Heart failure
and how it changed
my life

Rob Green
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As the nation's heart charity, we have been funding cutting-edge research that has made a big difference to people’s lives.

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Heart failure is when the heart becomes less effective at pumping blood around the body. The term ‘heart failure’ can sound quite frightening, so it might be helpful to think of it as: ‘My heart is failing to work as well as it should, and needs medicine to help it work better.’

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’ll probably need to be treated in hospital. Your doctor may tell you that you have ‘acute heart failure’ either if you are diagnosed with heart failure for the first time, or if you have long-term (chronic) heart failure and your symptoms have suddenly become worse.

- **Chronic heart failure** is when someone has heart failure as a long-term condition.

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**WHAT IS HEART FAILURE?**

Heart failure is when the heart becomes less effective at pumping blood around the body. The term ‘heart failure’ can sound quite frightening, so it might be helpful to think of it as: ‘My heart is failing to work as well as it should, and needs medicine to help it work better.’

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- **Chronic heart failure** is when someone has heart failure as a long-term condition.
How your heart works
To understand what heart failure is and what causes it, it can help to know about how your heart works.

- Your heart is a muscle that pumps blood around your body, delivering oxygen and other nutrients to all your cells.
- There are two sides to 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 oxygen.
- Oxygen-rich blood then enters the left side of the heart. From here it is pumped through the aorta (the largest artery in the body) 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 arrows show the direction the blood flows in.
WHAT CAUSES HEART FAILURE?

There are many reasons why heart failure may happen. The most common causes are:

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

Heart failure can also be caused by:

- a viral infection affecting the heart muscle
- congenital heart problems (heart problems you’re born with)
- an abnormal heart rhythm (arrhythmia)
- some lung diseases
- thyroid gland disease
- anaemia (lack of oxygen-carrying haemoglobin or red blood cells in your blood)
- some types of chemotherapy, or
- alcohol or recreational drugs.

In some cases, the cause of heart failure is unknown.

WHAT ARE THE SIGNS AND SYMPTOMS OF HEART FAILURE?

The main signs and symptoms of heart failure are:

- **being short of breath**, when you’re either resting or being active
- **swelling** of your ankles, feet, legs, 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’s most likely to happen when you’re 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, using pillows to support you.
Swelling of the ankles, feet or abdomen
People with heart failure often have swelling (oedema) of their ankles and feet. This may extend to your legs and groin, and there may also be swelling of the abdomen, or in the small of your back.

Fatigue (feeling unusually tired)
A common problem for people with heart failure is loss of energy and feeling unusually tired, either while you’re 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 can depend on how severe your heart failure is and how well your symptoms are controlled.

What causes these symptoms?
Heart failure happens because your heart is not pumping as well as it should. This can cause a number of things.

It can lead to a build-up of fluid that backs up into the lungs. This results in ‘congestion’ and causes breathlessness. It’s a bit like a traffic jam. Sometimes doctors refer to it as ‘congestive heart failure’.

Also, because blood is not pumped to the kidneys properly, the kidneys can retain salt and water. This extra fluid in your body can cause swelling in your ankles, feet or legs, or in the small of your back, abdomen or groin. The extra fluid can also cause sudden weight gain.

Heart failure can also cause fatigue because your heart may not be able to deliver enough blood and oxygen to the muscles in your body.

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 surgery or being very overweight.
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 suddenly feel unwell, talk to your doctor or call 999.

Other symptoms
Some people with heart failure may also have other symptoms, such as feeling light-headed, memory problems or difficulty concentrating. If any of these are a problem for you, talk to your doctor.
An echocardiogram can help to diagnose heart failure by checking the pumping action of your heart. An echocardiogram is an ultrasound scan that looks at the structure of your heart and how well it’s working. It allows doctors to measure your ‘ejection fraction’. This is the amount of blood that can be pumped out of your heart every time it beats. This helps to tell how well your heart is pumping. It’s given as a percentage, and a normal reading is 55% or above.

HOW IS HEART FAILURE DIAGNOSED?

If you have some or all of the symptoms described on page 07, your doctor may suspect that you have heart failure. 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’ll probably also need to have more tests, including an electrocardiogram (ECG), which looks at the electrical activity of your heart, and a chest X-ray.

You may have various blood tests, including a natriuretic peptide blood test. This test measures the levels of certain hormones in your body. A high natriuretic peptide level is seen in people with heart failure, and a normal level means that you don’t have heart failure. Different natriuretic peptides can be measured – for example, B-type natriuretic peptide (BNP).

For more information about the tests you may have, see our booklet Tests.
WHAT IS THE TREATMENT FOR HEART FAILURE?

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

Heart failure and its symptoms are managed using a combination of medicines. We explain more about the medicines used on page 17.

It may be possible to treat some of the conditions that can cause heart failure – for example, abnormal heart rhythms, severe anaemia or problems with the thyroid gland. 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 page 40, we describe some 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 30.

Can heart failure be cured?
Unfortunately, heart failure can’t be cured yet. But with treatment and management of your symptoms and lifestyle, many people can lead a full and good-quality life.

Could my heart failure get worse?
Your condition may not necessarily get worse, but 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 keep you as well as possible. Treatments are constantly being improved and new ones are becoming available. See page 54 for information on the help and support you can get if your heart failure does become worse.

Could having heart failure shorten my life?
It’s not possible to tell anyone with heart failure how long they’ll live for. Heart failure affects different people in different ways. It does shorten the lives of some people, but others live with heart failure for many years. Your outlook will depend on the cause of your heart failure, your age, your symptoms and your
general health. Talk to your doctor or nurse if you have questions about this. They can offer you information and support.

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

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

If you’re 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 42).

For information on what to do if someone has a cardiac arrest, see page 61.

Your doctor will prescribe a combination of medicines for you, to treat your heart failure and to help control your symptoms. On pages 19 to 27 we describe some of the common medicines people with heart failure take.

It may take some time to reach the right dose or the right combination 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’s important that you take the right medicines at a suitable dose for you to get the most effective treatment.

Some people may get side effects from their medicines. Some side effects are temporary and 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

Examples of diuretics include furosemide and bendroflumethiazide.

Diuretics (water tablets) help your kidneys get rid of excess fluid by making you pass more urine. They’re a great help in relieving any swelling in your ankles or legs, and shortness of breath.

There are several different types of diuretic medicines. If you take a diuretic but you still have symptoms, your doctor may suggest that you take another type of diuretic as well.

Once you start taking diuretics, you’ll need to have regular blood tests, both to check that your kidneys are working OK and to check the levels of salt 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’ll need to plan to take the tablets at a time that fits in with your daily activities.

Tell your doctor if any of the following apply to you while taking your diuretic medicine:

TOP TIPS...
on taking your medicines

1 Read the information that comes with your medicines, to find out why you need to take them, how to take them safely, and the side effects to look out for.

2 Keep a list of the names of each medicine you take, the dose, and when you need to take it. Using a dosette box can help you organise your medicines. You can get these from pharmacies. (The box has separate compartments for storing your tablets for each day of the week, and sometimes also for different times of day.)

3 Don’t suddenly stop taking any medicine without talking to your doctor first. Stopping taking your medicine suddenly can sometimes make your condition and symptoms worse.

4 Check with your pharmacist or doctor before taking any over-the-counter medicine. Also, many herbal or natural remedies can affect the way your heart medicines work.
• You get any symptoms, including feeling dizzy or faint.
• You start vomiting, get diarrhoea or become dehydrated. (If this happens, you may be asked to stop taking your diuretic for a short time, so that you don’t become more dehydrated.)
• You have diabetes. (Taking diuretics can increase your blood sugar level.)
• You get gout, or its symptoms become worse.

**ACE inhibitors**
Examples of ACE inhibitors include **ramipril** and **perindopril**.

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.

These medicines are very effective at treating and helping to prevent the symptoms of heart failure, and can greatly improve your quality of life. They may also slow down the rate at which your heart failure gets worse and help improve your life expectancy.

ACE inhibitors can lower your blood pressure, so your blood pressure will be closely monitored. 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.

Before prescribing this medicine, your doctor will do a blood test to measure how well your kidneys are working. The test is repeated from time to time once you’ve started taking the medicine.

ACE inhibitors can increase the potassium level in your blood. If you are taking them, it’s important not to take potassium supplements or use salt substitutes, because these contain potassium too.

Some people taking ACE inhibitors develop side effects, such as a troublesome cough. If this happens, you may be given another medicine called an **angiotensin II receptor blocker** (sometimes known as an **ARB**). It works in a similar way to ACE inhibitors but is less likely to cause a cough. You’ll still need regular blood tests to monitor your kidney function. Examples of this medicine are **candesartan** and **losartan**.

Not all patients with heart failure benefit from taking
ACE inhibitors. Your doctor is less likely to prescribe these for you if you have narrowed heart valves or certain forms of cardiomyopathy.

**Sacubitril valsartan**
A newer medicine, called sacubitril valsartan, is now available. Your doctor may prescribe this for you instead of an ACE inhibitor or an angiotensin II receptor blocker (ARB). Research suggests that this medicine can increase life expectancy and help relieve the symptoms of heart failure.

Sacubitril valsartan tablets combine an ARB (valsartan) and a medicine called a neprilysin inhibitor (sacubitril). It works by widening your blood vessels, increasing blood flow and lowering blood pressure to reduce the strain on your heart. It’s not suitable for everyone with heart failure, but your specialist team may offer this medicine to you if:

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

Side effects can include low blood pressure, high potassium levels and kidney problems. But your heart failure specialist team will monitor you carefully while you’re taking this medicine.

**Beta-blockers**
Examples of beta-blockers include **bisoprolol** and **carvedilol**.

Beta-blockers help to prevent the heart from beating too quickly and too forcefully, and so they reduce the amount of work it has to do. Taking beta-blockers can help to:

- keep you well
- prevent your condition getting worse
- improve your life expectancy, and
- improve the amount of exercise you’re able to do.

You will probably be given a small dose of beta-blockers to begin with. The dose can then be increased slowly until you reach the right amount for you. You may feel that your symptoms get worse for a while, as it can take a few weeks or months to get to the right dose and to feel the benefits of taking beta-blockers.
Mineralocorticoid receptor antagonists (MRAs)
These are sometimes called aldosterone antagonists. Examples include spironolactone and eplerenone.

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

MRAs can help to slow down the progression of your condition and may help to improve life expectancy for some people with heart failure.

If you’re taking an ACE inhibitor or beta-blocker but you’re still having symptoms, your doctor may prescribe an MRA for you. The decision about whether to prescribe them depends on your symptoms and how severe your heart failure is.

MRAs can lead to the body retaining too much potassium and can also affect kidney function, especially in older people. So you’ll have regular blood tests to monitor the effects of the medicine.

A possible side effect of spironolactone is swelling of the breast tissue in men. Tell your doctor if this happens. He or she can decide whether to reduce the
dose, stop the medicine, or change your prescription to a different type of MRA.

**Ivabradine**  
This medicine can help with the symptoms of heart failure. It slows your heartbeat so that your heart doesn’t have to work so hard. Your doctor may prescribe ivabradine for you if:

- you still get symptoms even though you’re taking other medicines to treat your heart failure, or
- you can’t take a beta-blocker.

You can’t take ivabradine if you have certain abnormal heart rhythms, or if your heart beats at less than 75 beats per minute.

Possible side effects of this medicine include a slow heart rate, tiredness, dizziness, and problems with your eyes. If you get any side effects, let your doctor know.

**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.

Your doctor may consider giving you digoxin if you’re still having symptoms from your heart failure despite being on other medicines.

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

**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 to protect yourself against these infections.

For more information on the medicines you may need to take, see:
- our booklet *Medicines for your heart*, or
- our book *An everyday guide to living with heart failure.*
Lisa had two heart attacks in 2011 and heart surgery in 2013. She’s now living with heart failure.

“I’d been doing well but had a relapse in 2014. I felt breathless, and found it difficult to climb stairs. I got tired quickly. But I started some new medicine and did cardiac rehab, and I started to feel better again.

People are often surprised when they find out I have heart failure. They say ‘You look normal’ and I say ‘Yes, but there’s lots going on inside’. I don’t think people realise the severity of it. I still work full time, but I need to pace myself. My boss is really understanding about my appointments and sometimes if I feel tired, I can work from home.

I love reading, writing poems and all kinds of music. Relaxing outside of work keeps me going. I’m not the type of person who gives up. I just think of it as having a new life to adapt to.”
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 and taking your medicines as prescribed can help to slow down the progression of your heart failure.

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

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

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

**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 first thing in the morning.** If you notice that your weight goes up by about 1 kilo (about 2 to 3 pounds) in a day, you’re 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 you feel OK, continue to keep an eye on your weight, but if you’re worried, contact your nurse or doctor.

If the weight gain continues and you notice an increase over three days, or if you start getting more out of breath or have more ankle-swelling, you should talk to your nurse or doctor.

For more detailed information on what you can do to help yourself, see our book *An everyday guide to living with heart failure.*
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.

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 on 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 or may ask you to check it yourself at home.

Cut down on salt
Too much salt in your diet can make your body hold on to water. Also, having too much salt can affect the way your water tablets work. So it’s important to watch how much salt you have. Aim to have less than 6 grams a day – which is about a teaspoonful.

• Don’t add any salt to your food at the table.
• Avoid eating foods that contain a lot of salt, such as cheese, bacon, canned meat, sausages, crisps, smoked fish and canned and packet soups. Use food labels on products to help you choose lower-salt ingredients and meals.
• Choose alternatives to salt when cooking or preparing food. Use herbs and spices to add flavour instead.
• Avoid salt substitutes. These are not recommended if you have heart failure.

For more information on salt, see our booklets Cut down on salt and This label could change your life.
Limit your alcohol
Drinking too much alcohol can sometimes make the symptoms of heart failure worse, so stay within the sensible limits for alcohol. Men and women should not drink more than 14 units of alcohol a week. 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.

Keep to a healthy body weight
If you’re overweight, your heart has to work harder to pump the blood around your body. Keeping to a healthy weight will help reduce the risk of health problems.

The best way to lose weight is to cut down on your calorie intake and increase your physical activity. Don’t try to lose the extra weight too quickly. Losing weight slowly and steadily – about a half a kilo (a pound) a week – is 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.

If you smoke, stop
If you’re a smoker, 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. Or you can call the Smokefree National Helpline on 0300 123 1044, or visit their website at www.nhs.uk/smokefree.

It’s also important to tell your nurse or doctor if you’re losing weight (without trying to), or if you can’t put weight on. This may be because your appetite isn’t very good, and so you’re not eating enough. Or it may be because your body is not able to absorb nutrients properly. Your doctor may 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.

See our booklet Facts not fads: Your simple guide to healthy weight loss.

For more information, 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, keep your heart healthy, and increase your sense of well-being.

Recommended activities include walking, dancing or cycling. These activities should make your heart beat a little faster and leave you feeling a little short of breath. Your doctor may ask you to avoid strenuous activities such as carrying heavy objects, doing heavy DIY or gardening, and also vigorous sports such as squash or weight-lifting.

Start at a level that suits you and set realistic goals about what you can do. If you’re limited in how much you can do, being active can be a challenge, but even a small amount of activity every day is good for your heart. Ask your doctor or nurse about how much activity you should be doing and how you can build up your activities gradually.

Try and be active every day. Each time you start 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. Try not to overdo the amount of activity you do. Overdoing things can leave you exhausted, which can limit your activity in the following days.

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

You may be invited to a cardiac rehabilitation programme. The aim of the programme is to help you recover quickly and to get you back to as full a life as possible. The programmes usually include exercise sessions (which can be adapted to suit your needs), education sessions on healthy lifestyles, and psychological support. To find out more, see our booklet Cardiac rehabilitation.
Air pollution

Being exposed to high levels of air pollution can make heart failure worse. The level of air pollution varies from day to day, depending on the weather and season. Pollution levels are classed as low, moderate, high or very high.

If you have heart failure, where possible it’s best to avoid places where there are high levels of air pollution, such as areas of busy traffic. It’s a good idea to monitor air pollution levels in your area. To check the air pollution levels near you, visit uk-air.defra.gov.uk

When air quality is poor, it’s advised that you make changes to your level of physical activity and consider exercising indoors.

If you have heart failure, it’s important to be as active as you can, because of the health benefits of an active lifestyle (see page 36 for more about this). But if the air pollution level is ‘high’, it’s recommended that you reduce strenuous activity, particularly outdoors, and especially if you’re experiencing symptoms (see pages 07–08).
As well as taking medicines, there are other treatments that can help with heart failure. We describe some of 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 affected heart valve.

If you have heart failure and you also have **angina** (symptoms, such as chest pain and breathlessness, caused by coronary heart disease), then a **coronary angioplasty** or **coronary bypass surgery** may be an option for you.

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

**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.

**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. If so, you may benefit from having a treatment called cardiac resynchronisation therapy (CRT). This is where a certain type of pacemaker called a ‘bi-ventricular pacemaker’ is implanted, to help co-ordinate the contractions of the heart muscle and help it pump better.

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For more information on the treatments mentioned above, see our booklets:
- **Heart valve disease**
- **Coronary angioplasty**, and
- **Heart surgery**.

For more information on pacemakers and CRT, see our booklet Pacemakers.
Implantable cardioverter defibrillator (ICD)
If you have heart failure and you’re at high risk of life-threatening heart rhythms and dying suddenly (see page 16), your doctor might recommend that you have a device called an implantable cardioverter defibrillator (ICD) implanted.

An ICD is similar to a pacemaker but, if you were to suffer from a dangerous heart rhythm, the ICD would give your heart 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 with both functions.

Other treatments
If you have severe heart failure and your symptoms aren’t controlled by treatment, you may be assessed for a heart transplant. For more information, see our booklet Heart transplant.

Life can sometimes feel quite up and down, and you’ll find that you have good days and bad days. Below, we explain some of the things that may affect you.

Coping with the symptoms
Tiredness (fatigue), shortness of breath, and swelling of your ankles, feet, legs 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’re still able to do the things you want to do.

Tell your doctors and nurses about how you feel, and about the ways in which heart failure is affecting your everyday life. They may be able to adjust your treatment to help improve your quality of life and make suggestions to help you carry on with your everyday life.

For more information, see our booklet Implantable cardioverter defibrillators (ICDs).
Follow-up appointments
It’s very important to go to all your appointments with your doctor, nurse or heart failure team. They will:

- monitor your condition and your symptoms
- check your medicines and make changes if needed
- discuss other treatment options, or
- offer you information and support.

Work
Most people with heart failure can continue to work, as long as they feel able to and their symptoms are OK. But 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 duties or the work that you do to reduce the workload on your heart. Speak to your employer about your work options.

You may also decide that you need to reduce your hours, either for a while or permanently, to help you cope with your symptoms. You can discuss with your employer what options are available to you.

For more information, see our booklet Returning to work.

Money matters
If you’ve had to reduce your working hours, or can’t 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 citizens advice office
  www.citizensadvice.org.uk
- Department for Work and Pensions
  www.dwp.gov.uk
- Gov.uk
  www.gov.uk
Rob had a heart attack in 2014, which left him with heart failure and needing an ICD.

“I had some quite severe damage to my heart. I’m aware it’s not right, but I try and look after myself as much as I can. I monitor my weight and blood pressure regularly and have to go for a blood test now and then. I have my ICD checked regularly and it’s been fine.

I’ve gone back to work, but I’m always careful. I don’t do anything that’s beyond me. Now I just enjoy doing the everyday things, like spending time with my granddaughter. I like live music too, so I do a lot of festivals and concert-going.

The healthcare I receive is excellent. The last time I went to see my heart failure nurse, I bounced in to my appointment and my nurse said ‘I can just tell you’re doing alright.’”
Driving
If you have an ordinary licence to drive a car or motorcycle, you’re likely to be able to continue to drive, as long as you don’t have any symptoms that might affect your driving. Talk to your GP about whether it’s OK for you to drive and whether you need to tell the Driver and Vehicle Licensing Agency (DVLA) about your condition. You should also tell your motor insurance company about your heart condition.

If you have a licence to drive a lorry or bus, special regulations apply. You’ll need to tell the DVLA about your medical condition and check with them whether you can continue to drive.

If you have a treatment such as an ICD, different rules about driving may apply. For more information on this, contact the DVLA.

To find out if you need to tell the DVLA about your medical condition, or about a change in your health, visit www.gov.uk/browse/driving/disability-health-condition. Or call the DVLA on 0300 790 6806. Or write to them at DVLA, Swansea SA99 1TU.

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 and whether it’s OK for you to fly.

When you go on holiday, you might want to think about staying in accommodation that’s easily accessible. Avoid hilly destinations unless you’re fit enough for that level of activity. And it’s a good idea to avoid very hot or very cold destinations.

If you take diuretics and you’re going somewhere hot, talk to your doctor before you go away. He or she may advise you that if you get dizzy or faint, you may need to reduce or stop your dose of diuretics to prevent further dehydration.

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

Travelling can be tiring and long journeys can increase your risk of developing a type of blood clot called deep vein thrombosis (DVT). So make sure that you have frequent breaks when you can get up and walk...
around. Whichever form of transport you’re using, 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 failure 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.

If you’re not sure whether it’s safe for you to have sex, talk to your GP.

Loss of sex drive, or a lack of energy to have sex, is not uncommon and some men may experience impotence (having difficulty getting or keeping 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’re 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 other medicines you’re taking.

*For more information on and support about sexual problems, contact the Sexual Advice Association. Phone: 020 7486 7262. Website: www.sda.uk.net*

**Anxiety and stress**

It’s 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’s also important to discuss your worries 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.

Emotions
It’s normal to feel low or sad from time to time. You may feel down about your symptoms and your limitations, or feel that you have a lack of control over your life. Some people find it very difficult to live with the uncertainty of having heart failure. But learning about your condition and being involved in making decisions about your treatment will all help you to feel more in control.

If you’re finding things hard, talk to your care team, who will be able to help you. If you feel low all of the time, you may be depressed. Talk to your doctor or nurse about the best way of dealing with this.

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 help. Some people also find joining a heart support group helpful, because you can meet others who have gone through similar experiences (see page 73).

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 other people. Discuss how you feel with the relevant people, and listen to them when they tell you how they feel.

If you have children or grandchildren
You may find that your condition makes it harder for you to look after your children or grandchildren. If you get tired very easily, you may need to make some adjustments. Although you may not be able to play more active games 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.

For more information, see:
• our book An everyday guide to living with heart failure, and
• our DVD One step at a time – Living with heart failure.
**IF YOUR HEART FAILURE GETS WORSE**

Heart failure is a progressive condition, so there may come a time when your symptoms get worse or you’re told that nothing more can be done to improve your condition. This can be a shock and may make you feel very sad or angry. But remember that you’re not alone, and support and help are available. 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 either in hospital or 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 also be referred to other health professionals who can help.

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

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

**Palliative care**
If your heart failure has got worse with on-going symptoms, despite being on treatment, 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 can’t be cured.

Your specialist heart failure nurse may provide this, or you may be supported by 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, such as:

- where you’d like to be cared for towards the end of your life – for example, at home or in a hospice
- what treatment you would or wouldn’t like to have, or
- how to get information on different types of wills.

This is known as **advance care planning**. It’s good to talk to people who are supportive, knowledgeable and understanding. Conversations like this can be difficult, but they can help you to be cared for in the best way. 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 Hospice UK on **020 7520 8200** (website [www.hospiceuk.org](http://www.hospiceuk.org)). Or see the NHS website [www.nhs.uk/Planners/end-of-life-care](http://www.nhs.uk/Planners/end-of-life-care).

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

It’s important to allow the person you’re caring for to do things for themselves. This can be difficult, but allowing them to make their own decisions can help them feel in control. Talk to them about how you can help them.

As the carer, you might be entitled to extra support, services and benefits, to help you care for the person you’re looking after. For information on this, contact one of the organisations listed in *Money matters* on page 45. For information about the Carer’s Allowance contact the Carer’s Allowance Unit at [www.gov.uk/carers-allowance-unit](http://www.gov.uk/carers-allowance-unit), or call **0345 608 4321**.

It’s important that you look after your own health and have regular breaks. Don’t be afraid to ask for help, and accept help if people offer it. Remember that doctors, nurses, social workers, relatives, friends and voluntary groups can all support you.

You may be able to arrange for someone to come into your home and take over caring for the person.

For more information about palliative care and end-of-life decisions or decisions about your future care, see our book *An everyday guide to living with heart failure*. 
A heart attack is when a part of the heart muscle suddenly loses its blood supply. This is usually due to coronary heart disease.

**The symptoms of a heart attack**

- Pain or discomfort in the chest that doesn’t go away.
- The pain may spread to the left or right arm ...
- ... or may spread to the neck and jaw.
- You may feel sick or short of breath.

For more information for carers, see the section for carers in our book *An everyday guide to living with heart failure*, or our booklet *Caring for someone with a heart condition.*
A cardiac arrest is when a person’s heart stops pumping blood round their body and they become unconscious and stop breathing or stop breathing normally.

A person who is having a cardiac arrest may develop a dangerously fast heart rhythm which can be fatal. It is sometimes possible to shock the heart back into a normal heart rhythm by giving defibrillation. This means giving the heart an electrical shock using a defibrillator.

There are now public access defibrillators – or PADs for short – in many workplaces, shopping centres, train stations, leisure centres and village halls. It’s very easy to use a PAD. The machine gives clear, spoken instructions and you don’t need training to use one.

Once switched on, the PAD will instruct you on how to attach the pads, whether or not a shock is needed and how to deliver it.

Find out where the PADs in your local area are.
For more information, go to bhf.org.uk/defibs
The most important thing you can do to help save a person’s life is CPR – cardiopulmonary resuscitation. This, along with defibrillation, can double someone’s chance of survival in some cases. We explain how to do this on the next pages.

If someone has had a cardiac arrest, they will be unconscious, and either not breathing or not breathing normally. The person needs immediate help or they will die within minutes.

First check that it is safe to approach the person.

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, the person is unconscious.

You will need to assess the person’s airway and breathing.

Open the person’s airway by tilting their head back and lifting their chin.

Look, listen and feel for signs of normal breathing. Only do this for up to ten seconds. Don’t confuse gasps with normal breathing. If you’re not sure if their breathing is normal, act as if it is not normal.

Now remember: **Call Push Rescue**
Start chest compressions.

- Place the heel of one hand in the centre of the person’s chest.
- Place the heel of your other hand on top of your first hand and interlock your fingers.
- Press down firmly and smoothly on the chest 30 times, so that the chest is pressed down between five and six centimetres each time. Do this at a rate of about 100 to 120 times a minute. That’s about two times each second.

If the person is unconscious and is either not breathing or not breathing normally, they are in cardiac arrest. Call 999 immediately.

- Send someone else to call 999 for an ambulance while you start CPR.
- Or, if you are alone with the person, call 999 before you start CPR.

CALL...

Call for help.

PUSH...

Push hard and fast on the centre of the chest.
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 soft parts of the person’s nose closed. Take a normal breath, make a seal around their mouth with your mouth, and then breathe out steadily. The person’s chest should rise and fall with each breath. It should take no more than five seconds to give the two rescue breaths.

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

Keep doing the 30 chest compressions followed by two rescue breaths until:

- the person starts to show signs of regaining consciousness, such as coughing, opening their eyes, speaking, or moving purposefully and starts to breathe normally, or
- you become exhausted.

If you prefer not to give rescue breaths
If you’d rather not give rescue breaths, call 999 and then deliver hands-only CPR. Keep doing the chest compressions – at a rate of about 100 to 120 times a minute.

For more on this, see bhf.org.uk/handsonly

For more information about training in how to do CPR, see page 72.
Booklets and DVDs
To order our booklets or DVDs:

- call the BHF Orderline on 0300 200 2222
- email orderline@bhf.org.uk or
- visit bfh.org.uk/publications

You can also download many of our publications from our website.

Our resources and services are free of charge, but we rely on donations to continue our vital work. If you’d like to make a donation, please call our donation hotline on 0300 330 3322 or visit our website at bfh.org.uk/donate
For more information on heart failure

An everyday guide to living with heart failure
A book with 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.

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 Failure Matters website – www.heartfailurematters.org
This website, produced by the European Society of Cardiology, provides information and practical advice for people with heart failure, their families and carers.
Our services
For more information about any of our services, contact the BHF on 0300 330 3322 or visit bhf.org.uk

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 eligible secondary schools, and for a small fee to workplaces and community groups. It has everything you need to learn CPR, including a training DVD.

Heart Matters
Heart Matters is the BHF’s free, personalised service offering information to help you lead a heart-healthy lifestyle. Join today and enjoy the benefits, including Heart Matters magazine and access to online tools. Call the Heart Matters Helpline on 0808 802 1234, or join online at bhf.org.uk/heartmatters

Heart Support Groups
Local Heart Support Groups give you the chance to talk about your own experience with other heart patients and their carers. They may also include exercise classes, talks by guest speakers, and social get-togethers. To find out if there is a Heart Support Group in your area, contact the Heart Helpline on 0808 802 1234.

Help shape the BHF – Heart Voices
Heart Voices is a growing network of heart patients who use their experiences to make sure our work meets the needs of patients. By signing up, you’ll get the chance to shape the BHF by getting involved with anything from helping us to make new resources to informing our research. Visit bhf.org.uk/heartvoices for more information and to sign up.
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THANK YOU

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- **Iftekar Gogah**, Heart Failure Nurse Specialist, King’s College Hospital NHS Foundation Trust.

This booklet is part of the *Heart Information Series*. We distribute 2 million booklets from this series each year. Without your hard work and support the British Heart Foundation wouldn’t be able to provide this vital information for people with heart conditions.

Donate to the fight at [bhf.org.uk/donate](http://bhf.org.uk/donate), or text **FIGHT** to **70080** to donate £3 to fund our life saving research.

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 [bhf.org.uk/contact](http://bhf.org.uk/contact). Or, write to us at:

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Birmingham Business Park
Birmingham B37 7YE
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.

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