British Heart Foundation

Your guide to heart failure

Heart attacks that strike without warning, strokes that shatter futures, newborn babies born with broken hearts. These are just some of the cruelties of heart and circulatory diseases. And the reality is, there's so much more for science to discover before we can beat the world's biggest killers.

That's why British Heart Foundation (BHF) exists. Funding research is how we change the game. And we all have a role to play. The tools we have at our disposal today, from heart transplants and pacemakers to statins and portable defibrillators, are all down to research. Research made possible by people like you, funding people like us.

When we join forces, we can make the impossible possible. We can take the best and brightest ideas from scientists' minds and help turn them into treatments you can get at your GP. We can make theories on pages jump into reality. Research can save your life and your family's lives. But without you? It all stops tomorrow.

Medical breakthroughs do not just happen. Driven by love, your donations and the awe-inspiring research we fund, we make them happen together.

bhf.org.uk

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How to use this guide

This guide is for adults of all ages living with heart failure and their families or carers.

Being told that you have heart failure can be very frightening for you and your family. It raises all sorts of questions, such as:

- why me?
- what can I do about it?
- what's my future going to be like?

We've made this guide to help you understand and manage your condition better. Think of it as a source of practical help and guidance rather than something that must be followed.

Your heart failure nurse may work through this guide with you, or you can use it at home. You may want to share it with your carer or family and friends so they understand your condition and know how they can support you. By 'carer' we mean the main person who looks after you. It could be your partner, a relative or a friend.

As someone living with heart failure, you'll be treated by a number of medical experts, sometimes called healthcare professionals.

This may include a:

- heart failure specialist nurse
- practice nurse
- nurse practitioner
- nurse
- GP
- doctor (this includes any doctor who might see someone in hospital e.g. general medical consultant)
- cardiologist
- cardiologist specialising in heart failure
- cardiac rehabilitation specialist (this could be a nurse or physiotherapist)
- pharmacist.

When we talk about medical experts in this booklet we'll generally refer to them as 'doctor' or 'nurse'.

If you still have questions after reading your guide to heart failure:

- Talk to your doctor or nurse. They're in the best position to answer your questions.
- Visit the useful websites listed on page 86 for more information and support.

All the information in this guide has been checked very carefully, but:

- Please check with your own doctors and nurses before you do anything different from the guidance they've given you.
- Remember that it can be dangerous to suddenly stop taking medication.
- If you plan to start doing more activity than you're doing now, make sure you check this with your doctor or nurse first.

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About heart failure

What's heart failure?

Your heart is a powerful muscle that moves blood and oxygen around your body with every heartbeat.

Heart failure is a condition where your heart cannot pump blood around your body as well as it should. It does not mean your heart has stopped working but you may need support to help it work better.

There are many reasons why this may happen, including:

- damage to your heart
- weakness and/or stiffness of your heart muscle
- narrowed or leaking valves.

The name heart failure can sound frightening, so it might be more helpful to think of it as: 'My heart is not working as well as it should and needs treatment to help how it works.'

How does my doctor know I've got heart failure?

Your doctor may suspect you have heart failure by talking to you about your symptoms and doing a physical examination. The most common symptoms of heart failure are:

- Shortness of breath when you're resting or being active.
- Swelling of the feet, ankles, legs, abdomen (tummy area) or in the small of your back.
- Fatigue, which is when you feel unusually tired and weak.

We say more about symptoms on page 10.

These symptoms can be caused by other medical conditions, so in most cases further tests will be needed to confirm a diagnosis of heart failure.

Some of the tests you may have include:

- An electrocardiogram (ECG) to assess your heart rate and rhythm.
- A blood test to measure BNP (B-type natriuretic peptide). If you live with a heart condition, raised levels of this protein can be a sign you're at risk of heart failure.
- A chest X-ray to show a picture of your heart and lungs.
- An echocardiogram, which is an ultrasound scan of your heart to see how your heart is working.
- An MRI scan to show detailed pictures of the inside of your heart.
- General blood tests to check, for example, how well your kidneys are working.

What causes heart failure?

Heart failure can be caused by one or more conditions. The most common causes are:

- heart attack
- high blood pressure
- cardiomyopathy
- problems with your heart valves.

Heart failure can also be caused by:

- viral infections that affect your heart muscle
- too much alcohol or recreational drugs
- an abnormal heart rhythm (arrhythmia)
- some chemotherapy medication
- congenital heart disease
- thyroid gland disease
- anaemia.

Sometimes we just do not know what the cause is, which can be hard to accept. The important thing is to treat your condition and control your symptoms.

This will help you have the best possible quality of life and improve your life expectancy.

Can heart failure be cured?

When heart failure is caused by an underlying problem that can be treated like high blood pressure or heart valve disease, your symptoms may go away or not be as bad.

In most cases, heart failure is caused by a heart attack when part of your heart muscle becomes damaged or dies. Many people make a good recovery after a heart attack but sometimes your heart cannot pump blood around your body as well as it used to. If this happens, it causes the symptoms of heart failure. While you can control and manage these symptoms, your heart failure cannot be cured.

With good management of symptoms and the right treatment, many people with heart failure can lead a full and active life.

How bad is my heart failure?

Doctors put heart failure into four 'symptom classes', also known as the New York Heart Association (NYHA) classification system.

The four classes are:

Class 1. No symptoms
Your heart is not working as well as it should, but you may not have any symptoms. You can usually do everything you want to and might have as much energy as you'd expect. You may still need medication or other treatment to reduce the risk of your condition getting worse.

Occasionally, some people have one or two symptoms which will need to be treated or controlled.

Class 2. Symptoms on moderate exertion
You get breathless more than usual, like when when you're gardening, shopping or doing the housework.

Class 3. Symptoms on mild exertion
You're quite limited in what you can do. It does not take much effort to make you feel exhausted and too breathless to carry on. You're usually comfortable while you're resting.

Class 4. Symptoms at rest
You become breathless even when you're not being particularly active like when walking around at home or even when sitting down. You may find it difficult to look after yourself properly on your own and need to sleep sitting up because you get out of breath or cough when you lie down.

You may find that you do not fit exactly into one class of heart failure. Your doctor or nurse will be able to tell you more based on your examination and tests and they'll work out an appropriate 'management plan' for you.

It's not unusual to move to a different class. For example, you may be told that you're in class 2. Then you have a period of being unwell and move to class 3. When you recover, you may find that you return to class 2.

Will my heart failure get better?

For some people, heart failure gets better. The pumping of your heart can improve, or even if it remains the same, sometimes symptoms can improve. However, people usually find that their heart failure gets worse over time.

Taking your medicines and making changes to your lifestyle can help control your symptoms and keep you well, allowing you to have a good quality of life (we say more about this in 'self-management' on page 20).

There are many treatments to help improve your life expectancy and quality of life. Treatments are being improved and new ones are becoming available all the time.

Please discuss any concerns about your symptoms, treatments or future with your doctor or nurse and ask them to explain your management plan to you. They should also be able to give you an honest view of how your quality and length of life may be affected.

Bear in mind that it's not possible for them or anyone to tell you exactly how long you'll live. Heart failure affects people of all ages and everyone is different. It shortens the lives of some people while others live for many years.

Common questions, answered

What does my ejection fraction mean?

Ejection fraction is the amount of blood that's pushed out of your heart every time it beats.

No one has an ejection fraction of 100% as there's always some blood left in your heart after each heartbeat. A normal ejection fraction is around 50-65%.

Heart failure can be classed into different groups depending on your ejection fraction:

- Heart failure with preserved ejection fraction (HFpEF) (EF>50%).
- Heart failure with mildly reduced ejection fraction (HFmrEF) (EF 40-49%).
- Heart failure with reduced ejection fraction (HFrEF) (EF<40%).

Visit bhf.org.uk/heart-failure to learn more about heart failure with preserved ejection fraction.

Is having heart failure just a part of getting older?

Many people think heart failure happens because you're getting older. It's true that heart failure is more common in older people. As we get older, we're more likely to have one of the conditions that cause it.

However, heart failure does not happen just because you get older. Heart failure can happen at any age. It's important that you learn to manage your symptoms and do what you can to keep your condition under control.

Is there a risk of dying suddenly?

Heart failure can cause changes to the structure of your heart muscle, which can affect the electrical activity of the heart. Some people with heart failure are at risk of dying suddenly because they may develop a life-threatening heart rhythm. This can lead to a cardiac arrest, which is when a person's heart stops pumping blood around their body and they stop breathing normally.

If you're at risk of dangerous heart rhythms, your doctor can prescribe medicines for you to reduce the risk. Your doctor may also suggest that you have an ICD (implantable cardioverter defibrillator) implanted (see page 35).

Mending broken hearts

BHF is the largest independent funder of research into heart and circulatory diseases in the UK.

Our research has contributed to a substantial reduction in the number of people dying from heart attacks. But the damage caused cannot be repaired by the heart, which steadily loses its ability to pump effectively. This is called heart failure, and it affects over one million people across the UK.

Over the years, BHF has funded research to help those at all stages of a heart failure journey. From medications straight after heart attack to improve long term survival, to supporting some of the great pioneers of heart transplant, which is the last line of defence against severe heart failure.

The gold standard is to encourage the heart to heal itself. BHF-funded researchers are exploring this 'regenerative medicine' from every angle. We support investigations to remind hearts of the regeneration they were capable of before birth and we fund research into new medications that could give them the catalyst they need to heal the damage.

Ultimately, our goal is to mend broken hearts. Whether by protecting them, repairing them, or replacing them, BHF will continue to fund the sharpest minds and strongest research to achieve that goal.

For more information on BHF research into heart failure, see bhf.org.uk/heartfailureresearch

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Symptoms and treatments for heart failure

Symptoms of heart failure

What are the most common symptoms of heart failure?

- Shortness of breath when you're resting or being active.
- Swelling of your feet, legs, ankles, abdomen (tummy area) or in the small of your back.
- Fatigue, which is when you feel unusually tired and weak.

Heart Helpline

bhf.org.uk/helpline
For information and support about your heart and circulatory condition.

What causes these symptoms?

The symptoms happen because your heart muscle is not pumping as well as it should.

This can cause a build-up of fluid that backs up into your lungs (sometimes called congestion). It can mean that you're sometimes breathless or have severe shortness of breath.

Your blood carries oxygen, salt, water and other nutrients to all parts of your body and takes away all the stuff you do not need. If your heart is not able to pump blood around your body well enough, some parts of your body will not work as well as they should.

Your kidneys can end up keeping too much salt and water. This extra fluid can cause swelling in your ankles, feet or legs or in the small of your back (oedema) or in your abdominal area (ascites). The extra fluid can cause sudden weight gain.

Heart failure can also cause unusual tiredness and weakness (fatigue) because your heart cannot deliver enough blood and oxygen to the muscles in your body.

Other symptoms

Some people with heart failure may have other symptoms such as memory problems, difficulty concentrating or feeling lightheaded.

What you can do to control your symptoms

Controlling your symptoms is an important part of treating heart failure. On the following pages, tick all the symptoms you get. Share this section with your carer or family so that you all know what to do if your symptoms get worse, or if you get new ones.

Important

If any of the symptoms mentioned in this section are new or getting worse, you should speak to your doctor or nurse as soon as possible. If the symptoms are very bad or if you feel very ill and you're frightened, phone 999 for an ambulance.

If you have any of these symptoms:

☐ **Swelling of your feet, legs, ankles or abdomen**

Your kidneys have the job of keeping the right balance of water and salt in your body. If your heart is not pumping enough blood through them, the kidneys cannot get rid of any extra water and salt (which you usually pass as urine). This extra water can build up in different parts of your body, causing it to swell. A build-up of water can make your weight go up by several pounds in just a few days.

☐ **Sudden weight gain**

If you put on weight over two to five days, it's probably caused by fluid retention. An extra one to two kilograms (two to four pounds) can mean that your body is holding onto extra fluid. However, if you put on weight over a period of weeks, it's more likely to be caused by an increase in body mass (muscle or fat).

☐ **Feeling breathless, wheezing or coughing**

These problems can happen when there's a build-up of fluid in the lungs. You may find that you're more out of breath when you're doing activities such as walking or going upstairs. You may also find it difficult to lie flat.

Some people find that they may wake up in the night coughing, extremely breathless or have difficulty breathing. This is a sign of worsening heart failure, so report it to your doctor or nurse as soon as possible.

Being extremely out of breath can be a very frightening and unpleasant experience. Being frightened and anxious can make you feel worse and even more out of breath.

☐ **Fatigue (feeling unusually tired and weak)**

Fatigue is very common in any long-term illness. It can be caused by your muscles not getting enough oxygen, or because you're not active enough or sleeping properly. It could also be a side effect of your medication.

your symptoms can be controlled like this:

☐ **Manage your medication**

There are several medications that can reduce congestion, control your symptoms and help strengthen your heart. See pages 21 to 34.

☐ **Live a healthy lifestyle and keep active**

All the symptoms we've described could be caused by congestion. You can reduce your risk of congestion by:

- eating healthily to control your weight
- lowering how much salt you have
- being careful how much liquid you drink (especially if you've been told to restrict your fluids)
- keeping a record of your weight
- stopping smoking
- including physical activity in your everyday plan.

☐ **Learn to deal with stress and worry**

Symptoms can be made worse by worry, anxiety and stress. See page 61 for more information.

☐ **Helping your breathing at night**

Being propped up by pillows at night can help. If you wake up breathless, sit yourself up as much as possible, try and calm yourself and take some deep breaths. Some people find that having an open window can help with their breathing.

Regular activity can help you to feel less tired, but you should also schedule some time each day for some rest or relaxation. Keep a diary of your energy levels on a normal day and after certain activities so you can monitor any changes.

If you have this symptom:	here's what you should do:
Lightheadedness or dizziness This is quite common in people with heart failure. It can be caused by not getting enough oxygen to your brain. Other possible causes are: • side effects of the medication you're taking • anxiety • arrhythmias (abnormal heart rhythms) • getting up too quickly • low blood pressure • being dehydrated.	If the lightheadedness or dizziness is a new symptom, contact your nurse or doctor immediately. They'll want to check your blood pressure and may want to do an ECG to check your heart rate and rhythm. Ask your doctor or nurse if the lightheadedness or dizziness could be caused by your medication. They may be able to lower the dose or change your medication to reduce the symptoms. Try some relaxation techniques if you're anxious. See page 64. Take your time getting up from a chair or from your bed. Do not get up suddenly. Make sure that you're drinking enough. If you feel thirsty all the time, talk to your doctor about any diuretics (water tablets) you've been prescribed. Or, your fluid allowance may need reviewing.

If you have this symptom:	here's what you should do:
Blackouts or fainting (syncope) When you faint, you'll feel weak and unsteady before passing out for a short period of time.	Call 999 for an ambulance. Tell your carer, family or friends that they must call 999 immediately if you ever have a blackout.
Memory problems or problems with concentration You may find that you're forgetting things, having trouble concentrating, or have short-term memory problems. This is very common and can happen when not enough oxygen is getting to your brain. It can also be caused by stress or worry and can be made worse by some of the medication you're taking.	Try writing things down and re-reading any information you need to remember a few times. Use a diary or a calendar and write in it every day. For example, important events, meetings, birthdays, appointments and so on. Check it every morning. Ask a family member or friend to remind you about things like hospital appointments. You can also use the calendar on your phone or tablet device to set alerts or alarms to remind you. Many pharmacists will arrange for your medication to be supplied in pill (dosette) boxes. These come marked with the day and time you should take them. See our tips on page 34. Ask your doctor if the problem could be a side effect of any of the medications you're taking. If so, ask if there's something else you can take instead.

If you have this symptom:	here's what you should do:
Palpitations Palpitations is a word used to describe the feeling you get when you're aware of your heartbeat. Your heart may feel like it's beating too quickly, slowly or irregularly. Palpitations can often be due to stress or anxiety. It may also be an arrhythmia (abnormal heart rhythm).	If you only get palpitations when you're feeling anxious, try the breathing and relaxation exercises on page 65. Avoiding caffeine, smoking and alcohol will help. If you get palpitations, talk to your nurse or doctor.
Poor sleep The most common reasons for poor sleep are: • lack of activity during the day • worry, anxiety or depression. You may also find it difficult to sleep well because: • you cough if you lie down • you need to use the toilet often.	• Take a walk in the fresh air every day. • Have a warm drink before bedtime but avoid anything with caffeine in it. • A warm bath with a few drops of lavender oil or putting lavender oil on your pillow can sometimes help you to relax and drop off to sleep. • Try the relaxation techniques on page 65 when you're in bed. • Make sure that you have enough pillows to support you in a comfortable position. • If you suffer from a cough or need to go to the toilet often during the night, have a chat with your doctor or nurse.

If you have this symptom:	here's what you should do:
Feeling helpless or fed-up You may feel: • That you have little control over your life and that your illness has taken over. • Powerless to change your situation or hopeless about changing it. • Uncertain about the future or even how you'll feel the next day.	Look at the support that you have and see what changes you can make. For example, do you need: • To change the way you do something? For example, make adjustments to the type of work you do. You do not always have to give up your activities or work. • To look at your commitments? Be realistic about how much you can juggle. • Someone to talk to? Like a family member or friend. • More help in the house? Other people can help with chores or childcare. • Financial support? Money can be a huge cause of emotional distress. Getting good support and coming to terms with changes in your life will help you to feel calmer and more in control. If you're having difficulties with this for more than a few weeks, talk to your doctor or nurse as there are people who can help you. Your doctor or nurse may also suggest some counselling, therapy or medication to help feelings of anxiety or depression (see page 61).

If you have this symptom:	here’s what you should do:
Good and bad days You might feel good one day and terrible the next. It could just be the way your illness makes you feel or because you’ve overdone things one day and have made yourself tired.	Look at the overactivity-rest cycle on page 49. Try to adjust what you do each day to keep your symptoms stable.
Problems keeping sexually active Sex may be the last thing on your mind. You might not have the energy for it. Your medication may affect your sex life or desire for it. Worry, anxiety or depression can also cause a lack of interest in sex.	Talk to your partner about how you feel. You might find it hard at first but they’ll want what’s best for you. You can have an active sex life even if you’re not feeling ready for sexual intercourse. Try using different positions that you feel more comfortable in. Think about having sex at times of the day when you’re less likely to be tired. Have a chat with your nurse or doctor who’ll be able to give you support (see page 72). Find out more about sex and heart conditions at bhf.org.uk/sex

If you have this symptom:	here’s what you should do:
Slow weight gain (over three to six months) Your weight may go up slowly because you’re not being very physically active, but still eating the same amount of food. Living with excess weight can make it difficult for you to keep fit and active. It will also make your heart work harder and make your symptoms worse (see page 40).	Make sure that you’re eating a healthy diet and not snacking on unhealthy food. Healthy food has calories too, so you still need to watch your portion sizes (see more on page 38). Ask your nurse or doctor for further information and support. They may be able to refer you to a dietitian for more help. If you do not do the cooking in your house, ask the person who does to go with you.
Slow weight loss Your weight may go down because your appetite is poor and you’re not eating enough. Your heart condition might make it difficult for you to absorb nutrients, which could be another reason for weight loss. Weight loss can also be a symptom of depression (see page 68).	If you’re losing weight, your doctor will want to try and find out the reason for this. Your doctor may refer you to a dietitian who may tell you to try a high-calorie diet and food supplements. If you do not do the cooking and shopping, take the person who does with you to see the dietitian.

Self-management

Understanding your condition and being in control of your symptoms will help you to feel more in charge. Self-management involves:

- Always talking to your doctor or nurse if you experience a symptom for the first time or if your symptoms are getting worse.
- Thinking about what you normally do when you get these symptoms, knowing what helps and why.
- Thinking about problems that stop you managing your symptoms. For example, your physical ability.
- Knowing how and when to ask for help.
- Learning to notice any changes in your symptoms.

Not everyone will feel overwhelmed by their diagnosis. If you are, it may be easier to try tackling changes to your lifestyle one at a time.

Your doctor or nurse will be able to help you understand what's safe for you to do yourself and when you should ask for help. Ask them to explain anything that you do not understand about your condition. Talk to your family and friends. They may be able to help you stay on track.

Managing your medication

To treat your heart failure and keep it under control, you may have to take several different medications. Many people have told us that one of the hardest things about living with heart failure is keeping track of what their different medications are for and taking them properly.

Your doctor may need to change the doses of your medications or give you different ones from time to time, depending on your condition and symptoms.

Taking the right medications properly can help to:

- control the symptoms of your heart failure
- improve your quality of life
- prevent your condition from getting worse
- improve your life expectancy
- treat the cause of your heart failure.

It's important that you, your doctor and nurse know all the medications you're taking. Include the name, dose, how often and any changes to your prescription.

If you have a lot of prescriptions with the NHS, it might be cheaper for you to buy a prescription prepayment certificate (PPC). The PPC is a fee you pay to cover the cost of all your prescriptions rather than paying for each one. Find out more on the NHS website.

If you have any old medications, return them to your pharmacist who'll dispose of them safely. This will help you to stay on top of exactly what you need to take and avoid confusion.

On the next few pages, we look at three steps to organise your routine:

1. keep track of the medications you're taking
2. understand what your medications are for
3. take your medications properly.

Important

Never take medications that have been prescribed for someone else. Even if you think they're the same, the doses may be different.

1. Keep track of the medications you're taking

We've listed the most common types of medications that are used in treating heart failure. You may also be prescribed medications for other conditions that you may have that are not listed below. Fill out the chart to keep track of your medications.

I am taking:	When? How much?
Diuretics (water tablets): ☐ Amiloride ☐ Bendroflumethiazide (Bendrofluazide) ☐ Bumetanide ☐ Furosemide (Frusemide) ☐ Metolazone	
ACE inhibitors: ☐ Captopril ☐ Enalapril ☐ Lisinopril ☐ Perindopril ☐ Ramipril	
Angiotensin II receptor blockers (ARBs): ☐ Candesartan ☐ Losartan ☐ Valsartan	
Angiotensin receptor-neprilysin inhibitor (ARNI): ☐ Sacubitril valsartan (Entresto)	

I am taking:	When? How much?
Beta blockers: ☐ Atenolol ☐ Bisoprolol ☐ Carvedilol ☐ Nebivolol	
Mineralocorticoid receptor antagonists (MRAs), sometimes called aldosterone antagonists: ☐ Eplerenone ☐ Spironolactone	
☐ Ivabradine	
☐ Digoxin	
SGLT2 inhibitors: ☐ Dapagliflozin ☐ Empagliflozin	
Anticoagulants: ☐ Warfarin ☐ Apixaban ☐ Dabigatran ☐ Edoxaban ☐ Rivaroxaban	

2. Understand what your medications are for

At the start of your treatment, your doctor, nurse or pharmacist may make changes to your medications and doses quite often. This can be confusing, but it has to happen to make sure you're getting the best treatment. We explain what the different types of medications do and some common side effects.

Side effects

Not everyone will experience side effects. Some side effects are short-term and will go away after some time. Your doctor or nurse may be able to adjust the dosages or change to different medications to reduce your side effects.

Tell your doctor about any side effects that you get, especially if you notice them for the first time. Side effects can be unpleasant, but never stop taking your medications without first talking to your doctor.

Potassium levels

Some medications given for heart failure may increase or decrease your potassium level.

Potassium is a mineral that helps control the balance of fluids in your body and helps your heart muscle work properly.

Potassium is found in most types of food. Too much or too little potassium in your body can seriously affect your health.

You'll have regular blood tests to keep an eye on your potassium levels. You may be told by your doctor or nurse to take potassium supplements to increase your potassium level or follow a low-potassium diet to help decrease the level. It's important to only do this if you're told by your doctor or nurse looking after you.

Alternative and complementary medicines

Alternative and complementary medicines such as homeopathic or herbal remedies, and food supplements such as vitamins and minerals, may interact with the medications you've been prescribed. Talk to your doctor before taking any of these medicines or supplements.

Important

Always read the information leaflets that come with your medications. The information we provide here does not replace those information leaflets. Some manufacturers use different packaging and names for the same medication. If the packaging is different to what you normally get and you're not sure it's the right medication, check with your pharmacist.

Do not suddenly stop taking any medication without talking to your doctor first. If you suddenly stop taking your medicine your condition and symptoms could get worse.

Diuretics

Amiloride • Bendroflumethiazide (Bendrofluazide) • Bumetanide Furosemide (Frusemide) • Metolazone

What are they for?
Diuretics are sometimes called 'water tablets'. They help your kidneys get rid of excess fluid by making you pass more urine. As a result, your heart does not have to work as hard to pump blood around your body. Diuretics can:

- Reduce swelling in your ankles, legs and other parts of your body.
- Help improve the symptoms of shortness of breath.
- Help you to lower your blood pressure levels.

What are the main side effects?

- Gout. This is a condition where uric acid and salts build up in the joints, causing pain. Diuretics may cause gout or if you already have it, make it worse. Gout can be treated.
- They can make you go to the toilet more during the day and possibly at night.
- They can make you feel dizzy or lightheaded.

Which side effects should I tell my doctor or nurse about?

- any difficulty passing urine
- passing much less urine than normal
- constipation
- pain in your joints
- dizziness, lightheadedness, fainting or blackouts.

What checks do I need?
You should have a blood test regularly to check that your kidneys are working properly.

What else do I need to know?
Diuretics may raise your blood sugar. If you have diabetes, speak to your doctor.

Diuretics change the balance of water, salts and minerals in your body because they make you pass a lot of urine.

They're normally taken in the morning but think about when it might be best for you to take them and ask your doctor or nurse about it.

You should have no more than six grams of salt a day, which is about the same as one level teaspoon (we say more about this on page 40). Having too much salt will stop the diuretics working as well as they should. It's also important to avoid using salt substitutes that are labelled 'lite/light', 'low-sodium' or 'sodium-free' as these often contain potassium which may not be good for you.

If you experience any diarrhoea, early signs of weight loss, increased thirst, dizziness and/or increased fatigue, make sure that you're drinking enough fluid.

Dehydration is common in people taking water tablets. If your fluid intake is restricted or if you're unsure about your symptoms, speak to your doctor or nurse. Sometimes you may be told to stop taking your diuretic for a while if you become dehydrated.

If you take diuretics, it can be a problem finding a toilet quickly when you're out. The National Key Scheme allows access to thousands of locked public toilets across the UK and is available to people who have a disability or health condition.

These toilets can be found in shopping centres, cafes, shops, bus and train stations.

You can buy a key from some local authorities or from the Disability Rights UK shop online.

ACE inhibitors

Captopril • Enalapril • Lisinopril • Perindopril • Ramipril

What are they for?
ACE inhibitors have a relaxing effect on the arteries which makes it easier for your heart to pump blood around your body. They can prevent your heart failure from getting worse and can help:

- prevent symptoms of heart failure
- lower your blood pressure
- increase your chances of living longer
- increase the exercise you can do.

What are the main side effects?

- irritating cough
- a decrease in blood pressure
- dizziness.

If you get any of the following side effects, get urgent medical attention or call 999:

- swollen face, lips or mouth
- a severe rash or itching
- sudden wheeziness or problems with breathing.

What checks do I need?
Your doctor or nurse will want to check your blood pressure. You should have a blood test regularly to check your kidneys are working properly and to make sure that you do not have too much potassium in your blood.

What else do I need to know?
ACE inhibitors can lower your blood pressure. Your doctor will usually start the medicine at a low dose. If you tend to feel dizzy when you stand up, try to avoid getting up too quickly.

Make sure you do not eat too much salt (see page 40). Avoid taking salt substitutes (as most contain potassium) and you should not take potassium supplements.

Important

If you have heart failure, you should be taking an ACE inhibitor unless you cannot take them. If you cannot take an ACE inhibitor, there are other medications you may be able to take instead. Discuss this with your doctor or nurse.

Angiotensin II receptor blockers (ARBs)

Candesartan • Losartan • Valsartan

What are they for?
They work in a similar way to ACE inhibitors but are less likely to cause a troublesome cough.

What are the main side effects?

- dizziness
- a decrease in blood pressure.

What checks do I need?
You should have a blood test regularly to check your kidneys are working as they should and to make sure that you do not have too much potassium in your blood. Your doctor or nurse will also want to check your blood pressure when you start an ARB, and then at regular periods, particularly if the dose is changed.

What else do I need to know?
These medications are like ACE inhibitors. Your doctor may give them to you if you get side effects such as a persistent cough from taking an ACE inhibitor. Avoid taking salt substitutes (as most contain potassium) and you should not take potassium supplements.

Angiotensin receptor-neprilysin inhibitor (ARNI)

Sacubitril valsartan (Entresto)

What's it for?
Your doctor may prescribe this for you instead of an ACE inhibitor or an ARB.

This medicine can increase life expectancy and help with the symptoms of heart failure.

It works by widening your blood vessels, increasing blood flow and lowering blood pressure to reduce the strain on your heart. It's not suitable for everyone, but your heart failure specialist team may offer this medicine to you if:

- You still have symptoms despite already receiving treatment, such as taking an ACE inhibitor or an ARB, and:
- Your heart is pumping a reduced amount of blood around your body.

What are the main side effects?

- low blood pressure (a low starting dose may be recommended)
- it can cause high potassium levels
- it can cause kidney problems.

What checks do I need?
Your doctor or nurse will keep an eye on you while you're taking this medicine. It's important that you have a blood test to check your kidneys soon after starting the medicine or after increasing the dose.

Beta blockers

Atenolol • Bisoprolol • Carvedilol • Nebivolol

What are they for?
Beta blockers help to prevent your heart from beating too quickly and too forcefully, reducing the work the heart must do. Beta blockers can:

- help keep you well
- help prevent your condition from getting worse
- control heart rhythm problems
- increase your chances of living longer
- increase the amount of exercise you can do.

What are the main side effects?

- tiredness (usually only for the first few days of starting this medication or increasing its dose)
- dizziness or fainting
- mood swings when you first start taking them
- shortness of breath
- disturbed sleep
- cold hands and feet
- diarrhoea
- impotence
- psoriasis may get worse (if you have this skin condition).

What checks do I need?
You'll need to have your blood pressure checked regularly. Your nurse or doctor will tell you how often you need to do this, either by yourself, at home or by the nurse.

What else do I need to know?
You'll be prescribed a low dose of beta blocker to begin with. It may have to be increased slowly until the right dose is reached.

It can take a few weeks or months to feel the benefits of taking beta blockers and you may even feel that your symptoms are getting worse to begin with. In the long term, they'll help to reduce the risk of your condition getting worse.

Other medications, such as diuretics (see page 25), may also need to be changed when you start taking beta blockers.

If you have diabetes, taking beta blockers can affect the way that you feel if you have low blood sugar. You may need to check your blood sugar more often when you first start taking this medication.

If you have asthma, you may not be able to take beta blockers, as they may make your asthma worse. Have a chat with your doctor if you have asthma.

Important

You should never stop taking your beta blockers suddenly without speaking to your doctor, as it can make your condition and symptoms much worse.

Mineralocorticoid receptor antagonists (MRAs)

(Also called aldosterone antagonists)
Eplerenone • Spironolactone

What are they for?

These medicines are used to help prevent and treat the build-up of fluid in your body. They work by helping to block the effect of a hormone called aldosterone.

They have a mild diuretic effect (which means that they help you to get rid of excess fluid by passing more urine). They can help to slow down the progress of heart failure, help to improve life expectancy and are often taken together with other heart failure medicines.

If you're taking ACE inhibitors or beta blockers but you're still having symptoms, you may be prescribed an MRA. It depends on your symptoms and how severe your heart failure is.

What are the main side effects?

- diarrhoea
- reduced kidney function
- passing less urine than usual.

What checks do I need?

In some people, these drugs can affect the kidney function, so regular blood tests will be needed to watch the effects of the medication.

What else do I need to know?

Spironolactone can sometimes cause swelling of the breast tissue in men.

Ivabradine

What's it for?

This medicine can help with the symptoms of heart failure. It slows your heartbeat so that your heart does not have to work so hard.

Your doctor may prescribe Ivabradine if you:

- Still get symptoms even though you're taking other medicines to treat your heart failure.
- Cannot take a beta blocker because it causes side effects.

What are the main side effects?

- slow heart rate
- tiredness
- dizziness
- problems with your eyes.

If you experience any of these side effects, let your doctor know.

What checks do I need?

When you see your doctor or nurse, they'll want to check your heart rate and rhythm.

What else do I need to know?

You cannot take Ivabradine if you have certain abnormal heart rhythms, or if your heart beats at less than 75 beats per minute.

Digoxin

What's it for?

Digoxin slows down and strengthens your heartbeat. It can:

- control irregular heart rhythms
- help your heart pump blood better.

What are the main side effects?

- feeling sick and vomiting
- diarrhoea
- dizziness or light-headedness
- rash
- disturbed vision
- a slower or irregular heartbeat
- tiredness or feeling unwell.

The side effects are usually caused by the blood levels of digoxin being too high. Your doctor may reduce your dose, which will normally result in the side effects disappearing.

What checks do I need?

You may have a blood test to check your digoxin level to make sure your dose is effective but does not cause you side effects.

What else do I need to know?

You may not be prescribed digoxin if you have a very slow heart rate or if you suffer from heart block.

SGLT2i

Dapagliflozin • Empagliflozin

What are they for?

Sodium-glucose co-transporter-2 inhibitors (SGLT2i) are also known as 'gliflozins'. These medications were first used for people with type 2 diabetes. They have been found to reduce the development and progression of kidney disease and heart failure, even in those without diabetes.

What are the main side effects?

- thrush
- urine infection
- rash
- dizziness
- dry mouth
- passing urine more often
- difficulty passing urine.

What else do I need to know?

SGLT2i should be avoided if you're:

- pregnant or breast feeding
- at risk of becoming pregnant.

If you get any of the following side effects, get urgent medical attention:

- upper abdominal pain
- passing blood or red or black poo
- vomiting blood
- swelling of the face or eyelids
- difficulty breathing
- an asthma attack.

Anticoagulants

Anticoagulant drugs prevent harmful clots from forming. If you have an abnormal heart rhythm problem such as atrial fibrillation, or an artificial heart valve, you're more likely to be prescribed an anticoagulant.

Conditions like these increase the risk of a blood clot forming inside your heart which can increase your risk of having a stroke.

Warfarin

How does it work?
Vitamin K helps blood to clot and warfarin works by getting in the way of the production of vitamin K.

What checks do I need?
You'll need regular blood tests to check how much warfarin you need. These are done at your doctor's surgery or at an anticoagulation clinic at a hospital.

What else do I need to know?
Remember to tell anyone treating you, such as your doctor, dentist or pharmacist that you're taking anticoagulants.

Always check before taking any other medication as some medication can affect the way that warfarin works.

You should avoid cranberries and cranberry juice as these foods can increase the anticoagulant effect of warfarin.

Eating large amounts of foods high in vitamin K, such as liver, brussels sprouts and broccoli, can prevent warfarin working as well as it should. This does not mean that you should stop eating these foods. Just eat a small amount of them regularly rather than having large amounts in one go.

Alcohol can affect the level of warfarin in your blood so it's important to make sure you drink within the recommended guidelines (see page 45) and avoid large amounts. Talk to your doctor or nurse for guidance.

Direct oral anticoagulants (DOACs)

Apixaban • Dabigatran • Edoxaban • Rivaroxaban

These medicines are not affected by the amount of vitamin K in your diet or cranberries. You do not need to have your blood tested as regularly as you do when you take warfarin.

Although these medicines are not affected by alcohol, you should keep to the recommended guidelines for drinking alcohol (see page 45).

Your doctor will chat to you about the risks and benefits of taking these medications.

What side effects should I tell my doctor or nurse about?
Anticoagulants can cause bleeding and bruising. They can also cause internal bleeding or make bleeding from a minor injury worse.

If you notice any of the following signs, tell your doctor or nurse immediately:

- cuts which bleed longer than usual
- bleeding that does not stop by itself
- nose bleeds longer than a few minutes
- bleeding gums
- severe bruising
- red or dark brown urine
- red or black poo
- heavier bleeding during periods
- other vaginal bleeding.

If you suffer from a head injury, seek medical help so you can be assessed for any possible internal bleeding which may not be obvious straight away.

3. Take your medications properly

To keep your condition and symptoms under control, it's important to take each medication you've been prescribed at the right time. This is not always easy if you take many medications at different times.

Here are some tips to help you:

1. Write down all the different medications you take and when you take them.
2. Do not stop taking any medication without medical guidance, even if you feel better. Stopping suddenly can be dangerous.
3. Do not run out of medication. Plan and make sure you have plenty for when you go away and during holiday periods when many pharmacies are closed.
4. Never take a double dose. If you have missed taking a dose by a few hours, take it as soon as you remember. If it's nearly time for your next dose, skip the one you missed and take the next dose at its scheduled time.
5. Use a pill (dosette) box available from pharmacies to help you organise your medication.
6. Tell your pharmacist or doctor if you think a medication is giving you a problem. If you think your symptoms are getting worse or if you get a new symptom, talk to your doctor about it.
7. Always check with your pharmacist or doctor before taking any over-the-counter medication that's not been prescribed for you. Show them the list of medications you're taking.
8. Do not give your medication to other people as it may harm them, even if the other person also has heart failure.
9. If you have a lot of prescriptions with the NHS, it might be cheaper for you to buy a prescription prepayment certificate (PPC). Visit the NHS website for more information.

Surgery and other treatments

If your heart failure is caused by heart valve disease, you may be able to have an operation to repair or replace the affected valve. If you have angina which has been caused by coronary heart disease, then an angioplasty and stent or coronary bypass surgery may be an option for you. These treatments may help to improve your heart failure symptoms.

Pacemaker

Having a pacemaker implanted can improve the strength, rate and rhythm of your heartbeat. This can help to improve the pumping of your heart.

Cardiac resynchronisation therapy

If your symptoms of heart failure are severe, they may be caused by the bottom chambers of your heart beating out of time with each other. A treatment called cardiac resynchronisation therapy (CRT) may help. This is where a certain type of pacemaker called a 'bi-ventricular pacemaker' is implanted to help coordinate the contractions of the heart muscle and help it pump better.

Implantable cardioverter defibrillator (ICD)

If you have heart failure and you're at high risk of life-threatening heart rhythms and dying suddenly (see page eight), your doctor might recommend that you have an ICD implanted.

An ICD is like a pacemaker, but if you were to suffer from a dangerous heart rhythm, the ICD would give your heart an electrical shock to help get you back to a normal heart rhythm.

Some ICDs can also work as a pacemaker. So, if you need a pacemaker and an ICD, you'd only need one device that does both.

Your doctor or nurse will talk to you about these treatments and if they're the right option for you.

Other treatments

If you have severe heart failure and your symptoms are not controlled by treatment, you may be assessed for a heart transplant. For more information, visit bhf.org.uk/hearttransplant.

Learn more about surgery and other treatments for your heart and circulatory condition at bhf.org.uk/treatments

3

Reducing your risk of further problems

People can often manage their symptoms of heart failure well and improve their quality of life by making changes to their lifestyle.

Making these changes and taking your medicines as prescribed can help to slow down your heart failure and increase your life expectancy. Here are some things you can do:

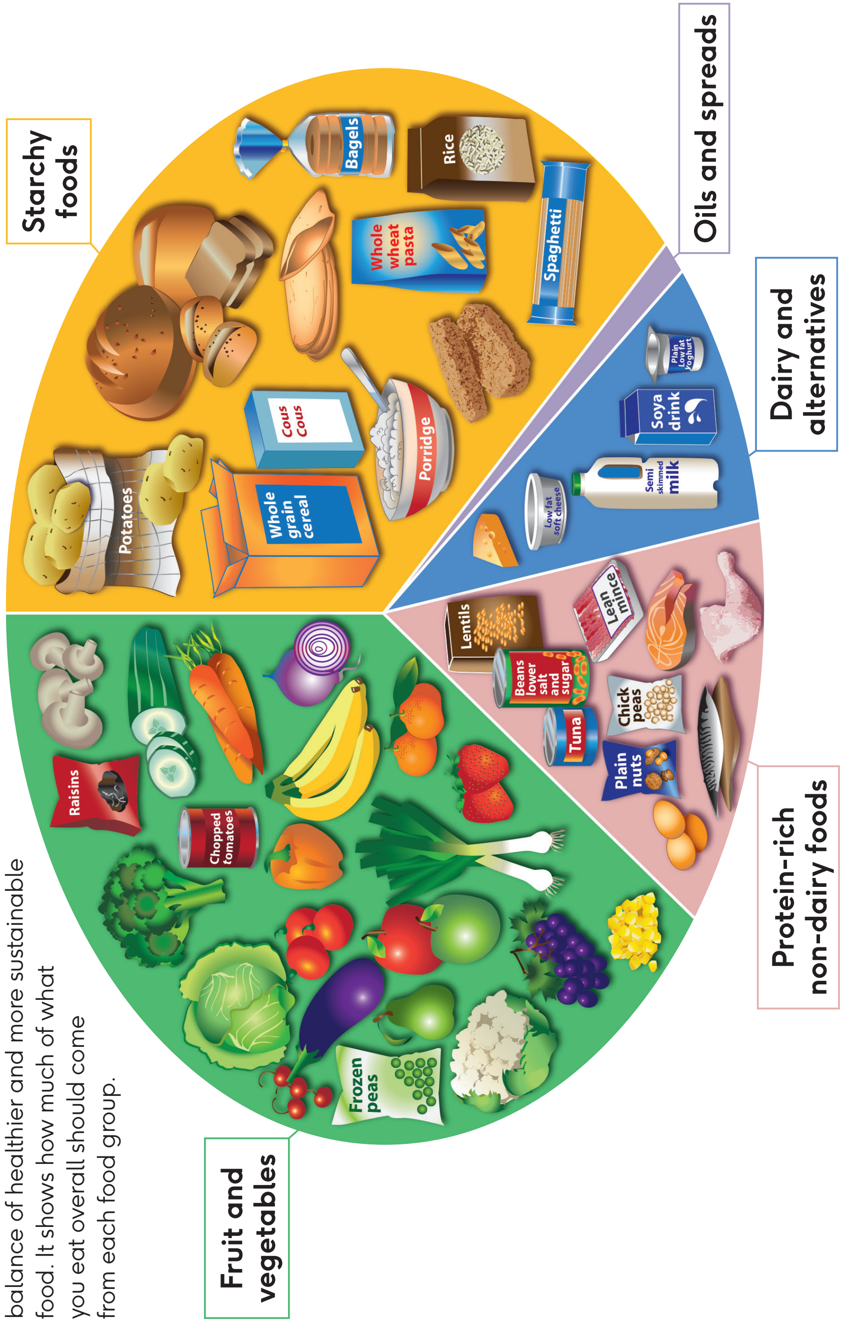
- have a healthy, balanced diet
- maintain a healthy weight
- reduce the amount of salt you eat
- manage your fluid balance
- control your blood pressure
- keep alcohol use under the recommended limit
- stop smoking
- stay active
- set realistic goals.

Have a healthy, balanced diet

Having a healthy, balanced diet is one of the best things you can do to help you feel better. It will help you to:

- maintain a healthy weight
- control your symptoms
- feel more energetic.

Your diet is your body's fuel. If you eat well, it will help you to feel better overall.



Eatwell Guide

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.

To help keep your heart healthy

Aim for three balanced meals a day, with healthy snacks in-between if you're hungry.

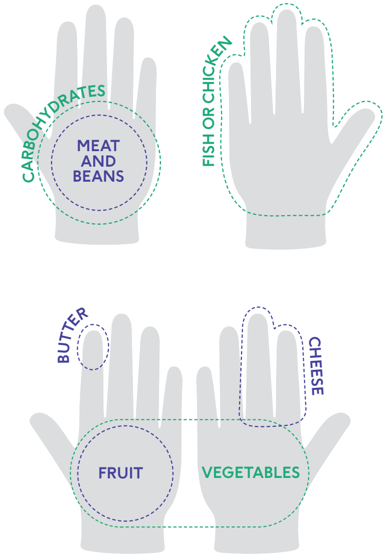
Having small, regular meals may help if you lose your appetite, feel full or bloated.

The Eatwell Guide (see page 37) shows how much of what we eat should come from each food group to achieve a healthy, balanced diet.

Eat at least five portions of fruit and vegetables each day. Include a variety of fruit and vegetables of all different colours. Fresh, frozen, dried or canned (in natural juice or water) all count, as does unsweetened fruit juice and smoothies (maximum 150ml once a day).

One portion equals:

- three tablespoons of vegetables (raw, cooked, frozen or canned)
- one cereal bowl of salad (tomato, cucumber and onion)
- one whole fruit (apples or pears)
- two pieces of smaller fruit (kiwis or apricots)
- one slice of larger fruit (melon or pineapple)
- one cupful of small fruits (grapes, cherries or berries)
- one heaped tablespoon of dried fruit (30 grams).



Using your hands is an easy way to measure food portions.

Include starchy carbohydrates at each meal

Bread, breakfast cereals, chapatis, pasta, plantain, potatoes, pasta, rice and yam are all examples of starchy foods that provide a good source of energy. Choose wholegrain and higher fibre versions for more fibre, vitamins and minerals.

Choose lean sources of protein

- Go for lean cuts of meat and remove the skin from poultry.
- Include fish a couple of times a week, one of which should be oily such as mackerel or salmon. You can eat fresh, frozen or tinned fish.

Remember tinned fish in brine and smoked fish can be high in salt. Look for an alternative such as fish in tomato sauce or water.

- Beans, dhal, lentils and peas contain protein and fibre, are low in fat and can be used to bulk out meat dishes or as vegetarian alternatives to meat or fish.
- Eggs can be eaten as part of a balanced diet, but it's best to cook them without added salt or fat.
- If you're trying to lose weight, nuts and seeds are high in calories, so keep to a handful. Always choose unsalted nuts.

Have some dairy, or dairy alternatives

Milk, cheese, yoghurt, fromage frais and dairy alternatives such as soya, oat, rice or nut milks are good sources of calcium and protein. When buying dairy alternatives, choose calcium fortified versions.

Choose lower fat, unsweetened and lower sugar products where possible like 1% milk, reduced fat cheese or plain low-fat yoghurt.

If you're a vegetarian

It's important not to rely on cheese for your protein as it can be high in saturated fat and you may miss out on some essential nutrients.

Make sure that you eat a good mix of plant-based protein foods such as beans, peas and lentils (like in dhal). They're good sources of low-fat protein and fibre. Balance your meals with a variety of fruit, vegetables, unsalted nuts and wholegrain cereals.

Choose unsaturated oils and spreads

- Swap saturated fats like palm oil, coconut oil, ghee, lard or butter with small amounts of healthier unsaturated fats such as olive oil, rapeseed oil or sunflower oil.
- Measure out oil with a spoon or use a spray and try a low-fat spread.
- Remember that all fats are high in calories, so if you're trying to lose weight, reduce your overall intake of fats.

Have less food high in fat and sugar

These foods include chocolate, sweets, cakes, biscuits, puddings, pastries, jams and savoury snacks like crisps, mayonnaise and sugary drinks.

Food and drinks high in fat and sugars have large amounts of calories which can cause weight gain. These foods are not needed in our diet so they should not be eaten often and only in small amounts. Checking food labels can help you choose foods and drinks that are lower in fat, sugar and salt.

Maintaining a healthy weight

I've been told to lose weight. Will eating a healthy diet help?

Maintaining a healthy weight will help with your symptoms and can help prevent other health problems. Controlling how much you eat, as well as what you eat, will help with your weight. It's important to have a healthy diet. Follow the advice on page 36.

Being physically active is an important part of managing your weight. Your condition and symptoms may make it difficult for you to be physically active, but you should try to keep as active as you can (see page 46).

Speak to your doctor or nurse about how you can do this. Remember that if you're not as active as you used to be and you're eating the same amount as before, you may still put on weight. If you're struggling to lose weight, your portion sizes could be the reason why (see page 38).

I've lost a lot of weight and I cannot put it back on

If you think you're underweight, losing weight (without trying to) or not able to put on weight, talk to your doctor or nurse. Your weight may go down because your appetite is poor and you're not eating enough or it may be because your body is not able to take in nutrients properly. Your doctor will want to look into the cause of your weight loss and possibly refer you to a dietitian. The dietitian will give you some guidance on how to increase your weight safely or about supplements you may need to take.

Reducing the amount of salt you eat

Do I need to have salt in my diet?

You need salt to help keep the balance of water in your body. Most of us eat more salt than we need. A diet high in salt can make your body hold onto water causing sudden weight gain and breathlessness. It can also lead to high blood pressure. Eating less salt can help reduce the amount of water your body holds onto.

How much salt should I be eating?

Adults should eat less than six grams of salt each day. That's about one level teaspoon.

Most of the salt we eat is not what we add to food. It's already in foods such as bread, cereals and pre-prepared meals. Check the food labels to keep an eye on your salt intake.

Food tastes awful without salt

When you first cut out salt, food may taste a bit boring. Most people get used to the different taste quickly. Try using herbs and spices to flavour your food instead. Look at our tips for reducing salt on page 43.

Salt substitutes are labelled 'lite', 'low-sodium' or 'sodium-free'.

What about salt substitutes or low-salt foods?

Some salt substitutes can be very high in potassium and are not recommended if you have heart failure.

Most supermarkets have low-salt or no-salt versions for many foods. You can check the information on the products or ask at your supermarket what's available. Be careful to check whether these products contain salt substitutes.

If a food carries the label 'lower salt' it should mean that a serving of the food contains 25% less salt than standard versions of the same product. If the standard version is very high in salt, the lower salt version could also still be high. A product will be low in salt if it has a green label for salt.

I get 'Meals on Wheels'. How can I make sure I'm not eating too much salt?

Meals on Wheels provide low-salt options for those who need them.

How do I know how much salt is in my food?

About three-quarters of the salt we eat comes from processed foods. Some foods like crisps, cheese and bacon taste salty, but others such as bread, breakfast cereals, cakes, biscuits, soups and baked beans can also add salt to our diets without us knowing it. So, it can be difficult to know exactly how much you're eating.

The easiest way to find out how much salt a food contains is to check the nutrition information labels on packets and cans. This is usually shown as the amount of salt per 100 grams. As a simple guide, try to go for low-salt foods. These are foods that contain 0.3 grams or less of salt per 100 grams or have a green food label.

You might see salt written as sodium on a food label. Sodium is just another way of talking about the salt content of food. It's measured differently to salt. If you can only see a listing for sodium on a food label, you can work out how much salt is in the product by multiplying the sodium (in grams) by 2.5.

Salt = sodium x 2.5

How much is too much per 100g?

	Low	Medium	High
Salt	0g to 0.3g	0.3g to 1.5g	More than 1.5g
Sodium	0g to 0.1g	0.1g to 0.6g	More than 0.6g

Nutrition information on food labels can change, so use the following list as a guide alongside reading food labels.

Limit foods high in salt. This includes:

- tinned meats (like spam, corned beef or chopped pork)
- pre-packed sliced meats (like ham, turkey or chicken)
- tinned fish in brine (try to buy fish that's canned in water or vacuum-packed and if you can only find fish in brine, rinse it very well)
- bacon, kippers and smoked foods
- crisps and salted snacks
- cured, pickled or salted foods (like pickled onions or olives)
- salted butter and margarine
- cheese
- instant sauces or yeast extract instant drinks
- stock cubes
- tinned soup and dry soup mixes
- instant noodles and instant pasta snacks
- processed meats (like sausages, pies and burgers)
- pre-packed dinners (if you're having these, try to find ones with less than 0.3 grams of salt per 100 grams)
- bread and rolls with salted tops
- sauces with a high-salt content (like soy sauce, Worcestershire sauce or relishes)
- cereals with a high-salt content (porridge and some wholegrain cereals are better, but check the food labels to make sure)
- ready-mixed spice blends or seasonings.

Tips for reducing salt

- Do not add salt to your food when you're eating.
- Use herbs and spices instead of salt to flavour your food.
- Avoid canned foods in brine where possible. Choose those canned in water instead.
- Read the labels on packaged and canned foods. Wherever possible, choose foods that have a green label for salt.

Managing your fluid balance

If you have problems with swelling, sudden weight gain and increased shortness of breath, it could be because your body is holding onto too much fluid.

You can usually tell if your weight gain is due to fluid if you put on more than one to two kilograms (two to four pounds) in two days.

Weight gain due to fluid retention will usually happen over a couple of days rather than weeks. You may also notice more swelling in your ankles, feet or tummy area and your clothes or shoes might feel tighter. If this is the case, you should tell your doctor or nurse who'll be able to guide you on what to do. They may suggest restricting your fluids and/or adjusting your dose of water tablets (diuretics).

If you notice a persistent cough or increased shortness of breath, these may be signs that fluid is building up in your lungs. You should contact your doctor or nurse immediately. These changes may happen because your heart is struggling to cope with the build-up of water in your body.

To help you manage your fluid balance and control your symptoms:

- Reduce the amount of salt in your diet (see page 40).
- Keep a record of your fluid intake and talk to your doctor or nurse about whether you need to restrict your fluid.
- Make sure you take your medication as prescribed.
- Weigh yourself every day at the same time. The best time is in the morning, without clothes and after emptying your bladder.
- Use reliable weighing scales. Use the same scales in the same place each time and put them on a firm flat surface, preferably not on a carpet.
- Keep a daily weight chart to track. This can be on paper, a phone or a computer.
- Choose to weigh yourself either in stones and pounds or in kilograms and stick to that.
- If you're going to see your doctor or nurse, take your weight chart with you.

Do you know how much fluid you can have in a day? If you're not sure, ask your doctor or nurse.

Tips for watching or restricting your fluids

- Keep a record of all the fluids you have each day.
- Pour an amount of water the same as everything you drink in a day into an empty two litre bottle (or two, one litre bottles). Do this for a couple of days. You can then see how much you're drinking.
- When recording your fluids, remember to include foods that contain a lot of water, such as soups, gravy, sauces, ice cream, jelly, lollies, sorbet, canned fruit, or tinned tomatoes.

When you get thirsty, try some of the following:

- Chew gum or have an occasional boiled sweet.
- Have a bit of frozen fruit like an orange, lemon or some grapes.
- Rinse your mouth with water or chilled mouthwash, but do not swallow it.
- Use ice cubes instead of fluids. Ice may satisfy your thirst more than water.
- Add a little lime juice or lemon juice to water. The sour taste will quench your thirst more quickly.

If you take diuretics, have a look at the advice given on page 25.

Controlling your blood pressure

Having high blood pressure can put a strain on your heart and increase the risk of getting heart failure. Taking your prescribed medicines will help to control your blood pressure, as will cutting down on salt and alcohol.

Eating healthily, staying a healthy weight and keeping active will also help. Even if you do not have high blood pressure now, these things will help to keep your blood pressure low and reduce the risk of other heart problems.

One unit of alcohol =

A small glass (125ml) of 11% ABV wine

or

half a pint (about 330ml) of normal-strength lager, cider or beer (for example, 4% ABV)

or

a pub measure (25ml) of spirits

Limiting your alcohol

Can alcohol affect my heart?

Drinking more than the recommended limits of alcohol may:

- cause high blood pressure
- damage your heart muscle
- cause arrhythmias (problems with your heart rhythm)
- change your fluid balance (and increase swelling)
- lead to weight gain (due to its calories)
- make some symptoms of heart failure worse.

If you're taking warfarin you need to speak to your doctor or anticoagulation clinic about how much alcohol you can drink.

Should I stop drinking alcohol?

Unless your doctor has told you to give up alcohol completely, it's important to keep within the guidelines and avoid binge drinking:

- Men and women should not drink more than 14 units of alcohol each week.
- You should have several alcohol-free days each week.

Stopping smoking

Smoking increases the workload of your heart and decreases the amount of oxygen that can be carried in your blood. Giving up smoking is the single most important thing that you can do to help to protect your heart and improve your symptoms.

Surely the odd cigarette will not make any difference to me now?

Yes, it will. Stopping smoking can:

- lower heart attack and stroke risk
- lower the risk of lung diseases (like cancer)
- increase your energy levels
- help you sleep better
- improve your blood circulation and oxygen levels
- improve your symptoms
- help you feel good about yourself.

I want to stop smoking. Where can I get help?

It can be hard to give up, but getting the right support will help you to succeed.

- GPs, practice nurses or pharmacists can provide advice, information and tips on how to stop smoking.
- Visit bhf.org.uk/smoking for more information and support on smoking and your heart.
- Nicotine replacement therapy, including patches, gum, lozenges, inhalators and e-cigarettes, is available and has been found to improve your chances of quitting.
- Visit the NHS website for support to help you quit.

Keeping active

Being active can be a challenge if you're limited in how much you can do. However, physical activity is an excellent way to protect your heart.

Being active can:

- reduce symptoms like fatigue and breathlessness
- improve oxygen flow in your body
- boost your energy levels
- maintain and improve your fitness and stamina
- reduce your blood pressure
- increase your body's protective type of cholesterol
- help to control your weight
- help you sleep
- keep your joints flexible
- improve your general wellbeing.

Is it safe?

Unless you've been told by your doctor to rest completely, regular activity and exercise will help strengthen your heart, control your symptoms and make you feel better. Even just getting out of your chair or not lying in bed all day can help to improve your flexibility and mental wellbeing.

If you've not been active for a long while or are new to exercise, talk with your doctor or nurse about how to start.

What type of activity is best?

If you're already quite fit, brisk walking or dancing is good. For some people it might be a more relaxed activity such as a gentle walk or easy yoga class.

Some people may not be able to do these types of activities but will still be helped by strengthening or chair-based exercises.

Physical activity is not limited to sports, exercise or going to the gym. There are many regular activities we do on a daily basis that involve being active, such as walking the dog, playing with children or grandchildren, washing the car and doing the housework.

It's important that:

- the activity is regular
- it suits your level of heart failure
- you do some every day.

Is there anything I should not do?

You may be told to avoid hard physical sports such as squash or weightlifting and strenuous activity such as DIY or carrying heavy objects.

You need to take care not to be too competitive (either with others or with yourself). You might get carried away, end up doing more than is safe and get into the overactivity-rest cycle (see page 49).

I do not feel I can do very much at all

Think about what you already do every day. This includes activities like going to the shops or walking down the street, doing the housework or even preparing a meal or making a cup of tea. Any activity, even walking around at home, is good for you if you do it regularly.

What about cardiac rehabilitation?

Talk to your doctor or nurse about being referred to a cardiac rehabilitation course. This is a course for people with heart conditions to help them live as full a life as possible. It includes tailored, supervised exercise sessions and provides information on topics such as healthy eating and managing your medication. Many programmes also include psychological support.

To take part in cardiac rehab, you'll need to have an assessment to make sure it's suitable for you. Your heart failure needs to be stable and your blood pressure under control.

As well as improving your fitness, stamina and symptoms, cardiac rehab can help improve your confidence and wellbeing. It also gives you the chance to talk about any concerns you have and meet others who may be in a similar situation to you.

If it's difficult for you to get to a course, you may be able to follow a programme at home or watch a cardiac rehab video, with support from your rehab team.

You could join a local exercise class to help keep you motivated. Some leisure centres and gyms run classes for people with heart conditions and have specially trained instructors.

But I've been told to rest

It's important to make sure you have regular rest periods throughout the day, but resting all the time is not good for you. If you want to keep fit and active, you need to plan both rest and activity.

How often should I be active?

Ideally it should be every day. It's much easier to get into the habit of doing something every day even if it's small. Making activity part of your daily routine also means you're more likely to remember to do it.

What happens if I miss a day?

Not being active for a day or two can mean that you must build up to your previous level of fitness again.

Make sure you start at a level you're comfortable with. This may mean going back a step or two.

Visit bhf.org.uk/rehab to learn more about cardiac rehab.

I have young children and I get exhausted trying to keep up with them

It can be difficult to balance childcare on top of everything. You may feel you struggle to keep up with your children. Talk to your friends and family and encourage them to do activities that you can join in with. When it's time for you to rest, they can increase their level of activity while you watch, rest or do something less tiring.

Do not be tempted to overstretch yourself and try to keep up with everyone as this can make you feel worse. It can be hard to force yourself to rest, particularly if you feel well. In the long run it will mean that you're able to keep your condition and symptoms under control.

Do not be afraid to ask for help with looking after your family and accept offers of help so that you're not too tired to enjoy being with the children and doing things they enjoy. You may also be entitled to help and benefits. See page 74 for more details.

The overactivity-rest cycle

If you push yourself to a point of exhaustion on a regular basis, you may find that you're not balancing your activity and rest well enough. As a result, instead of getting fitter or maintaining your level of fitness, you decrease it. You may be in an overactivity-rest cycle if you find that you have good and bad days of activity levels. On good days you may feel that you can do anything. On these days you may:

- try and do everything at once
- tackle all of your chores
- walk a bit further than you'd normally.

You may also have bad days where you do not want to get out of bed and feel tired and ill all day. You may be so tired you cannot do anything for a few days.

Many of us tend to overdo things when we're feeling full of energy but we suffer for it afterwards. This is known as the overactivity-rest cycle. So, even though you work hard on one day to get fitter, the fact that you must rest for a couple of days afterwards means that you do not stay fit.

The way to overcome this problem is to make an activity plan.

Making an activity plan

If you want to increase your fitness, you must do it in a planned way and find a balance between doing too much and too little.

Your plan will change according to your commitments and how well you are. Plan to do what you know you can achieve, rather than continuing because you feel like you can. Learn to stick to your plan and stop when you've done what you wanted.

1. Make a list of weekly activities
Jot down all the activities that you must do in a week and how many times you have to do them. These could include:

- The days when you have a heavy workload, whether that's housework or a manual job.
- How often you have to do the shopping or gardening.
- How often you have to look after your children or grandchildren.
- The hours you spend at work or volunteering.

List of weekly activities	How many times a week
Daily walk	7
Shopping	3
Gardening	2
Collecting children or grandchildren	1
Going out with friends	1
Yoga	1
Walk to work, bus or train station	5

2. Write down when you need to do your activities
Use a weekly activity plan like the one on this page. Then plan all the other things you need or want to do in the week and write them down.

- Set yourself realistic goals so that you do not overdo it.
- Work out how much of each activity you can do easily on each day and only do that amount in one go.
- Mix activities together so that you do not have too many heavy ones on the same day and mix ones you enjoy with those that are not as enjoyable.

3. Stick to your plan
Unless you're feeling ill, do what you planned to do that day, even if you do not feel like it. If you've planned to do the shopping on one day and look after the grandchildren the next, stick to that plan. If you do not, you'll end up doing too much in one day and you'll get over-tired and be back in the overactivity-rest cycle.

Build up your activity gradually and rest between activities each day. As you get fitter, you'll be able to do more without getting tired.

You may find it helpful to do some things more slowly, to start and finish with a less tiring activity and reflect on how much you're achieving.

What about the days when I have something special like a birthday celebration or a wedding?

There are some days when you'll do more than you usually do. For example, organising a birthday celebration or going on a trip. Special events will not affect some people but for others it may require planning ahead.

If you think events like this may affect you, try to reduce the amount of activity you do the day before, the day after and add rest periods during the day. If you're organising a party or celebration, make sure you have enough help before, during and after the event. Plan early so that you're not doing everything at the last minute. The most important thing is to enjoy occasions like this.

What would you like to do more of?

Write a list of the things you'd like to do more of, then read on for our tips on setting realistic goals so that you can do more of the things you enjoy.

I would like to be able to:

Setting realistic goals

You might have given up doing certain things because you've not felt able to do them. Or, there may be some things that you want to do more of. Setting yourself realistic goals will help you to plan your activities at a manageable pace and avoid the overactivity-rest cycle.

1. Choose a goal

Look back at the activities you've written in the 'I would like to be able to' list. These are your goals. Pick one of those goals to start with. Try something straightforward like walking more. Work out what part of your goal you can do quite easily now. For example, if you chose walking, your goal might be to do a 10-minute walk each day. This is your baseline. It should be a level that you can manage comfortably.

2. Reach the goal

Practice at your baseline. If possible, do it every day for a week. If working at this level makes you so tired that you must rest the next day, your baseline is too high. Try walking every other day instead. Once you've found your baseline and managed it for a fixed time, you'll have reached your goal.

3. Choose a new goal

When this level becomes easy, add the next bit of your goal or do the activity for longer.

Goal setting is the safest way for you to get back to doing things. You can set goals for more than one activity. Just keep them realistic and do not put yourself under pressure to do too many things at once.

How long will it take to get fit?

Levels of fitness vary between different people and are dependent on how well you are. It will also depend on how fit you are to begin with. The main thing is that you take things slowly and try to do something to help your fitness levels every day. That way you should notice a difference in a few weeks.

How can I tell if I'm improving?

You should feel stronger, less tired and able to do more things without becoming breathless. Why not make a note of your progress? Perhaps you could keep a diary and show it to your doctor or nurse. Make a chart and pin it on your kitchen wall to remind yourself just how well you're doing.

What are the challenges?

You may find that you're getting caught up in the overactivity-rest cycle or that you're unable to meet the goals that you've set yourself. If any of this happens, do not give up. Reduce your baseline so that it's just right for you and then carry on. You'll soon make progress again.

Remember the golden rules:

- increase your activity over time
- do what you planned, not what you feel like
- start each activity at a level right for you
- go slowly and build up gently.

Your nurse or cardiac rehabilitation team should be able to help you set a realistic goal to work from as a baseline.

What about times when I'm ill?

If you're ill or recovering from illness, like a cold or the flu, you may have to take it easy for a few days. Do not worry if you're not able to meet your baseline. Follow your doctor's or nurse's guidance on how much activity you can manage. When you're well enough to start again, remember that you may not be able to start at the same point that you were before you became unwell. Build up your strength slowly. You'll soon get back to where you were before.

What about holidays?

While you're on holiday, it's still possible and a good idea to fit some activity into each day. For instance, you could go on a walk exploring the local area.

Tell your doctor if your symptoms get worse

If you suddenly feel ill and tired for no reason, your symptoms get worse, come on with less effort or more often, you must tell your doctor.

If your doctor or nurse has told you not to do certain things, it's important you follow their guidance. If you're going to change what you're doing, check with your doctor or nurse first. Take this guide with you and show them how you plan to get back to being more active.

How to use goal setting to work out how much activity you can do

Example: walking
Think about an activity you want to do. For example, walking. Imagine a line from 'too easy' to 'too much'. Ask yourself: "How far could I walk that would be somewhere in the middle like 'just right'?"

1. Choose a goal
Let's say you think that walking for 10 minutes down to your local shop or the school gates and back would be just right (do not forget that you've got to come back). That's your goal.

2. Reach the goal
On day one, do the walk. Do not do more, even if you feel you should have chosen a longer walk. Do what you planned, not what you feel like. If, before you reach your goal, you feel that you've chosen a walk that was too far, stop and go back.

When you get back from the walk, check on the line. If it was really 'just right', keep to it as your baseline. Or if it was closer to 'too much' or 'too easy', adjust your baseline the right way. Do the 'just right' walk every day for one week. This gives you time to see if you get the effects of too much exercise like muscle soreness and stiffness. These effects may only begin after a few days.

3. Choose a new goal
After a week, check with yourself that it still feels 'just right'. If not, ask yourself what would be 'just right' now. Make that your new goal.

Tips on activity

- Check with your doctor or nurse that what you plan to do is safe for you.
- Make sure you warm up first when doing any activity. For example, if you plan to go for a walk, do the first few minutes at a slow pace and then go a little bit faster. It's important to cool down towards the end of an activity or exercise.
- Start each activity at a level that's just right for you. If you're (or have been) unwell, go back to a lower level of activity until you feel better.
- Build up slowly and gently. If activities hurt, you're not likely to keep them up. A gradual increase works better.
- If you feel any pain, feel unwell, get more breathless than usual or become exhausted, stop.
- Be careful if you're doing activities with other people, as they may go too fast for you.
- Think of different activities and change them to keep yourself interested.

4

Living with heart failure

Looking after yourself

Is it all right to keep working?

Most people with heart failure can continue to work if they feel well enough. However, you might need to make some adjustments because of your symptoms or the level of your heart failure. For example, you might need to work shorter hours or if you have a very physical job, you may need to consider reducing the workload or changing your job.

You may find that certain jobs, such as airline pilots, bus and lorry drivers, or roles within the armed forces have restrictions about long-term illnesses.

You may decide that continuing to work is not the best option for you. If you're not sure about what you can do at work or feel unable to continue with your present job, ask your doctor or nurse for guidance.

If you have financial concerns see page 73.

Can I still get pregnant and use contraception?

Women with heart failure can have an increased risk of problems during pregnancy and it can make your condition worse. The risk will vary from person to person and it's possible that you may be told not to get pregnant. If you're planning a family, it's important to discuss with your doctor about what's best for you before trying.

Medications that you take can have an effect on your baby and sickness during pregnancy can lead to dehydration, so pregnancy needs to be planned.

If you have cardiomyopathy that developed in pregnancy (peripartum cardiomyopathy) and it did not go away after the delivery, you may be told that you should not become pregnant again.

Many types of contraception are available to prevent a pregnancy. The type of contraception suitable for you will depend on your condition, the medicines that you're taking and personal preference. Talk to your doctor or nurse to choose the best option for you.

What about menopausal hormone therapy (MHT) or hormone replacement therapy (HRT)?

MHT or HRT is prescribed to treat symptoms of menopause. Some types of MHT may increase the risk of blood clots, including deep vein thrombosis (DVT) and stroke. DVT happens when a blood clot forms in one of the veins in your leg. DVT can go on to cause a pulmonary embolism (PE), where the blood clot moves up to your lungs.

If you have heart failure, it's likely that MHT will not be suitable for you but have a chat with your doctor or nurse to discuss the benefits and risks.

Can I carry children or heavy items?

If you have or care for small children often, it's difficult not to carry them. But carrying children or other heavy items can be tiring. If your children can walk, encourage them to do so, or use a pushchair.

Around the home, reduce the effort on your part by asking children to climb onto your lap rather than lifting them up.

Ask a partner or friend to pass you a child rather than picking them up yourself and limit the amount of time you spend carrying them.

If you have heavy shopping or regularly lift heavy items, try to use a shopping trolley with wheels to take your shopping home or move heavy things. Take someone with you to help take the shopping from the trolley to the car.

Pushing or pulling heavy items will increase the workload of your heart. Try to keep the distance you need to move things to a minimum. While it's important for you to remain independent and get on with your everyday life, remember to watch how much you're doing and avoid getting into the overactivity-rest cycle (see page 49).

Should I have seasonal vaccination for flu, pneumonia and Covid?

It's important to protect yourself against colds, flu, pneumonia, Covid and lung infections because you may be at risk of complications to do with your heart failure. Protecting yourself includes making sure that any visitors know not to visit you if they're unwell.

You only need one vaccine for pneumonia in your lifetime but the flu and Covid vaccine is different every year. This will reduce your risk and how bad the infection will be if you get it.

Many GP surgeries now have regular vaccination dates for people over 65 or with long-term illnesses and they'll send you a reminder when yours is due. Ask to be put on the list at your surgery if you're not already on it.

Getting out and about

Can I still drive?

You can drive if you do not have any symptoms or if your symptoms are stable and not likely to distract you or affect your ability to drive safely. You do not need to notify the Driver and Vehicle Licensing Agency (DVLA).

If you have symptoms at rest, you must not drive and you need to tell the DVLA. Once your symptoms are controlled, and your doctor tells you it's safe to, you can start driving again. The DVLA will need to give you clearance.

If you drive a bus or lorry, special rules apply. You must notify the DVLA that you have heart failure. You can drive if you do not have symptoms, if your symptoms are stable or if you meet certain other criteria. If you do not meet the criteria or you're experiencing symptoms, you must not drive.

While the DVLA may not always need you to declare your condition to them, you should tell your insurance company. If you do not let them know, your car insurance may not be valid.

To find out more visit
bhf.org.uk/driving

Can I still go on holiday?

A holiday can give you the chance to unwind and rest. Talk to your doctor about whether it's okay for you to go away and for you to fly. When you go on holiday, you might want to think about staying in accommodation that's easily accessible. Make sure you're fit enough for destinations that may make you more active than usual.

If you take diuretics (see page 25) and you're going somewhere hot, talk to your doctor before you go away. Your doctor might tell you that if you get dizzy or faint, you may need to reduce or stop your dose of diuretics to prevent further dehydration.

Make sure you have enough of your medicines to last for the whole holiday. Keep an up-to-date list of all your medicines with you just in case you lose any of them.

It's not always simple or cheap to find insurance when you're living with a heart condition. Start shopping for it early and get fully covered. Sometimes an insurance broker can help, but at a cost which may make the insurance more expensive than if you find it yourself.

I'm worried about travelling. Is it safe?

Travelling can be tiring for everyone, so make sure that you plan any journeys carefully and include plenty of breaks. This is particularly important if you're driving. Try and share the driving if possible.

If your journey is for two to three hours in a train or car, try to walk about or plan stops every hour for at least five or 10 minutes. You can do ankle and foot exercises while you're sitting to keep the blood flowing around your legs and reduce the risk of a deep vein thrombosis (DVT).

If you want to travel for longer, or by air, talk to your doctor or nurse beforehand. Sitting still for long periods of time (like on a long-haul flight) can increase the risk of a DVT. Again, it's important to get up often for a short walk and do ankle and foot exercises while seated.

A flight may make you breathless and increase the risk of swelling in your ankles.

This is because there's less oxygen on board the aircraft and the cabin pressure is different to the air pressure on land. If your symptoms are severe before you travel, your doctor may tell you to have oxygen available while you're on a flight.

Before booking your holiday, remember the following tips:

- Leave plenty of time to organise your travel plans so that everything's ready for your journey and you do not have to rush.
- Make sure there's someone to help you lift any heavy luggage at the check-in.
- Departure gates at airports can be a long walk from the security gate. It may be better to organise transport to your departure gate or ask to use a wheelchair so that you're not rushing to get to the plane.
- If you travel away from home, take details of your medical history, a recent clinic letter if you have one and a list of medications. It's useful to have this information if you become unwell while away.

For more information on finding travel insurance, visit bhf.org.uk/travel-insurance

Will air pollution affect my health?

Being exposed to high levels of air pollution can make your heart failure worse. It's best to avoid spending time in places where there are high levels of air pollution such as areas of busy traffic and go out at times when there will not be as much traffic.

It's a good idea to check on the air pollution level around where you live. The government's UK-AIR website has a daily pollution forecast. You can search for your postcode and see whether pollution levels are low, moderate, high or very high in your area. It also gives health advice for each level.

For most people, the benefits of being active outdoors outweigh the potential risk of breathing in polluted air. However, if you have heart failure and the air pollution level is moderate or higher, it's best to reduce difficult activity. This is especially true if you have symptoms or you're outdoors. It's still important to be active indoors if it's not possible to exercise outside.

Dealing with stress, worry and anxiety

We all experience stress and anxiety from time to time. What's stressful for one person may be a positive challenge for someone else. However, any situation that leaves you feeling unwell or unable to cope may be defined as stressful. For example, worrying about getting something done on time, or worrying about money or your children.

Stress is the opposite of relaxation and it's a natural part of life. We need both to live a full and active life.

Without some stress, you'd lose energy and feel demotivated. It's when you have more stress than you feel able to cope with that problems occur.

Anxiety is a feeling of uncertainty, fear and worry. It's normal for people with a long-term illness to be worried about their condition. The term heart failure sounds frightening and some of the symptoms feel frightening. When you're worried, your heart rate increases and you become short of breath, which can increase anxiety.

Understanding your condition and knowing how to control your symptoms will help to relieve some of the stress and anxiety that you feel. Knowing what triggers your stress and anxiety can also help, as it means you can address the problem.

What are the symptoms of stress and anxiety?

When you're stressed or anxious, adrenaline is released into your blood. Adrenaline is a hormone that helps to prepare your body for the 'fight, flight or freeze' response when you're challenged or in danger. You'll feel your heart rate increase and some people become very aware of their heartbeat (palpitations). You may find that you're breathing more heavily or become breathless.

You may experience other physical and emotional symptoms such as:

- headaches
- tense shoulders and jaw
- indigestion
- butterflies in the stomach
- difficulty concentrating
- dry mouth
- sweating
- difficulty thinking clearly
- trouble sleeping
- restlessness
- low spirits
- feeling tired.

You may find that you develop unhealthy habits to help you deal with these feelings, like:

- smoking
- drinking more alcohol
- eating unhealthy foods or eating very little
- being less active.

It's important to understand how you cope with feelings of stress and anxiety. Lifestyle choices can make your symptoms better or worse and increase or decrease your risk of developing other heart problems.

Being told I have heart failure was a terrible shock

Many people say that it was a terrible shock to be told that they had heart failure. The words themselves can be frightening. They bring with them a feeling that life will be short or difficult, or that it will have to change a lot.

You may experience many different emotions such as anger and sadness. You might have lots of questions about how you'll cope physically, mentally and financially. It can feel like your whole world has turned upside down.

These are all common feelings and fears. Understanding your condition and being in control of it will help you to live as normal a life as possible. Some people may find that their life changes very little, while others may have severe symptoms and need to adjust more.

I'm afraid of doing anything in case I get worse

Some people are scared of being active and do as little as possible in case it makes their symptoms worse. However, your heart is a muscle and like all muscles in your body it needs exercise to keep it healthy. Your physical ability or tolerance levels may have changed, but you should still follow a plan that fits your lifestyle and symptoms (see page 50). This will help your heart to remain in the best condition possible.

Avoiding things because you're afraid of making your symptoms worse can make you feel alone, stressed or depressed. Talk to your doctor or nurse about what you should be doing to keep your heart as fit as possible.

I cannot cope with my symptoms. I get really frightened

Most people find that being out of breath is one of the most frightening symptoms of heart failure. By learning to recognise the start of symptoms that can cause shortness of breath, such as a build-up of fluid, you can spot the problem early and treat it before it happens. See page 43 on managing your fluid balance.

Being out of breath is not always a sign that something's wrong. You may find that you breathe more quickly when you're worried or frightened. Try the relaxation techniques on page 64 if you feel a sense of panic or fear. Relaxing will help to calm you, reduce your heart rate and the workload of your heart.

My loved ones will not let me do anything

People who love you may be as upset and confused by your diagnosis as you are.

They'll want to protect you and you may feel that you're being smothered or wrapped in cotton wool. They're only trying to do what they think is best for you.

Tell your family and friends that you appreciate their concern, but going out and doing the things you enjoy (within your limits) will help your mental health.

It'll help to share this guide with them so that they understand your condition better. Talk to them honestly about how you feel and what you're doing to manage your symptoms. Explain that you need to stay active to help keep your heart as healthy as possible.

If there are things they can help you with, like looking after children or carrying shopping, let them help so that you feel well enough to do the things you want or need to do. Being honest about the things you need help with, and accepting the help that's offered, will allow you to be in control and prevent you from feeling smothered.

I'm so frustrated because I'm too weak to do things and other people have to help me all the time

If your symptoms are severe, you might find it more difficult to do what you think are simple tasks. You might find it easier to break jobs down into smaller steps and take a rest between each one.

For example, you do not have to do all the washing up at once. Do a bit, have a rest, relax and then do a bit more. It may take longer that way, but if it means that you're still able to do the things you want to, then you'll feel in control. It may help to save energy if you do some activities while sitting down, like preparing the vegetables or washing and drying yourself.

If you're very ill, you may have to accept help from others so that you're not overwhelmed by your symptoms.

Allowing them to do things for you may also help them cope with their own anxiety.

Accepting help from friends and family will help keep your energy up, stay in control and allow you to do some other things that you'd like to do.

I have to get my carer to do things I normally do. It's embarrassing

There may be some everyday tasks that you find difficult, such as bathing and getting to and from the toilet. You may not want to ask your carer for help with these things.

Speak to your doctor or nurse who may be able to suggest how to have this conversation.

How can I reduce my levels of stress and anxiety?

When your body detects stress, it reacts by producing hormones like adrenaline. This helps you to deal with the pressure you're facing.

Your adrenaline levels change depending on how stressed, worried or anxious you are. If you're panicking and feel anxious, your body will produce more adrenaline than if you feel calm and relaxed.

Have a look at the emotions in the graphic on the right. Where do you think you are right now?

See if you can find a way to get your feelings back to the relaxed and calm level. Can you think of something that will help you get there? Like:

- listening to your favourite music
- reading a book you enjoy
- sharing quality time with family or friends
- having a warm bath and daydreaming
- sitting in your garden
- stroking your pet.

You'll not always be able to avoid feeling stressed and anxious but by knowing what triggers these feelings, you can control how they affect you.

The following things should help you avoid getting too stressed:

- Talking to someone. Trying to cope on your own can make matters worse. Remember, other people can help.
- Being organised and prepared for events such as weddings and celebrations.
- Knowing what makes your symptoms worse and how to control them.

Emotion	e.g. when you:
Rising panic, anxious or fearful	Feel out of control or receive bad news
impatient or aggressive	are waiting for results, are not able to complete everyday tasks
snappy or tense	have lost something or are late for an appointment
pleasantly excited	are attending a family event or party
relaxed and calm	are on holiday, reading or relaxing

Adrenaline level

Breathing exercise for stress

This breathing technique only takes a few minutes and can help you cope with feelings of stress and anxiety. It can be done anywhere and will work better if you do it regularly as part of your daily routine. You can do it standing up, sitting in a chair that supports your back or lying on a bed or yoga mat on the floor. Make yourself as comfortable as you can and loosen any clothes that may restrict your breathing.

- Let your breath flow as deep down into your belly as is comfortable, without forcing it.
- Try breathing in through your nose and out through your mouth.
- Breathe in gently and regularly. Some people find it helpful to count steadily from one to five. You may not be able to reach five at first.
- Then, without pausing or holding your breath, let it flow out gently, counting from one to five again, if you find this helpful.
- Keep doing this for three to five minutes.

It can be difficult to relax and get used to this at the start but eventually you'll notice that the symptoms of stress trouble you less and less. When you get good at this technique, you can use it whenever you need to get some peace and relief.

Going to classes in relaxation, meditation or yoga can help to relieve stress and anxiety. Find out if there are any classes in your area (search online or look out for advertisements) or watch a video on YouTube at home. You can also read up on this subject at your local library or bookshop.

Other things you can do to address your stress

- Be active. Being active can help to relieve your stress. Getting out and about, even if it's just outside your front door, can help to clear your thoughts and deal with your worries.
- Avoid unhealthy habits. Do not rely on alcohol, smoking and caffeine as your ways of coping. In the long run it's best to tackle the cause of your stress.
- Have some 'me time'. We often do not spend enough time doing the things we enjoy. Try setting aside an evening, or a few hours in the day for some quality 'me time'.

Dealing with negative thoughts

Each time you have a negative thought, give yourself a 'reality check' by asking yourself: is there any truth in that thought?

For instance, if you find yourself:	Ask yourself:
Jumping to conclusions Something happens. You see the situation in a negative way. Example: You ask your carer to do something for you and he says, "I'll do it later. I'm busy." You think: "He's sick of me. I'm getting him down. He cannot be bothered with me now I'm ill. He does not love me anymore."	Is my carer busy? Yes. Does he usually say, "later" and then help me in his own time? Yes. Nothing new there then. I'll ask him how he feels.
Over-generalising One person does something. You apply it to everyone. Example: Someone you used to work with passes you in the street without speaking to you. You think: "She does not want to speak to me anymore. She's avoiding me. I've really upset her. She does not like me. No one likes me."	Did that person simply not see me when we passed in the street? Yes. So, is it true that she's avoiding me? No. Have I upset her? No. Is it true she does not like me? No. Does everyone ignore me? No. You cannot know what someone else is thinking, so do not waste your time trying to guess.
Exaggerating the negative A setback happens. You imagine a disaster. Example: You see the nurse and they say, "Your blood pressure has gone up a bit." You think: "That's it. None of these medications are working. If my blood pressure goes up, it means I'll have a heart attack. I will not survive that."	Has my blood pressure been up before? Yes. Did it go back down again? Yes. Maybe it will this time as well.

Join a support group

You may find it helpful to join a heart support group. They're open to anyone with a heart condition and their family and friends. They offer the chance to meet others and share experiences in a friendly, supportive environment which can help relieve worries and concerns. They may also provide activities such as exercise sessions, walking groups, relaxation classes, guest speakers, coffee mornings and other social events (see page 86).

Visit bhf.org.uk/supportforyou for tips on everyday living, emotional support, support groups and much more.

Depression

If you have constant negative thoughts, you feel sad often or you're tearful a lot of the time, you may be depressed.

What's depression?

Depression is not just feeling unhappy or low for a few days. When you're depressed, you feel sad a lot of the time for weeks or months, have constant negative thoughts and are often tearful.

Depression is common and affects many of us at some point in our lives. It can happen because of serious illness or life stresses such as a bereavement, job loss or money worries. Or it can happen unexpectedly for no apparent reason.

I just keep thinking there's no point

It can be difficult to recognise if you're depressed. It's often a slow process that affects the way you see your life and everything around you. You might feel worthless and believe that you do not deserve help, or that getting help is pointless.

You may also feel that you should 'pull yourself together' or 'snap out of it', but depression is an illness with real symptoms.

What can help?

Depression is treatable. If you think that you might be depressed or if someone suggests that you might benefit from getting help, speak to your doctor or nurse who'll know the best way to help you.

If you'd like to learn more about depression, visit nhs.uk or mind.org.uk and look for information on depression.

I cannot enjoy things anymore. Even watching TV seems pointless

We all have times when we feel worried and down. It's natural to feel angry, sorry for yourself and lonely at times.

Find someone you can talk to. They may help you to put your feelings into perspective. Try to think about the positive things that you've done and what you'll try the next day, but do not be too ambitious.

If you feel like this all the time, you may be depressed and need to speak to your doctor or nurse. They'll talk to you about why you might be feeling like this.

If necessary, they'll be able to arrange for you to have some counselling or therapy and discuss the possibility of medication.

The good news is that with the right treatment and support, people living with depression can make a full recovery.

I've always enjoyed company but now I cannot be bothered. I just want people to leave me alone

It's a natural part of being ill to withdraw from others. When you're fed up or have a problem, it can be painful to be with people who seem to be happy and have no difficulties. Time on your own can be very helpful, but in the long run being alone and giving up company can leave you feeling lonely and without support.

What can help?

- Talk to your carer, relative, friend or doctor or nurse about how you're feeling. It can be helpful to talk and they may be able to suggest things to help you feel better.
- Plan something to look forward to every day.
- Even if you do not feel like doing something, it's often worth a try as you may surprise yourself and enjoy it.

I've had to stop work and I feel that my life is over

If your doctor has told you to stop working, it can have a huge impact on your life. You may even feel that you've lost your purpose in life.

It may help to discuss other types of employment that you might be able to do instead of your current job. If this is not possible, you may be entitled to benefits to help you cope (see page 74). You could also try finding a new purpose, hobby or join a group. This may bring back a sense of fulfilment and enjoyment.

Managing changing relationships

You may find that your relationships with your family, friends or colleagues have changed. Your own role at home or at work may have changed too. All of this can be frustrating. To manage the changing relationships, it helps to be honest and realistic in your expectations, both of others and yourself.

Think about any limitations or changes you're feeling due to your condition. This will help you to look at your everyday life and responsibilities. What can you continue to do and what do you need help with? You need to lay down the ground rules and manage people's expectations, so that they can understand what you need from them in terms of physical help or emotional support.

Why not use the goal setting or activity plan methods (page 53) with your family, friends or carer and together work out the best way of carrying out your responsibilities and activities?

You may feel guilty that you cannot do as much as you used to or because you must rely on others to do things for you. It's perfectly normal to feel this way but it's important to accept the physical limitations of your condition.

If you force yourself to 'soldier on' you may end up in an ever-increasing cycle of exhaustion. It's better to set realistic goals for what you can achieve.

You might feel that your condition has made you a burden on your family and friends. You may not be able to do the same work or the same number of hours, which may affect you financially.

Or you may not be able to do the same jobs around the home. If you've been a person who has particular responsibilities, this can be very difficult to accept and can lead to a feeling of worthlessness.

Talk to your family about how you can take on different responsibilities to ensure you still play a part. This will help you to feel valued and will boost your self-esteem. Balancing what you do while accepting help from family and friends will help you stay in control, keep your energy up and let you do the things you like. Remember to talk openly and honestly with those around you. You need to know what your partner, carer and family are feeling and they need to know what you're feeling.

I often get annoyed with my partner

You may sometimes feel angry and frustrated if your partner has to do more for you than they used to. Or you might feel that your partner is 'fussing over you' or being over-protective. It may be that they just want to care for you and feel that they're doing something helpful. Confusion and frustration often happen because each of you is unclear about what you need help with. Take time to talk to each other about your roles.

If you feel that your relationship with your partner is suffering, it may help to ask for some relationship counselling. Talk to your doctor or nurse about referring you for some counselling or visit the organisation, relate.org.uk for relationship support.

I feel frustrated that I cannot play with my children or grandchildren as much as I used to

Although you may not be able to play games like football or tennis with your children or grandchildren, there are a lot of other games and activities that do not require as much physical effort. For example, arts and crafts, board games, reading stories or even taking them with you on your daily walk, are all activities that young children enjoy. Some children may enjoy watching a film with you or playing cards.

Children also need to know what your condition means, so talk to them about it and explain why you may not always be able to do everything with them, even if you'd like to. They'll enjoy the attention you give them and appreciate the time that you do spend with them.

Being honest with them about your condition and giving older children responsibilities in the home will help make them feel that they're still involved in your life and that their support makes a difference.

Focus on the positive

By focusing on the positive parts of your life, you can begin to accept the changes that happen:

- If you're no longer able to work, you may be able to spend more time with your partner or carer, friends, children or grandchildren.
- Your family may appreciate you more and you may see more of them.
- Your relationship with your partner or carer may become stronger.
- It might mean you're able to pursue other activities or hobbies.

Although you may be frustrated by the changes, once you have a routine for your treatment and everyday life, you'll be able to enjoy the time that you spend with your family and friends. You might find that your relationships get stronger and that you have a different perspective on life.

Tips to help you cope with changing relationships:

- Recognise and accept that you may not be able to do everything that you want to and focus on what you can do rather than what you cannot.
- Learn how to change your activities so that you can still take part in fulfilling activities with your family or friends.
- Learn as much as possible about your condition and take an active role in your treatment. This will help you to take some control of your situation.
- Make sure your carer knows what your needs are and can work with you.
- Discuss how you feel with your carer and family and listen to them when they tell you how they feel.
- If you feel you need to talk to others in the same situation, join a support group. For information on how to find one locally, see page 86.

Sex and relationships

My partner and I never seem to get round to having sex anymore

You or your partner may be frightened that having sex may be harmful. This is common in couples where one partner has a heart problem. The good news is that most people with heart failure can enjoy sex if your symptoms are managed well.

Having sex makes you feel good and brings you closer physically and emotionally to your partner.

Talk to your partner about your concerns and feelings. Listen to what you both need and try different ways of showing your feelings. There are plenty of ways of being physically close and sharing intimacy that do not involve sexual intercourse.

If you have an ICD (implantable cardioverter defibrillator), you may be worried that sexual activity will cause a shock. It's safe to have sex if you have an ICD.

I just do not have the desire for it anymore

There may be many reasons why your desire for sexual activity becomes affected. These include:

- Side effects caused by the medication you're taking. In particular, beta blockers may cause problems with erections (impotence).
- You're tired and lack the energy to have sex.
- You're worried about physically overdoing it and tiring yourself out.
- Worry, anxiety and feeling low are natural when you have heart failure and can often cause a loss of interest in sex.

I'm having problems with my erection / reaching orgasm

If you have heart failure, it's common to have physical problems with sex such as erectile problems (impotence) or being unable to reach orgasm.

You may be anxious about your heart but the cause of the problem could also be worrying about it.

Poor blood supply can cause difficulties with erections. Your erection is caused by large blood vessels in the penis filling with blood. This is what makes the penis hard. With heart failure, there may be a reduced supply of blood to all parts of your body.

Some types of medication can cause problems with erections, such as diuretics, beta blockers and anti-arrhythmic drugs.

Your doctor may be able to change these which may help.

One clue that can help you decide whether the problem is caused by medication, a reduced blood supply or a result of anxiety is if you still have morning erections. If you have morning erections but have problems when you want to have sexual intercourse, then it's more likely to be anxiety causing the problem, rather than the blood supply or the medication.

Men have a rush of hormones in the early morning. You may find it easier to get and keep an erection in the morning, so this may be a good time to have sex, instead of at night.

Have a chat with your doctor or nurse if you have any concerns and they'll be able to guide you on possible treatments.

Can I use PDE-5 inhibitors such as Viagra?

Be sure to discuss it with your doctor first before you take this medicine as it may not be safe for you to take it with your other medication. Viagra is also available over the counter in a pharmacy without a prescription. It's best not to buy it over the counter and instead chat with your doctor who'll decide if it's safe for you to take and then prescribe it for you.

Financial worries

I'm worried about how I'm going to cope financially

If your working life has changed because of your health and you're facing financial problems, it can be very distressing. There are several benefits that can help to support you.

What if I need to take time off work?

If your health means you need to take time off work, you may be entitled to a weekly payment of Statutory Sick Pay from your employer. You can talk to your employer about this or contact the Citizens Advice Bureau for more information.

Help with prescription charges

Medical prescriptions are free of charge in Scotland, Wales and Northern Ireland. They're also free for people in England who meet certain criteria, such as those aged over 60.

If you live in England and you're not entitled to free NHS prescriptions for your medicines, you may be able to save money by purchasing prescription prepayment certificates (PPCs).

You can purchase PPCs with fixed monthly payments which allow you to get all the prescriptions you need, instead of paying for each prescription individually.

To find out if these may help you with the cost of prescriptions, or if you're eligible for free prescriptions, visit the NHS website.

What state benefits are available?

The benefits system can be complicated, so you should get advice about what you're entitled to. Your entitlement may include Universal Credit, which is a regular benefit payment that can help with your living costs if you're on a low income or out of work.

You may also be entitled to:

- Personal Independence Payment or Attendance Allowance. These are benefits for people with disabilities or long-term health conditions.
- Child Benefit. These are benefits for people bringing up a child.
- Carer's Allowance. This is a taxable benefit available for informal carers (see page 82).

You can contact the following places for information on benefits:

- your local Jobcentre Plus: www.gov.uk
- your local Citizens Advice Bureau: www.citizensadvice.org.uk
- the UK Government's Department for Work and Pensions in England and Wales: www.gov.uk
- in Scotland: www.mygov.scot
- in Northern Ireland: www.nidirect.gov.uk

Facing severe illness

You may find that there are times when your symptoms become severe because you've caught a cold or become unwell for another reason. When this happens, it's important to see your doctor so that your condition can be assessed to make sure that your heart failure is under control.

It's possible that you move up a class of heart failure (see page six). When you recover from your period of being unwell, you may find that you return to the class of heart failure that you had before.

Heart failure is a progressive disease and there may be a time when your condition gets worse despite your treatment. You may believe, or you may have been told, that you're approaching the end of your life.

Coping with the effects of advanced heart failure can be difficult. If you're unable to get about and do things, you may find that you're dwelling on things and worrying more. Try to focus on what you can do rather than what you can no longer do.

If you can, talk to someone about your feelings. Although it might feel difficult to start with, talking does help. Chat to your family and friends or to your doctor or nurse. If you prefer to talk to someone else, ask your doctor or nurse about being referred to a counsellor or therapist. Remember that you do not have to manage alone.

Here we explain how you can get support with the issues that may arise when your condition is advanced.

I cannot manage at home. How can I get help?

Talk to your doctor or nurse or contact your local social care services department at your local authority.

They'll be able to guide you on a range of services available in your area, including home care, housing issues and offering help to support anyone who already cares for you.

A 'health and social care assessment' may be needed to find which services you need with your condition. Your local authority can provide more information on this.

You can find contact details for your local authority by visiting www.gov.uk and searching for your local council.

What about Meals on Wheels?

If you have difficulty preparing meals for yourself or find it hard to shop for food, you can have meals delivered to your home. This service is sometimes known as 'Meals on Wheels'.

To find out if your local authority offers this service, visit www.gov.uk (England and Wales) or www.nidirect.gov.uk (Northern Ireland) and search for 'meals at home'.

I'm scared of being on my own in case something happens

Talking this through with family, friends or carers helps. Decide on a plan for contacting someone if you feel you need help.

If you live on your own, talk to your doctor or nurse about home care services. You might not want or need help at home on a regular basis but it can give you peace of mind to have contact details for emergencies. Ask about community alarm services which can be arranged in case you should ever need help urgently.

My symptoms are so bad that I cannot get out of the house

If it's no longer possible for you to get out and about on your own, here are some suggestions that may help:

- Use a wheelchair so that you can still get out with your family and friends.
- If you're very breathless, talk to your doctor or nurse about getting a prescription for oxygen.
- Make sure to have plenty of rest periods in the day.

Planning for the future

When facing long-term or severe illness, it's natural to think about the future. You might ask yourself questions like, "what if my condition worsens and I'm too unwell to let people know my wishes?" or "what'll happen to my family if I'm not around to care for them?"

Although it can seem difficult at first, making plans and sorting out practical matters such as your will, finances and sources of support can be a positive thing to do. It can help with some of the worries or questions that you may have so you can get on with living as well as you can for as long as you can. Your family or friends will also be more confident in knowing exactly what you do and do not want to happen.

It's a good idea to start thinking about the situations that might happen as soon as you feel comfortable. By having these conversations and making decisions while you're well, you can help make sure that your wishes are done.

What if I do not want any more treatment?

It's important that you have control over your treatment. Discuss the treatment you want or when you want to stop it with your doctor or nurse. Chat about your wishes with your family and friends so that they can help you in the future. Try and have these conversations when you're feeling well, as it can be difficult to make decisions when you feel unwell.

Sharing difficult decisions will help you and your loved ones understand each other better.

What's palliative and end of life care?

Palliative care is the holistic care of people with an advanced illness which cannot be cured. By 'holistic' we mean it deals with the 'whole' person rather than just one aspect of care. It includes the management of physical symptoms such as breathlessness and discomfort, as well as emotional, spiritual and social support. Its goal is to help you and your family achieve the best quality of life possible.

End of life care is support for people who are approaching death. It helps them to live as well as possible until they die and to die with dignity. It also includes support for their family and carers.

Your doctor and nurse, as well as professionals working in palliative care, can help you think about, discuss and plan for the last months, weeks and days of life. This helps make sure your wishes are met and that you receive the care you'd like and the treatments you want to avoid. It helps make your family and friends aware of your preferences and offers them support too. Ask your doctor or nurse any questions you have about palliative and end of life care and the services available in your area.

5

Caring for someone with heart failure

Caring and support

When someone is diagnosed with heart failure, it affects everyone in the family and those involved in the care of that person. Expectations and relationships will change and it can be hard to know what to do for the best.

Understanding heart failure

Understanding the condition and how it affects your partner or the person you're caring for will help you to deal with the ups and downs that you may face.

This guide has been designed to help the person with heart failure manage their symptoms and have a good quality of life.

Striking the right balance

The person you're caring for may need different levels of care and support at different times. There will be good and bad days for them and for you too. You need to be able to let them manage their condition, but also tell you when they need help. There will be times when they're trying to do too much and you might have to intervene.

Knowing how to do this without taking away their independence can be tricky.

I'm worried that I'm going to be overprotective

It's natural to want to help the person with heart failure as much as possible, but being overprotective may frustrate them or encourage them to be too dependent on you.

The key is to make sure that you talk to each other about how you feel and what boundaries need to be set. Finding the right balance to live as normal a life as possible will mean that both of you'll feel happier and more in control of your lives. Remember that you have a life and other responsibilities too.

Ask them what they feel they can do and if there are any areas that they need help with. It may mean organising a few people on a rota to do the shopping, organise meals, collect the children or stay with them while the person is resting. Let them talk to you about what they want to do.

If you think that they're doing too much, talk it over and suggest other things that they can do that are not so tiring. If you still have concerns, discuss them with the nurse or doctor. They'll be able to let you know if you're being overprotective.

While the nurse or doctor may be happy to give you tips and advice, they're not able to share information about the person unless they have permission from them to do so.

Making sure that the person you're caring for is in control of their life and condition can:

- Help them to feel more positive about their situation.
- Reduce their feelings of being a burden or dependent on you.
- Allow you to do something else while they're managing themselves.

What if they do not seem to want to do anything for themselves?

It may be that the person you're caring for has lost their self-confidence. Perhaps they've been unwell recently or their symptoms have changed. Give them time and space to adjust and get back on their feet. Gently encourage them to do things for themselves and for you. Sometimes people are more encouraged if you ask them to do jobs for you or other people.

Try to focus on what's important and not on the little things. If they're not looking after themselves, try inviting someone around or suggest going out. This can motivate them to make an effort with their appearance. We all have good and bad days and like things to look forward to.

There are times, however, when you may be concerned that they're depressed. Depression can be a serious condition, but once diagnosed it can be treated.

If you're worried, talk to your doctor or nurse for support and advice. See page 68 for more information on depression.

Coping with stress

Why do I feel stressed?

You'll probably be worried about the health of the person you're caring for and about the future. You may also be overwhelmed about the amount of information you have to deal with. All these factors can make you feel anxious and stressed.

What can I do about it?

There are many things that you can do to cope with stress:

- Accept that you cannot do everything. If you have to ask for help, it does not mean that you're not coping.
- Try to figure out when you might need to ask for more help. For example, if you have other responsibilities like looking after children or going to work.
- Change your expectations for yourself. For example, let the housework go more than you'd like to.
- Look after yourself. Try to eat healthily and exercise regularly.
- Do some relaxation exercises. Try the ones on page 64, or you might like to try going to local classes.
- Make sure that you have enough time for yourself.
- Speak to the person you're caring for about what you need to do and how you can best allocate your time.
- Join a support group for carers. You might find this helpful as it lets you meet other carers who may be in a similar situation. You can talk about your experiences and pick up practical tips.

Having a social life

I feel isolated

Looking after yourself is as important as caring for your partner or relative. Feeling isolated is a common feeling. You may feel that although there's support and help for the person who's unwell, no one seems to understand how you feel. You may have become so focused on your carer responsibilities that your friends and hobbies have been ignored.

Talk to your friends and family about your feelings and ask them for help. Do not try and do everything yourself. If you overdo things, you may make yourself ill, which will not help in the long run. You need a break and time to yourself.

If you need to go out but the person you're caring for needs someone with them, ask a friend or relative to call or be available on the phone. Or contact an organisation called Carers Trust 4all which may be able to provide someone to sit in for you.

If you're unable to leave your partner or relative on their own for long, you may be able to arrange respite care. With this care, they'll be looked after by someone else so that you can have a break or holiday. Talk to your doctor or nurse about arranging this.

I feel guilty about wanting to have a social life

For your own wellbeing, you need to have a life outside of caring. By taking a break, you'll feel more relaxed and better able to cope with the demands of caring.

What can I do to help the person I'm caring for manage their symptoms?

The information in this guide will help you do what's best for the person you're caring for. There's plenty of practical guidance on:

- recognising and managing symptoms
- managing medications
- eating healthily
- getting the right amount of exercise.

Read through the guide together and work out how you could help with putting this guidance into practice. For example, you could shop for healthy ingredients and help to prepare meals.

Are there any warning signs that I should look out for?

If the person you're caring for is ever in distress, unable to breathe properly, experiencing chest pain or collapses, dial 999 for an ambulance immediately.

If the person you're caring for develops the following new symptoms, or their symptoms get worse, tell your doctor or nurse as soon as possible:

- swelling of the feet, ankles or abdomen
- sudden weight gain
- breathlessness, wheezing or coughing
- light-headedness or dizziness
- fatigue (feeling unusually tired and weak)
- palpitations
- memory problems or problems concentrating.

If they're very bad, or if the person feels very unwell, call 999.

Help with caring

There are benefits and services to help you look after someone with a long-term illness. These may be in the form of financial or practical assistance.

What's carer's allowance?

Carer's allowance is a taxable benefit available for informal carers. An informal carer is someone who provides care to another person and is not paid to do it. This could be a spouse, a friend or a relative.

How can I find out if I'm eligible for carer's allowance?

There are quite a few conditions to receiving carer's allowance. It may be available for you if you meet certain criteria, like:

- The person (or people) that you care for receives certain benefits.
- You spend more than a certain number of hours caring per week.
- You earn less than a certain amount of money per week.

The rules for claiming carer's allowance in Northern Ireland is different from England, Scotland and Wales. Use the contact details below to find out more:

- In England, Scotland and Wales, contact the 'Carer's Allowance Unit' on the www.gov.uk website.
- In Northern Ireland, visit the nidirect.gov.uk website and look for 'financial support when caring for someone.'

What's a carer's assessment?

A carer's assessment aims to find out your needs as a carer. If you look after a friend or relative who cannot manage without your help, you may qualify for a carer's assessment. In Scotland, it's called an 'Adult Carer Support Plan'.

The assessment looks at:

- help you need with caring
- help you need maintaining your own health
- commitments that you have.

How do I get a carer's assessment?

You can ask your local social care services department for a carer's assessment. Your doctor or nurse can contact them on your behalf or you can contact them directly. Visit 'carersuk.org' for more information on getting a carer's assessment.

What happens in a carer's assessment?

A social worker will ask you to provide as much information as possible about what your role as a carer involves. This helps them work out what assistance you may be eligible for.

For a week or so before the assessment, it might be a good idea to keep a diary about what your role as a carer involves.

For example:

- How many hours a week do you spend caring, including at nighttime?
- Are you able to leave the house and have time for yourself?
- How is your health and is it affected by being a carer?
- Does your role as a carer impact on any other areas in your life? For example, your job, other relationships, your hobbies or your sleep.

What happens after my assessment?

After your assessment, your social care services department will develop a 'care plan' based on the results, as well as the needs of the person you care for.

This could include information, support and services that you may need for your situation, such as helping you to take breaks from caring. You should be involved in any decisions taken as part of the 'care plan' before they're finalised.

Tips for carers

Heart failure cannot be cured but the symptoms can be controlled to help prevent it from getting worse and allow the person to have a good quality of life. You and the person you're caring for can work together to do this. Talk to each other about the things you both need as individuals.

- Work out with the person you're caring for the everyday jobs that they can do and plan your weekly chores around each other's needs.
- Make time for yourself. Do not be afraid to ask for help. When people offer help, accept the offer and suggest specific things that they can do.
- Recognise that it takes time to get used to change. Both you and the person you're caring for may experience changes to daily life and to habits you've had for years. The person with heart failure will need plenty of support and encouragement. Do not be too hard on yourself either. Try to accept that change will involve some stress, especially at the beginning.
- Take part in any hospital, doctor and nurse appointments or visits but let the person you're caring for answer most questions. Work out beforehand with the person you're caring for the main questions you'd like answered and write down the answers to any questions that are asked.
- Learn about heart failure and how the condition is managed. Read through this plan with the person you're caring for so that you can identify the things that most concern you and plan how to deal with them.
- If you have any questions or concerns, speak to your doctor or nurse.

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Getting help and information

Talking to your doctor or nurse

I would like more information

Information about your heart failure is essential if you're to understand how to manage your symptoms and treatment. If there's something you do not understand, ask your doctor or nurse.

Before you go for your appointment, write down a list of questions about all the things you want to know. If you think you'll not remember the answers, make notes of the answers or ask your doctor to write things down for you.

You may receive a written care plan about how your condition will be managed. This will include your prescribed medicines, details about your care, rehabilitation, contact details for your doctor or nurse and where you can find more information. Talk to your doctor or nurse about this and if you'd like to be involved.

I do not always understand what I've been told

It's very important to understand what your doctor or nurse is telling you. Medical information can be complicated, so if there's anything you do not understand, do not be shy to ask them to repeat it or to explain it to you.

There never seems to be enough time to talk about things

Many people with heart failure say that this is a big problem.

There never seems to be enough time to talk about all the things that concern you. There are certain things that you can do to make the most of your time with your doctor or nurse.

Before you visit your doctor or nurse, think about why you're going to see them and what you'd like to talk about.

- Make notes on how you're feeling for about a week before your appointment.
- Write down all of your concerns. If you end up with a long list, be realistic and decide which ones are the most important and tell your doctor or nurse about these right at the beginning of your visit.
- Let them know that there are other things you want to talk about and arrange when to discuss them.
- It's not unusual for us to forget what we're told, so take someone with you and ask them to write things down. This can be particularly useful if you have trouble hearing, or if you get nervous.
- If you think there's a lot to talk about, have a chat with the receptionist about booking a longer appointment.

What to do if you get chest pain

If you've not already been diagnosed with angina or coronary heart disease and you get chest pain, call 999 immediately as you could be having a heart attack.

If you already have coronary heart disease you may get chest discomfort from time to time. Sometimes this will be angina, which you'll be able to manage at home with your GTN. It could also be a symptom of a heart attack.

If you get chest pain:

1. Stop what you're doing and sit down and rest.
2. Use your GTN spray or tablets, as your doctor or nurse has told you. The pain should go away within five minutes. If it does not, take your GTN again.
3. If the pain has not gone away within five minutes of taking the second dose of GTN, call 999 immediately.
4. Chew an adult aspirin tablet (300mg) if there's one available unless you're allergic to aspirin or have been told not to take it. If you do not have an aspirin next to you or if you do not know if you're allergic to it, just stay resting until the ambulance arrives.

If you have symptoms that do not match the ones we've described but you think you're having a heart attack, call 999 immediately.

For more information

If you want more information on living with heart failure or other heart and circulatory conditions, visit the following websites:

- BHF website
  bhf.org.uk
- Heart Failure Matters
  www.heartfailurematters.org
- Pumping marvellous
  www.pumpingmarvellous.org

How to order or download our booklets
We make a number of booklets on heart and circulatory conditions, tests and treatments.
To order or download your free booklet, scan the QR code or visit bhf.org.uk/publications.

Our services

Heart Helpline
bhf.org.uk/helpline
Speak to our experienced nurses who are here to help answer your questions or concerns about heart and circulatory diseases.

Genetic information service
bhf.org.uk/GIS
For information and support on inherited heart conditions.

RevivR
bhf.org.uk/revivr
Many of us will witness a cardiac arrest in our lifetime. Be ready for that day with RevivR, our fast, free and easy-to-use online training course.

Online community
bhf.org.uk/ouronlinecommunity
Share your experiences, stories, tips and ideas with other people like you in our online community.

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@TheBHF

Facebook
Facebook.com/bhf

Instagram
@the_bhf

Notes

Notes

bhf.org.uk

British Heart Foundation

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