hospital Line
- Planned Hospital Line
- Cardiac Device Line
- Advanced Therapies Line

Welcome to your marvellous map of heart failure in the NHS. This is not a patient's journey, but a reflection of the stops that you can access on your own journey. The stops represent treatment and services that are available to you in our NHS. It could be that you visit many of the stops, get on and get off, and revisit stops that you have been to on other occasions. There may be stops that you do not feel are for you. You may like to try them and see what they have to offer.

We have considered the many guidelines, audits, pathways, and documents that have been produced by the NHS in the UK in relation to heart failure, with the aim of providing you with a patient friendly, easy to understand document of what Clinicians feel is 'best practice'.

Clinicians seek to provide the very best care that they can for their patients, however they are not always able to due to circumstances beyond their control. If after reading this guide you feel you are not being given the care and treatment that you feel you are entitled to, then discuss this with your heart failure team or doctor.

For further information on any of the zones, please visit [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org).

## ZONE 1 PREVENTION

We do know that the earlier that your condition is diagnosed, the better you will do. The underlying cause of a patient's heart failure will often determine if this is something that has occurred very quickly, for example if a virus has caused heart failure or if there has been a gradual onset. If you have high blood pressure or have previously had a heart attack, then your GP should be monitoring you every 12 months to ensure that you are not developing heart failure. We do know that these two conditions, in time, can lead to 75% of heart failure diagnoses.

## ZONE 2 DIAGNOSIS

This will depend on when you first see someone due to the symptoms of heart failure that you have begun to experience such as breathlessness, tiredness, swollen ankles or feet. Depending on how severe your symptoms are, you may feel you need to go to your hospital or your General Practice. If you present to your GP your doctor will wish to understand your symptoms.

- Your GP will ask you detailed questions about your previous history including any heart problems in your family
- They will take your blood pressure, pulse, and a tracing of your heart (ECG)
- They will also arrange a number of blood tests including how effectively your kidneys and liver are working, if you are anaemic, or have a thyroid problem
- They may arrange a chest X-ray

**Importantly** they should perform a blood test called B-type Natriuretic Peptides or BNP. When the heart is under stress it releases a hormone, called a natriuretic peptide. If this is above normal it means there is a possibility that you have heart failure. If this is very high your GP will refer you to hospital for an ultrasound scan of your heart (echo) to be completed within two weeks, otherwise you should have an appointment in six weeks. If you have had a previous heart attack, again the aim should be for you to be seen in two weeks. An echo will confirm a diagnosis of heart failure and the reason why you have it.

### Heart Failure Care in the Hospital

If you have been admitted into hospital with suspected heart failure, there is evidence to suggest certain care and treatment will provide you with the best outcome. The National Heart Failure Audit in England and Wales has shown that you will do significantly better if you are given good clinical management, are under the care of a Specialist Cardiologist and are followed up by a heart failure team after you have been discharged. The aim should be that you get the right treatment, at the right time, in the right place. If you are admitted with severe symptoms, including severe breathlessness, extreme swelling, this is called acute heart failure.

### Tests and Investigations

If it is suspected that you are in acute heart failure then you should have the specialist blood test, natriuretic peptides (as above). If this comes back raised then you should have an ultrasound scan of your heart (echo) within 48 hours. If you are in acute failure you should see the specialist team within 24 hours.

### Treatment

You are likely to be offered diuretic therapy in order to rid the body of excess fluid that may have gathered in your lungs and other parts of the body. This is likely to be given via an injection or drip and you will be closely monitored to see how your body is coping. If you are critically unwell the team should assess you for specialist intervention therapy which may include life support machines to assist your breathing and machine support to help your kidneys to function. You will be started on treatment that is known to treat heart failure in the most effective way, including tablets such as Beta Blocker therapy, ACE inhibitors and specialist diuretics (water tablets).

### Discharge Arrangements

You should not be discharged from hospital until you are stable and you are on optimised treatment. Your wishes and those of your carers should be taken into account, support services in the community should have been arranged and your GP and any supportive services in the community should be aware of your treatment plan. You should be given education, support and monitoring advice to ensure you know what to do if you experience any difficulties and who you should contact. You should also be seen by a specialist heart failure team, who are either hospital based or who sit in the community, within two weeks of leaving hospital, as early reviews reduce the chance of you being re-admitted and ensures that your long-term outcomes are better and that you are able to have a better quality of life.

## ZONE 3 MANAGING HEART FAILURE - MEDICATION

Research has identified key medication which can help your heart to function more efficiently and improve your quality of life and life expectancy. If your heart is failing to pump efficiently it is called HFrEF or LVSD. Listed below is a group of drugs you should be assessed for and prescribed if they are appropriate for you. You can look up how they work and the side effects on our marvellous website in the Patient Academy or our 'Marvellous Pocket Guide to Living Well with Heart Failure.'

**ACE inhibitor or ARB** (ease the workload by relaxing the blood vessels around the heart)

**Beta Blocker** (make the heart beat slower but stronger)

**Diuretic therapy** (remove fluid)

**MRA** (a type of diuretic)

You may also be considered for the following drugs;

**Ivabradine** (if you are unable to tolerate a Beta Blocker, or as an addition if your heart rate is too fast)

**Sacubitril Valsartan** (a new type of drug that block enzymes which may strain your heart and enhances the systems that protect your heart)

Usually, these drugs are started at low dosages and are gradually increased until you are on the target dose or a maximum dose that you are comfortable with. During this process you should be seen every two weeks to ensure your pulse and blood pressure are within normal range and that your potassium levels aren't affecting your kidneys. If a heart failure specialist believes that your heart failure is due to your heart being unable to relax and fill sufficiently it is called HFpEF, you will be prescribed a diuretic and possibly other medication to control high blood pressure or diabetes. Your team should include as a minimum a Cardiologist, Heart Failure Nurse and your GP.

## ZONE 4 MANAGING HEART FAILURE - REHABILITATION

Cardiac rehabilitation should be offered to patients with a menu of a choice of activities including education and psychological support, offered in the patients preferred setting, either at home, or in a community or hospital setting, and at a time which makes accessibility easy for everyone. The guidance also recommends that you have access to psychological support if you have any anxiety or depression issues. This support should be offered via a team of health professionals that are devoted to heart failure. You will find as you are getting used to managing your heart failure that the pharmacist will have a big role to play to help you understand your medications and their interactions with common off the shelf medications. The guidance recommends patient to patient support, so do visit [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org) where you will find a vast range of interactive support tools to support and advise you and your family.

## ZONE 5 CARDIAC DEVICE

Depending on your symptoms and along with a number of tests and investigations which will show how efficiently your heart is working, you may be appropriate for a complex pacemaker. The criteria to ensure that you are a suitable candidate for a device is complicated, therefore we recommend that you have a look at our 'Marvellous Guide to Having a Cardiac Device Fitted' which is available in our Patient Academy section on our website.

## ZONE 6 ADVANCED THERAPIES

In severe heart failure, your Clinician will discuss with you the various options that may be available to you and a detailed assessment may be offered to you at a specialist cardiac centre (known as a tertiary centre). At various times palliative care services may be suggested to you. At Zone 6, all treatment options are supported by palliative care services.

### Left Ventricular Assist Device (LVAD)

An LVAD is a mechanical pump that assists the heart to pump. This is a highly-complex procedure that requires open heart surgery, as the device sits inside the chest connected to a control system and a battery that sits outside the body. The device may be permanent or as a bridge to transplant.

### Heart Transplantation

Specialist referral should be considered for those patients with severe symptoms that are not improving despite good drug and device treatment.

### Palliative Care

The guidance also acknowledges that for some patients their condition may deteriorate markedly and are not suitable for heart transplant. Early discussion with patients and their carers around prognosis and how their heart failure is failing to improve should be undertaken and palliative services offered. We believe that Palliative care isn't just end of life care, it has positive impact on your quality of life. Hence our branch line connecting you back into the community line where you have as much right as anyone to access services if you need them.

**PLEASE NOTE:** This document 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.

Our thanks go to the Marvellous Clinicians of the NHS who supported us in the production of this document and our Marvellous patients and carers of Pumping Marvellous. We would also like to thank Boston Scientific for providing this unrestricted educational grant.

# Contact Us



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



01772 796542



@pumpinghearts



helpforhearts (closed support group)



heartfailureaware (open)