



A QUICK GUIDE TO
**CARING FOR
SOMEONE**
WITH HEART FAILURE



You may be a husband, wife, son, daughter, friend or a neighbour. You may live 24 hours a day with the person you are caring for, or you may live a 24 hour journey away.

But you are the one who is recognised as significant in helping someone with heart failure live with their condition.

This booklet – which has been co-developed with substantial input and support from the Pumping Marvellous Foundation, the UK’s patient-led Heart Failure Group – has been developed based on people’s experience of supporting those living with heart failure. It has been developed as an easy reference guide to enable you to begin to understand the condition and how you can help your loved one to self-manage it.

We would 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.

We would also like to thank you – on behalf of patients, healthcare professionals and wider society – for reading this booklet and helping in the way you do.

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



2) CARER'S CHARTER

At the heart of your commitment to your loved one or friend with heart failure, can be a set of principles that helps you to take care of yourself, as well as him or her. Caring for someone with heart failure means understanding the condition and its impact on life as well as you can, but should not mean that you are defined by the condition.

Try to always remember the following and talk these through with your loved one.

- Remember you are doing a great job, take pride in that.
- Try and have time for yourself, ensure that you still undertake hobbies or events that you most enjoy.
- Take care of yourself - it is important to remember this is not being selfish but sensible, you need to be well in order to be able to help your loved one be well.
- Don't be afraid to ask for support - everyone has their limits, recognise yours and call on those who can support you.
- It is perfectly normal to have a range of difficult emotions, to feel angry or down, to have good days and bad days; on those days do not feel guilty.
- It is important that your commitment to your loved one is recognised and that family and friends also understand the significance of your role, so talk about your role and any difficulties that you may be having.



UNDERSTANDING HEART FAILURE

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 the 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 after a heart attack, or when someone has high blood pressure, which has affected the heart. Other causes include^{1,3}:

- A virus has affected the efficiency of the 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.

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, a number of effective treatments available and in development, and several things you and your loved one or friend can do to play an active role in the management of their heart condition.

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 health care professionals³.



SO WHERE IS YOUR LOVED ONE 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 your loved one is limited during physical activity.³

So where is your loved one on this scale today?

NYHA CLASS	SYMPTOMS ⁴
I	Your loved one can perform all physical activity without getting short of breath or tired, or having palpitations.
II	Your loved one gets short of breath or tired, or has palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps.
III	Your loved one gets short of breath or tired, or has palpitations when performing day-to-day activities (for example, walking along a flat path).
IV	Your loved one feels breathless at rest, and is mostly housebound. He/she is unable to carry out any physical activity without getting short of breath or tired, or having palpitations.

“I am always saying to him ‘will you slow down and give yourself a rest’”

Caregiver

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 the battery generally depends on how the 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 your loved one or friend has and to try and plan out how they will use it throughout the day and to prioritise the activities that are most important to them.



WHAT DOES THIS MEAN FOR ME?

Where your loved one or friend is on the New York Heart Association (NYHA) classification scale and what your own circumstances are will determine how much of an impact the heart condition has on your day-to-day life.

One of your most important roles is to help your loved one try to stay positive and have a can-do attitude – this can really help them to play an active role in their own condition. Research shows that those who can adapt to their illness and take control of it have a better quality of life.⁵

Although it will probably change aspects of your own life, it does not need to take over your life completely. Your first instinct might be to try and do everything for your loved one, but you need to take a step back every now and then and live your own life. We have seen time and again that focusing on yourself and giving yourself some time away from ‘caregiving’ makes you a better carer.

Your loved one’s heart failure may impact areas of your life for which you may need to consider seeking some help and guidance, whether that is related to:

- Finances
- Work
- Intimacy of your relationship

Do contact your healthcare professional or social support if you feel you need help.

PRACTICAL SUPPORT

One way that you can help your loved one or friend to take control of their condition is to encourage them to keep an eye on the following symptoms day-to-day, and there may be ways you can help along the way.



SYMPTOMS TO KEEP AN EYE ON ⁶	TIPS AND ADVICE
<p>Shortness of breath Heart failure can cause the fluid in the body to gather in the lungs which may cause your loved one to feel short of breath during everyday activities.</p>	<p>If their breathlessness is severe, or increasing, encourage your loved one to contact their doctor.</p>
<p>Shortness of breath when lying down Lying flat may also make them feel short of breath so that they need to sleep sat up with multiple pillows.</p>	<p>Suggest to your loved one that they support themselves with multiple pillows so they are more upright.</p>
<p>Rapid heartbeat The heart sometimes starts to speed up to compensate for its reduced ability to pump blood around the body.</p>	<p>Encourage your loved one to try spending more time relaxing to keep stress at bay.</p>
<p>Loss of appetite A build-up of fluid around the gut can affect digestion and might cause a loss of appetite, or make them feel sick when eating.</p>	<p>Encourage your loved one to eat smaller, more regular meals to stop feeling too full after meals.</p>
<p>Tiredness Heart failure means less oxygen-rich blood is circulating the body. Because your muscles and tissues need oxygen for energy, this means people with heart failure can feel tired very easily.</p>	<p>Encourage them to stay as active as possible to maintain energy levels. Suggest they speak to their doctor about an exercise regimen that suits them.</p>
<p>Swelling in the ankles, legs and abdomen Clothes or shoes might feel tighter as fluid in the body builds up in the legs, ankles or abdomen causing them to swell up.</p>	<p>Remind your loved one to regulate how much they drink to help control the fluid build-up in their body.</p>
<p>Sudden weight increase Worsening heart failure may cause an increase in weight of more than two kilograms (about six pounds) in one week because fluid builds up in the body.</p>	<p>Encourage them to weigh themselves daily. Maintaining a healthy weight will help you and them to notice any weight gain due to fluid build-up.</p>
<p>Frequency of urination A reduced amount of blood reaches the kidneys when you have heart failure, causing you to urinate less frequently. Conversely, if your loved one is taking diuretics (eg. water pills), they might urinate more frequently, when the excess fluid in their body is removed.</p>	<p>Remind them to go to the toilet before bed and limit the amount they drink in the evening, which may help to reduce the number of times they have to get up in the night!</p>

If you or your loved one notice any changes in their heart failure symptoms, tell them to talk to their doctor right away

EMOTIONAL SUPPORT

Your loved one will have good and bad days, both physically and emotionally. Although you will always try to be as supportive as possible, you too will have good and bad days, and sometimes you may find it gets too much. At times like these you need to talk to someone else, whether that is a healthcare professional, a member of the family or a friend.

Remember the caregiver charter at the beginning of this booklet. You need to take care of yourself, recognise your own limits and seek help from others when necessary. You need to maintain elements of your own life, including ones that do not necessarily include your loved one. None of this is selfish, it is essential to help you be a better carer.

In addition, if you find that you and your loved one are finding it challenging to manage the physical symptoms of the condition, then contact your loved one's healthcare professional and make an appointment as soon as possible. Get help when you need it - you do not have to do it all on your own.

CARER STRESS

Caring for someone can have a big impact on your own mental and physical wellbeing and so it is important to try and recognise if you are beginning to get into difficulties. Some things you may experience along the way may include:

- Feelings of anxiety, irritability and depression
- Being unable to sleep
- Failing to eat properly
- Increasing alcohol intake, or excessive smoking
- A decline in your physical health
- Having difficulties concentrating
- Tiredness and lethargy
- Neglecting responsibilities

If you begin to experience these symptoms, remember the caregiver charter, ask for help so that you can share out the load and don't be reluctant to accept offers of help. Give yourself a short time in the day that is just for you e.g. take a long hot bath. Investigate if there are any carer support groups in your area. If you are concerned about your physical or mental health then do see your healthcare professional.

“The carer is on the same journey as the patient”

Caregiver

MEDICATIONS AND INTERVENTIONS

How was your loved one's heart failure diagnosed⁶?

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

- **Blood Tests**

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

- **Electrocardiogram (ECG)**

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

- **Echocardiogram**

This is vital in diagnosing heart failure. It gives a scan of the heart that shows how efficiently it 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 the heart.

MEDICATIONS

Following a diagnosis of heart failure, your loved one may have been given different medications to take. Read the next pages for some tips on taking medications.

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

We also know, however, that if people take their medications regularly as instructed by healthcare professionals, then this may have a positive effect on health and wellbeing.

Your loved one may find some of the medications take a little time to get used to but it is important to persevere and they generally will adapt to them in no time. If they continue to find they are struggling, do urge them to speak with their healthcare professional.

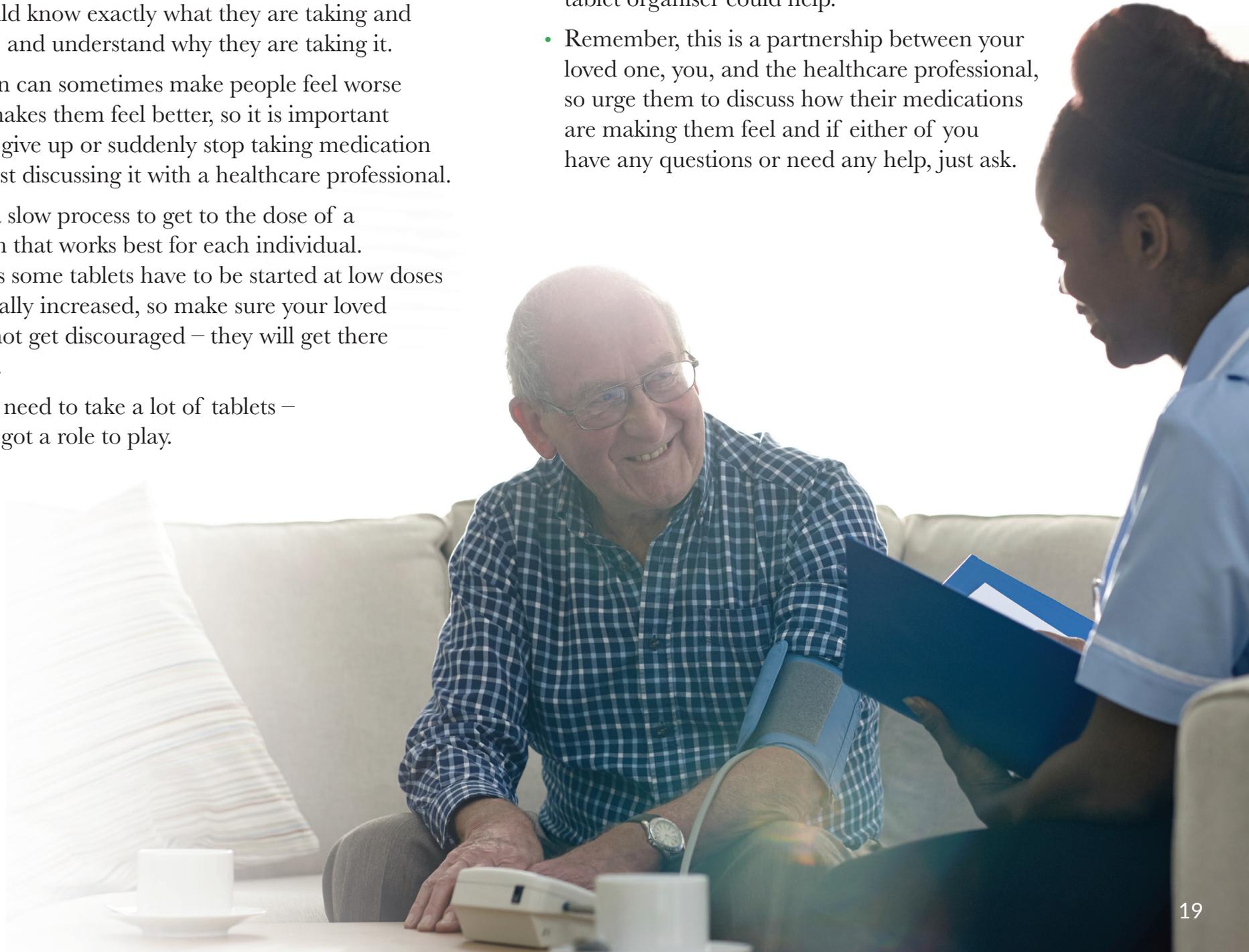
“Get the reassurance that you need by frequently asking your loved one if they are ok”

Caregiver

Some general tips on taking medication:

- Patients should be in charge of their own medication. They should know exactly what they are taking and how often, and understand why they are taking it.
- Medication can sometimes make people feel worse before it makes them feel better, so it is important they don't give up or suddenly stop taking medication without first discussing it with a healthcare professional.
- It can be a slow process to get to the dose of a medication that works best for each individual. Sometimes some tablets have to be started at low doses and gradually increased, so make sure your loved one does not get discouraged – they will get there in the end.
- They may need to take a lot of tablets – they've all got a role to play.

- They should try not to miss taking their medication and make sure they take each one on time and as recommended. A daily tablet organiser could help.
- Remember, this is a partnership between your loved one, you, and the healthcare professional, so urge them to discuss how their medications are making them feel and if either of you have any questions or need any help, just ask.



IMPLANTABLE DEVICES / PACEMAKERS

- **Cardiac Resynchronisation Therapy (CRT) / biventricular pacing device⁶**

A CRT / biventricular pacing 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)⁶**

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.



PROVIDING CARE FROM A DISTANCE

It is not always possible to live with or nearby someone with heart failure that you are helping to care for, due to work, family or other commitments. These are some particular things to think about when caring for someone from a distance:

- Try to develop a routine for keeping in touch. Find a time of day for regular telephone calls or calls via your computer using (often free) software such as Skype or Viber. This means that both you and your loved one or friend know when to expect a call and ensures you can feel confident and comfortable that your loved one is OK.
- Make sure your loved one knows exactly what to do if they get into problems. Ensure they have a list of people to contact. Have a plan in place.
- Have your loved one's healthcare professional name and contact details to hand. If you are at all worried, or if your loved one has missed a regular call, contact the healthcare professional or someone local to your loved one (such as a neighbour) who can go around to check on them if needed.
- Consider if an assessment is needed. If you are worried about how your loved one is coping, either physically or emotionally, consider organising an assessment by your local social services, but make sure you discuss this with your loved one first.



A REGULAR TEAM TALK

A significant part of caring for someone with a heart problem is helping them to get on with their life and have as much independence as possible, within the limits of the symptoms they experience. That's why it's good to talk regularly about the help you are giving, and to find out what is important to them to be able to do.

It may be they would like to try to do a little more for themselves and don't need some of the help you have been giving, or that there are particular tasks – like taking a shower or getting dressed in the morning – that with your help would become less daunting.

During these 'team talks' you may also find that the person you care for opens up about how they feel about being diagnosed with heart failure (angry, confused, fearful, relieved they are alive, frustrated) which can also help you make decisions together about the support you give. For example if the person you care for feels depressed or frustrated and these feelings don't go away, it might be a good idea to encourage them to speak to their family doctor.

Talking to the person you care for about what is important to you is also essential. It can help them understand why you are, for example, over protective (you don't like to see them struggle) or why you sometimes try to persuade them to do more (you want them to be as independent as possible) or get a bit irritated with them (it's maybe because you are worried

about how you are doing as their caregiver). It can also help to ensure that the person you are caring for understands that whilst you want to support and help them, you also need time to look after yourself too.

TAPPING INTO A WIDER TEAM

Remember, you don't need to try and do it all on your own. There are other people who can be in your wider support team, and you can have a big say on who is in your support team, including healthcare professionals, family members, friends and others. Try and share it out among others, and talk about it with them.

Remember, your loved one may not see the need for support in the same way that you do. They are receiving support from you – the caregiver. You need to make sure that there is someone to look after you as well, and that there are enough people on the team to make sure you do not feel isolated and overburdened.

For more information on heart failure, visit:

www.KeepItPumping.com

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