An everyday guide to living with heart failure
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How to use this guide

This guide is for adults of all ages who have heart failure, and for 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 is my future going to be like?

We have developed An everyday guide to living with heart failure to help you understand and manage your condition better. We want to show you how to control your symptoms well, so that you can have a good quality of life and continue to do many of the things that you enjoy.

We have based this guide on advice from people with heart failure and from medical and nursing experts on heart failure. Think of it as a source of practical help and guidance rather than something that has to be followed rigidly. Feel free to dip in and out of it in your own time – the index at the back will help you find what you need.

Your heart failure nurse may work through this guide with you, or you may use it as a personal reference guide at home. You may also want to share it with your carer or family and friends, so that they understand your condition and know how they can support you. (By ‘carer’ we mean the main person who cares for you. It could be your partner, a relative or a friend.)

In the back pocket you will find a handy pull-out Personal record. Use this to record your symptoms and other important information, and take it with you to your hospital or GP appointments.

If you still have questions after reading An everyday guide to living with heart failure:

- Talk to your heart failure specialist doctor or nurse, or to your GP, if your questions are about your particular condition. They are in the best position to advise you on your symptoms and treatment.
- Contact the useful organisations and helplines listed on pages 99-101 for information and support.
- See the booklets or DVDs listed on pages 102-103 for additional information on the things we discuss in the guide.

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

- please check with your own doctors and heart failure nurses before you do anything different from the advice they have given you
- remember that it can be dangerous to suddenly stop taking medication
- if you plan to start doing more activity or exercise than you are doing now, make sure you check this with your doctor or nurse first.
What is heart failure?

Your heart is a powerful muscle that delivers blood and oxygen around your body through a regular pumping action. ‘Heart failure’ is the term we use to describe a set of symptoms that occur when your heart fails to deliver as much blood and oxygen around your body as it should. There are many reasons why this may happen, including weakness and/or stiffness of the heart muscle, narrowed or leaking valves and abnormal heart rhythms.

The term ‘heart failure’ sounds pretty frightening, so it might be more helpful to think of it as: ‘My heart is failing to work properly and needs medication to support how it works.’

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

Your doctor can usually work out if 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 are resting or doing normal activities
- swelling of the feet, ankles or abdomen (stomach area)
- fatigue (which means being unusually tired and weak).

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

- an electrocardiogram (ECG) to assess your heart rhythm
- a BNP test – a blood test which measures the levels of certain hormones related to heart failure
- a chest x-ray, which shows a picture of your heart and lungs
- an echocardiogram, which allows doctors to see how the valves, muscle and pumping action of your heart are working
- general blood tests – to check, for example, how well your kidneys are working
- lung function tests to see how well your lungs are working.

We say more about symptoms on page 11.
Heart failure can be caused by one or more conditions. The most common causes are:

- heart attack
- high blood pressure
- cardiomyopathy (a disease of the heart muscle).

Heart failure can also be caused by:

- a viral infection affecting the heart muscle
- heart valve problems
- alcohol or recreational drugs
- an uncontrolled irregular heart rate (arrhythmia)
- some chemotherapy medication
- congenital heart problems (heart problems you are born with)
- thyroid gland disease, or
- anaemia.

Sometimes we just don’t know what the cause is. This can be hard to accept. But the important thing is to control your symptoms well. By doing so, you’ll help to prevent them from getting worse and ensure that you have the best possible quality of life.

We say more about managing your symptoms in Section 2, ‘The symptoms and how to control them’ and Section 3, ‘Reducing your risk of further problems’. We look at dealing with everyday situations in Section 4, ‘Living with heart failure’.

We discuss the causes and treatments of heart failure in more detail in our booklet Living with heart failure (see page 102 for how to order).

Can heart failure be cured?

When heart failure is caused by an underlying problem that can be treated, such as heart valve disease, uncontrolled high blood pressure or severe anaemia, there is a good chance that your heart failure symptoms will go away or be reduced, and your heart muscle could return to normal. And with the right treatment and good management of symptoms you could lead a full and active life.

However, in most cases heart failure is caused by a heart attack, and currently cannot be cured. When you have a heart attack often part of your heart muscle dies. This means that the rest of your heart has to work harder, causing the symptoms of heart failure.

Over recent decades, BHF-funded research has contributed to a substantial reduction in the number of people dying from heart attacks and strokes. And through research into the causes of heart and circulatory disease, we have become better at preventing heart attack victims from having another heart attack. But this means that more and more people are surviving to live with the often debilitating consequences of their disease, in particular heart failure.

The next big challenge is to discover how to help the heart repair itself, so that heart failure can be cured rather than treated. Our Mending Broken Hearts appeal aims to do just that. By raising money to fund research into regenerative medicine we hope that, in as little as ten years’ time, we will have treatments that will mend heart muscle that has been damaged by a heart attack. We also hope to learn how to mend blood vessels and repair heart valves, so that heart and circulatory disease will no longer be a major cause of disability in the UK.

For more information about this research visit bhf.org.uk/science

Doctors divide heart failure into four ‘classes’. These are sometimes known as the New York Heart Association (NYHA) scores. They 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 may have as much energy as you would expect. You may still need medication or other treatment to reduce the risk of your condition getting worse.

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

**Class 2 – Symptoms on moderate exertion**

You may not be able to do quite as much as you used to. You get breathless more than usual – for example, when you are gardening, shopping or doing the housework.

**Class 3 – Symptoms on mild exertion**

You are quite limited in what you can do.

**Class 4 – Symptoms at rest**

You become breathless even when you aren’t being particularly active – for example, when walking around at home or even when sitting down. You may find it difficult to look after yourself properly on your own – for example, you get too breathless when having a bath or shower.

You may need to sleep sitting up because you get out of breath or cough when you lie down.

You may find that you don’t fit exactly into one class of heart failure. Your doctor will be able to tell you more based on your examination and tests. Whichever stage your heart failure is at, your heart failure nurse and doctor will work out an appropriate ‘management plan’ for you. This will identify things that they can do and help you to do, to improve your symptoms and try to stop things getting worse.

**How bad is my heart failure? Will it get worse?**

**Can heart failure be cured?**

When heart failure is caused by an underlying problem that can be treated, such as heart valve disease, uncontrolled high blood pressure or severe anaemia, there is a good chance that your heart failure symptoms will go away or be reduced, and your heart muscle could return to normal. And with the right treatment and good management of symptoms you could lead a full and active life.

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**How bad is my heart failure? Will it get worse?**

Your condition may not necessarily get worse with time. This guide will show you how to make changes to your lifestyle that will help control your symptoms. It will also show you how you can recognise early on that something may have changed. We say more about this in ‘Self-management’ on page 18.

It’s also encouraging to remember that only a few years ago, little could be done if you had heart failure, but now there are many treatments to help you. Treatments are being continually improved and new ones are becoming available all of the time.

Please discuss any concerns about your symptoms, treatments or future with your nurse or doctor 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. (See Facing severe illness’ on page 80.)

Do bear in mind, however, that it isn’t possible for them or anyone to tell you exactly how long you will live. They can only say what is likely, or what happens to the average person. Heart failure affects people of all ages and everyone is different. Some people live for many years with heart failure.
Does having heart failure mean that my heart is dead or dying?
Heart failure means that your heart is not able to deliver as much blood and oxygen to various parts of your body as it used to. It does not mean that your heart is dead or dying but that it is not working as well as it should be. This may be because of damage to your heart muscle caused by a heart attack, because of problems with your heart valves, or for other reasons. Medication and other treatment can help to control and improve your symptoms.

What does my ejection fraction mean?
Your doctor may have told you about the ejection fraction of your left ventricle in your heart. The ejection fraction is the amount of blood that is pushed out of the left ventricle every time the heart beats. It is usually expressed as a percentage (%).

No-one has an ejection fraction of 100% as there is always some blood left in the left ventricle after each heartbeat. A normal ejection fraction is around 50-65%. An ejection fraction below 40% is abnormal but may not be associated with any symptoms to suggest heart failure. On the other hand, some people with heart failure have a normal ejection fraction. So, ejection fraction is used alongside other tests to help to diagnose heart failure.

Is having heart failure just a part of getting older?
Many people put the symptoms of heart failure down to old age and think that nothing can be done about them. It’s true that heart failure is more common in older people, because as we get older we are more likely to have one of the conditions that cause it. However, heart failure is not an inevitable part of getting older. About one in ten of us will get it, and it can happen at any age. Sometimes it happens to young adults, or to children with congenital heart disease.

No matter how old you are, it’s vital that you learn to actively manage your symptoms and do what you can to keep your condition under control.

“I felt devastated because I had given birth to my first child five weeks beforehand and I didn’t know whether I would still be alive to look after him and watch him grow up…The fact that my symptoms can improve over time was very helpful as it gave me hope and something to focus on.”
The symptoms of heart failure

What are the most common symptoms of heart failure?
The main symptoms are:
- **shortness of breath** when you are resting or being active
- **swelling** of your feet, ankles or abdomen (stomach area)
- **fatigue** (feeling unusually tired or weak).

What causes these symptoms?
The symptoms happen because your heart muscle has become stiff or weak and stretched, and these changes have affected the pressure inside the heart.

The poor pumping action of the heart can cause a build-up of blood to your lungs and other parts of your body. It’s a bit like a traffic jam. It is even called ‘congestion’. You may have heard your doctors calling it ‘congestive heart failure’.

Your blood carries oxygen, salt, water and other nutrients to all parts of your body and takes away all the waste products. When there is congestion, the blood doesn’t do this as well and some parts of your body don’t work as well as they used to. Your heart works harder to try to clear the problem, but is not able to.

This congestion can cause **swelling in your ankles, in the small of your back (oedema) or in your abdomen (ascites)**. If the congestion is in your lungs (pulmonary oedema) it can lead to severe shortness of breath. If your muscles are affected, this can cause unusual tiredness and weakness, which is called **fatigue**. Your doctor may also say that you have either **left or right heart failure**, which describes which part of your heart is most affected.

“It’s not a ‘tired’ tired where you want to go to bed and sleep, it’s a weary tired as if everything is an effort… I can’t say it’s a ‘go to sleep’ tired. I don’t really know, it’s just an ‘I must sit down’ tired, ‘I just can’t take another step’ tired.”

“I initially suffered from breathlessness, fatigue, panic attacks, waking at night feeling I couldn’t breathe etc. These have lessened now that the fluid is under control but I still get tired and there is a limit to my physical activity.”

“Initially the breathlessness was the thing that got to me most. After a long uncertain journey, life got back to a manageable course. I could not have imagined four years ago that I could breathe so well again.”
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 they know what to do if your symptoms get worse, or if you get new ones.

If you have any of these symptoms…

☐ Swelling of your feet, ankles or abdomen

Your kidneys have the job of keeping the right balance of water, salt and potassium in your body. If your heart is not pumping enough blood through them, the kidneys can’t get rid of any extra water and salt (which you usually pass in the form of 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. See pages 42-47.

☐ Sudden weight gain

If you put on weight over 2-5 days, it is probably caused by fluid congestion. An extra 2-3 pounds (1-2 kilos) can mean that your body is holding on to an extra 1 litre of fluid. However, if you put on weight over a period of several weeks, it is more likely to be caused by an increase in body mass (muscle or fat).

☐ Feeling breathless, wheezing or coughing

These problems are also caused by congestion and can happen when there is 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.

Being 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 are not sleeping properly or not getting enough exercise. Or it could be a side effect of your medication.

…your symptoms can be controlled like this

☐ Manage your medication

There are a number of medications that can reduce congestion, control your symptoms and help strengthen your heart. See pages 19-34.

☐ Live a healthy lifestyle and keep active

All the symptoms we have described could be caused by congestion, which we described on page 11. You can reduce your risk of congestion by:

- being careful how much liquid you drink, especially if you have been advised to restrict your fluids. See page 46.
- reducing the amount of salt in your diet. See page 42.
- keeping a record of your weight. See page 47.
- eating a healthy diet to control your weight. See page 38.
- including physical activity in your everyday plan. See page 50.
- stopping smoking. See page 48.

☐ Learn to deal with stress and worry

Symptoms can be made worse by worry, anxiety and stress. It may help if you learn how to do relaxation or relaxation exercises. See page 68.

Important

If any of these symptoms are new, you should call and speak to your heart failure nurse or doctor or your GP. If the symptoms are very bad and you are frightened, or if they suddenly get worse, phone 999 for an ambulance.
If you have this symptom…

A heavy pressure across your chest, or chest pain, or both

This is called **angina**. It may be caused by too little blood and oxygen getting to your heart muscle.

If this is the first time you have experienced chest pain, **call 999 immediately** as you may be having a heart attack. See page 104 for information about what to do if you think you are having a heart attack.

Or

If you know you have coronary heart disease and you have been prescribed medication such as GTN (glyceryl trinitrate), take your medication as prescribed and follow the steps on page 104.

Remember, if your chest pain does not go away after taking your GTN medication the second time, **call 999 for an ambulance** as you may be having a heart attack.

In some conditions, such as cardiomyopathy, the pain may occur for other reasons. Your doctor will have told you how to deal with these symptoms.

**Blackouts (syncope)**

**Call 999 for an ambulance.** Tell your carer, family or friends that they must call 999 immediately if you should ever have a blackout.

**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
- uncertain about the future or even how you will feel the next day.

Look at the support system that you have and see what changes you can make. For example, do you need:

- more help in the house
- help with looking after your family or children
- financial support
- to look at your commitments – be realistic about how much you can juggle
- to change the way you do something (for example, make adjustments to the type of work you do) – you don’t always have to give up your activities or work
- someone to talk to – a family member, friend or professional
- to make some changes to your lifestyle?

**Good days and bad days**

You might feel full of beans 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 exhausted yourself.

Light-headedness or dizziness

This is quite common in people with heart failure. It can be caused by not enough oxygen getting to your brain.

Other possible causes are:

- a side effect of the medication you are taking
- anxiety
- arrhythmias (abnormal heart rhythms)
- getting up too quickly
- low blood pressure
- not drinking enough fluid and becoming dehydrated.

If the light-headedness or dizziness is a new symptom, contact your nurse or doctor immediately. **This may be particularly important if you have cardiomyopathy.** (See our booklets on cardiomyopathy in our *Inherited heart conditions series*, listed on page 103.)

Ask your doctor or nurse if the light-headedness 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 are anxious. See page 68.

Your doctor can do an ECG to check your heart for an abnormal rhythm.

Take your time getting up from a chair or from your bed. Don’t get up suddenly.

Make sure that you are drinking enough. If you feel thirsty all the time, talk to your doctor about any diuretics (water tablets) you have been prescribed. Or you may need to review your fluid allowance.
If you have this symptom...  

<table>
<thead>
<tr>
<th>Memory problems or problems with concentration</th>
<th>...here’s what you should do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>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 it can be made worse by some of the medication you are taking.</td>
<td>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, doctor’s appointments and so on. Check it every morning. Ask a family member or friend to remind you about things like hospital appointments. Use a dosette box for your medication and see our tips on page 34. Many pharmacists will arrange for your medication to be supplied in dosette boxes. Most boxes now come marked with the day that you should take them. Use the medication chart in the Personal record to help you. Ask your doctor if the problem could be a side effect of any of the medication you are taking. If so, ask if there is something else you can take instead.</td>
</tr>
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<table>
<thead>
<tr>
<th>Palpitation</th>
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<tbody>
<tr>
<td>Palpitation is a word used to describe the feeling you get when you are aware of your heartbeat. The heart may be beating at a normal rate, quickly, slowly or irregularly, or it may feel as if it is missing beats. Palpitation can often be due to stress or anxiety. It may also be an arrhythmia (abnormal heart rhythm).</td>
<td>If you only get palpitations when you’re feeling anxious, try the breathing and relaxation exercises on pages 68-69. If you get palpitations even when you are not anxious, you should talk to your nurse or doctor.</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Poor sleep</th>
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</table>
| The most common reasons for poor sleep are:  
• a lack of activity during the day  
• worry, anxiety or depression. | Include a walk in the fresh air every day. Have a milky drink before bedtime. 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 pages 68-69 when you are in bed. |

You may also find it difficult to sleep well because:  
• you cough if you lie down  
• you have to go to the toilet frequently in the night. Make sure that you have enough pillows to support you in a comfortable position.  
If you suffer from a cough or going to the toilet frequently during the night, ask your doctor if your medication may be causing the problem.

Problems keeping sexually active  
Sex may be the last thing on your mind. You might not have the energy for it. Your medication may have had an effect on 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 will want what’s best for you. You can have an active sex life even if you’re not feeling ready for sexual intercourse. Your nurse or doctor will be able to discuss these issues with you and/or your partner. See ‘Sex’ on page 77.

Slow weight gain (over 3-6 months)  
Your weight may go up slowly because you are not being very physically active, but still eating the same amount of food. Being overweight can make it difficult for you to keep fit and active. It will also make your heart work harder, and can make your symptoms worse. Make sure that you are eating a healthy diet and not snacking on unhealthy food. Healthy food has calories too, so try cutting down on your portion size. 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 don’t 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 are not eating enough. Your heart condition might make it difficult for you to absorb nutrients, and that could be another reason for weight loss. Weight loss can also be a symptom of depression. Tell your doctor about any slow weight loss. He/she will refer you to a dietician who will help you to manage the problem with a high-calorie diet and food supplements. If you don’t do the cooking and shopping, take the person who does with you to see the dietician.

### Important

If any of these symptoms are new, you should call and speak to your heart failure nurse or doctor or your GP. If the symptoms are very bad and you are frightened, or if they suddenly get worse, phone 999 for an ambulance.
Self-management

Understanding your condition and being in control of your symptoms will help you to feel more in charge. This is what we mean by self-management.

Self-management involves:
- learning to recognise your symptoms
- thinking about what you normally do when you get these symptoms, knowing what works and why
- knowing when to seek help
- thinking about problems that stop you managing your symptoms – for example, lack of knowledge or physical ability
- learning to recognise any changes in your symptoms
- always talking to your doctor or nurse if you experience a symptom for the first time, or if what you are doing does not work.

Not everyone will feel overwhelmed by their diagnosis. But if you are, it may be easier to try tackling adjustments to your lifestyle one at a time. We suggest that you choose an action at a time from the list on the right and do it for one week. Start with the one you most want help with.

Managing your medication (page 19)

Reducing your risk of further problems (pages 37-51) – this includes advice on:
- Controlling your blood pressure
- Eating a healthy diet
- Managing your fluid balance
- Stopping smoking
- Limiting your alcohol
- Keeping active

Dealing with stress, worry and anxiety (page 64)

Managing the changing relationships (page 74)

Facing severe illness (page 80)

Getting help and information (pages 91-105).

Your doctor or heart failure nurse will be able to help you understand what is safe for you to do yourself, and when you should ask for help. Ask them to explain anything that you don’t understand about your condition, or see our booklet Living with heart failure for more information. Also, talk to your family and friends – they may be able to help you stay on track.

Managing your medication

In order to treat your heart failure and keep it under control, you may have to take a combination of many 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 dose of your medication or give you a different one from time to time, depending on your condition and symptoms.

Taking the right medication properly:
- will help to control the symptoms of your heart failure
- can help to treat the cause of your heart failure
- will treat other conditions you may have, such as diabetes or arthritis.

It is important that you, your doctor and nurse know all the medication you are taking – including the name, dose and frequency – and any changes to your prescription.

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

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

1 Keep track of the medications you are taking

2 Understand what your medications are for

3 Take your medications properly.

Never take medication that has been prescribed for someone else. Even if you think it is the same, the dose may be different. Remember never to run out of your medication.
1 Keep track of the medications you are taking

Here we have listed the most common types of medications that are used in treating heart failure and where you will find more information about them. You can use the Personal record at the back to note down which ones you’re taking.

You may also be prescribed medications for other conditions that you may have, that are not listed below. It is important that you record these in the Personal record too.

<table>
<thead>
<tr>
<th>I am taking:</th>
<th>This is a:</th>
<th>I need to read page:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amiloride</td>
<td>Diuretic (water pill)</td>
<td>23</td>
</tr>
<tr>
<td>Bendrofluazide (Bendroflumethiazide)</td>
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<tr>
<td>Bumetanide</td>
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<td>Chloralidone</td>
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<td>Furosemide (Frusemide)</td>
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<td>Metolazone</td>
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<td>Torasemide</td>
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<tr>
<td>Captopril</td>
<td>ACE inhibitor</td>
<td>24</td>
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<tr>
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2 Understand what your medications are for

Most types of heart failure medication will help to reduce the workload of your heart and help to control any symptoms that you may have. At the start of your treatment, your doctor may frequently make changes to your medication and doses. This can be unsettling, but it’s necessary for making sure that you’re taking the appropriate amount of each medication to control your symptoms. Here we explain what the different types of medication do, and some common side effects.

Not everyone will experience side effects and some may have very few. Some side effects are temporary and will go away after you have taken the medication for a while, and others may be because you are taking several medications together. Your doctor may be able to adjust the dosage or change to a different medication to reduce your side effects. Or he/she may decide that it’s important for you to continue taking the medication and will prescribe another one to help you to deal with the side effects.

Important

Always read the information leaflet that comes with your medication. 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 are not sure it is the right medication, check with your pharmacist.

Side effects

Tell your doctor about any side effects that you may get, especially if you notice them for the first time. Side effects may be very unpleasant, but never stop taking your medication without first consulting your doctor – doing so may make your symptoms much worse.

Alternative/complementary medicines

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

Diuretics

Amiloride, Bendrofluazide (Bendrofluamethiazide), Bumetanide, Chloralidone, Furosemide (Frusemide), Metolazone, Torasemide

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. They can:

• reduce swelling
• relieve shortness of breath
• lower blood pressure
• help ACE inhibitors and beta-blockers (two other types of drugs) to work better.

What are the main side effects?

• Going to the toilet more during the day and possibly at night
• Dizziness or light-headedness
• Gout (a condition where uric acid and salts build up in the joints, causing pain). Diuretics may cause gout or, if you already have gout, make it worse. But gout can be treated.

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

• Any difficulty passing urine
• Passing much less urine than normal
• Constipation
• Dizziness or light-headedness (if it’s a new symptom).

What checks do I need?

You should have a blood test every six months to check that your kidneys are working properly. Some people may have to have more frequent checks depending on their condition, or if their medication has changed.

What else do I need to know?

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

If you have heart failure you should already be on a low-salt diet (we say more about this on page 42). Having too much salt will counteract the effects of the diuretics. It’s also important to avoid using salt substitutes as these contain potassium which may have an effect on your blood test results.

If conditions are hot or warm, or if you experience any diarrhoea, early signs of weight loss, increased thirst, dizziness and/or increased fatigue, make sure that you are drinking enough fluid. Dehydration is common in patients taking water tablets. If your fluid intake is restricted or if you are unsure about your symptoms, speak to your doctor or nurse.
ACE inhibitors
Captopril, Cilazapril, Enalapril, Lisinopril, Perindopril, Ramipril, Trandolapril

What are they for?
ACE inhibitors lighten the workload of your heart and make it easier for your heart to pump blood around your body. They can prevent your heart failure from getting worse and can also:
- help you to live longer
- help protect you from having a heart attack by improving the blood flow to your heart muscle
- help you be more active.

What are the main side effects?
- Irritating cough
- Dizziness.

Which side effects should I tell my doctor or nurse about?
If any of these side effects becomes severe, contact your doctor or nurse immediately:
- Nausea
- Vomiting
- Skin rash
- Stomach pains
- Trouble breathing or swallowing.

Important
If you have heart failure, you should be taking ACE inhibitors – unless you can’t take them for some reason. If you can’t take ACE inhibitors, there are other medications you may be able to take instead. Discuss this with your doctor or nurse.

What checks do I need?
You should have a blood test every six months to check your kidneys are working properly and to make sure that you don’t have too much potassium in your blood.

What else do I need to know?
ACE inhibitors can lower your blood pressure dramatically, so you may be given your first dose under the supervision of your heart specialist or even in hospital. If you tend to feel dizzy when you stand up, try to avoid getting up too quickly.

Make sure you are on a low-salt diet (see page 42). Avoid taking salt substitutes (as most contain potassium), and you should not take potassium supplements.

Angiotensin-II receptor antagonists
Candesartan, Irbesartan, Losartan, Valsartan

What are they for?
These medications relax the blood vessels to allow the blood to flow easily, reducing the workload of your heart. They will reduce your blood pressure and your risk of having a heart attack.

What are the main side effects?
- Dizziness
- A decrease in blood pressure
- Diarrhoea.

Which side effects should I tell my doctor or nurse about?
If any of these side effects becomes severe, contact your doctor or nurse immediately:
- Nausea
- Vomiting
- Skin rash
- Stomach pains
- Trouble breathing or swallowing.

What checks do I need?
You should have a blood test every six months to check your kidneys are working properly and to make sure that you don’t have too much potassium in your blood.

What else do I need to know?
These medications are similar to ACE inhibitors. Your doctor may give them to you if you develop 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.
Beta-blockers

Atenolol, Bisoprolol, Carvedilol, Metoprolol, Nebivolol, Propranolol

What are they for?
Beta-blockers help to prevent the heart from beating too quickly and too forcefully. They can:
• increase the amount of blood your heart pumps out
• control heart rhythm problems
• increase your chances of living longer.

What else do I need to know?
You will 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 experience the benefits of taking beta-blockers and you may even feel that your symptoms are getting worse to begin with. But in the long term, taking beta-blockers helps to reduce the risk of your condition getting worse.

Other medication, such as diuretics, 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 frequently when you start taking beta-blockers.

If you have asthma, you may not be able to take beta-blockers, as they may make your asthma worse. Check with your doctor before taking them.

What are the main side effects?
• Tiredness, usually only for the first few days of starting this medication or increasing its dose
• Mood swings when you first start taking the beta-blockers
• Disturbed sleep
• Cold hands and feet
• Diarrhoea
• Impotence
• If you have psoriasis, beta-blockers may make this skin condition worse.

Which side effects should I tell my doctor or nurse about?
• Shortness of breath
• Extreme dizziness or fainting.

What checks do I need?
You will 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.

Aldosterone antagonists

Eplerenone, Spironolactone

What are they for?
These medications have a mild diuretic effect (which means that they help you to get rid of excess fluid by passing more urine). They help to control the potassium levels in your blood and are often prescribed along with other diuretics to help improve your symptoms.

What are the main side effects?
• Diarrhoea
• Tender and slightly enlarged breasts in men (feminisation)
• Reduced kidney function.

Which side effects should I tell my doctor or nurse about?
• Passing less water than usual
• Tender and slightly enlarged breasts in men.

If you get this side effect, report it to your doctor immediately:
• Diarrhoea.

What’s the down side?
In some people, these drugs can affect the kidney function.

Spironolactone can cause some men to develop tender and slightly enlarged breasts, testicular shrinkage and impotence. Eplerenone is free of these feminising side effects.

What checks do I need?
You will need blood tests every one to four weeks to begin with, and then once every three to six months.

Important
You should not stop taking your beta-blockers suddenly without speaking to your doctor, as it can make your condition and symptoms much worse.
Digoxin

What is it for?
Digoxin slows down and strengthens your heartbeat. It can:
• control irregular heart rhythms
• help your heart pump blood around your body more efficiently.

What are the main side effects?
• Nausea and vomiting
• Diarrhoea or constipation
• Dizziness or light-headedness
• Rash
• Confusion
• Disturbed vision
• A slower or an irregular heartbeat
• Enlarged breasts in men.

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

Which side effects should I tell my doctor or nurse about?
• Nausea
• Disturbed vision
• Poor appetite (if it’s a new symptom).

What checks do I need?
You will have a blood test to check your digoxin level at regular intervals as required to ensure your dose is effective but does not cause side effects. This test is done six hours after taking your dose.

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.

You should not take an antacid (to settle heartburn or an upset stomach) or a fibre supplement within two hours of taking your digoxin.

Antiplatelets

Aspirin, Clopidogrel

What are they for?
Antiplatelet drugs help to:
• make the blood less ‘sticky’
• reduce the risk of clots forming
• reduce the risk of having a heart attack or stroke
• reduce your symptoms.

What are the main side effects?
• Indigestion
• Nausea
• Vomiting

Aspirin may worsen heart failure symptoms – patients with severe symptoms of heart failure should discuss the need for aspirin with their doctor.

If you are prescribed aspirin, you are less likely to experience some of these side effects if you take enteric-coated aspirin (a preparation of aspirin with a special coating), or if you take antplatelets with food.

Which side effects should I tell my doctor or nurse about?
• Skin rash
• Any signs of stomach bleeding.

If you get any of the following side effects, report them immediately:
• Swelling of the face or eyelids
• Difficulty breathing
• An asthma attack.

What else do I need to know?
If you are prescribed aspirin, you will normally have to take it for the rest of your life. If your doctor prescribes both aspirin and warfarin for you, don’t take extra aspirin as a painkiller in between doses.

Anti-inflammatory medication (such as those taken for arthritis) can also reduce the effectiveness of aspirin.

Aspirin may not be suitable for you if you have asthma.

Always try and take your antiplatelet with or after food.
Statins and fibrates
(cholesterol-lowering drugs)
Statins: Atorvastatin, Fluvastatin, Pravastatin, Rosuvastatin, Simvastatin
Fibrates: Bezafibrate, Clofibrate

What are they for?
Statins and fibrates lower the level of cholesterol in your blood. They can:
• reduce your risk of a heart attack and stroke.

What are the main side effects?
• Stomach upsets
• Nausea
• Diarrhoea
• Constipation
• Muscle cramps and weakness (rare).

Which side effects should I tell my doctor or nurse about?
If you have any signs of unusual muscle pain, cramps or weakness, tell your doctor or nurse immediately.

What checks do I need?
Your doctor will do a blood test to check your cholesterol levels after three months, and then probably once a year. They will also do a blood test to check your liver function.

Anticoagulants
Warfarin

What is it for?
Warfarin prevents clots from forming in your bloodstream and reduces your risk of having a heart attack or stroke.
If you have an abnormal heart rhythm problem such as atrial fibrillation, you are likely to be prescribed warfarin. This is because atrial fibrillation increases the risk of having a stroke.

What side effects should I tell my doctor or nurse about?
If you get any of the following signs of unusual bruising or bleeding, report them immediately:
• Prolonged bleeding from cuts
• Bleeding that does not stop by itself
• Nose bleeds that last for more than a few minutes
• Bleeding gums
• Severe bruising
• Red or dark brown urine
• Red or black stools
• For women, heavier bleeding during periods, or other vaginal bleeding.

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

Important
If you notice any signs of unusual bruising or bleeding, tell your doctor or nurse immediately.
**Nitrates**

GTN spray, nitroglycerin tablets, Oral nitrates: Isosorbide mononitrate, isosorbide dinitrate

This section also contains information on a vasodilator called **hydralazine**.

**What are they used for?**

Nitrates are vasodilators (they relax the muscle in the blood vessel walls, making them widen and increasing the flow of blood). They are often prescribed for people who have angina (chest pain). They also help to reduce the workload of the heart.

**What side effects should I tell my doctor or nurse about?**

- Throbbing headache
- Flushing
- Dizziness
- Fainting
- Rapid heartbeat.

**What else should I know?**

Sometimes isosorbide dinitrate is used with another medication called hydralazine. Hydralazine is a vasodilator that lowers the blood pressure and therefore reduces the workload of the heart. If you cannot take other medication such as an ACE inhibitor, your doctor may prescribe a combination of isosorbide and hydralazine instead. When taking hydralazine, you might possibly experience side effects such as headache, rapid heartbeat, fever and blood disorders.

Tell your doctor or nurse if you have had an unusual reaction to a vasodilator in the past.

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**Potassium chloride**

Kay-Cee-L, Slow-K, Sando-K

**What is it for?**

Potassium is one of the minerals that your body needs. It is important that you have the right amount of potassium in your blood as too little or too much can lead to serious arrhythmias. When you are taking a diuretic, sometimes your body loses too much potassium. Potassium chloride helps to prevent your potassium level getting too low.

**What are the main side effects?**

- Diarrhoea
- Nausea and vomiting
- Stomach pain.

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

- Stomach pain
- Nausea
- Chest or throat pain.

**What checks do I need?**

You will need a blood test to check your levels of potassium before being prescribed these medications, especially if you are also taking a diuretic. And you will need to continue having blood tests regularly while taking these medications.

**What else do I need to know?**

Potassium is an important substance in the blood that helps your heart function. But having too much or too little potassium can be dangerous. You should not use salt substitutes as they may contain potassium and if you take them you may get more potassium than is safe for you.

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**3 Take your medications properly**

In order to keep your condition and symptoms under control, it’s important to take each medication you’ve been prescribed at the right time. However, it can be overwhelming if you’re having to take many medications at different times.

“**My drug dosage is based on three applications a day: a morning, a lunchtime and an evening dosage … I have three boxes divided into the days of the week which anybody can buy from the pharmacist and I have found them most useful because … I have a terrible memory, incredibly bad memory. So I … put all the relevant tablets into the relevant boxes.**”
Here are some tips to help you

• Record all the different medications you take, and when you take them. Use your Personal record at the back of this guide to do so.

• Don’t stop taking any medication without medical advice, even if you feel better. Stopping suddenly can be dangerous.

• Don’t run out of medication. Plan ahead and make sure you have plenty for when you go away and during holiday periods when many pharmacies are closed.

• 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 is nearly time for your next dose, skip the one you missed and take the next dose at its scheduled time. Use a dosette box available from pharmacies to help you organise your medication.

• 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.

• Always check with your pharmacist or doctor before taking any over-the-counter medication that has not been prescribed for you. Show them the list of medications that you are taking.

• Don’t give your medication to other people. They may harm them, even if the other person also has heart failure.
Controlling your blood pressure

Your heart failure may have been caused by high blood pressure. You can read about blood pressure in detail in our booklet Blood pressure (see page 102 for how to order this).

Even if you don't have high blood pressure now, or if it's well controlled with medication, there are still things you can do to keep it under control. These things include:

• eating a healthy balanced diet, including reducing or cutting out salt
• managing your fluid intake
• maintaining a healthy body weight
• keeping your alcohol intake to the recommended limits
• stopping smoking
• keeping active.

We look at each of these things in the following pages.
Eating a healthy diet

Does a healthy diet help people with heart failure?
Eating 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 generally.

To help keep your heart healthy

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

Eat at least five portions of fruit and vegetables every day
• Include a variety of fruit and vegetables of all different colours – think of 'eating a rainbow'.
• Fruit and vegetables can be fresh, frozen, dried or canned, or in the form of pure juice. If you're having canned produce, choose fruit canned in natural juice rather than syrup, and choose vegetables canned in water without added salt.

One portion equals:
• 2 tablespoons of vegetables (raw, cooked, frozen or canned)
• 1 cereal bowl of salad (eg. with tomato, cucumber and onion)
• 1 whole fruit (apple or pear)
• 2-3 whole pieces of smaller fruit (eg. 2 kiwis or 3 apricots)
• 1 slice of larger fruit (melon or pineapple)
• 1 cupful of small fruits (grapes, cherries or berries)
• 1 small glass of fruit juice (only 1 glass a day can count towards your 5 portions a day).

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 also miss out on some essential nutrients. Make sure that you eat a good mix of protein foods – include beans, peas and lentils (for example, in dhal) as they are good low-fat sources of protein and fibre. And balance your meals with a wide variety of fruit, unsalted nuts and wholegrain cereals.

If you are making curries or stews, don't add butter, ghee, palm oil or coconut, as they are high in saturated fat. Instead, use unsaturated oils such as olive, rapeseed or sunflower.

Include starchy carbohydrates at each meal
• Bread, chapatis, pasta, plantain, potatoes, pasta, rice and yam, are all examples of starchy foods that provide a slow release of energy.
• Try to eat whole grain or wholemeal versions of bread, cereals, chapatis, noodles, pasta and rice, as they contain more fibre, vitamins and minerals than the white versions.

Choose lean sources of protein
• Go for lean cuts of meat and include fish a couple of times a week. See the advice on saturated fat and fish below.
• 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 take care not to add fat during cooking.
• If you're trying to lose weight, eat nuts and seeds only occasionally, as they are high in calories. Always choose unsalted nuts.

Eat two or more portions of fish every week
• In particular, have one portion of oily fish a week, or 2-3 if you have had a heart attack. Oily fish includes mackerel, salmon, sardines, herring, trout, pilchards and fresh tuna. (Tinned tuna doesn't count as an oily fish, but it's still a good source of low-fat protein.)
• All types of fish are a good source of low-fat protein – unless you coat them in batter or fry them! Fresh or frozen fish can be steamed, grilled or baked.
• If you buy tinned fish, look for fish in tomato sauce or water rather than brine, which contains a lot of salt. If you can only find fish in brine, make sure you rinse the fish well before eating it.
Have less saturated fat and sugar
• Avoid fatty meat and meat products like sausages or meat pies. Instead, choose lean meat, poultry or fish, and remove the skin from meat and poultry.
• Many dairy products are high in saturated fat. Try to use semi-skimmed or skimmed milk instead of full-fat milk. Choose low-fat yoghurts and limit the amount of cheese you eat, or try reduced-fat versions.
• Replace fatty and sugary snacks such as cakes, biscuits and chocolate with healthier alternatives such as fruit, vegetable sticks or low-fat yoghurt.
• Swap palm oil, coconut oil, ghee, lard or butter with small amounts of monounsaturated or polyunsaturated fats such as olive oil, corn 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 salt
Salt can increase the amount of fluid that you retain in your body, leading to sudden weight gain and oedema (collection of fluid in the ankles, legs and lungs).
So it’s very important to:
• cut down on the amount of salt and salty foods you eat
• avoid adding extra salt to your food
• check food labels when shopping, to keep an eye on ‘hidden’ salt in foods.
We say more about salt on pages 42-44.

Weight and your diet
I’ve been told to lose weight.
Will eating a healthy diet help?
Maintaining a healthy weight and shape will help with your symptoms. Controlling how much you eat, as well as what you eat, will also help with your weight management. Follow the advice on pages 38-40.
However, if you need to lose weight, simply changing your diet may not be enough. Being physically active is a vital part of weight control.
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. Speak to your doctor or nurse about how you can do this.
Remember that if you are not as active as you used to be and you are still eating the same amount as before, you will still put on weight, as even healthy food has calories.
Please note: People with heart failure can often put weight on over a few days if they are retaining fluid. This is not the same as the weight gain that happens over time if you’ve been eating too much or not doing enough physical activity. It is important that you know what the reason is for your weight gain so that you can manage it properly. See pages 46-47 for more on managing your fluid intake.

I’ve lost a lot of weight and I can’t put it back on.
Being underweight can be as much of a problem as being overweight. If you think you are underweight or not able to put on weight, you need to talk to your doctor. He or she may recommend that you see a dietitian who will give you some advice on how to increase your weight safely.

Where can I find more information about healthy eating and weight loss?
You will find much more information in our booklets listed below. Because of your heart failure, you’ll have to be particularly careful about the amount of fluid and salt you have, so read pages 42-46 of this guide. However, the information in our other booklets should not conflict with the advice for heart failure, as we recommend that everyone eats a low-salt diet whether or not they have a heart condition.
• Cut down on salt
• Cut the saturated fat
• Eating well
• This label could change your life
• Facts not fads, your simple guide to weight loss
See page 102 for information on ordering our publications.
Managing your fluid balance

If you have problems with swelling, sudden weight gain and increased shortness of breath, it could be because you are retaining too much fluid.

You can usually tell if your weight gain is due to fluid if you put on 1-2 pounds in 2-3 days. If this is the case then you should tell your doctor or heart failure nurse who will be able to advise you on what steps you should take.

To help you to control your fluid intake and avoid the sudden weight gain:

- reduce the amount of salt you eat
- watch the amount of fluid you drink
- weigh yourself every day at the same time
- make sure you take your medication properly.

How much salt should I be eating?

Our bodies need some salt to stay healthy. Experts recommend that adults should eat less than 6 grams of salt a day. (This is equivalent to 2.5 grams – or 2,500 milligrams – of sodium). If you have heart failure, you should try and keep your intake even lower than this – as low as possible or at the level your doctor has recommended for you.

Most of the salt we eat isn’t what we add to food – it’s already present in foods such as bread, cereals and pre-prepared meals. Check the food labels to keep an eye on your salt intake.

But food tastes awful without salt!

Most people get used to the different taste within a month or two. Try using herbs and spices to flavour your food instead. Also, look at our tips for reducing salt on the next page.

What about salt substitutes?

Be careful with these. Some salt substitutes can be very high in potassium and are not recommended if you have heart failure. It would be better just to try and gradually get used to the different taste of your food without 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. Salt is often ‘hidden’ in these foods and it can be difficult to know exactly how much you are eating.

The easiest way to find out how much salt there is, is to check the nutrition information labels on packets and cans. Look for the salt or sodium content. This is usually shown as the amount of salt or sodium per 100 grams. As a simple guide, try to go for low-salt foods – that is, foods that contain 0.3 grams or less of salt per 100 grams. See the sample food labels on page 45.

Tips for reducing salt

- Don’t have a salt mill on the table. This alone can reduce your salt intake by up to a third.
- Use herbs and spices instead of salt to flavour your food.
- Avoid instant or flavoured snacks, including soups.
- Rinse canned foods and avoid those in brine wherever possible – choose those canned in water instead.
- Read the labels on packaged and canned foods. Wherever possible, choose foods low in salt (0.3 grams or less per 100 grams).
- If a food carries the label ‘Low salt’ it should mean that a serving of the food contains 25% less salt than standard versions of the same product. But beware that if the standard version is very high in salt, the low-salt version could still be high. A product truly low in salt should contain 0.3 grams of salt or less, per 100 grams.
Low-salt or no-salt foods

Most supermarkets have low-salt or no-salt versions of many foods. You can check the information on the products, or ask at your supermarket what’s available.

However, do be careful to check whether these products contain salt substitutes. Remember that some salt substitutes are very high in potassium and are not recommended if you have heart failure.

If you can’t find the information or can’t get to your supermarket, ask your doctor to refer you to a dietitian for information on low-salt eating.

Foods to limit or avoid

- Tinned meats such as spam, corned beef or chopped pork
- Pre-packed sliced meats such as pre-packed ham, turkey or chicken
- Tinned fish in brine (Try to buy fish canned in water, or vacuum-packed. If you can only find fish in brine, rinse the fish thoroughly)
- Bacon, kippers and smoked foods
- Crisps and salted snacks
- Cured, pickled or salted foods such as pickled onions or olives
- Salted butter and margarine
- Cheese
- Instant sauces, stock cubes or yeast extract instant drinks
- Tinned soups and dry soup mixes, instant hot noodles and instant pasta snacks
- Processed meats such as sausages, pies and burgers
- Pre-packed dinners (If you are having these, try to find ones with less than 0.3 grams of salt or 0.1 grams of sodium per 100 grams)
- Bread and rolls with salted tops
- Sauces such as soy sauce, Worcestershire sauce or relishes
- Cereals with a high sodium content (Porridge and some wholegrain cereals are better – check the food labels)
- Ready-mixed spice blends or seasonings.

Also be aware that salt can be ‘hidden’ in bread and some breakfast cereals, and in sweet foods such as cakes and biscuits.

How to find out how much sodium is in your food

Salt often appears as sodium on nutrition information labels (or food labels). On the next page there are sample labels from some everyday foods. Ideally, you should choose foods that contain less than 0.1 gram of sodium per 100 grams. So which of these foods would be OK?

Cereal

Nutrition Information

<table>
<thead>
<tr>
<th>Typical values</th>
<th>Per serving (30g)</th>
<th>Per 100g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>120kcal</td>
<td>400kcal</td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
<td>13.3g</td>
</tr>
<tr>
<td>Carbohydrate:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Of which sugars</td>
<td>12g</td>
<td>40g</td>
</tr>
<tr>
<td>Sodium</td>
<td>0.15g</td>
<td>0.5g</td>
</tr>
<tr>
<td>Fat</td>
<td>1g</td>
<td>3.3g</td>
</tr>
<tr>
<td>Of which saturates</td>
<td>0.2g</td>
<td>0.7g</td>
</tr>
<tr>
<td>Fibre</td>
<td>2g</td>
<td>6.7g</td>
</tr>
</tbody>
</table>

Chocolate digestive biscuit

Nutrition Information

<table>
<thead>
<tr>
<th>Typical values</th>
<th>Per biscuit</th>
<th>Per 100g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>700kj</td>
<td>2101kj</td>
</tr>
<tr>
<td>Energy</td>
<td>167kcal</td>
<td>502kcal</td>
</tr>
<tr>
<td>Protein</td>
<td>2.3g</td>
<td>6.9g</td>
</tr>
<tr>
<td>Carbohydrate:</td>
<td>21g</td>
<td>62.2g</td>
</tr>
<tr>
<td>Of which sugars</td>
<td>11.1g</td>
<td>33.4g</td>
</tr>
<tr>
<td>Sodium</td>
<td>0.17g</td>
<td>0.5g</td>
</tr>
<tr>
<td>Fat</td>
<td>8.3g</td>
<td>250g</td>
</tr>
<tr>
<td>Of which saturates</td>
<td>4g</td>
<td>120g</td>
</tr>
<tr>
<td>Fibre</td>
<td>0.5g</td>
<td>2.4g</td>
</tr>
</tbody>
</table>

Low-sodium chicken broth

Nutrition Information

<table>
<thead>
<tr>
<th>Typical values</th>
<th>Per portion (1 can)</th>
<th>Per 100g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>106kj</td>
<td>42.4kj</td>
</tr>
<tr>
<td>Energy (kcal)</td>
<td>29kcal</td>
<td>10kcal</td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
<td>1.6g</td>
</tr>
<tr>
<td>Carbohydrate:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Of which sugars</td>
<td>1g</td>
<td>0.4g</td>
</tr>
<tr>
<td>Sodium</td>
<td>0.14g</td>
<td>0.056g</td>
</tr>
<tr>
<td>Fat</td>
<td>0.5g</td>
<td>0.2g</td>
</tr>
<tr>
<td>Of which saturates</td>
<td>0.5g</td>
<td>0.2g</td>
</tr>
<tr>
<td>Fibre</td>
<td>0g</td>
<td>0g</td>
</tr>
</tbody>
</table>

Lentil and bacon soup

Nutrition Information

<table>
<thead>
<tr>
<th>Typical values</th>
<th>Per serving (1/2 can)</th>
<th>Per 100g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>477kj</td>
<td>230kj</td>
</tr>
<tr>
<td>Energy (kcal)</td>
<td>113kcal</td>
<td>55kcal</td>
</tr>
<tr>
<td>Protein</td>
<td>6.0g</td>
<td>2.9g</td>
</tr>
<tr>
<td>Carbohydrate:</td>
<td>16.2g</td>
<td>7.8g</td>
</tr>
<tr>
<td>Of which sugars</td>
<td>11.1g</td>
<td>33.4g</td>
</tr>
<tr>
<td>Sodium</td>
<td>0.69g</td>
<td>0.33g</td>
</tr>
<tr>
<td>Fat</td>
<td>2.7g</td>
<td>1.3g</td>
</tr>
<tr>
<td>Of which saturates</td>
<td>1.0g</td>
<td>0.5g</td>
</tr>
<tr>
<td>Fibre</td>
<td>1.7g</td>
<td>0.8g</td>
</tr>
</tbody>
</table>
Watch the amount of fluid you drink

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 your daily fluids. You can use the Personal record in the back of this guide.

• Pour an amount of water equivalent to everything you drink in a day into an empty 2-litre bottle (or two 1-litre bottles). Do this for a couple of days. You can then see just how much you are drinking.

• When recording your fluids, remember to include foods that contain a lot of water, such as soups, gravy, sauces, ice cream, jelly, canned fruit, or tinned tomatoes.

• When you get thirsty, try some of the following:
  – Chew chewing gum or have an occasional boiled sweet.
  – Have a bit of frozen fruit such as grapes, orange or lemon.
  – Rinse your mouth with water or chilled mouthwash, but don’t 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.

Please note the advice given on page 23 (Diuretics).

Weigh yourself regularly

I’ve been told to weigh myself regularly. Why is this?

Managing your fluid intake is important to control your symptoms, and weighing yourself regularly is a part of this. Weighing yourself at the same time every day will tell you if you are retaining fluid or putting on weight for the reasons we discussed on page 41. Weight gain due to fluid retention will usually happen over a couple of days rather than weeks.

You might notice that your weight has gone up by 2-3 pounds (about 1 kilo) in a day. If this gain continues for a few days, it is probably because your body is holding on to too much water. You may also notice more swelling in your ankles, feet or abdomen, and your clothes or shoes might feel tighter.

What should I do if my weight goes up suddenly?

Your doctor or nurse should have told you about things that you can do to manage any small weight gain because of fluid retention. They may suggest restricting your fluids and adjusting your dose of water tablets (diuretics). If you notice a gain of more than 6 pounds (about 2.5 kilos) over three days, you should tell your doctor or nurse.

Also, if you notice a persistent cough or increased shortness of breath, these may be signs that fluid is building up in your lungs – so you should phone 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.

How often should I weigh myself?

It’s best to weigh yourself every day. Some people with heart failure find that their weight can go up quite suddenly. It is important to know exactly how much it has gone up by. Weighing yourself every day is the best and most accurate way to judge this.

I find it difficult to weigh myself.

If you have difficulty with balancing on the scales or reading the dial, ask a family member, friend or district nurse to help you whenever they visit.

Tips on weighing yourself

• The best time to weigh yourself 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. Use the one in your Personal record at the back of this guide.

• Choose to weigh yourself either in stones and pounds or in kilos and stick to that.

• If you are going to see your doctor, take your weight chart with you.
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.

I’ve smoked for years and I really enjoy it!

Smoking is a strong habit. Nicotine acts like a drug and it’s addictive. It can:
- make you feel alert
- cheer you up
- stop you feeling hungry
- make you feel at ease and sociable
- be one of the few things you enjoy at the moment.

But surely the odd cigarette won’t make any difference to me now?

Yes it will. Stopping smoking can:
- prevent further damage to your lungs
- reduce your risk of having a heart attack or stroke
- reduce your risk of lung diseases like cancer
- increase your energy levels
- help you to sleep better
- improve your circulation and the oxygen levels in your blood
- 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.
- Our booklet Stop smoking offers more information – see page 102 for how to order this.
- Nicotine replacement therapy – in the form of patches, gum, lozenges or inhalers – is available and has been found to almost double your chances of success.
- If you have access to the internet, have a look at www.smokefree.nhs.uk
- Helplines such as the Smokefree National Helpline on 0300 123 1044 can provide advice and encouragement.

Can 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.
- Our booklet Stop smoking offers more information – see page 102 for how to order this.
- Nicotine replacement therapy – in the form of patches, gum, lozenges or inhalers – is available and has been found to almost double your chances of success.
- If you have access to the internet, have a look at www.smokefree.nhs.uk
- Helplines such as the Smokefree National Helpline on 0300 123 1044 can provide advice and encouragement.

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 (as it is high in calories).

Alcohol may make some symptoms of heart failure worse – for example dizziness, tiredness or fatigue. If you are 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, you can enjoy having a drink so long as you drink sensibly. That means a modest amount – avoid binge-drinking.

Men and women should not drink more than 14 units of alcohol a week, and you should have several alcohol-free days each week. These guidelines apply whether you drink regularly or only occasionally. Talk to your doctor or nurse about what’s a safe amount for you to drink.

1 unit of alcohol =

- a small glass (100ml) of wine (10% ABV [alcohol by volume])
- half a pint (about 300ml) of normal-strength lager, cider or beer (for example, 3.5% ABV)
- a pub measure (25ml) of spirits.
Keeping active

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

Being active can:
• help reduce some of your symptoms such as shortness of breath and fatigue
• improve the flow of oxygen around your body
• raise your energy levels and reduce stress levels and fatigue
• maintain and improve your fitness and stamina
• reduce your blood pressure
• help to increase the protective type of cholesterol in your blood
• help to control your weight
• help you sleep
• keep your joints flexible
• improve your general wellbeing.

But is it safe?

Unless you have 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.

What type of activity is best?

If you are already quite fit, brisk walking, swimming or dancing is good. For some people it might be a more modest activity such as a gentle walk or a 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.

And physical activity isn't 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. What is important is that:
• the activity is regular
• it suits your level of heart failure
• you do some every day.

Is there anything I shouldn’t do?

You may be advised to avoid hard physical sports such as squash or weightlifting. Vigorous activity may not be good for you. This is because when you make a sudden, hard physical effort, your blood pressure goes up. You also need to take care not to be competitive (either with others or with yourself) as you might get carried away and end up doing more than is safe. You may become stiff and sore and will be getting into the overactivity-rest cycle (see page 52).

I don’t feel I can do very much at all.

Think about what you already do every day. This includes everyday 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 just walking around at home – is good for you as long as you do it regularly and every day.

What about when there is bad weather like snow, or when it is windy?

You could work out a walk inside your home that is the same distance as you usually walk outside, and do it at home instead.

I’m not very good at sticking to things.

You might want to join a class to help keep you motivated. Ask your doctor or nurse about exercise on prescription. Or they may know of cardiac rehabilitation classes in your area. (This is a class for people with lots of different types of heart problems. It includes specially tailored exercise sessions as well as information sessions on topics such as healthy eating and managing your medication.)

But I’ve been told to rest.

It’s important to make sure you have regular rest periods, 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 is much easier to get into the habit of doing something on a daily basis. Making activity part of your daily routine also means you are 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 have to build up to your previous level of fitness again. Make sure you start at a level that you are comfortable with – this may mean going back a step or two.

I have young children and I get exhausted trying to keep up with them – let alone with my friends.

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

Don’t 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 are feeling well, but in the long run it will mean that you are able to keep your condition and symptoms under control.

Don’t be afraid to ask for help with looking after your family, and certainly accept offers of help so that you are not too tired to enjoy being with the children and doing things they enjoy too. You may also be entitled to help and benefits that will enable you to look after your children. See page 79 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 effectively. 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 the gardening, or do all the housework that’s been piling up
• walk that bit further than you would do normally.

You may find that you then end up with bad days where you don’t want to get out of bed and you feel tired and ill all day. You may be so tired you can’t 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 really hard on one day to get fitter, the fact that you have to rest for a couple of days afterwards means that you don’t stay fit, and may even make yourself feel worse. It’s also easier to become unfit than it is to be 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 have to do it in a planned way and find a balance between doing too much and too little.

Your plan will vary according to your commitments and how well you are. Plan to do what you know you can achieve, rather than continuing because you feel you can. Learn to stick to your plan and stop when you have done what you planned.

1 Make a list of weekly activities

Jot down all the activities that you have to do in a week, and how many times you have to do them. These could include:

• how often you have to do the shopping or gardening
• how often you have to look after your children or grandchildren
• the days when you have a heavy workload, whether that’s housework or a manual job
• the hours you spend at work.

List of weekly activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>How many times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily walk</td>
<td>7</td>
</tr>
<tr>
<td>Shopping</td>
<td>3</td>
</tr>
<tr>
<td>Gardening</td>
<td>2</td>
</tr>
<tr>
<td>Collecting children or grandchildren</td>
<td>1</td>
</tr>
<tr>
<td>Going out with friends</td>
<td>1</td>
</tr>
<tr>
<td>Yoga</td>
<td>1</td>
</tr>
<tr>
<td>Walk to work, bus or train station</td>
<td>5</td>
</tr>
</tbody>
</table>

The dotted line shows how fitness decreases over time
2 Write down when you need to do your activities

Use a weekly activity plan like the one below. Then plan all the other things you need or want to do in the week, and write them in.

- Set yourself realistic goals so that you don’t over-exert yourself. See ‘Setting realistic goals’ on page 56.
- Work out how much of each activity you can do fairly easily on each day, and only do that amount in one go.
- Mix activities together so that you don’t have too many heavy ones on the same day, and mix ones you enjoy with those that are more tedious.

3 Stick to your plan

Unless you are feeling ill, do what you planned to do that day, even if you don’t feel like it. If you have planned to do the shopping on one day and look after the grandchildren the next, stick to that plan. If you don’t, 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 will 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 strenuous activity, and reflect on how much you are achieving.

Activity plan

<table>
<thead>
<tr>
<th>Activity</th>
<th>M</th>
<th>T</th>
<th>W</th>
<th>T</th>
<th>F</th>
<th>S</th>
<th>S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily walk</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Shopping</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Work</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going out with friends</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yoga</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

There are some days when you will do more than you usually do – for example, going to or organising a birthday celebration or wedding, or on a trip. Special events which can be tiring will not affect some people but for others it may require planning ahead.

If you think such events may affect you, try to reduce the amount of activity you do the day before and the day after, and try to build rest periods into the day. If you are organising a party or celebration, make sure you have enough help before, during and after the event, and that your planning starts early so that you are not doing everything at the last minute. The most important thing is to enjoy such occasions.

What would you like to do more of?

Write a list of the things you would 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:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Goal 1</th>
<th>Goal 2</th>
<th>Goal 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
Setting realistic goals

You might have given up doing certain things because you haven’t 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 have written in the ‘Things I would like to do more of’ list on page 55. 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 fairly 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

Practise at your baseline. If possible do it every day for a week. If working at this level makes you so tired that you have to rest the next day, your baseline is too high. Try walking every other day instead. Once you have found your baseline and you have managed it for a fixed time, you will 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 don’t put yourself under undue pressure to do too many things at once. The diagram below shows you how you will be able to do more as your fitness increases.

Number of minutes of activity per day

<table>
<thead>
<tr>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 minutes’ activity a day</td>
<td>20 minutes’ activity a day</td>
<td>25 minutes’ activity a day</td>
<td>30 minutes’ activity a day</td>
</tr>
</tbody>
</table>

The dotted line shows how fitness improves

How long will it take me to get fit?

Levels of fitness vary between different people and are dependent on how well you are generally. 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 begin to 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 too breathless.

Why not make a note of your progress? Perhaps you could keep a diary and show it to your doctor or nurse. Or make a chart and pin it on your kitchen wall to remind yourself just how well you are doing!

What are the challenges?

You may find that you are getting caught up in the overactivity-rest cycle (see page 52) or that you are unable to meet the goals that you have set yourself. If any of this happens, don’t give up. Reduce your baseline so that it’s just realistic and don’t put yourself under undue pressure to do too many things at once. The diagram below shows how you will be able to do more as your fitness increases.

Remember the golden rules:

- Increase your activity gradually.
- Do what you planned, and not what you feel like.
- Start each activity at a level that’s just right for you.
- Go slowly and build up gently.

Your heart failure nurse or cardiac rehabilitation nurse 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, for example with a cold or flu, you may have to take it easy for a few days. Don’t worry if you aren’t able to meet your baseline – follow your doctor’s or nurse’s advice 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 is still possible, and advisable, to fit some activity into each day. For instance, you could go on a walk or do chair-based exercise.

Any other problems?

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

If your doctor or nurse has told you not to do certain things, you must do as they say. If you are going to change what you are doing, check with your doctor or nurse first. Take this Everyday guide with you and show them how you plan to get back to being more active.

“I used to do so much and had so many life plans. Energy pockets are so slim [now] and I have learned to use pacing as much as possible.”

I use d to do so much and had so many life plans. Energy pockets are so slim [now] and I have learned to use pacing as much as possible.
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’?”

Step 1 Choose a goal.
Let’s say you think that walking for ten minutes – say down to the newsagent’s or the school gates and back – would be just right. (Don’t forget that you’ve got to come back!) That’s your goal.

Step 2 Reach the goal.
On day 1, do the walk. Don’t 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 have chosen a walk that was too far, stop and go back.

Check if it was ‘just right’.
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 in the appropriate 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 – muscle soreness, stiffness and so on – which may only begin after a few days. (You don’t want to make yourself so stiff and sore that you have to stop your activity altogether.)

Step 3 Choose a new goal.
After a week, ask yourself again, “Is this still ‘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.
• Do your activities at the same time every day.
• 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 is also 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 are (or have been) unwell, go back to a lower level of activity until you feel better.
• Build up slowly and gently so it doesn’t hurt. If activities hurt, you’re not likely to keep them up. A gradual increase works better.
• If you feel any pain or get exhausted, stop.
• Be careful if you are doing activities with other people, as they may go too fast for you.
• Think of different activities, and vary them to keep yourself interested.
Looking after yourself at home and at work

Is it all right to keep working?
Most people with heart failure can continue to work as long as they feel well enough. However, you might need to make some adjustments because of the degree of your heart failure or your symptoms. 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.

In some employments such as the armed forces, airline pilots and HGV drivers there may be restrictions with regard to long-term illnesses. You may decide that continuing to work is not the best option for you. If you are not sure about what you can do at work or feel unable to continue with your present job, ask your doctor, GP or nurse for advice.

Should I have flu and pneumonia jabs?
It is very important to protect yourself against colds, flu and lung infections because you may be at risk of developing complications related to your heart failure. Protecting yourself includes making sure that any visitors know not to visit you if they are unwell.

Everyone who has heart failure should be immunised against pneumonia and flu.

You only need one vaccine for pneumonia in your lifetime, but the flu vaccine is different every year so you need to have it annually. This will reduce your risk of getting flu and will also reduce the intensity of the infection.

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

I have diabetes. Is there anything I need to do?
Having diabetes increases your risk of getting coronary heart disease. Uncontrolled blood sugar levels can also make you feel tired and generally unwell. Talk to your heart failure doctor, GP or diabetic nurse about what you can do to make sure your diabetes is controlled.
What about pregnancy and contraception?

Being pregnant puts extra strain on the heart and could make your condition worse. If you are a woman of childbearing age and have heart failure, you may be advised against becoming pregnant. Talk to your doctor about what is best for you and about methods of contraception.

If you have cardiomyopathy, especially if it was caused by your pregnancy (post-partum dilated cardiomyopathy), your doctor may advise that you do not become pregnant again. You may also be concerned about passing on your condition to your children. For more information see our booklet Inherited heart conditions: Dilated cardiomyopathy (see page 103 for how to order this).

Can I carry children or heavy items?

If you have small children or care for them regularly, physical contact is important and it would be unrealistic to exclude carrying them. However, carrying children or other heavy items will increase the workload of your heart and can make you feel breathless. 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 them to climb onto your lap rather than lifting them up. Or 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 a trolley to move heavy things. Take someone with you to help transfer the shopping from the trolley to the car. Pushing or pulling heavy items will also 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 are doing and avoid getting into the overactivity-rest cycle (described on page 52).

What about HRT?

Hormone replacement therapy (HRT) may increase the risk of deep vein thrombosis (DVT) in people with heart failure. (A DVT is when a clot forms in one of the large veins in your body, usually the leg). You should speak to your doctor about the risk to you.

Can I drive?

The Driver and Vehicle Licensing Agency (DVLA) has laid down regulations about when you have to declare your condition to them. Not everyone with heart failure will be affected by the regulations. You can find out about whether you can continue to drive or not from their website www.dft.gov.uk/dvla

While the DVLA may not always require you to declare your condition to them, you should tell your insurance company separately. Failing to tell them about your condition may affect any claims you may make in the future.

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 are 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 or hour-and-a-half, for at least five or ten minutes. You can also do ankle and foot exercises while you are sitting to keep the blood flowing around your legs and reduce the risk of a DVT.

If you want to travel for longer, or by air, it’s sensible to 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.

A flight may also make you breathless and increase the risk of swelling in your ankles. This is because there is less oxygen on board the aircraft and the cabin pressure is different to the air pressure on land. If your symptoms are severe, your doctor may advise that you have oxygen available while you are on a flight.

Leave plenty of time to organise your travel plans so that everything is ready for your journey and you don’t have to rush. Make sure there is someone to help you to lift any heavy luggage at the check-in. Remember that departure gates at airports can be a 20-minute walk from the security gate. It may be better to organise for transport to your departure gate or ask to use a wheelchair so that you are not rushing to get to the aeroplane.

What about travel insurance?

For more tips and information on travel, including insurance, please see our website bhf.org.uk/travel or call our Heart Helpline on 0300 330 3311 (similar cost to 01 or 02 numbers).
Dealing with stress, worry and anxiety

What are stress and anxiety?
We all experience stress and anxiety from time to time and what is 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 something done on time, or worrying about money or your children.

Stress is the opposite of relaxation and it is a natural part of life. We need both in order to live a full and active life. Without some stress you would lose energy and feel demotivated. It is 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 is normal for people with long-term illness to be worried about their condition. The term heart failure sounds frightening, and some of the symptoms feel frightening. When you are worried, your heart rate increases and you become short of breath, which in turn can increase your level of 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. Then you can start to relax.

What are the symptoms of stress and anxiety?
When you are under stress or are anxious, the hormone adrenaline is released into the blood. Adrenaline helps to prepare our bodies for the fight or flight response when we are challenged or in a position of danger. You will feel your heart rate increase and may find that you are breathing more heavily. You may also experience other physical and emotional symptoms such as:

- headaches
- tense shoulders and jaw
- indigestion
- butterflies in the stomach
- difficulty concentrating
- dry mouth
- difficulty thinking clearly
- trouble sleeping
- restlessness
- low spirits
- feeling tired
- eating more unhealthy foods or eating very little
- becoming physically inactive.

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

- smoking more
- drinking more alcohol
- being less active.

It is important to understand how you cope with feelings of stress and anxiety so that you can make positive changes to any poor lifestyle choices and prevent your symptoms getting worse as a result. Poor lifestyle choices can also increase your risk of developing coronary heart disease. If you already have coronary heart disease, they can increase your risk of having a heart attack.

Stress and heart failure

Being told I have heart failure was a terrible shock!
Many people with heart failure 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 dramatically.

You will have lots of questions about how you will cope, both mentally and financially. Will you be able to work? What about your family or children? Who will look after you? You may feel that your whole world has turned upside down.

These are all common feelings and fears. But 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 more severe symptoms and need to adjust more.

I’m afraid of doing anything in case I get worse.
Some people are scared of dying and do as little as possible in case it makes their symptoms worse and leads to dying early. 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 ‘Making an activity plan’ on page 53.) This will help your heart to remain in the best condition possible.

Being afraid to do anything for fear of making your symptoms worse can make you feel isolated, stressed or depressed. Talk to your heart failure nurse or doctor or to your GP about what you should be doing to keep your heart as fit as possible.

I can’t 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. But by learning to recognise the onset 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.

Being out of breath isn’t always a sign that something is wrong. You may find that you breathe more quickly when you are worried or frightened. Try the relaxation techniques on pages 68-69 if you feel a sense of panic or fear. Relaxing will help to regulate the flow of blood to your heart and lungs and reduce the workload of your heart.

I can’t enjoy things any more. Even watching TV seems pointless.
We all have times when we feel worried and down. When this happens, it may help to accept that this is a day when you need to rest more. 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 have done and what you will try the next day, but don’t be too ambitious.

However, if you feel like this all the time, you may be depressed and need to speak to your GP. Your medication may be the reason you are feeling this way. Your GP may be able to change your medication or arrange for you to see a counsellor. We say more about depression on page 72.
I’ve had to stop work and I feel that my life is over.

If you have had to stop work on your doctor’s advice, 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 to cope (see page 79). Or try finding a new purpose or hobby, or join a group – this may bring back a sense of fulfilment and enjoyment.

People are driving me mad. They won’t let me do anything.

People who love you may be as upset and confused by your diagnosis as you are. They will want to protect you and in some cases it can feel that you are being smothered or wrapped in cotton wool. They are 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 the limits of what you find comfortable – will help you to keep stress and depression at bay. It will help to share this Everyday guide with them so that they understand your condition better.

It may also help them to read our booklet Living with heart failure. Talk to them honestly about how you feel and what you are doing to manage your symptoms. Allowing them to do things for you may also help them cope with their own anxiety.

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 – but you may not want to ask your carer for help with these things. The best way to cope with this is to ask your carer how he or she feels about it and tell them how you feel. Speak to your GP or nurse who may be able to suggest how you can get someone else’s help without upsetting your carer.

However your symptoms affect your life, you may feel that your condition has made you a burden on your family and friends or a nuisance.

Your role in the household may have changed. For instance, you may not be able to do the same job, or the same number of hours, as before, and this may affect you financially. If you’ve always been the one who takes care of things, handing some or all of this over to someone else can be very hard to accept. You may even feel that you are of little use to anyone.

But remember that balancing what you can do while accepting help from friends and family will allow you to conserve energy, remain in control and reduce your level of anxiety.

Even if you are really limited in what you can do, just being with others may be enough to make them – and you – happy.

Fighting back against stress, worry and anxiety

Your adrenaline level changes with your level of stress, worry or anxiety and will affect how you feel and behave.

There may be some everyday tasks that you find difficult – such as bathing and getting to and from the toilet – but you may not want to ask your carer for help with these things. The best way to cope with this is to ask your carer how he or she feels about it and tell them how you feel. Speak to your GP or nurse who may be able to suggest how you can get someone else’s help without upsetting your carer.

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“ITalk to the people who are close to me. I write a journal which helps to focus my feelings…”

Have a look at the emotions above. 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? What about:

- listening to some favourite music
- reading
- sharing a quiet time with children or grandchildren
- having a warm bath and daydreaming
- sitting in your garden
- stroking your cat or dog?
How can I reduce my levels of stress and anxiety?

You won’t always be able to avoid feeling stressed and anxious, but by knowing what triggers these feelings and what to do about them, you can control how they affect you.

The following things should help you:

• Being organised and prepared for events such as weddings and celebrations.
• Knowing what makes your symptoms worse, and how to control them.
• Talking to someone. Trying to cope on your own can make matters worse, but another person can help you put your concerns and worries into perspective or help you to deal with them.

If you do feel overwhelmed, try one of the three relaxation techniques below.

The ‘Relaaax’ technique
You can use the ‘Relaaax’ technique whenever you need to get some peace and relief. After a while, just saying ‘Relaaax’ will make you feel calm.

A couple of hours after a meal, lie down somewhere quiet and warm. Prop yourself up on pillows, or sit in a chair if it helps with your breathing. Don’t cross your legs. Let your arms rest beside you.
1. Let all of the tension drain out of your body.
2. Notice how your body relaxes slightly every time you breathe out. Concentrate on your breathing.
3. Each time you breathe out, say the word ‘Relaaax’ silently to yourself as the air goes out. Don’t force the air out. Let it go by itself.
4. When thoughts distract you, just bring your mind back to your breathing, saying the word ‘Relaaax’ silently to yourself each time you breathe out.

Keep doing this for ten minutes. That’s it!

For this technique to work, practise it for ten minutes once or twice every day and follow these rules:
• Don’t worry about whether you are succeeding.
• Don’t hold your breath.
• Don’t get angry when your mind wanders – which it will do very quickly. It doesn’t matter at all. If you get angry, it won’t work.
• Don’t worry if nothing seems to be happening right away. That’s normal. If you worry about this, it won’t work.
• Don’t worry about how often you get distracted – everyone does. It takes weeks of practice to get good at this.

In time you will notice that you are becoming more relaxed and the symptoms of stress trouble you less and less. When you get good at this technique, you can use it whenever you need to.

The ‘Deep relaxation’ technique
You can buy relaxation tapes in most good book shops. They can help get your adrenaline level right down – in some cases lower than it is when you sleep. They may also help with shortness of breath and fatigue. It usually takes six weeks’ practice or more before deep relaxation starts working.

Attending classes in relaxation, meditation or yoga can also get your adrenaline levels right down. Find out if there are any in your area.

Once you find something that works for you, practise it for 20 minutes every day.

The ‘Worry list’ method
One of the effects of worry is feeling constantly anxious. Some people have found that the ‘Worry list’ method helps. Make a list on a piece of paper of every possible thing you feel worried about.
Just write a word or two to remind you what you mean. Fill as many bits of paper as you need to, until you have written down everything you are worrying about.

Next, go through the list, crossing out all the things you can’t do anything about. Tell yourself, “There’s no point in worrying about something I can’t do anything about.” If ever that thing comes into your mind, say in your head, “Stop. I will not worry pointless.” Each time you say “Stop” to one of these thoughts it will get easier and the thought will come back less often.

Go through the list again, this time crossing out all the things you can’t do anything about today. Tell yourself, “I promise I will start worrying about them again tomorrow morning at 9 o’clock. It is quite safe to leave all these things until tomorrow.” If they come back into your mind, tell them to “Stop until tomorrow”.

Then look at what is left on your list. This should only be things you can do something about today. Count them and then give them all a number, starting with 1 for the most important. Now you have a plan. You know what you have to do and the order in which you have to do them. Work through the items on your list in a calm and controlled way. When you feel tired, stop.

For the ‘Worry list’ method to work, you need to write the things down. Do this each day and you will soon start to gain control and become good at stopping worries in their tracks.

How stress, worry and anxiety can take over your life
If you don’t fight back against stress, worry and anxiety, they can begin to take over your life.

Are you experiencing any of the following?

General anxiety
This is where you have the symptoms of anxiety most of the time. They can make life wretched. It becomes even worse if you start to worry about the symptoms of anxiety as well.

Avoiding things
Part of the job of adrenaline is to make you avoid anything you feel may be dangerous or embarrassing. For example, you may avoid visiting your grandchildren in case they get too noisy or going out with friends in case you can’t keep up. You might even put off doing things you enjoy, like going out, going for a drive in the country or even going on holiday.

As long as you’re sure that it’s safe for you to do the things you’d like to do, it is better to make yourself do them, even if you dread them. Doing the things you like and enjoy, can help you to fight stress. It’s just the adrenaline that makes you feel like putting them off. The more you avoid doing things, the more adrenaline your body will produce at the thought of doing them. If you put them off, you may feel relieved – but it then becomes even harder to do them the next time.

You have less fun and slowly lose control over your life.
Panic attacks
When your adrenaline level hits the top you experience panic. (See page 67.) All of the symptoms of stress are at their maximum. Some people feel like they’re going to collapse. Although panic attacks can be very frightening at the time, they are not harmful to the heart and don’t last long. But if you’re concerned about them, talk to your GP. He or she may be able to refer you to someone who can help.

Are you feeling really down?
Very few people are left unmoved by serious illness. It is natural to feel sad, angry, sorry for yourself and lonely at times. If you are feeling really down, read the next few pages.

I’ve always enjoyed company but now I can’t be bothered. I just want people to leave me alone.
It is a natural part of being ill to withdraw from others. When you are 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 longer run, being alone and giving up company can leave you feeling isolated and deprived of moral support.

What can help?

Dealing with negative thoughts
When you are feeling low, your thoughts can become negative and distorted. You may find yourself jumping to conclusions, overgeneralising or exaggerating the negative. Without realising it, you can get caught up in a cycle of constant pessimism.

What can help?
Each time you have a negative thought, give yourself a ‘reality check’ by asking yourself:

Is there any evidence for that gloomy thought?

For instance, if you find yourself...

Jumping to conclusions
Something happens.
You make a negative interpretation.
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 can’t be bothered with me now. I’m ill. He doesn’t love me any more.”

Ask yourself:
Is my carer busy? Yes. Does he usually say “Later” and then help me in his own time? Yes. So nothing new there then. I’ll ask him how he feels and if he’s sick of me.

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 “He doesn’t want to speak to me anymore. He’s avoiding me. I’ve really upset him. He doesn’t like me. No-one likes me.”

Did that person just not see me when we passed in the street? Yes. So is it true that he is avoiding me? No. Have I upset him? No. Is it true he doesn’t like me? No. Does everyone ignore me? No. There you go then!

Exaggerating the negative
A setback happens. You imagine a disaster.
Example:
You see the nurse and she says, “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 won’t survive that.”

Has my blood pressure been up before? Yes. Did it go back down again? Yes. Well then, maybe it will this time.

Checking out the evidence will help you to separate the fears from the facts. It will help to put your negative thoughts into proper perspective. You might even find that things are better or more manageable than you thought.
Depression

If you have constant negative thoughts, your mood never rises or you are tearful a lot of the time, you may be depressed.

What is depression?

Depression is not just feeling sad or feeling low. It is an illness, caused by an imbalance of chemicals in the brain. It is not a sign of weakness any more than catching a cold is.

Depression can affect anyone. One in six of us will experience depression at some time in our lives. It can happen as a result of serious illness or life stresses such as a bereavement, job loss or family crisis. Or it can happen unexpectedly for no apparent reason.

But depression can be successfully treated and the majority of people with depression will make a full recovery.

I just keep thinking there’s no point.

It can be difficult to recognise if you are depressed. It is often a slow process that affects the way you see your life and everything around you. You might feel worthless and believe that you don’t 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 not something you have brought on yourself and you are not to blame.

What can help?

Depression is a common, treatable illness. If you think that you might be depressed or if someone suggests that you might benefit from getting help, speak to your GP or nurse who will know the best way to help you.

How can you tell if you’re depressed?

If you answered ‘Yes’ to most of these questions, you may be suffering from depression. (However, remember that your heart failure or another illness might cause some of these symptoms. Some can even be a side effect of your medication.)

If you answered ‘Yes’ to most of these questions, and you also notice the following, then you may be in a major depression:

☐ Your thoughts, speech and actions have all become very slowed down.
☐ Almost all of your life seems unbearable.
☐ You have a strong temptation to commit suicide.
☐ You have been making plans to commit suicide.

If you ticked either of these last two symptoms you must speak to your GP.

If you feel you can’t, please phone the Samaritans on 116 123 (FREE from any phone).

You may not believe it now, but if you talk to someone it can make you feel much better.
Managing the 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 this can be frustrating. To manage the changing relationships, it helps to be honest and realistic in your expectations – both of others, and yourself.

First understand any limitations or changes you are experiencing due to your condition. This will help you to look realistically 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 (pages 53-56) 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 can’t do as much as you used to, or because you have to rely on others to do things for you. It is perfectly normal to feel this way, but it is important to accept the physical limitations of your condition. As we have said on page 52, 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.

Living with a long-term condition requires even stronger communication skills. You need to know what your partner, carer and family are feeling and they need to know what you are feeling. Keep the lines of communication open and honest.

“Some family members keep mentioning my limits and needs when even I have forgotten I have a heart condition! I know they care but sometimes I don’t want to be labelled the ill person. On the opposite side of the spectrum, work colleagues and friends judge me on how well I look and occasionally expect too much!”

“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 if you 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 are doing something helpful. Confusion and frustration often arise 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. Either ask your GP to refer you for some counselling, or phone the organisation Relate (see page 99 for their contact details).

“I feel frustrated that I can’t 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 don’t 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. Older children may enjoy watching a DVD or video 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 will 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 reassure them that they are still very much involved in your life and that their support makes a difference.

“I feel angry and frustrated that I am no longer the breadwinner in the family. If you are no longer able to work, you may feel that you have lost your role as breadwinner in the family. Feeling that you have burdened your partner with earning the money as well as looking after you and the home can lead to feelings of depression and lack of self-worth. Talk to your partner about how you can take on a different role or responsibility. This will ensure that you are still ‘pulling your weight’ and will help your self-esteem.

See if you can manage reduced hours at work, or if there is another type of employment that you can do. If you would like advice on finance, including advice on benefits and allowances, contact your local Citizens Advice Bureau. See also ‘Financial worries’ on page 79.

“Oh yes, you do rely on your wife a lot, yes. I do now. I’ve never been one to rely on anybody as such but you do rely on your wife a lot now.”

See also page 52 for advice on how to manage your responsibilities and activities.
Focus on the positive

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

• If you are 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.

Although you may be frustrated about the changes caused by your symptoms at first, once you have identified a routine for your treatment and everyday life, you will be able to enjoy the time that you spend with your partner, family and friends. You might find that your different relationships are strengthened and that you have a different perspective on life.

“I value the people in my life even more than I used to.”

Tips to help you cope with the 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 can’t.
• Learn to adapt and modify 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.
• Include your carer as much as possible so that he or she knows what your needs are and is able to 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 101.

My partner and I never seem to get round to making love any more.

You or your partner may be frightened that an active sexual life may be harmful. This is common in couples where one partner has a heart problem. But there is no reason why you should not have a normal sexual relationship if you manage your symptoms well.

Making love makes you feel good and brings you closer physically and emotionally to your partner. There are many ways that you can be intimate without physical exertion if you don’t actually want to have sexual intercourse. Talk to your partner about what you feel is most comfortable for you.

If you have an ICD (implantable cardioverter defibrillator) you may be worried that sexual activity will initiate a shock. It is perfectly safe to have sex if you have an ICD. For further information see our booklet ICDs (implantable cardioverter defibrillators) and our booklets on cardiomyopathies from the Inherited heart conditions series (see pages 102-103).

I just don’t have any desire for it any more.

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

• side effects caused by your medicines – in particular, beta-blockers may cause impotence
• tiredness or fear of overexerting yourself
• a change in the way you express your feelings as you get older – there may be less of a focus on sexual intercourse
• mood swings or depression
• resentment or anger towards 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 sharing intimacy that don’t necessarily involve sexual intercourse. See our tips on ‘Sex and heart disease’ on our website bhf.org.uk.
I’m having problems with my erection.

There can be many reasons for this. We’ve already mentioned anxiety about your heart, but the cause of the problem could also be worrying about the erection and your performance.

Another problem is a poor blood supply. Your erection is caused by large blood vessels in the penis filling with blood. This is what makes the penis hard. As you know, in 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. Diuretics, beta-blockers and anti-arrhythmic drugs can all have this effect. Your doctor or GP may be able to change these to help.

Can I use Viagra?

Be sure to ask your doctor or GP first before you take Viagra as it may not be safe for you to take it with your other medication.

One clue that can help you decide whether the problem is caused by the medication or a diminished 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 is probably 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.

I am worried about how I am going to cope financially.

If you have had to reduce your hours, change your job or give up work altogether and you are facing financial problems, it can be very distressing. You might feel that you are letting your family down, but it is not your fault. You may be concerned about paying a mortgage. There are benefits in place that can help to support you and your family.

What state benefits are available?

The benefits system can be complicated, so you should get advice about what you are entitled to. Remember that this includes entitlement to help in the house or childminding facilities as well as nursery places.

For information on state benefits – income support, housing benefit, family credit, disability living and carers’ allowances, pensions and so on – contact your local Social Security office. They will be able to advise you or put you in touch with relevant services. If you are not sure how to contact your local Social Security office, contact the Department for Work and Pensions (DWP).

You can also find out information about benefits and allowances at your local Citizens Advice Bureau or from the www.gov.uk website.

Contact details for the Department for Work and Pensions, Citizens Advice Bureau and other useful organisations can be found in ‘Financial help’ on page 100.

Some benefits can be claimed quickly under ‘special rules’ by people who have been deemed to be in the last six months of life – see page 81.

What is the carer’s allowance?

The 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).

You can find out if you are eligible for the allowance from:

In England, Scotland and Wales:
Carer’s Allowance Unit
Mail Handling Site A
Wolverhampton WV98 2AB
Telephone: 0345 608 4321
Textphone: 0345 604 5312

In Northern Ireland, call the Benefits Enquiry Line: 0800 220 674

Financial worries
Facing severe illness

You may find that there are times when your symptoms become severe, because you have caught a cold or become unwell for another reason. When this happens, it’s important that you see your doctor so that he or she can assess your condition and make sure that your heart failure is under control. Your doctor may tell you that where you had, say, class 2 heart failure, you now have class 3 (see page 7 for more information). 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.

However, heart failure is a progressive disease and there may be a time when your condition gets worse despite your treatment. Coping with the effects of advanced heart failure can be difficult. If you are unable to get about and do things, you may find that you are dwelling on things and worrying more. Try to focus on what you can do rather than what you can no longer do.

Remember that you don’t have to manage alone. Here we explain how you can get support with things you can no longer do.

I can’t manage at home. How can I get help?

Talk to your GP or nurse, or contact your local social services department at your local authority. They will be able to advise on a range of services available in your area including home care, housing issues, mobility schemes (schemes that provide travel opportunities to help you stay independent), and so on.

What about Meals on Wheels?

If you have difficulty cooking meals for yourself, your council can deliver ready-made meals to your home. This service is sometimes known as ‘Meals on Wheels’. See www.gov.uk for more information.

What if my doctor doesn’t have the time to talk to me about everything I want to know?

Most doctors, GPs and nurses have a limited time they can spend with each patient, but you can make the most of this time. For tips on how to do so, see ‘Talking to your doctor, GP or nurse’ on page 91.

You can also get further information from the useful organisations listed on pages 99-101.

I’m scared of being on my own if 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 assistance at home on a regular basis but it can be reassuring 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 can’t get out of the house.

If it is 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.
• Ask your doctor for a prescription for oxygen if you get very breathless.
• Have plenty of rest periods in the day.
• Watch your fluid levels very carefully and tell your GP or nurse if you have swelling that you can’t control.
• Ask your heart failure nurse or palliative care team for tips on how to cope.

What is 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 GP and heart failure nurse, as well as professionals specifically 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 not treatments you want to avoid. It helps make your family and friends aware of your preferences and offers them support too. We talk more about this in the ‘Planning for the future’ section.

Who provides palliative or end of life care?

Your GP or heart failure nurse can meet many of your needs as you reach the end of your life, and should make sure that these aspects of your care are addressed right from when you are first diagnosed.

However, your GP or nurse might suggest the involvement of a specialist palliative care team for their expert advice – especially if you have complex symptoms or support needs. Palliative care teams provide care and support in a hospice, hospital, care home or your own home and will work alongside your GP and/or nurse.

Ask your GP or heart failure nurse any questions you have about palliative and end of life care and the services available in your area.

What about financial and other help?

Although most people with heart failure experience a gradual progression of their condition, occasionally it can come on suddenly and despite treatment there is little improvement. If this happens, and your doctor says that you may be facing the last six months of your life, you may be entitled to quickly claim an Attendance Allowance or Disability Living Allowance under ‘special rules’. For more information contact the organisations listed under ‘Financial help’ on page 100. When applying for one these benefits you will need to send in a short medical report called a DS1500 form about your condition. Ask your GP or nurse for this report.

Also, there are a number of organisations that can offer practical and emotional support with end of life issues for patients, families and their carers (see pages 99-101).
Planning for the future

I'm frightened of dying.

Severe symptoms, particularly having difficulty breathing, can be very frightening. You may believe, or you may have been told, that you are approaching the end of your life. Hearing this can cause you and your family and friends to experience many different emotions, such as shock, anger or sadness.

If you can, try to talk to someone about your feelings. Although it might feel difficult to start with, talking does help. If you're finding it tricky to talk to your family or friends, ask your GP or nurse to help and visit www.dyingmatters.org for advice on how you can begin these conversations.

You can also make practical plans to help you cope in the future and to give you peace of mind. We look at this more in the next section, ‘Planning for the future’.

What if I don’t want any more treatment?

It is very important that you have some control over your treatment in the later stages of your illness. You should discuss the treatment you want or when you want to stop it with your GP or heart failure nurse or doctor. You should try and have these discussions when you’re feeling well, not only when you’re feeling unwell, as it can be difficult to make a decision when you’re tired, breathless or anxious.

There will be many options, so you need to discuss your wishes with your partner, family or friends. Include them in your conversations and make sure that they know your wishes so that they can help you in the future. You might find it easier to talk to your GP or nurse on your own first and then to your family or friends. Sharing difficult decisions will help your relationship and understanding of each other.

If you decide you don’t want to receive particular treatments, you should write this down. In England and Wales the legal term for this is an advance directive. Northern Ireland currently has no legal equivalent. You may have heard about a “living will” but this is not a recognised legal term. We explain more about advance decisions and directives on page 84.

What kinds of decisions do I need to make?

You should start thinking about:

• where you would like to be cared for - in your own home or somewhere else - and the sort of care you would like if you become unable to make that decision in the future. This is a process known as advance care planning and involves making an advance statement about your health and social care which can include stating your preferred place of care

• any specific treatments you’d like to refuse and how to make an advance decision about this

• whether you would like to donate your organs to help someone after your death

• if you have an implanted device such as an ICD (implantable cardioverter-defibrillator), when would be an appropriate time to deactivate its shock component to avoid unnecessary discomfort.

When facing long-term or severe illness, it’s natural to look at the future and think ‘what if?’ For example, you might ask yourself questions like ‘what if my condition worsens and I am too unwell to let people know my wishes?’ or ‘what will happen to my family if I’m not around to care for them?’

Although it can seem difficult at first, making plans for the future and sorting out practical matters such as your will, finances and sources of support can be a very positive thing to do. Planning for tomorrow can help address some of the worries or questions that are at the back of your mind. Once they’re out of the way, planning ahead lets you get on with living as well as you can. Your family or friends will also be more confident in knowing exactly what you do and don’t want to happen.

When should I plan?

It’s a good idea to start thinking about the situations that might arise and how you and your family or carer would like them to be dealt with as soon as you feel comfortable doing this. By having these conversations and making decisions while you are relatively well, you can help make sure that your wishes are taken into account. It’s best that you make these decisions while you have the ability or “mental capacity” to make them for yourself. Your wishes will then be clear if, at some time in the future, you lose the mental capacity to make these kinds of decisions - for example if you are no longer able to understand the information provided about your treatment. The Mental Capacity Act 2005 (England and Wales) and the Adults with Incapacity (Scotland) Act 2000 set out guidelines as to when a person may not be able to make a decision, and are designed to protect you in this situation.
What is an advance statement?
An advance statement is a document that outlines your wishes about the care you would and would not like in the future, in case there is a time when you are unable to express your wishes and views yourself. It can also be used to nominate who you would like to be consulted if someone else has to make a decision about your treatment. It can cover social and personal care as well as medical care.

If you want to make an advance statement you should discuss your options with your GP, heart failure nurse or doctor and anyone else looking after you. You should review your advance statements from time to time to make sure they still reflect what you want. Remember you can always change your mind if you want to, while you have the mental capacity to do this.

An advance statement can help the professionals looking after you to understand what your wishes are, but it does not bind them to a particular course of action.

What is an advance decision?
An advance decision specifically applies when you want to refuse medical treatments. You may decide that in some or all circumstances in the future you don’t want certain treatments. For example, you may not want antibiotics for a chest infection or you may not want professionals to attempt to resuscitate your heart and lungs if they stop.

An advance decision (in England & Wales) or an advance directive (in Scotland) is a document prepared by a mentally competent adult that sets out their specific wish to refuse some or all forms of medical treatment in the event of serious illness and impending death. It is intended to make your wishes about treatment known and it would only be used if you are too ill to speak for yourself at the time. This means that your family or friends do not have to make difficult decisions on your behalf later on.

Preparing an advance decision or directive can also be an opportunity to discuss difficult issues with your GP, heart failure nurse and family and friends. If you’re worried about having these conversations, try to talk to your GP or nurse first or visit www.dyingmatters.org for help and advice.

What is a ‘Do Not Attempt Resuscitation’ order?
A ‘Do Not Attempt Resuscitation’ (DNAR) order is a specific kind of advance decision or directive. It is an instruction that you are not to be resuscitated if you stop breathing or your heart stops beating. It does not mean ‘do not treat’. It means only that if you stop breathing or your heart stops beating, you will not be resuscitated. You will still get other treatments if you need them - for example, treatment with antibiotics, treatment for discomfort or pain, transfusions, dialysis or use of a ventilator. However, you can also refuse those treatments through an advance decision if you want to.

When might I have a DNAR order?
You may feel that even if there is a good chance that an attempt at resuscitation would be successful and restore you to a reasonable quality of life, you would prefer to be allowed the option of natural death. It is your right to refuse resuscitation treatment that would usually be offered to you in these circumstances.

There may come a time when your illness means that an attempt at resuscitation may not restart your breathing and your heart, and/or if it did, there would be a real risk that your brain or kidneys would be damaged. In these circumstances, your wishes would be sought on resuscitation and if you didn’t wish to take this risk, then a DNAR order would be put in place.

If your illness becomes very severe, there may be no realistic chance of successful recovery from your heart or breathing stopping. Heart and lung resuscitation would therefore not be offered and a DNAR order would be put in place. Other treatments without a realistic chance of success, such as surgery, would also not be offered at this stage and an overall discussion about your care and the treatments that could be useful for you would be explained. Some people wish to talk about this in detail and others do not. You should let your team know if you want them to explain which treatments are not suitable for you at this stage.
How is an advance statement different from an advance decision?

An advance statement covers the type of care you would and wouldn't like to receive and where you would like to be cared for. It will be used to inform your care, but does not legally bind health professionals to a particular course of action.

An advance decision applies specifically to medical treatments. It is legally binding in the same way that refusing treatment would be if you had mental capacity. The law about advance decisions is set out in the Mental Capacity Act 2005 which covers England and Wales and the Adults with Incapacity (Scotland) Act 2000 in Scotland. If you have made an advance decision, your doctor and other health professionals must comply with it.

How do I make an advance decision to refuse treatment?

An advance decision should be written down and include:

- your name and address
- your signature
- the date
- the name and signature of a witness (this person should not be a spouse, partner, relative or anyone who stands to benefit from your will)
- a clear statement of your wishes, specifying the treatment you wish to refuse and whether you wish to refuse it in all or just certain circumstances. If the treatment could potentially prolong your life, include a statement saying that you wish to refuse it even if this puts your life at risk as a result
- the name, address and phone number of a nominated person to be consulted if you are unable to make a decision about your treatment (optional).

You don't have to involve a solicitor in writing an advance decision, but it is a good idea for you and your family to discuss your wishes with your GP or nurse. They can explain the advantages and disadvantages of choosing or refusing certain treatments and the impact your wishes will have on the course of your illness. Your GP or nurse will then be able to confirm that you were mentally competent at the time of writing the document.

What should I do once the advance statement or advance decision is written?

Your GP, heart failure nurse or doctor and other relevant health professionals should be made aware of your advance statement or advance decision and an up-to-date copy should be kept in your medical records and, if appropriate, in your hospital notes. It should also be shared with teams involved in your care outside of normal GP surgery hours, such as the 'out of hours' and ambulance teams. In case it is not, it is a good idea to keep a copy of the document(s) to hand. You should also make your friends and family aware of your advance statement or advance decision.

Should I make a will?

Everyone should have a will, not just those facing advanced illness. Making a will can bring you peace of mind as you know what will happen to your assets when you die. Making a will is very easy. You can do it through a solicitor for a small cost or, if it's a very straightforward will, you can do it yourself. There are plenty of guides available to help you do this, from organisations such as the Citizens Advice Bureau and Age UK.

You'll also need to think about financial issues like insurance or pensions so you may wish to seek independent financial advice.

What about my funeral?

Some people find it useful to talk about and plan their funeral. This might include telling your family or friends your preferences for cremation or burial and even planning the details. Talking to family and friends about this can ensure your funeral reflects your life and it can make a difficult time easier for your loved ones. You might want to contact a funeral director for advice - see page 101 for details of organisations who can help.
Looking forward, there are plenty of things that can help you get the best of everyday life, right now:

- Think about all the useful tips in this guide about taking positive action and managing your symptoms. Pick a couple and put them into practice, and use the Personal record at the back to keep track of your symptoms and stay in control.

- There are plenty of other relevant publications or DVDs available from the BHF or other organisations. Many of these are free of charge. We list some titles and details on how to obtain them on pages 102-103.

- Your family or carer can be an enormous source of practical and emotional support. Talk with them openly and honestly about your feelings. Share this guide with them, especially the chapter ‘Help for carers’ on pages 92-98.

- And please remember that you, and your family or carer, never have to cope alone. In addition to your GP, doctor and nurse, there are many organisations that can offer valuable help and support. We list these on pages 99-101.

Now please use the next section to help you get further help and support.
Talking to your doctor, GP or nurse

I would like more information from my doctor or GP.

Information about your heart failure is essential if you are to understand how to manage your symptoms and treatment. If there’s something you don’t understand, ask your doctor or GP. Before you go for your appointment, write down a list of questions about all the things you want to know about. If you think you won’t remember the answers, make notes of the answers or ask your doctor or GP to write things down for you.

I don’t always understand what I’ve been told.

It is very important to understand what your doctor, GP or nurse is telling you. Medical information can be complicated, so if there’s anything you don’t understand, don’t be shy to ask them to repeat it or to explain it in ‘layman’s terms’.

There never seems to be enough time to talk about things.

Many people with heart failure say that this is a very 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, GP or nurse. See our tips on the right.

Tips on talking to your doctor, GP or nurse

Before you visit your doctor, GP or nurse, think about why you are going to see them and what you would like to talk about.

• Make notes on how you are 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 pressing, and tell your doctor, GP 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 these.
• If you have trouble hearing, or if you get very nervous, take someone with you and ask them to write things down.

“I often forget what I’ve been told.”

It’s not unusual for us to forget what we have been told, especially if we are slightly nervous or worried. There is only so much we can take in at any one time. Our tips below will help you keep track of what you’ve been told. Doctors, GPs and nurses expect to have to repeat things, but you need to tell them which things.

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“The Heart Failure Nurses have often been the most practical and understanding.”
Help for carers

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. Whether you are the partner, relative, friend or carer of the person who has been diagnosed, this chapter has been written to help you.

Understanding heart failure

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

This guide has been designed to help the person with heart failure to manage their symptoms and have a good quality of life. If you have time, we recommend that you have a look at the rest of the guide. It will help you to understand how they cope and what you can do to support them.

You will find more information in our booklet Living with heart failure (see page 102). Read this if you’d like a greater understanding of the condition, its causes and treatment.

Striking the right balance

At each stage of their condition, the person you are caring for will need different levels of care and support. 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. Of course there will be times when they are trying to do too much and you might have to intervene (see ‘The overactivity-rest cycle’ on page 52). Knowing how to do this without taking away their independence can be tricky.

I am worried that I am going to be overprotective.

It is 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 for them to live a normal life as possible will mean that both they and you will 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 particularly need help with. It may mean organising a few people on a rota basis 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 are doing too much, talk it over and suggest other things that they can do that aren’t so tiring. If you still have concerns, discuss them with the heart failure nurse or GP. They will be able to be objective and let you know if you are being overprotective.

While the nurse or GP may be happy to give you tips and advice, they are not able to share information about the patient unless they have permission from them to do so. You should talk to your partner or the person you are caring for, about what information about their condition they are happy for the GP or nurse to share with you.

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

• help them to feel positive about their situation
• reduce their feelings of being a burden or dependent on you
• allow you to do something else while they are managing themselves.

What if they don’t seem to want to do anything for themselves?

It may be that the person you are caring for has lost their self-confidence. Perhaps they have 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 is important and not on the little things. If they are neglecting themselves, try inviting someone around or suggesting an outing – 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 are depressed. Depression can be a serious condition, but once diagnosed it can be treated successfully. If you are worried, talk to the heart failure nurse or GP for support and advice. (See page 72 for more information on depression.)

“That’s one thing you have to be very aware of – that you can actually make people worse by running around after them and doing too much ... You just make them worse ... you will make them an invalid eventually.”

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Coping with stress

Why do I feel stressed?
You will 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 lead to you feeling very anxious and under a lot of stress. The symptoms are the same as the ones we described on page 64.

What can I do about it?
There are many things that you can do to cope with stress:
• Recognise that you can’t do everything. You are not a failure if you have to ask for help.
• Try and anticipate 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 would like to.
• Look after yourself. Try to eat healthily and take regular exercise.
• Do some relaxation exercises. Try the ones on pages 68-69, or talk to the nurse or your GP about going to local sessions.
• Make sure you have time for yourself.
• Speak to the person you are caring for about what you need to do and how you can best allocate your time.
• Join a support group for carers. Some people find this very helpful as it enables them to meet people in the same situation as them, which can very therapeutic. (See next page.)

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 is support and help for the person who is 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. Don’t try and do everything yourself. If you overdo things, you may make yourself ill, which won’t help in the long run. You need a break and time to yourself.
If you need to go out but the person you are caring for needs someone with them, ask a friend or relative to call round or be available on the phone. Or, contact an organisation called Carers Trust (see page 99) which may be able to provide someone to sit in for you.
If you are unable to leave your partner on his or her own for long, you may be able to arrange ‘respite care’ where they will be looked after in a care home so that you can have a longer break or holiday. Talk to the nurse about arranging this.

I am thinking about joining a support group.
For some people that can be a very good idea. Sometimes talking with other people who are in the same situation can be very helpful. Talk to your nurse who will have information on the support groups in your area.

It might also be a good idea for your partner to join a support group. That way they can meet others in the same situation as them. See page 101 for details of how to find a local support group.

I feel guilty about wanting to have a social life.
You should not feel guilty about wanting a life outside of caring for your partner. You’re not being selfish. By taking a break from caring you will feel more relaxed and better able to cope with the demands of caring.

Helping the person you are caring for

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 him or her. There is plenty of practical advice on:
• eating healthily (see page 38)
• getting the right amount of exercise (page 50)
• managing medications (page 19)
• recognising and managing symptoms (page 12).
Read though the guide together and work out how you could help with putting this advice into practice. For example, you could shop for healthy ingredients and help to prepare meals.
Warning signs to look out for

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

If the person you’re caring for is ever in severe distress, is unable to breathe properly, experiencing severe pains in the chest or has a blackout, dial 999 for an ambulance immediately.

If any of these symptoms are new, call and speak to the heart failure nurse or doctor or to the GP. If they are very bad or suddenly get worse, call 999 for an ambulance:

• Palpitation
• Memory problems or problems with concentration
• Poor sleep
• Slow weight gain
• Weight loss
• Feeling helpless or fed up
• Problems keeping sexually active.

If any of these symptoms are new or have got worse, you must tell the doctor immediately:

• Swelling of the feet, ankles or abdomen
• Sudden weight gain
• Wheezing or coughing
• Light-headedness or dizziness
• Fatigue (feeling unusually tired and weak).

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. We discuss some of them below.

What is the carer’s allowance?

The 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. It can be a spouse, a friend or a relative.) You will need to have an assessment from the social services department to see if you are eligible (see below).

What is a carer’s assessment?

A carer’s assessment is a free service that is carried out by social services 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.

The assessment looks at:

• what help you need with caring
• what help you need to maintain your own health
• other commitments that you have.

How do I get a carer’s assessment?

You can ask your local social services department for a carer’s assessment. Your GP or district nurse can contact them on your behalf. Or, if you want to contact them directly, you can find their phone number in your local phone book, under the name of your local authority.

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 night time? Are you able to leave the house?
• Do you have any time for yourself?
• How is your health, and how 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?

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

There are quite a few conditions attached to receiving the carer’s allowance. To find out if you are eligible, contact:

In England, Scotland and Wales:

Carer’s Allowance Unit
Mail Handling Site A
Wolverhampton WV98 2AB
Telephone: 0345 608 4321
Textphone: 0345 604 5312

In Northern Ireland, call the Benefit Enquiry Line: 0800 220 674

For more information on financial help available to the person you are caring for, see page 79.
Tips for carers

Heart failure cannot be cured, but the symptoms can be controlled to help prevent it from getting worse. 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. Don’t be afraid to ask for help. And, 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. Don’t be too hard on yourself either – try to accept that change will involve some stress, especially at the beginning.
- Participate in any hospital, doctor, GP and nurse appointments or visits, but don’t dominate the appointment. Work out beforehand with the person you’re caring for the main issues you would like to be covered, 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 are 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 the doctor, GP or heart failure nurse.
- For details of national organisations for carers, see next page.

“I’m certainly more aware that time’s valuable and try to do more with my time, with my family… I mean it’s great, it’s like we’re courting again. It’s lovely; it really is lovely…”

Useful organisations

**General information**

- **British Heart Foundation (BHF)**
  Greater London House
  180 Hampstead Road
  London NW1 7AW
  0300 330 3311 (local rate number)
  bhf.org.uk
  Our Heart Helpline is an information service for the public and health professionals on issues related to heart health.

- **AntiCoagulation Europe**
  PO Box 405
  Bromley BR2 9WP
  020 8289 6875
  admin@anticoagulationeurope.org
  www.anticoagulationeurope.org
  Provides information for people who use warfarin or other anticoagulants.

- **British Cardiac Patients Association**
  15 Abbey Road
  Bingham
  Nottingham NG13 8EE
  01223 846845
  admin@BCPA.eu
  www.bcpa.eu
  Offers support, information and resources for people with heart problems and their carers.

**Carers**

- **Carers UK**
  20 Dover Street
  London SE1 4LX
  0808 808 7777
  info@carersuk.org
  www.carersuk.org
  Offers advice for carers and can put carers in touch with one another.

- **Carers Direct**
  0300 123 1053
  www.nhs.uk/carerselect
  Provides information, advice and support for carers.

- **Relate**
  Premier House
  Carolina Court
  Lakeside
  Doncaster DN4 5RA
  0300 100 1234
  www.relate.org.uk
  Offers relationship counselling and support.

- **Counselling services**
  British Association for Behavioural and Cognitive Psychotherapies (BABCP)
  Imperial House
  Hornby Street
  Bury BL9 5BN
  01671 705 4304
  babcp@babcp.com
  www.babcp.com
  Provides information on how to find a therapist in your area.

- **British Association for Counselling and Psychotherapy**
  BACP House
  15 St John’s Business Park
  Lutterworth LE17 4HB
  01455 883 300
  www.bacp.co.uk
  Has directories of individual counsellors and counselling organisations throughout Britain.

- **Relate**
  0300 100 1234
  www.relate.org.uk
  Offers relationship counselling and support.
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British Heart Foundation

Provides confidential non-judgemental emotional support for people who are experiencing feelings of distress or despair.

Life saving skills

BHF London office
0300 330 3311
heartstart@bhf.org.uk
bhf.org.uk/heartstart

An initiative co-ordinated by the BHF to teach you the simple skills needed in a life-threatening emergency.

For information about a free, two-hour Heartstart course in your area, visit bhf.org.uk/heartstart

On a Heartstart course you will learn:
• how to recognise and deal with a heart attack
• how to help someone who is choking
• how to deal with serious bleeding
• how to deal with someone who is unconscious and breathing normally
• how to recognise and deal with someone in a cardiac arrest by performing cardiopulmonary resuscitation (CPR).

Financial help

Citizens Advice Bureau
Head office
Citizens Advice
3rd Floor North
200 Aldersgate
London, EC1A 4HD
www.citizensadvice.org.uk

Your local Citizens Advice Bureau is listed in the phone directory.

Department for Work and Pensions
Caxton House
Tothill Street
London SW1H 9DA
ministers@dwp.gsi.gov.uk
www.dwp.gov.uk
For information on all aspects of financial management, benefits and support.

GOV.UK
www.gov.uk
For information on a range of benefits including disability living and carer’s allowances.

Help for the older person

Age UK
Tavis House
1-6 Tavistock Square
London WC1H 9NA
0800 678 1174
www.ageuk.org.uk
For advice and information on issues related to the older person.

Palliative care

Dying Matters
www.dyingmatters.org
A website to support people in thinking about end-of-life decisions, death and bereavement.

Hospice UK
34-44 Britannia Street
London WC1X 9JG
020 7520 8200
info@hospiceuk.org
www.hospiceuk.org
For information about UK and international hospice and palliative care services.

National Council for Palliative Care
Hospice House
34-44 Britannia St
London WC1X 9JG
020 7697 1520
enquiries@ncpc.org.uk
www.ncpc.org.uk
For advice and information about the causes of impotence, and treatments that are available in your area.

Support groups

British Heart Foundation
0300 330 3311
heartsupportgroups@bhf.org.uk
There are around 250 support groups associated with the British Heart Foundation (BHF) who support heart patients and their families in the local community. For more information about groups in your area, contact the BHF.

Sexual problems

Institute of Psychosexual Medicine
Building 3
Chiswick Park
566 Chiswick High Road
Chiswick
London, W4 5YA
020 7580 0631
admin@ipm.org.uk
www.ipm.org.uk
Can provide contact details of counsellors in your area.

The Sexual Advice Association
020 7486 7262
info@sexualadviceassociation.co.uk
www.sexualadviceassociation.co.uk
For advice and information about the causes of impotence, and treatments that are available in your area.

Bereavement services

Bereavement Advice Centre
0800 634 9494
www.bereavementadvice.org
Offers support and advice on how to manage practical issues.

Cruse Bereavement Care
PO Box 800
Richmond
Surrey TW9 1RG
0808 808 1677
info@cruse.org.uk
www.cruse.org.uk
A bereavement service for people of all ages.

British Cardiac Patients Association
01223 846845
admin@bcpa.eu
www.bcpa.eu
Runs support groups for people with heart problems and their carers and can provide information on the groups in your area.

Heart Voices
heartvoices@bhf.org.uk
bhf.org.uk/heartvoices
Our growing network of heart patients who use their experience of heart disease to influence and shape BHF’s work.

Funeral services

National Association of Funeral Directors
618 Warwick Road
Solihull
West Midlands B91 1AA
0121 711 1343
info@nafd.org.uk
www.nafd.org.uk
For information and help with funerals. Provides contact details of local funeral directors.

Samaritans
116 123
(24-hour free helpline)
jo@samaritans.org
www.samaritans.org
Provides confidential non-judgemental emotional support for people who are experiencing feelings of distress or despair.

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heartstart@bhf.org.uk
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34-44 Britannia Street
London WC1X 9JG
020 7520 8200
info@hospiceuk.org
www.hospiceuk.org
For information about UK and international hospice and palliative care services.

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Hospice House
34-44 Britannia St
London WC1X 9JG
020 7697 1520
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Offers support and advice on how to manage practical issues.

Cruse Bereavement Care
PO Box 800
Richmond
Surrey TW9 1RG
0808 808 1677
info@cruse.org.uk
www.cruse.org.uk
A bereavement service for people of all ages.

“Just a knowledgeable voice at the end of the phone or on email is so reassuring.”
Useful publications and DVDs

Resources from the BHF

The British Heart Foundation (BHF) produces a wide range of educational resources that may interest you. Our resources are free, but a donation would enable us to help more people with heart disease.

To order the titles on this page, or to find out about our other resources:

- visit bhf.org.uk/publications
- call the BHF Orderline on 0870 600 6566, or
- email orderline@bhf.org.uk

You can also download many of our publications from bhf.org.uk/publications

One step at a time – Living with heart failure
A DVD featuring six inspirational stories from people with heart failure, who share their experience of learning about the condition and living a normal life. Healthcare professionals also answer some common questions.

Heart Information Series (HIS)
A series of booklets for people with different heart conditions, and their carers.

- Angina (HIS6)
- Atrial fibrillation (HIS24)
- Blood pressure (HIS4)
- Cardiac rehabilitation (HIS23)
- Caring for someone with a heart condition (HIS20)
- Coronary angioplasty (HIS10)
- Diabetes and your heart (HIS22)
- Having heart surgery (HIS12)
- Heart attack (HIS7)
- Heart rhythms (HIS14)
- Heart transplant (HIS13)
- Heart valve disease (HIS11)
- ICDs (Implantable cardioverter defibrillators) (HIS19)
- Keep your heart healthy (HIS25)
- Living with heart failure (HIS8)
- Medicines for the heart (HIS17)
- Pacemakers (HIS15)
- Peripheral arterial disease (HIS16)
- Primary angioplasty for a heart attack (HIS26)
- Reducing your blood cholesterol (HIS3)
- Returning to work with a heart condition (HIS21)
- Tests for heart conditions (HIS9)

Diet and wellbeing:
- Coping with stress
- Cut down on salt
- Take time out
- Eating well
- Facts not fads, your simple guide to weight loss

The Inherited Heart Conditions series:
- Arrhythmogenic right ventricular cardiomyopathy
- Dilated cardiomyopathy
- Hypertrophic cardiomyopathy
- Inherited abnormal heart rhythms
- Sudden arrhythmic death syndrome
- Familial hypercholesterolaemia

Publications from other organisations

Chronic heart failure in adults: management.
Published by the National Institute for Health and Clinical Excellence.

This booklet describes the guidance on heart failure that the National Institute for Health and Clinical Excellence (called NICE, for short) has issued to the NHS. It tells you what help, treatment and care people with heart failure can expect.

To order a copy, phone the Department of Health Publications orderline on 0300 123 1002 or visit guidance.nice.org.uk/CG108

Advance decision
Produced by The Patients Association.

This booklet explains how to make an advance directive or ‘living will’. To order, contact the Patients Association via their website www.patients-association.org.uk or call their helpline on 020 8423 8999.

End of life: A Guide
Produced by Marie Curie Cancer Care.

Available to download from www.mariecurie.org.uk

A booklet for people in the final stages of life, and their carers.
What to do if you think you may be having a heart attack

You may be having a heart attack:
• if you get a crushing pain, or heaviness or tightness in your chest, or
• if you get a pain in your arm, throat, neck, jaw, back or stomach.
• You may also sweat, or feel light-headed, sick, or short of breath.

This is what to do.
1 Stop what you are doing.
2 Sit to rest.
3 Use your GTN spray or tablets. If you have a GTN (glyceryl trinitrate) spray or tablets, use it as your doctor or nurse has told you. The pain should ease within a few minutes. If it doesn’t, take your GTN again.

If you do not have a GTN spray, call 999 immediately.

4 If the pain does not ease within a few minutes of taking the GTN the second time, call 999 immediately.

5 If you’re not allergic to aspirin, or there isn’t a reason that you should not take it, chew an adult aspirin tablet (300mg) if there is one easily available. If you don’t have an aspirin next to you, or if you don’t know if you should take it, just stay resting until the ambulance arrives.

Even if your symptoms do not match the ones we have described above but you think you are having a heart attack, call 999 immediately.

If you think someone is having a heart attack

1 Get help immediately.
2 Get the person to sit in a comfortable position.
3 Phone 999 for an ambulance.

If a person seems to be unconscious

• Approach with care, making sure that you, the person and anybody nearby are safe. To find out if the person is conscious, gently shake him or her, and shout loudly, ‘Are you all right?’
• If there is no response, shout for help.
• You will need to assess the casualty and take suitable action. Remember A, B, C – Airway, Breathing, Circulation.

A - Airway
Open the person’s airway by tilting the head back and lifting the chin.

B - Breathing
Check
Look, listen and feel for signs of normal breathing. Only do this for up to 10 seconds.

Action: Get help
If the person is unconscious, and is either not breathing or not breathing normally, phone 999 for an ambulance.

C - CPR
Action: Cardiopulmonary resuscitation (CPR)

How to do CPR:
1 Chest compression
Start chest compression.
Place the heel of one hand in the centre of their chest. Place the heel of your other hand on top of your first hand and interlock your fingers. Press down firmly and smoothly 30 times. Do this at a rate of about 100 times a minute – that’s a little less than two each second.

2 Rescue breaths
After 30 compressions, open the airway again by tilting the head back and lifting the chin, and give two of your own breaths to the person. These are called rescue breaths.

To do this, pinch the person’s nostrils closed using your index finger and thumb and blow into the person’s mouth. Make sure that no air can leak out and that the chest rises and falls with each breath.

Then give another 30 chest compressions and then 2 rescue breaths.

3 Continue CPR
Keep doing the 30 chest compressions followed by 2 rescue breaths until:
• the casualty shows signs of life, or
• professional help arrives, or
• you become exhausted.

If you are not able, or are not willing, to give rescue breaths, give chest compressions only, as described in step 1. Keep doing the chest compressions – at a rate of 100 times a minute – until:
• the casualty starts breathing, or
• professional help arrives, or
• you become exhausted.

A nation of life savers

The BHF is creating a nation of life savers – leading the fight to save more lives in the UK through a revolution in cardiopulmonary resuscitation (CPR) training and defibrillator awareness. Join our nation of life savers at bhf.org.uk/lifesavers

• Heartstart is a free, two-hour course where you can learn CPR and other emergency life saving skills.
• Our Call Push Rescue training kit is available free to secondary schools and eligible community groups, and for a small fee to workplaces. It has everything you need to learn CPR, including a training DVD.
About the British Heart Foundation

The British Heart Foundation (BHF) is the nation’s heart charity, dedicated to saving lives through pioneering research, patient care, campaigning for change, and providing vital information.

Our resources are free of charge, but a donation would enable us to help more people who are living with a heart condition.

If you would like to make a donation:

• please call our donation hotline on 0300 330 3322,
• visit bhf.org.uk/donate or
• post it to us at:
  BHF Customer Services,
  Lyndon Place, 2096 Coventry Road,
  Birmingham B26 3YU.

Thank you.

Have your say

We would welcome your comments to help us produce the best information for you. Why not let us know what you think of this Everyday guide to living with heart failure? Contact us via the website bhf.org.uk/contact or write to us at the address above.
For over 50 years our research has saved lives.
We’ve broken new ground, revolutionised treatments and transformed care.
But heart and circulatory disease still kills one in four people in the UK.
That’s why we need you.
With your support, your time, your donations, our research will beat heart disease for good.