



A QUICK GUIDE TO
LIVING
WITH HEART FAILURE



Firstly we would like to thank everybody who has had input into this booklet - including patients, carers and healthcare professionals - as they have contributed to what we believe is a very important tool to help you manage your heart failure.

We have developed this booklet as a quick reference guide to enable you to begin to understand your condition. We believe you will find the guidance useful as have many others with the same condition as you.

This guide has been co-developed with substantial input and support from the Pumping Marvellous Foundation, the UK's patient-led Heart Failure Group. We would especially like to thank Nick Hartshorne-Evans, Founder, CEO and heart failure patient and Angela Graves, Clinical Lead and heart failure specialist nurse, from the Pumping Marvellous Foundation, for their close collaboration in writing the guide.

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



WHAT IS HEART FAILURE AND WHY DO I HAVE IT?

The heart consists of muscle that pumps blood around the body. With heart failure, the heart is not pumping correctly and is often enlarged because it is having to work extra hard¹.

It is different to a heart attack - which involves a lack of blood to the heart usually caused by a clot to the arteries that supply it².

Generally there is a reason why your heart is not pumping correctly. The vast majority of the time this is due to the heart muscle being damaged because it is getting a poor blood supply^{1,3}. This can happen when you've had a heart attack, or you've had high blood pressure, which has affected the heart. Other causes include^{1,3}:

- A virus has affected the efficiency of your heart
- The heart's rhythm isn't normal
- Genetically the heart is not structured as well as it should be
- The valves in the heart are damaged
- Excessive alcohol intake
- Recreational drugs
- Some chemotherapy medication
- In rarer cases, there is a form of heart failure associated with pregnancy



Sometimes, we just don't know what the cause is.

Heart failure symptoms can sometimes get rapidly worse. This is called an acute episode or acute heart failure³.

This may be due to a temporary event and not last for long, but acute heart failure will require some form of intervention from healthcare professionals³.

SO HOW DO YOU FEEL ABOUT YOUR DIAGNOSIS?

First let us tell you - you are not alone, and being told you have heart failure can be a big shock. In fact, we don't know anybody who has anything good to say about being diagnosed with heart failure. We know that people go through their own process of coming to terms with living their life with heart failure and at different speeds as well. It is important to know that everybody is different and sharing your feelings and thoughts can sometimes be difficult - but generally in our experience it does help to share the burden.

We find that some people immerse themselves in their condition and others just want to forget it, but it is important to believe that you can manage it - you just need to find your own way.

In this booklet are some elements that will allow you to start your journey of conquering the challenges of living with heart failure. However high those challenges may seem right now, we believe they will become less steep as time goes by.

Stay positive.

“It’s not about the cards you are dealt, but how you play the hand. And remember, life is for living!”

Louise, Heart Failure patient, UK



GETTING ON WITH HEART FAILURE

There's no question that this heart condition is serious. But the good news is that there is a lot of understanding about the condition and a number of effective treatments available and in development.

This booklet can give you some ideas on several things you can do to help yourself and play an active role in the management of your heart condition. Research and patient experience show that people who can adapt to their illness and take control of it, have a better quality of life⁴.

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 the stage of this condition based on how much you are limited during physical activity³.

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.

“Listen to your body, keep calm, take a rest and gather your energies to restart”

Oberdan, Heart Failure patient, Italy

NYHA CLASS	SYMPTOMS ⁵
I	I can perform all physical activity without getting short of breath or tired, or having palpitations.
II	I get short of breath or tired, or have palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps.
III	I get short of breath or tired, or have palpitations when performing day-to-day activities (for example, walking along a flat path).
IV	I feel breathless at rest, and am mostly housebound. I am unable to carry out any physical activity without getting short of breath or tired, or having palpitations.

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.

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

- Your work
- Your social activities
- Driving
- 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.



SO NOW I KNOW WHERE I AM ON THE NEW YORK HEART ASSOCIATION (NYHA) CLASSIFICATION SCALE – WHAT CAN I DO TO HELP MYSELF?

Where possible, try to stay positive and have a can-do attitude – this can really help you to play an active role in your own condition.



Activity. Every muscle responds well to exercise - your heart is no different.

Talk to your healthcare professional about an activity programme that is suitable for you. In the meantime, listen to your body - pace yourself and remember your energy battery. If it's running low, rest and take it easy.



Diet. Ask your healthcare professional for advice or tips on how to pursue a healthy lifestyle. You may find that eating smaller meals more frequently helps you, as digesting small amounts of food may put less strain on the body and the heart.



Salt. Keep an eye your salt intake. We know that salt can affect how your body retains fluid, which can also put a strain on the heart. Try to choose meals with low salt content, and limit the amount of table salt you add to meals.



Smoking. If you have been diagnosed with heart failure, don't smoke.



Alcohol. Try to keep within the recommended daily and weekly alcohol intake limits.

“Keep physically active and enjoy life!”

Randa, Heart Failure patient, Egypt

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KEEP AN EYE ON HEART FAILURE

“Be smart and listen to your heart!”

Tania, Heart Failure patient, Brunei

KEEP AN EYE ON...

Sudden weight increase.

Sudden weight gain may mean that fluid is building up in your body because your heart failure is getting worse.

Swelling.

When the body retains fluid, you may notice swelling in your lower legs, abdomen or feet.

Breathing.

On occasion fluid may gather in your lungs which may affect your breathing.

Fatigue.

Many people with this heart condition will feel very lethargic.

Dizziness/light headedness.

Due to your condition and the medication you may be taking, you could experience dizziness and / or light headedness.

Patients with this condition often say they have good days and bad days. A general tip is to pace yourself through the day - remember your energy battery. However, there are also some specific things you need to keep an eye on - below are some of the main symptoms you may experience and tips for managing them^{3,6}.

TIPS	CONTACT YOUR HEALTHCARE PROFESSIONAL IF...
<ul style="list-style-type: none"> • Weigh yourself every day at the same time. • Watch how much fluid you are taking in. Don't exceed the amount suggested by your healthcare professional. 	<p>You gain about 4-5 pounds (about 1.8-2.3 kilograms) in the space of 2-3 days⁷.</p>
<ul style="list-style-type: none"> • Keep your legs elevated on a stool. • Have frequent rests during the day. An afternoon catnap in your bed may be helpful. 	<p>Swelling becomes significantly worse.</p>
<ul style="list-style-type: none"> • Ensure you get plenty of rest. • Try not to over-exert yourself and conserve your energy. If your breathing is worse at night, use plenty of pillows. 	<p>Your breathing or coughing is getting significantly worse.</p>
<ul style="list-style-type: none"> • Remember your energy battery. Pace yourself, your activities and ensure you take adequate rest. 	<p>Your fatigue worsens and begins to affect your day-to-day activities.</p>
<ul style="list-style-type: none"> • Don't rush around! • Try not to stand up or turn around too quickly. • Take your time to get out of bed and steady yourself before you begin to walk. 	<p>You find that this is causing you to stumble or fall.</p>

MEDICATIONS AND INTERVENTIONS

How was my heart failure diagnosed⁸?

You may have had a number of blood tests, tracings and scans of your heart, as well as a thorough examination by your healthcare professional to determine you have heart failure.

- **Blood Tests**

These are routine tests to check how effectively your kidneys and liver are working. Also, if you have anaemia (where you have fewer red blood cells than normal or you have less haemoglobin than normal in each red blood cell) or problems with your thyroid (a large gland in the neck), blood tests will have been conducted, to see if they have been affected by or caused your heart failure.

A specific blood test may have been taken which measures something called natriuretic peptides (a type of hormone produced by the heart), levels of which indicate that you may have heart failure.

- **Electrocardiogram (ECG)**

This gives your healthcare professional a tracing of the heart and is very informative. It lets the healthcare professionals know if your heart is going too fast, too slow, and if there are problems with your heart that may have occurred in the past.

- **Echocardiogram**

This is vital in diagnosing heart failure. It gives a scan of your heart that shows how efficiently your heart is pumping, its size, and the condition of the valves.

Other, more complex scans may also be undertaken which can help healthcare professionals understand what has happened to your heart.

MEDICATIONS

Following a diagnosis of heart failure, you may have been given different medications to take. You can read about them on the next pages along with some tips on taking them.

A good place to start, however, is to understand why it is very important to take your medications as instructed by your healthcare professional. We understand that taking lots of pills can sometimes feel like a burden, along with some of the symptoms you may incur along the way.

We also know, however, that if you take your medications regularly as instructed by your healthcare professional, then this may have a positive effect on your health and wellbeing. You may find some of the medications take a little time to get used to but it is important to persevere and you generally will adapt to them in no time. If you continue to find you are struggling, do speak to your healthcare professional.

“It is very important to take your medications regularly because it helps you manage your symptoms”

Jean, Heart Failure patient, France

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So, as discussed, one of the cornerstones to support the proper functioning of your heart is medication.

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.

These are some of the medicines you may be advised to take for your condition. The below provides a guide, but you should always check the prescribing information of any medicines you are taking.

Beta blockers⁹.

The names of these medicines will often end in ‘-olol’.

WHAT THEY DO

Make your heart beat slower and ease the workload of the heart, relaxing blood vessels around the body.

POTENTIAL SIDE EFFECTS

Most people taking beta blockers have either no or very mild side effects. More commonly reported side effects include:

- *Dizziness*
- *Tiredness*
- *Blurred Vision*
- *Cold hands and feet*
- *Slow heartbeat*
- *Diarrhoea and nausea*

These tablets are started at low doses and slowly increased because they may lower your heart rate too much.

ACE (Angiotensin Converting Enzyme) inhibitors^{10,11}.

The names of these tablets will often end in ‘-pril’.

WHAT THEY DO

Ease the workload of the heart by relaxing the blood vessels around the body, which reduces the strain on the heart.

POTENTIAL SIDE EFFECTS

Side effects do not appear very often and some may go away if you continue to take the medicine. More common side effects include:

- *Dizziness*
- *Headache*
- *Drowsiness*
- *Diarrhoea*
- *Low blood pressure*
- *Weakness*
- *Cough*
- *Rash*

A common side effect is a dry, irritable cough which often settles. However, if this proves troublesome, your healthcare professional may use an alternative medication, which is an ARB (see next page).

Expect to be monitored with blood pressure checks and tests.

ARB (Angiotensin receptor blockers)¹² - for patients who cannot tolerate ACE inhibitors, these make it easier for your heart to pump by widening your blood vessels. The names of these medications often end in ‘-sartan’.

WHAT THEY DO

These work in a similar way to ACE inhibitors (see page 18).

These medicines also increase the release of water and salt (sodium) to the urine, which in turn may lower blood pressure as well.

POTENTIAL SIDE EFFECTS

Side effects do not appear very often and some may go away if you continue to take the medicine. More common side effects include:

- *Dizziness*
- *Headache*
- *Drowsiness*
- *Weakness*
- *Rash*
- *Fever or chills*
- *Back pain*

Expect to be monitored with blood pressure checks and tests.

Diuretics^{13,14} - or “water pills” (e.g. furosemide, bumetanide, spironolactone, eplerenone). You may be on more than one type of water tablet because they work in different ways on the kidneys.

WHAT THEY DO

Help your body get rid of extra fluid, so there is less fluid for your heart to pump.

POTENTIAL SIDE EFFECTS

The following can occur in some people:

- *Nausea*
- *Dizziness*
- *Rash*
- *Muscle cramps*

You may find it inconvenient as you may need to visit the toilet more frequently than normal.

You may need to plan your day around your water tablets – for example, staying at home for a while after you have taken them.

You will require regular blood tests to ensure your kidneys are not affected by the number of water tablets you are taking.

IMPLANTABLE DEVICES / PACEMAKERS

- **Cardiac Resynchronisation Therapy (CRT) / biventricular device⁸**

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 not be suitable for everyone with heart failure.

- **Implantable Cardiac Defibrillator (ICD)⁸**

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.

“Remember you are no sicker than before you found out - only now you are getting treated!”

Louise, Heart Failure patient, UK



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YOUR TEAM

Being diagnosed with heart failure is an important time of change for you. We will go on and talk about your support team, but we recognise that not everybody has all these people around them to help, so it is important to discuss with your healthcare professional who they see as potentially being in your support team. Remember nobody needs to face heart failure alone. Teams can consist of a wide range of people, and it's very much your choice who is in your team. Also remember a team can be just two people.

Your heart failure team can help you share the burden of making decisions and plans, so that you are all involved and feel in control of your lives. Your team could include your healthcare professionals, your main caregiver, friends, family or people who you see regularly in your daily life. You may meet people who have heart failure themselves – often sharing your stories is an important part of managing your life with heart failure. Being open and honest about how you feel is important to help other members in your team understand how you feel and what you are going through as this will help them to help you better.

“I consider my husband, my doctors, the nurses and my family to be part of one important team that helps me win the battle with heart failure, every single day.”

Fredonia – Heart Failure patient, US

FORGING A RELATIONSHIP WITH YOUR HEALTHCARE PROFESSIONALS

You may have a specialist in heart failure involved in your care, or you may have more contact with a family doctor or medical nurse. Whoever is looking after you, it is important to try and build an honest and open relationship with them. Some of the ways patients have found to do this are:

- 1** Go prepared. Before you attend an appointment with your healthcare professional, make a note of any issues you are having and would like to discuss or any questions you may have.
- 2** Don't worry about asking what you feel may be stupid questions.
- 3** Say what's important to you. If there are certain aspects of your life that are particularly important, let your healthcare professional know so they can be taken into consideration when discussing your medication and other factors.
- 4** Be prompt. Make sure you arrive at appointments on time. Be respectful of each other.

YOUR FAMILY, FRIENDS / PRIMARY CAREGIVER

Many people say the most important person in helping them to manage their condition is their partner or other primary caregiver. You may find that a good place to start to help friends and family understand the ups and downs of the journey you are on with your heart condition would be to talk them through this booklet.

In addition, there is a caregiver booklet available, which you may want to recommend to someone if they are helping you live with your condition.

QUESTIONS FOR YOUR HEALTHCARE PROFESSIONAL

The time you have with your healthcare professional is important – therefore, take some time to think about the things you want to discuss.

Here are some tips:

- If you don't understand something, ask for further explanation - it's your health.
- You may find it useful to keep a diary - perhaps charting your weight and how you have been getting on with your medications - to help you to communicate how you have been getting on.
- Take your full list of medication or your tablets with you.
- Write down what you want out of your meeting with your healthcare professional before you attend.

Example questions

Below are a few examples questions you could ask your healthcare professional.

- What stage is my heart failure? Where am I on the New York Heart Association (NYHA) scale?
- How do you think this will affect my day-to-day activities?
- What should I expect within the next few weeks, months and years? How is the condition likely to progress?

- What are the most important things I can do to manage this condition?
 - Should I eat different foods?
 - How much exercise/activity can I do? What are good activities to start with?
 - How much water can I drink each day?
 - Is it ok to drink alcohol? How much is ok?
- What kinds of health checks do I need to do at home and how do I do them?
- If I feel my symptoms get worse or change suddenly, who should I contact and what's the best way to reach them?
- What treatment/medications do I need?
- What should I do if I miss a dose of medicine?
- Do I need to take water tablets?
- How often do I need to come in for a clinic visit/see a healthcare professional?
- What should I do if I am feeling down or anxious about my heart failure?
- Are there any local support services available you recommend?

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YOUR QUESTIONS

What other questions can you think of that you'd like to ask your healthcare professional?

Use this space to write them down.

For more information on heart failure, visit:

WWW.KEEPITPUMPING.COM



“Embrace the new
you - you’re going
to be marvellous!”

Daniel, Heart Failure patient, UK



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