



British Heart
Foundation

Living with heart failure



**FIGHT
FOR EVERY
HEARTBEAT**

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About the British Heart Foundation

The British Heart Foundation (BHF) is the nation's heart charity, saving lives through pioneering research, patient care and vital information.

What you can do for us

We rely on donations of time and money to continue our life-saving work. 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 the address on the back cover.

If you wish to make a gift to the BHF in your will, call **0844 847 2787** or email **legacy@bhf.org.uk** and ask for our free booklet, *My generation*.

For other ways to support our work, see **bhf.org.uk/supportus**

British Heart Foundation website

You may find other useful information on our website at:

bhf.org.uk

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About this booklet

This booklet is for people with heart failure, and for their family and friends. It explains:

- what heart failure is
- what causes it
- the symptoms
- how it is diagnosed
- how it is treated, and
- what you can do to have some control over your condition.

We explain the technical terms used in this booklet on page 61.

This booklet does not replace the advice that your doctor, nurse or any other health professional looking after you may give you, but it should help you to understand what they tell you.

In some areas of the country there are specialist heart-failure nurses who can offer you care, support and advice. They sometimes see you in a clinic or can also visit you at home. Ask your doctor if there is a heart-failure nurse who works in your area.

For more information on heart failure

If you have heart failure, you may also find it helpful to read our booklet *An everyday guide to living with heart failure*. The guide gives practical tips on recognising, managing and controlling your symptoms, understanding your treatment, dealing with everyday challenges and improving your quality of life. It also offers information, help and advice for carers. The guide has a pull-out *Personal record* in which you, your heart-failure nurse and doctor can record your symptoms and other important information about your condition. There is also a DVD called *Heart failure: Your questions answered*.

Information for South Asians

For people of South Asian origin, our booklet *Heart failure – Information for South Asians* is available in Bengali, Gujarati, Hindi, Punjabi, Urdu and English.

For details of how to order these resources, see page 57.

What is heart failure?

Heart failure is when the heart becomes less efficient at pumping blood around the body. The term 'heart failure' can sound quite frightening, so it might be more helpful to think of it as: 'My heart is failing to work as well as it should, and needs medication to support how it works.'

Many people with heart failure can have a good quality of life. You can have some control over your condition by taking your medicines and by making changes to your lifestyle. And for some people, other types of treatment can help.

Heart failure can be described as **acute** or **chronic**.

- **Acute heart failure** is when the symptoms of heart failure come on suddenly. If this happens, you will need to be treated in hospital. The term 'acute heart failure' can describe the symptoms for someone who is diagnosed for the first time, or it can be used when someone with long-term (chronic) heart failure has symptoms that have suddenly become worse.
- **Chronic heart failure** is when someone has heart failure as a long-term condition. If you have chronic heart failure, you may be able to control your symptoms quite well, with the help of your heart-failure nurse and doctor.

How your heart works

To understand what heart failure is and what causes it, it can help to know about how your heart works.

The heart is a muscular pump that pumps blood around your body. The blood circulates around the body and delivers nourishment to your body tissue and organs.

There are two sides of the heart – the right side and the left side. Blood from your body enters the right side of your heart. From here, the heart pumps the blood to the lungs where the blood takes up fresh oxygen. This oxygen-rich blood then enters the left side of the heart. From here it is pumped through the aorta to all parts of your body.

There are four valves inside the heart, to make sure that the blood flows in the correct direction.

The illustration on the next page shows the different parts of the heart and the direction the blood flows in.

Heart failure happens when the heart fails to deliver as much blood and oxygen around your body as it should do. This is because your heart is not working as well as it should.

What causes heart failure?

There are many reasons why heart failure may happen.

The most common causes are:

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

Heart failure can also be caused by:

- a viral infection affecting the heart muscle
- problems with the heart valves
- alcohol or recreational drugs
- an abnormal heart rhythm (arrhythmia)
- some lung diseases
- some types of chemotherapy
- congenital heart problems (heart problems you are born with)
- thyroid gland disease, or
- anaemia.

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

What are the signs and symptoms of heart failure?

The main signs and symptoms of heart failure are:

- **being short of breath** when you are resting or being active
- **swelling** of your ankles, feet or abdomen (stomach area), and
- **fatigue** (feeling unusually tired).

These signs and symptoms may come on suddenly – for example, after a heart attack – or may develop slowly over weeks or even months.

Being short of breath

Being short of breath is a common symptom of heart failure. It is most likely to happen when you are active or when you're lying flat in bed. You may get a cough, too. Being short of breath may actually wake you up at night, and you may need to sit up, with pillows to support you, or feel that you need to open the window for some fresh air.

Swelling of the ankles, feet or abdomen

People with heart failure often have swelling (oedema) of the ankles and feet. This may extend to your legs, thighs

and groin, and there may be swelling of the abdomen too (ascites), or in the small of the back.

Fatigue (feeling unusually tired)

A common problem for people with heart failure is loss of energy and feeling unusually tired, either while you are resting or after you've done only a small amount of activity. The tiredness can be quite overwhelming, making you feel that it's very difficult to carry on as normal. How tired you feel will depend on how severe your heart failure is and how well your symptoms are controlled.

Changes in weight

You may experience changes in weight – for example, a sudden increase in weight over a few days – or a slow loss of weight. See page 29 for what to do if this happens.

What causes these symptoms?

Heart failure happens because your heart is not pumping as well as it should. This can cause a build-up of blood back to your lungs and other parts of your body. This is called 'congestion'. It's a bit like a traffic jam. Sometimes doctors refer to it as 'congestive heart failure'.

Your heart works harder to try to clear the problem, but is not able to. This congestion can cause **swelling** in your ankles or feet or in the small of your back, or in your abdomen. (The swelling is caused by the extra fluid that builds up in your body.) The extra fluid can also cause sudden weight gain. If the congestion is in your lungs, it can lead to **shortness of breath**. If your muscles are affected, this can cause **fatigue**.

Keeping a record of your symptoms

Controlling your symptoms is an important part of treating heart failure. It may be helpful for you to make a note of your symptoms and talk to your nurse or doctor about how you can best manage them.

If your symptoms suddenly get worse or if you feel unwell, talk to your doctor or call 999.

Shortness of breath and swollen ankles are not always caused by heart failure. These symptoms can also be caused by other conditions. For example, breathlessness can be caused by lung problems, and swollen ankles can be caused by having varicose veins or being very overweight.

Other symptoms

Some people with heart failure may also have other symptoms. Sometimes people can feel light-headed or perhaps have memory problems or difficulty concentrating. If this is a problem for you, talk to your doctor.

How is heart failure diagnosed?

If you have some or all of the symptoms described on pages 11 and 12, your doctor may suspect that you have heart failure. In some cases a doctor can make a diagnosis after examining you. He or she will check your heart rate and rhythm, take your blood pressure, check whether you have fluid in your lungs, legs and in other parts of your body, and listen to your heart.

You will probably need to have some more tests. This will include an **electrocardiogram (ECG)**, which looks at the electrical activity of your heart, and a **chest X-ray**.

The most useful test to check the pumping action of the heart is an **echocardiogram**. This is an ultrasound scan which looks at the structure of your heart and how well it is working. It allows doctors to measure your 'ejection fraction'. This is the amount of blood that the heart can pump out of the heart every time the heart beats. This can help to tell how well your heart is pumping. It is given as a percentage – for example, 40%.

Another useful test to help diagnose heart failure is a **BNP test** (a B-type natriuretic peptide test). This is a blood test which measures the levels of certain hormones related to heart failure. You will have other blood tests as well.

For more details of the tests you may have, see our booklet *Tests for heart conditions*.

Classes of heart failure

After your tests, your doctor will be able to tell you if you have heart failure or not. He or she may also be able to tell you which 'class' of heart failure you have. However, you may find that you don't fit exactly into one class.

There are four classes of heart failure.

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 all your activities as normal and have as much energy as you would expect.

Class 2: Mild heart failure – symptoms when you exert yourself in a moderate way

You may not be able to do quite as much as you used to. You get breathless more often than usual.

Class 3: Moderate heart failure – symptoms when you exert yourself a little

You are quite limited in what you can do. It doesn't take much effort to make you exhausted and too breathless

to carry on. You are usually comfortable while you're resting.

Class 4: Severe heart failure – symptoms while you are resting

You become breathless even when you're not being particularly active – for example, when walking around at home or even when sitting down. You may be very restricted in your daily activities. You may be unable to sleep lying down because you get breathless or cough.

Left-sided and right-sided heart failure

Your heart failure may affect both sides of your heart or one side more than the other. Your doctor may use the terms 'left-sided heart failure' or 'right-sided heart failure' to describe your condition.

What is the treatment for heart failure?

Your treatment aims to improve your symptoms, to keep you as well as possible, and to prevent your condition from getting worse.

Heart failure and its symptoms are managed using a combination of **medicines**. We explain more about the medicines used on page 21.

It may be possible to **treat some of the conditions which can cause heart failure** – for example, abnormal heart rhythms, severe anaemia or problems with the thyroid gland. Or, if your heart failure is caused by heart valve disease or a congenital heart problem, it may be possible to treat these with surgery. Treating the cause won't cure your heart failure, but it can improve your symptoms and quality of life.

On pages 36 to 39, we describe **other forms of treatment** that may be suitable for some people with heart failure.

You can help to slow down the progression of your heart failure, with a combination of treatment and making changes to your lifestyle. We explain more about **what you can do to help yourself** on page 28.

Can heart failure be cured?

Unfortunately, heart failure cannot yet be cured. However, with treatment and management of your symptoms and lifestyle, many people can lead a full and good-quality life. They can also carry on with their everyday life and activities.

Research is gradually identifying more ways of treating and helping to prevent the causes of heart failure. Over the next five to ten years, there will be a lot of research looking at how damaged heart muscle may be repaired. This is known as regenerative medicine. This includes finding out how stem cells can become heart cells. This research hopes to improve the outlook for people with damaged hearts, such as those with heart failure.

Will my heart failure get worse?

Your condition may not necessarily get worse, although unfortunately some people do find it gets worse over time. However, taking your medicines, controlling your symptoms and making changes to your lifestyle can all help to prevent your condition from getting worse. Also, treatments are continually being improved and new ones are becoming available. See page 48 for information on the help and support you can get if your heart failure does become worse.

Will having heart failure shorten my life?

It's not possible to tell anyone with heart failure how long they will live for. Heart failure affects different people in different ways. Heart failure does shorten the lives of some people. However, other people live with heart failure for many years. Your outlook will depend on which class of heart failure you have, the cause, your age, your symptoms and your general health.

Is there a risk of dying suddenly?

Some people with heart failure are at risk of dying suddenly because they may develop a life-threatening heart rhythm. This can lead to a cardiac arrest. The abnormal heart rhythm can happen because the heart failure has caused changes to the structure of the heart muscle which can affect the way the heart beats.

If you are at risk of dangerous heart rhythms, your doctor can prescribe medicines for you, to reduce the risk.

If you are at high risk of developing a life-threatening heart rhythm, your doctor may suggest that you have an ICD (implantable cardioverter defibrillator) implanted (see page 38).

For information on what to do if someone has a cardiac arrest, see page 53.

Medicines to treat heart failure

Your doctor will prescribe a combination of medicines for you, to treat your heart failure and to help control your symptoms. Symptoms of heart failure usually respond well to treatment with medicines.

On pages 23 to 27 we describe some of the common medicines used for people with heart failure.

It may take some time to reach the right dose or the right type of medicines for you. You may also find that your doctor will change your medicines from time to time. This can be unsettling, but it is important that you take the right medicines for you, so that you have the most effective treatment.

To keep your condition and symptoms under control, the following advice on medicines is important.

- **Keep a list of the names of each medicine you take, the dose and when you need to take it.** You may find that using a dosette box helps you organise your medicines. You can get these from pharmacies. (A dosette box has separate compartments for storing your tablets for each day of the week, and sometimes also for different times of day.)
- **Always read the information that comes with your medicine.**

- **Never take a double dose.** If you have missed taking a dose by a short time, take it as soon as you remember. If it's nearly time for your next dose, skip the dose you missed and take the next one at its scheduled time.
- **Don't suddenly stop taking any medicine** without talking to your doctor first. And don't run out of medicines. Stopping taking your medicine suddenly can sometimes make your condition and symptoms worse.
- **Return any old medicines to the pharmacist** to get rid of them and to reduce the risk of you taking the wrong medicines.
- **Never take medicines prescribed for someone else,** even if they have the same condition as you.
- **Always check with your pharmacist or doctor before taking any over-the-counter medicine** that has not been prescribed for you. Also, many herbal or natural remedies can affect the way your heart medicines work. Always check with your doctor before taking them.

Some people may get side effects from their medicines. Some side effects will be temporary and will go away after a short while. Tell your doctor if you get any side effects. He or she may be able to change the dose or suggest another medicine.

Diuretics

Diuretics (water tablets) help your kidneys get rid of excess fluid by making you pass more urine. So they are a great help in relieving any ankle swelling and shortness of breath. There are different types of diuretic.

If you take a diuretic but you still have symptoms, your doctor may suggest that you take another type of diuretic as well.

You will also need to have blood tests every few months, both to check that your kidneys are working OK and to check the levels of salts and minerals in your blood.

Diuretics can act very quickly, which means that you may need to pass water urgently. This can be inconvenient, so you will need to plan to take the tablets at a time that fits in with your daily activities.

Having too much salt in your diet can affect the way your diuretics work. So don't add salt to your food. When you're buying food, check the food labels and choose the low-salt options. Also, avoid salt substitutes. See *Cut down on salt*, on page 30, for more ways to reduce the amount of salt you have.

ACE inhibitors

ACE inhibitors have a relaxing effect on the arteries. This

reduces the work the heart has to do to pump the blood around your body.

ACE inhibitors can lead to a substantial improvement in your quality of life, and improve your outlook. They may also slow down the rate at which your heart failure gets worse.

ACE inhibitors can also lower your blood pressure. Your doctor will take care to start the medicines at a low dose, so that you don't have a sudden fall in blood pressure. You may be given your first dose under the supervision of a specialist or in hospital, so that they can monitor your blood pressure.

Before prescribing ACE inhibitors, your doctor will do a blood test to measure how well your kidneys are working. This test is repeated from time to time once you have started taking the medicines.

ACE inhibitors can increase the potassium level in the blood. So, if you are taking ACE inhibitors, it is important not to take potassium supplements or salt substitutes because most of these contain potassium.

Some people on ACE inhibitors develop a troublesome cough. If this happens to you, another medicine called an **angiotensin II antagonist (ARB II)** may be a suitable alternative. It works in a similar way to ACE inhibitors.

Not all patients with heart failure benefit from taking ACE inhibitors. Some people with narrowed heart valves or certain forms of cardiomyopathy are less likely to be prescribed them.

Beta-blockers

Beta-blockers help to prevent the heart from beating too quickly and too forcefully. Taking beta-blockers can help to keep you well and prevent your condition getting worse.

You will normally be given a small dose of beta-blockers to begin with. The dose may then be increased slowly until the right amount is reached. It can take a few weeks or months to feel the benefits of taking beta-blockers, and you may even feel that your symptoms are getting worse before you feel any improvement.

If you have asthma, you may not be able to take beta-blockers, as they may make your asthma worse.

Digoxin

Digoxin slows down and strengthens your heartbeat. It can help control abnormal heart rhythms, and help your heart pump blood around your body more efficiently.

Sometimes digoxin can cause a person's heart to slow down too much, making them feel very tired or unwell.

If this happens to you, you should see your doctor. He or she can arrange for you to have a blood test to check whether you have the right level of digoxin in your blood. Depending on the test results, your doctor may decide to change your dose.

Anti-platelets

Blood clots can form in the blood vessels and in the heart itself, and can lead to strokes and heart attacks. Anti-platelets can reduce the risk of having a heart attack or stroke, as they help to stop the blood platelets from sticking together and forming a clot.

The most common kind of anti-platelet medicine is **aspirin**. Another medicine called **clopidogrel** is sometimes used instead.

Anti-platelet medicines can increase the risk of bleeding, so see your doctor immediately if you have any unusual bruising or bleeding.

Anticoagulants

If you are at high risk of developing blood clots – for example, because you have an artificial heart valve, or because you have an abnormal heart rhythm such as atrial fibrillation – you may need to take anticoagulants. Anticoagulants change the clotting mechanism of the

blood, so they reduce the risk of a clot forming.

The most common type of anticoagulant is **warfarin**.

You will need regular blood tests to make sure that your blood doesn't get too thick or too thin, and to check what dose of warfarin you will need. If you have any unusual bruising or bleeding, report it to your doctor immediately

Statins

Statins help to lower the cholesterol level in the blood and also help reduce the risk of a heart attack or stroke.

A side effect of statins can be muscle pain, so talk to your doctor if you experience this. Occasionally statins can affect the way the liver works, so you will have some blood tests to check this.

Flu and pneumonia vaccines

Both flu and pneumonia can increase the risk of complications for people with heart failure. So it's important to have vaccines against them, to protect yourself against these infections.

What you can do to help yourself

People can often manage the symptoms of heart failure effectively – and improve their quality of life – by making changes to their lifestyle. Making these changes can also help to slow down the progression of your heart failure.

The following are some of the things that you can do.

- Control your blood pressure.
- Weigh yourself regularly.
- Watch the amount of fluid you have each day.
- Cut down on salt and eat a healthy diet.
- Keep to a healthy body weight.
- If you smoke, stop smoking.
- Keep active.

We give some information about all these things on the next pages.

Control your blood pressure

High blood pressure can put a strain on your heart.

Staying a healthy weight, keeping active and taking the medicines your doctor has prescribed for you will help to control your blood pressure and reduce the workload of your heart.

Cutting down on salt can help keep your blood pressure down. (See the next page for how to reduce the amount of salt you have.)

Your doctor or nurse will want to check your blood pressure regularly.

Weigh yourself regularly

If you have heart failure, a sudden increase in weight could mean that there is a build-up of too much fluid in your body.

It's a good idea to keep a record of your weight. **Weigh yourself at the same time every day, preferably in the morning.** If you notice that your weight goes up by about 2 to 3 pounds (about 1 kilo) in a day, you are probably beginning to build up fluid in your body. You may also start to feel a little out of breath and may notice some swelling around your ankles, or feel bloated.

If the weight gain continues and you notice an increase

of 6 pounds (about 2.5 kilos) over three days, or if you start getting more out of breath or have more ankle swelling, you should contact your nurse or doctor.

Watch the amount of fluid you have each day

You may be advised to limit the amount of fluid you have each day. Keep a record of your fluid intake. And remember to include things like soup. If you're not sure how much fluid you should be having, or whether you need to restrict your fluid, talk to your doctor or nurse.

Cut down on salt and eat a healthy diet

Cut down on salt

Too much salt can make your body hold on to water. (On page 29 we explain why this can be a problem for your heart.) So it is important to watch how much salt you have. Aim to have less than 6 grams a day.

Don't add salt to your food at the table, and avoid cooking with it. Use herbs and spices to add flavour instead. Avoid salt substitutes, as these are not recommended if you have heart failure.

Avoid eating foods that contain a lot of salt. Foods that are high in salt include cheese, bacon, canned meat, sausages, crisps, smoked fish and canned soups. Try to

avoid processed foods as they can be high in salt. Check the food labels on products and choose the low-salt options.

For more information on salt, see our booklets *Cut down on salt* and *Guide to food labelling*.

Other ways to eat a healthy diet

- **Reduce the total amount of fat in your diet**, and eat starchy foods instead – for example, bread, pasta, rice, cereals and potatoes.
- **Cut down on saturated fats.** These are found in fatty meats such as sausages, and in cakes and biscuits. They are also found in some dairy products, so go for lower-fat versions of dairy products like milk, yoghurt and cheese.
- **Aim to eat at least five portions of fruit and vegetables a day.**¹
- **Eat two or more portions of fish every week.** One of the portions should be **oily fish**.¹ If you have had a heart attack, have two to three portions of oily fish a week.² Oily fish includes mackerel, salmon, sardines, herring, trout, pilchards and fresh tuna.

For more information on healthy eating, see our booklet *Eating well*.

Limit your alcohol

Drinking too much alcohol can sometimes make the symptoms of heart failure worse, so it's best to stay within the sensible limits for alcohol. Speak to your doctor or heart-failure nurse about what is safe for you. For more information about alcohol, see our booklet *Eating well*.

Keep to a healthy body weight

If you are **overweight**, your heart has to work harder to pump the blood around your body. Keeping to a healthy weight will help your symptoms and help reduce the risk of health problems.

The best way to lose weight is to cut down on your calories and increase your physical activity. Don't try to lose the extra weight too quickly. Losing weight slowly and steadily – about a pound, or half a kilo, a week – is more healthy, and you're more likely to keep the weight off for good.

For more information on how to lose weight, ask your doctor or nurse. Also, see our booklet *So you want to lose weight ... for good*.

It is also important to tell your nurse or doctor if you are **underweight** or **losing weight** (without trying to), or if you **can't put weight on**. This may be because your

appetite is not very good, and so you are not eating enough. Or it may be because your body is not able to absorb nutrients properly. Your doctor will want to investigate the cause of your weight loss and perhaps refer you to a dietitian. The dietitian can advise you on any changes you may need to make to your diet, or about supplements that you may need to take.

If you smoke, stop smoking

If you smoke, stopping smoking is the single most important thing you can do to live longer. Stopping smoking will also reduce the workload on your heart and will help improve your symptoms.

Ask your doctor or nurse for information, support and advice about ways to help you quit. These include tips on how to stop, joining a stop-smoking group or using nicotine-replacement products or medicines. Or try one of these helplines or websites:

- **NHS Smoking Helpline** 0800 022 4 332

www.smokefree.nhs.uk

- **Quitline** 0800 00 22 00

www.quit.org.uk

Quitline also runs helplines in different languages.

For more information on stopping smoking, see our booklet *Stop smoking*.

Keep active

Regular physical activity can help to improve your energy, stamina and fitness. This can help you to improve or cope with your symptoms and can also help to keep your heart healthy.

The type of activity that is recommended is moderate, rhythmic (aerobic) exercise such as walking or cycling. Walking is good as you can build it into your daily routine.

Start at a level that suits you and set realistic goals about what you can do. Ask your doctor or nurse about how much activity you should be doing and how you can build up your activities gradually.

If you are limited in how much you can do, being active can be a challenge, but even a small amount of activity is good for your heart.

Try and be active every day. But don't overdo the amount you do on one day just because you feel a bit more energetic than usual. Overdoing things can leave you exhausted the next day, which may then limit your activity in the following days.

You may find it helpful to spread your activity throughout the day. Doing a small amount each time, along with regular rest periods, can often be helpful.

When you first start doing your activity, begin slowly for the first few minutes and build up gradually. Before you finish, take time to slow down, and don't stop suddenly.

If you notice that you're getting more breathless than usual, or if you feel unwell or are in pain, slow down and stop, and tell your doctor.

Your doctor may ask you to avoid strenuous activities such as carrying heavy objects, or doing heavy DIY or gardening. It is not advisable to do weight-lifting or vigorous sports such as squash.

If you have been in hospital recently, you may be invited to a **cardiac rehabilitation programme**. The aim is for you to recover quickly and to get back to as full a life as possible. The programmes usually include exercise sessions. The staff can work out an activity programme suited to your needs. To find out more about cardiac rehabilitation, talk to your nurse or GP, visit www.cardiac-rehabilitation.net or call our Heart HelpLine on **0300 330 3311**.

In some areas there are special exercise programmes aimed at people who have heart conditions. To find out more, ask your GP or nurse.

See *An everyday guide to living with heart failure*, for information about being physically active and how to balance your activity and rest effectively. (See page 6.)

Surgery and other treatments

There are other treatments which can help with heart failure, such as surgery, or other procedures. We describe these below.

If your heart failure is caused by **heart valve disease**, you may be able to have an operation to repair or replace the heart valve. For more on this, see our booklet *Heart valve disease*.

If you have heart failure and you also have **angina** (chest pain caused by coronary heart disease), a **coronary angioplasty** or **coronary bypass surgery** may be an option for you. For more information on these treatments, see our booklets *Coronary angioplasty* and *Having heart surgery*.

Surgery may not always be possible for people with heart failure, as the risks may be high. So, adjusting your medicines and lifestyle instead may be better for you.

There are other procedures that can help to reduce and control the symptoms of heart failure, but these are only suitable for some people. We describe these on the next pages.

Pacemaker

Your doctor may tell you that you need to have a pacemaker implanted, to improve the strength, rate and rhythm of your heartbeat. This can help to improve the pumping mechanism of your heart. For more information on the different types of pacemakers, see our booklet *Pacemakers*.

Cardiac resynchronisation therapy

If your symptoms of heart failure are severe, they may be caused by the bottom chambers of the heart (the ventricles) beating out of time with each other (desynchronicity). If this is the case, you may benefit from having cardiac resynchronisation therapy.

This is where a 'bi-ventricular' pacemaker is implanted, to help co-ordinate the contractions of the heart muscle and help it pump better. 'Bi-ventricular' means that the pacemaker has two leads connected to the ventricles – one to the right ventricle, and one to the left – and it also has a lead connected to the right atrium. (See the diagram on page 9.) For more information, see our booklet *Pacemakers*.

Implantable cardioverter defibrillator (ICD)

If you have heart failure and you are at high risk of life-threatening heart rhythms and dying suddenly (see page 20), your doctor may recommend that you have a device called an implantable cardioverter defibrillator (ICD). An ICD is similar to a pacemaker but, if you were to suffer from a dangerous heart rhythm, the ICD would give an electrical shock, to help restore a normal heart rhythm. Some ICDs can also work as a pacemaker. So, if you need a pacemaker and an ICD, you would need only one device and not both. For more information on ICDs, see our booklet *Implantable cardioverter defibrillators (ICDs)*.

Left ventricular assist device (LVAD)

This may be an option for a small number of people with heart failure. An LVAD is a device to help support the heart if it has become very weak. It acts as a pump to support the circulation. The LVAD is normally used for people who are waiting for a heart transplant. More recently, these devices have been used for people with severe heart failure, who have not been well enough for a heart transplant. For more information, see our information sheet *Left ventricular assist devices*. (You can download this from our website bhf.org.uk, or order it from the Heart HelpLine on **0300 330 3311**.)

Heart transplant

In a small number of people whose heart failure is very severe and cannot be controlled by other treatments, a heart transplant may be an option. For more information, see our booklet *Heart transplantation*.

The number of transplants that can be performed is greatly limited by the number of donor hearts available. This is why we encourage people to carry a donor card. For more information about being a donor, see www.uktransplant.org.uk or call **0300 123 23 23**.

Everyday life with heart failure

Life can sometimes feel quite up and down, and you will find that you have good days and bad days. Our booklet *An everyday guide to living with heart failure* answers many of your questions about everyday life (see page 6). Below, we give you some brief tips on some of the things that may affect you.

Coping with the symptoms

Tiredness (fatigue), shortness of breath and swelling (of your ankles, feet or abdomen) can make it difficult for some people to live their lives normally. Breaking jobs down into smaller tasks can help. It may mean that things take longer, but it means that you are still able to do the things you want to do. Tell your doctors and nurses about how you feel, and about the ways that heart failure is affecting your everyday life. They may be able to adjust your treatment to help improve your quality of life.

Work

Most people with heart failure can continue to work, as long as they feel able to and their symptoms are OK. However, some people may need to make some adjustments.

If you have a manual job – for example, one that involves heavy lifting – you may need to think about changing your job to reduce the workload on your heart. Speak to your employers. They may be able to find you another job in the organisation.

You may also decide that you need to reduce your hours, either just for a while or permanently, to help you cope with your symptoms. Discuss this with your doctor and your employers to see what would suit you and your condition best.

Changing your work or reducing your hours may affect your income. See *Money matters* below for how to find out about the benefits you may be entitled to.

For more information, see our booklet *Returning to work with a heart condition*.

Money matters

If you have had to reduce your working hours, or cannot work, you may have some financial worries. There are benefits that can help support you. For information about what you may be entitled to, contact one of the following or visit their websites:

- your local social security office
- your local citizens advice office – www.citizensadvice.org.uk

- Department for Work and Pensions – www.dwp.gov.uk
- Directgov – www.direct.gov.uk
- Benefit enquiry line – 0800 88 22 00.

Driving

If you have an ordinary licence to drive a car or motorcycle, you are likely to be able to continue to drive, as long as you don't have any symptoms that might distract your attention. Talk to your GP about whether or not it is OK for you to drive.

If you have a licence to drive a lorry or bus, special regulations apply. You will need to tell the Driver and Vehicle Licensing Agency (DVLA) about your medical condition and check with them about whether you can continue to drive.

To find out if you need to tell the DVLA about your medical condition or about a change in your health, visit www.direct.gov.uk/driverhealth. Or call the DVLA on 0300 790 6806 for car drivers and motorcyclists, or 0300 790 6807 for lorry and bus drivers. Or write to them at DVLA, Swansea SA99 1TU.

You also need to tell your motor insurance company about your heart condition.

What about holidays and flying?

A holiday can give you the chance to unwind and rest. Talk to your doctor about whether it's OK for you to go away.

When you go on holiday, you might want to think about staying in accommodation that is easily accessible. Avoid hilly destinations unless you are fit enough for that level of activity. Keep an up-to-date list of all your medicines with you, just in case you lose any of them. And make sure you have adequate travel insurance.

Talk to your doctor about whether it's OK for you to fly.

Travelling can be tiring and long journeys can increase your risk of developing a deep vein thrombosis (DVT). So, if you are travelling, make sure that you have frequent breaks when you can get up and walk around. Whichever form of transport you are taking, plan your journey, allow plenty of time and don't carry heavy bags.

Sex

People with heart failure and their partners are often understandably anxious about how sex might affect their heart. But many people with heart conditions can continue to enjoy sex.

Like any other physical activity, having sex can increase

the heart rate and blood pressure. This increases the work of the heart and, in some people with heart problems, can lead to breathlessness. However, sex is just as safe as other equally energetic forms of physical activity or exercise.

If you are not sure whether it is safe for you to have sex, talk to your GP.

Some people may not have the energy to have sex. There are many ways that you can be intimate without having intercourse. Talk to your partner about how you feel.

Loss of sex drive is not uncommon and some men may experience impotence (the inability to get or keep an erection). This may be the result of anxiety, but it can also be due to other reasons. Impotence is a common problem, so if you are having difficulties, talk to your doctor about it.

Always check with your doctor before you take PDE-5 inhibitors such as Viagra, as it may not be safe for you to take this depending on your condition and the medicines you are taking.

For more information, see our DVD *Sex and heart disease* (see page 57).

Anxiety and stress

It is normal to worry about your condition, its effect on your life and your future, and the effect it has on your family. Understanding your heart failure and learning about your symptoms and about what you can do to help yourself can help to relieve anxiety. It is also important to discuss this with your family and close friends, and your doctor or nurse.

Stress affects different people in different ways.

People who don't manage their stress well may turn to unhealthy habits such as smoking, drinking alcohol, or snacking on unhealthy foods. Knowing what triggers the stress can help you to tackle the problem. Finding healthy ways of coping with stress and learning to relax can help you handle your heart failure. For more on dealing with stress, see our booklet *Coping with stress*.

Feeling low

It's normal to feel low or sad from time to time. You may feel down about your symptoms and your limitations. Some people say that they feel helpless as they have a lack of control over their life. Learning about your condition and being involved in making decisions about your treatment will all help you to feel in more control. Coming to terms with the changes in your life can help

you to be more positive. Planning something to look forward to every day can also help. However, if you feel low all of the time, you may be depressed. Talk to your GP to discuss the best way of dealing with this.

Changing relationships

You may find that your relationships with your family and friends change. You may not be able to do as much around the home or at work. You might feel frustrated or guilty that you have to rely on people. Discuss how you feel with the relevant people, and listen to them when they tell you how they feel.

Managing everyday life

You may find it difficult to juggle all the things you need to do, particularly if you are working or have children. Try not to overdo things, ask for help and accept offers of help.

If you have children or grandchildren

You may find that your condition makes it harder for you to look after your children or your grandchildren. You may find that you get tired very easily, so you may need to make some adjustments. Although you may not be able to play games such as football with your children or grandchildren, there are lots of other activities that don't

involve as much physical effort – such as playing board games, reading stories together, or going for walks.

Heart support groups

Many people with heart conditions can benefit from meeting other people who have had similar experiences. Heart support group activities vary from group to group, and may include:

- sessions where you can talk about your own experience with other heart patients and their carers
- exercise classes
- talks by guest speakers.

The BHF has resources and holds networking events to help new and existing heart support groups. For more details, or to find out about your local support group, contact the Heart HelpLine on **0300 330 3311**.

If your heart failure gets worse

Heart failure is a progressive disease so there may come a time when your condition gets worse. Remember that you are not alone and support and help are available.

You may be told that your outlook is poor. This can be a shock and may make you feel very sad or angry. Talking to your family, friends and the people looking after you can help you to get through this very difficult time.

Health professionals who can help

There are many people who can offer valuable information and support.

Some areas of the country now have **heart-failure nurses**. These nurses can see people in hospital and at home, and can give you and your family support, information and guidance. They can also help you to manage your condition on a day-to-day basis. Ask your doctor if there is a heart-failure nurse available in your area.

You may be referred to other health professionals who may help. For example, if you suffer from breathlessness, a **physiotherapist** can help you to breathe more easily. A **dietitian** can give you advice about healthy eating, particularly if you have lost your appetite. A **counsellor**

may be able to help you cope psychologically with your condition, or if you feel depressed or are finding it difficult to cope. Your GP or nurse may be able to refer you to a counsellor.

Other services and support may also be available locally, such as social care, or voluntary services.

If you are not coping and need help at home, talk to your GP or nurse or social services about getting some help.

Palliative care

There may come a time when you need palliative care. Palliative care is the term used to describe the support and care of people whose illness cannot be cured.

Your specialist heart-failure nurse may provide this, or you may be referred to another health professional who works in palliative care.

Palliative care focuses on controlling your symptoms and offering emotional support and social care for you and your family, and on helping you achieve the best quality of life possible. Support is provided at home, in hospital or in a specialist centre or hospice.

Palliative care is more than just end-of-life care. It can also be appropriate early on in the course of your illness, as people can live with a severe illness for a long time.

You may want to talk to the palliative care team about what care you would like to have in the future. For example, you may want to discuss decisions such as whether, towards the end of your life, you want to be supported at home, or ask them how to get information on different types of wills. It's good to talk to people who are supportive, knowledgeable and understanding. Expressing your wishes and talking about your concerns can be a great source of comfort and relief for you and your family.

For information about palliative care services in your area, ask your doctor or nurse or contact the organisation Help the Hospices on 020 7520 8222 (website www.helpthehospices.org.uk). For more information about palliative care and end-of-life decisions or decisions about your future care, see our booklet *An everyday guide to living with heart failure*.

Caring for someone with heart failure

Caring for someone who has heart failure can be very demanding – both physically and emotionally. Understanding about the condition can help you deal with the ups and downs of caring.

It is important to allow the person you are caring for to do things for themselves. This can be difficult, but allowing them to make their own decisions can help them to feel in control. Talk to them about how you can help them and ask them what they feel they need help with.

Remember that doctors, nurses, social workers, relatives and friends, and voluntary groups, can all help. Also, talk to your doctor or nurse, to find out what help and back-up can be provided.

You, the carer, might be entitled to extra support, services and benefits, to help you care for the person you are looking after. For information on this, contact one of the organisations listed in *Money matters*, on page 41. For information about the Carer's Allowance contact the Carer's Allowance Unit on 0845 608 4321.

It is important that you look after your own health and that you have regular breaks. Don't be afraid to ask for help, and if people offer help, accept the offer and

suggest things that they can do.

It is possible to arrange for someone to come into your home and take over caring for the person for a few hours, or sometimes overnight, so that you can have some time for yourself. Or some homes can provide short-term care for the person you look after, so that you can get a break for a weekend or longer. Talk to your doctor, nurse or social worker about how to arrange this.

If things are difficult, you may find it helpful to talk things over with someone, such as a friend, another carer or a counsellor. Or you might want to join a support group (see page 47).

For more information for carers

Carers Direct

Phone: 0808 802 0202

Website: www.nhs.uk/carersdirect

Direct Gov

Website: www.direct.gov.uk/en/CaringForSomeone/

Also, see the section for carers in *An everyday guide to living with heart failure*, or our booklet *Caring for someone with a heart condition*.

What to do if someone has a heart attack or cardiac arrest

If you think someone is having a heart attack

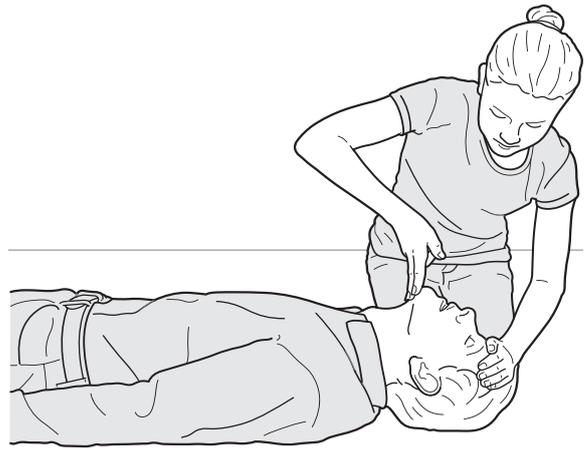
- 1 Get help immediately.
- 2 Get the person to sit in a comfortable position.
- 3 Phone 999 for an ambulance.

If the person seems to be unconscious and you think they are having a cardiac arrest

- 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 **ABC – airway, breathing, CPR.**

A Airway

Open the person's airway by tilting their 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.



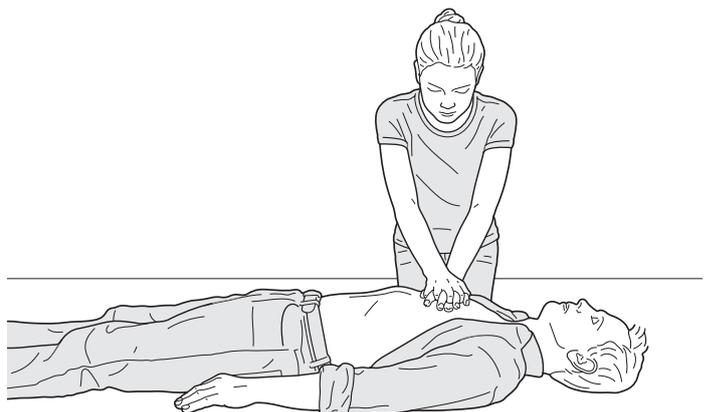
C CPR

Action: Cardiopulmonary resuscitation (CPR)

1 Chest compression

Start chest compression.

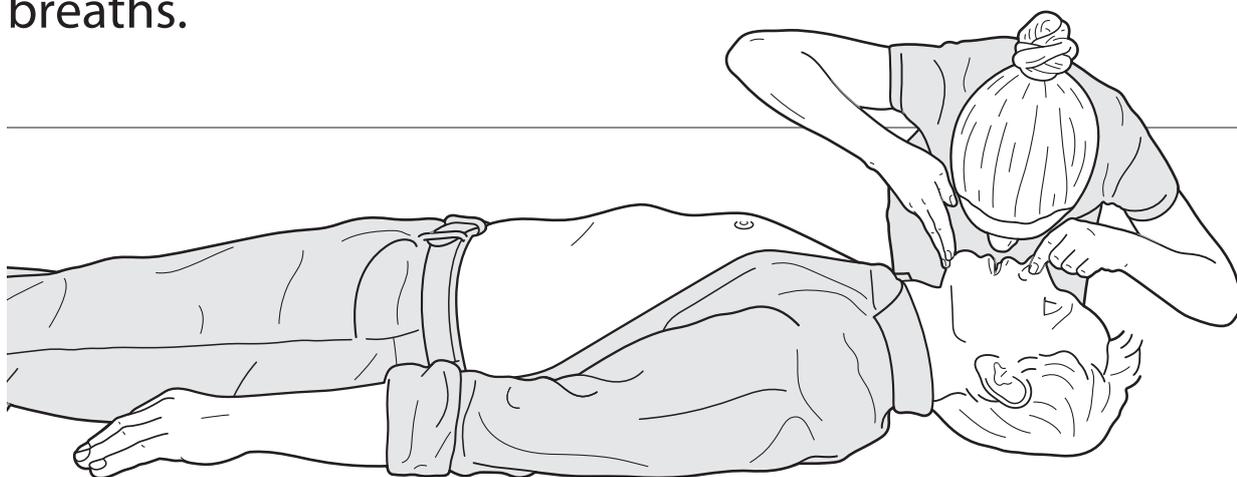
Place the heel of one hand in the centre of their chest. Place the heel of your other hand on top of your first



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 on page 54. 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.

Emergency life-support skills

For information about a free, two-hour course in emergency life-support skills, contact **Heartstart** at the British Heart Foundation. The course teaches you to:

- recognise the warning signs of a heart attack
- help someone who is choking or bleeding
- deal with someone who is unconscious
- know what to do if someone collapses, and
- perform cardiopulmonary resuscitation (CPR) if someone has stopped breathing and his or her heart has stopped pumping.

For more information

British Heart Foundation website

bhf.org.uk

For up-to-date information on heart disease, the BHF and its services.

Heart HelpLine

0300 330 3311 (a similar cost to 01 and 02 numbers)

For information and support on anything heart-related.

Genetic Information Service

0300 456 8383 (a similar cost to 01 and 02 numbers)

For information and support on inherited heart conditions.

Booklets and DVDs

To order our booklets or DVDs:

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

You can also download many of our publications from our website. For a list of resources available from the BHF, ask for a copy of *Our heart health catalogue*. Our booklets are free of charge, but we would welcome a donation. (See page 2 for how to make a donation.)

Heart Information Series

This booklet is one of the booklets in the *Heart Information Series*. The other titles in the series are as follows.

- 1 Physical activity and your heart
- 2 Smoking and your heart
- 3 Reducing your blood cholesterol
- 4 Blood pressure
- 5 Eating for your heart
- 6 Angina
- 7 Heart attack
- 8 Living with heart failure
- 9 Tests for heart conditions
- 10 Coronary angioplasty
- 11 Heart valve disease
- 12 Having heart surgery
- 13 Heart transplantation
- 14 Heart rhythms
- 15 Pacemakers
- 16 Peripheral arterial disease
- 17 Medicines for the heart
- 18 The heart – technical terms explained
- 19 Implantable cardioverter defibrillators (ICDs)
- 20 Caring for someone with a heart condition
- 21 Returning to work with a heart condition
- 22 Diabetes and your heart
- 23 Cardiac rehabilitation
- 24 Atrial fibrillation
- 25 Keep your heart healthy

An everyday guide to living with heart failure

Gives practical tips on recognising, managing and controlling your symptoms, understanding your treatment and improving your quality of life. It also offers information, help and advice for carers.

Heart failure: Your questions answered

Available as a DVD.

Heart failure – Information for South Asians

A booklet about heart failure, for people of South Asian origin. It is available in Bengali, Gujarati, Hindi, Punjabi, Urdu and English.

Heart Matters

Heart Matters is the BHF's **free**, personalised service to help you live with a healthy heart. Join today and enjoy the benefits, including *heart matters* magazine, a Heart HelpLine and an online members' area with articles, recipes and lifestyle tips. You can join online at **bhf.org.uk/heartmatters** or call **0300 330 3300** (a similar cost to 01 and 02 numbers).

Other booklets

For more information about the recommended care and treatment for people with heart failure see the following.

Management of heart failure: Understanding NICE guidance – information for people with heart failure, their carers, and the public. 2003.

Produced by NICE – the National Institute for Health and Clinical Excellence.

Phone: 0845 003 7780

www.nice.org.uk

Management of chronic heart failure

Produced by SIGN – the Scottish Intercollegiate Guidelines Network. 2007.

Phone: 0131 623 4720

www.sign.ac.uk

References

- 1 Food Standards Agency. Accessed from: <http://www.eatwell.gov.uk/healthydiet/>
- 2 National Institute for Health and Clinical Excellence. 2007. *MI: Secondary Prevention. Secondary Prevention in Primary and Secondary Care for Patients Following a Myocardial Infarction.* London. NICE.

Technical terms

ACE inhibitor	A medicine used to treat heart failure.
atrium	An upper chamber of your heart. There are two – the right atrium and left atrium.
BNP test	A blood test which measures the levels of certain hormones related to heart failure.
cardiomyopathy	A disease of the heart muscle.
digoxin	A medicine used to treat heart failure and certain heart rhythm problems.
diuretic	Also known as ‘water tablets’. Diuretics increase the amount of water and salt in the urine. They are used to treat heart failure and high blood pressure.
ECG	See ‘electrocardiogram’.
echocardiogram	An ultrasound scan which shows the structure of your heart and how it is working.
electrocardiogram	A test to record the electrical activity of the heart. Also called an ECG.

ICD (implantable cardioverter defibrillator)	A device which is implanted in the chest. It can deliver an electrical shock to restore a normal heart rhythm in someone who has a life-threatening heart rhythm.
LVAD (left ventricular assist device)	A device which is implanted in the heart. It acts as a pump to support the heart and circulation.
myocardium	The heart muscle.
oedema	Swelling caused by the build-up of fluid.
pacemaker	A device which is implanted in your chest. It stimulates the heart to contract and produce heartbeats.
resynchronisation therapy	A procedure where a special pacemaker is implanted to co-ordinate the pumping action of the heart muscle.
ventricle	A lower chamber of your heart. There are two – the right ventricle and left ventricle.

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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? Contact us through our website at [bhf.org.uk/contact](https://www.bhf.org.uk/contact). Or, write to us at the address on the back cover.

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**British Heart
Foundation**

Coronary heart disease is the UK's single biggest killer.

For over 50 years we've pioneered research that's transformed the lives of people living with heart and circulatory conditions. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

But so many people still need our help.

From babies born with life-threatening heart problems to the many Mums, Dads and Grandparents who survive a heart attack and endure the daily battles of heart failure.

Join our fight for every heartbeat in the UK. Every pound raised, minute of your time and donation to our shops will help make a difference to people's lives.

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk