



Implantable cardioverter defibrillators (ICDs)

Helen Cawthorne

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CONTENTS

About this booklet	02
What is an ICD?	03
Why do I need an ICD?	04
Abnormal heart rhythms	05
How does an ICD work?	12
Before your ICD is fitted	17
How is an ICD fitted?	19
Recovering after your ICD has been fitted	24
Possible complications	30
Getting used to your ICD	34
Adjusting emotionally to your ICD	38
Follow-up and battery life	40
Everyday life with your ICD	48
Can everyday equipment interfere with an ICD?	57
What’s the difference between a heart attack and a cardiac arrest?	64
Cardiac arrest? The symptoms ... and what to do	65
For more information	72
Index	77
Have your say	80

This booklet is for people who have been told they need an **implantable cardioverter defibrillator** (ICD) or who already have one. Your family and friends might also find it helpful.

This booklet explains:

- what an ICD is
- why you might need one
- how an ICD works and how it's fitted
- what it's like to live with an ICD, and
- how to take care of your ICD.

This information doesn't replace the advice that your doctor, nurse or other healthcare professional may give you, but it should help you to understand what they tell you.

An ICD is a small electrical device used to treat some types of abnormal heart rhythm, or arrhythmia, which can be life-threatening.

It's a little bigger than a matchbox in size, and it's usually inserted just under your collarbone. It's made up of:

- **a pulse generator** – a battery-powered electronic circuit, and
- one or more **electrode leads**, which are placed into your heart through a vein.

An ICD checks your heart rhythm all the time. If it senses a dangerous abnormal heart rhythm, it can give your heart electric pulses or shocks to get your heart rhythm back to normal.

We explain more about how an ICD works on page 12 and how it's inserted on page 19.

You might need an ICD if:

- you have already had a life-threatening abnormal heart rhythm and are at risk of having one again
- you haven't had a life-threatening heart rhythm but you have had tests that show you're at risk of one in the future. This is usually because you have inherited certain faulty genes and may have a heart condition such as **cardiomyopathy**
- you have another type of heart condition, such as **heart failure**, and have had, or are at risk of having, a life-threatening abnormal heart rhythm
- you have had other treatments to treat your heart rhythm which have been unsuccessful.

ICDs have transformed the lives of many people with life-threatening abnormal heart rhythms. Most people feel more confident once they've had an ICD.

How does your heart beat normally?

To understand how an ICD works, it helps to know how the heart beats normally and how it pumps blood around your body.

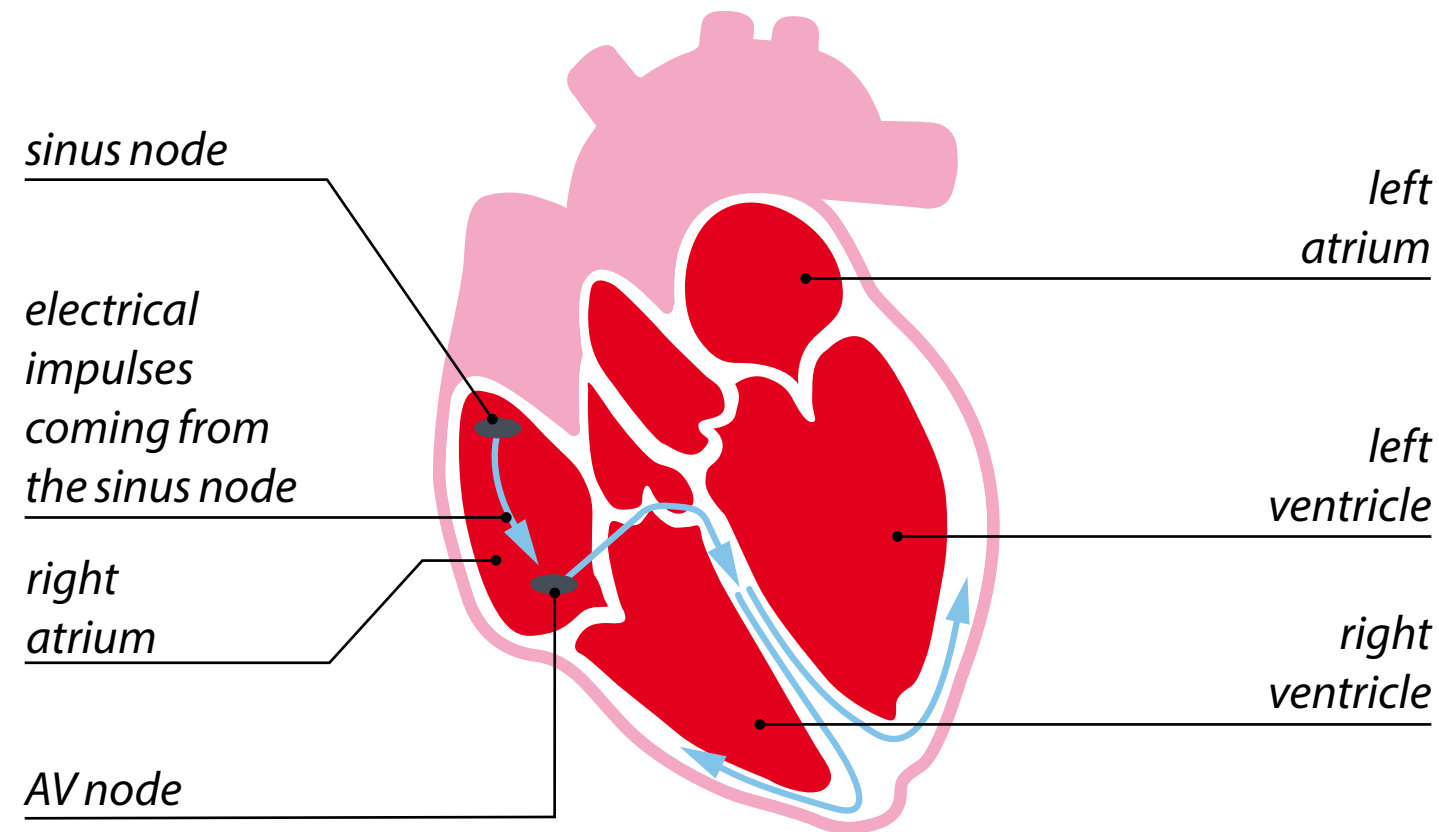
Your heart is a muscle which pumps blood to your lungs, your brain and the rest of your body. It has four chambers – two upper ones called the right and left **atria**, and two lower ones called the right and left **ventricles**. See the illustration on the next page.

Your heart's pumping action is controlled by tiny electrical impulses produced by a part of the right atrium called the **sinus node**. Your sinus node is your heart's natural pacemaker. It sends out regular impulses that travel through an electrical pathway in your heart.

These impulses help to co-ordinate the chambers of your heart as they contract and pump blood through your heart and out to your body. This is what causes your **pulse**.

A healthy adult heart has a regular beat that's usually between 60 and 100 beats per minute (bpm) while you are resting. When you exercise, it may go up, depending on your age and how fit you are.

Normal electrical signals in the heart



Watch our video showing how a normal heart beats at bhf.org.uk/arrhythmia

How is my heart different?

If you have an abnormal heart rhythm, or arrhythmia, this usually means something has gone wrong with your heart's electrical system. Your heart is beating too slowly, too quickly, or in an irregular way.

There are many different types of abnormal heart rhythm, some more serious than others. Here we focus on ventricular arrhythmias, which start in the lower chambers of your heart, and we look at how ICDs are used to treat them.

Ventricular arrhythmias

Ventricular arrhythmias are abnormally fast rhythms. They can happen suddenly and can be very dangerous.



For information on other abnormal heart rhythms, see our booklet **Heart rhythms**.

What causes ventricular arrhythmias?

Ventricular arrhythmias have many different causes, but they usually affect people whose heart muscle is damaged, including those:

- who are having, or have just had, a heart attack
- who have had a previous heart attack or heart bypass surgery
- who have a heart muscle disease called cardiomyopathy, or
- who have heart failure, which means their heart isn't pumping as well as it should.

Less commonly, people with a healthy heart muscle have ventricular arrhythmias. This might be because they have an inherited heart condition, such as **Long QT syndrome (LQTS)** or **Brugada syndrome**.

Occasionally, we don't know why someone has a ventricular arrhythmia, but this is extremely rare.

There are two main types of ventricular arrhythmia:

- **ventricular tachycardia (VT)**, and
- **ventricular fibrillation (VF)**.

Ventricular tachycardia

Ventricular tachycardia (VT) is an emergency condition that can happen when your heart beats much too fast. Symptoms include palpitations (heart 'flutterings'), dizziness, breathlessness and chest pain. VT can also cause you to sweat, feel sick or collapse. This may last for seconds, minutes or longer.

Sometimes VT stops on its own, without any treatment. However, if this doesn't happen then you'll need to be treated quickly to stop your blood pressure from falling too low, which could lead to a cardiac arrest.



For information on these conditions, see our booklet **Life with inherited abnormal heart rhythms**.

Ventricular fibrillation

Ventricular fibrillation (VF) is a fast rhythm that causes your heart to 'fibrillate', or quiver. When your heart fibrillates, blood doesn't get pumped around your body. This is known as a **cardiac arrest**. This is a medical emergency and without treatment the person will die within a few minutes. To find out what to do if someone has a cardiac arrest, see page 67. For information on a course in emergency life support skills, see page 75.

Treatment for ventricular arrhythmias

Emergency treatment

If you're unwell with VT but have not had a cardiac arrest, you'll be given **medicines** directly into your veins (intravenous) or a small **electric shock** through your chest (**electrical cardioversion**), or both.

If you have a VF, or if you have a VT that causes a cardiac arrest, you'll be given immediate **cardiopulmonary resuscitation (CPR)** and **defibrillation**, as well as medicines. We explain these treatments on page 65.

Non-emergency treatment

If you're at risk of ventricular arrhythmias then you're likely to be given medicines to help prevent the condition. Sometimes a **catheter ablation** is carried out to try to destroy the cells that are causing the problem. However, most people with ventricular arrhythmias will be offered an ICD.

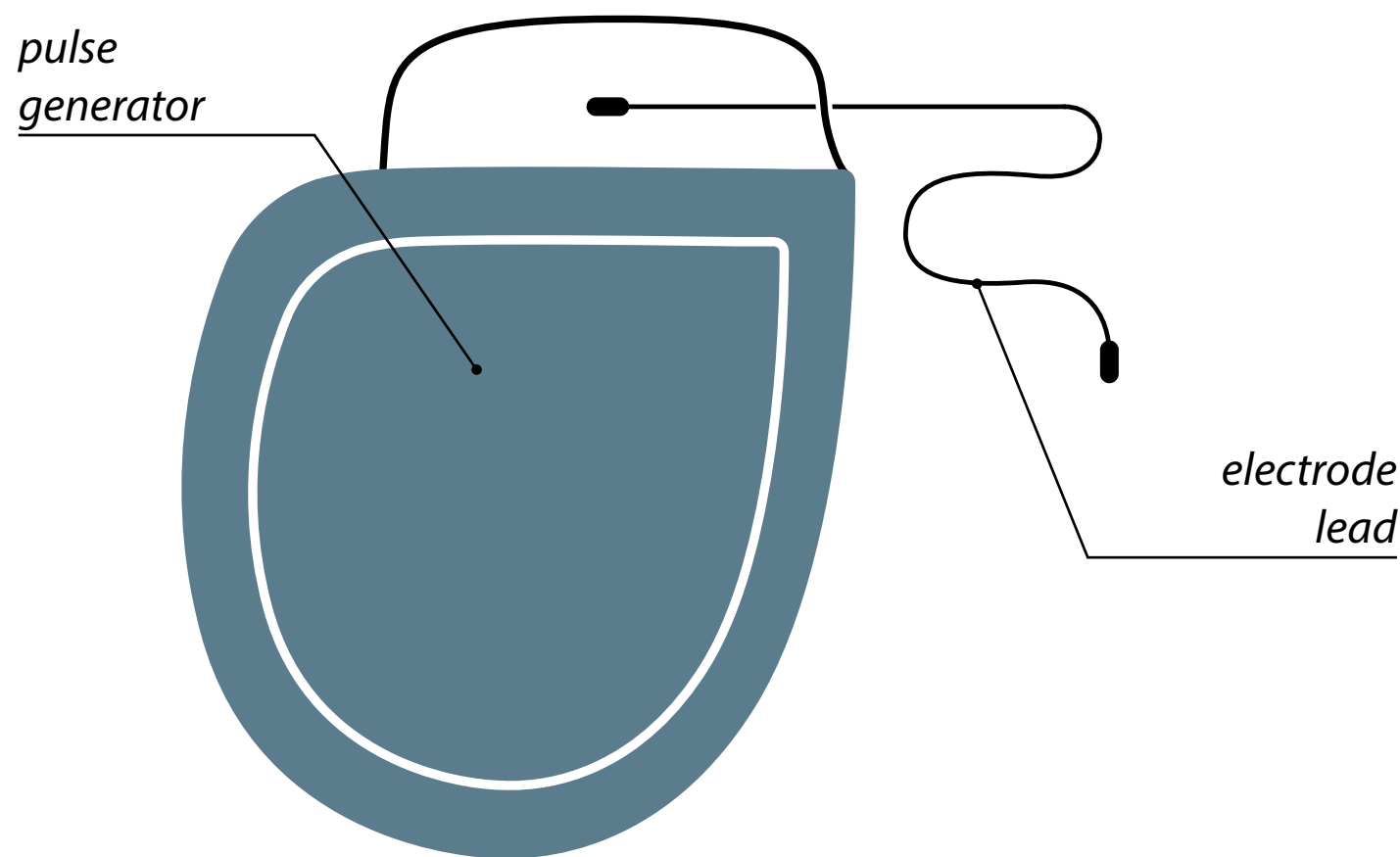
ICDs are used to treat ventricular arrhythmias. They don't prevent a heart attack, which is when the blood supply to part of the heart muscle is suddenly interrupted. See page 64 for more information on the difference between a heart attack and a cardiac arrest.



For more information, see our booklet **Heart rhythms**.

An ICD consists of a pulse generator (the box) and one, two or three leads.

ICD



*Actual size varies, but on average is about 5.1 centimetres (2 inches) wide by 6.4 centimetres (2.5 inches) high.
The electrode lead is longer than shown above.*

The pulse generator is slightly larger than a small matchbox and weighs about 75 grams (3 ounces). It contains an electronic circuit, powered by a lithium battery, in a sealed metal unit. The generator is connected to one or more leads which pass through a vein – usually the large vein under your collarbone – and into your heart. These leads are fine, flexible wires with electrodes at the end that are attached to your heart.

An ICD checks your heart rhythm all the time. If your ICD senses a dangerous abnormal heart rhythm it can give you two different types of treatment, depending on the type of abnormal heart rhythm your ICD picks up:

- **fast pacing**, and
- **electric shocks** (shock therapy).

Fast pacing

If the ICD detects ventricular tachycardia (VT), it delivers a short series of electric impulses (paced beats) at a fast rate. This often corrects the heart rhythm without the need for an electric shock. It's called **anti-tachycardia pacing** (ATP).

Electric shocks (shock therapy)

If the ICD still senses VT after the pacing, it can deliver an electric shock, known as **cardioversion**. If this isn't successful, or if the ICD detects the heart 'quivering' (ventricular fibrillation or VF), the device will deliver a larger shock, known as **defibrillation**, to try to restore the heart's normal rhythm. This type of shock can feel like a sharp thump or kick in your chest or back. Sometimes, more than one shock is needed.

An ICD is a very sophisticated device that uses a combination of fast pacing and electric shocks, depending on the type of abnormal rhythm that needs to be treated.

An ICD can also act like a regular pacemaker if your heart beats too slowly, sending a series of electric pulses to speed it up. These impulses are small and you won't usually feel them. This is called **anti-bradycardia pacing**.

Subcutaneous ICD

Some people are more suited to a new type of ICD called a **subcutaneous ICD**, or **SICD**.

With a SICD, the lead is inserted under the skin of your chest, rather than through your blood vessels and into your heart, so having it fitted is more straightforward. See page 22.

A SICD delivers electric shocks, or **defibrillation**, to restore your heart's normal rhythm. Currently, it doesn't deliver fast pacing (ATP) or pacing for slow rhythms (anti-bradycardia pacing), so if you need these functions then a SICD won't be suitable for you. Your doctor or nurse will discuss having a SICD with you and if they think it is suitable for your condition.

Cardiac resynchronisation therapy with a defibrillator (CRT-D)

Some people with heart failure who are also at risk of developing a life-threatening heart rhythm might be given **cardiac resynchronisation therapy with a defibrillator**, or CRT-D. This is a single device that combines a three-lead (biventricular) pacemaker with an ICD. The leads and the CRT-D work together to make sure that the ventricles beat in time. This is called cardiac resynchronisation therapy. The ICD works in the same way as any other ICD. The device can help to control your symptoms, but it won't cure heart failure.



For more on CRT-D, see our booklets **Living with a pacemaker** and **Living with heart failure**.

You'll have several tests before you have your ICD. They may include:

- an ECG (electrocardiogram), which records your heart's electrical activity. You may also need to have a 24-hour ECG recording
- a cardiac event recorder, or a small device called an implantable loop recorder, which measures your heart rhythm over a longer period
- an ultrasound scan of your heart (echocardiogram)
- an EPS (electrophysiological study) to diagnose abnormal heart rhythms and identify where they are coming from
- a coronary angiogram, which detects any narrowing of your arteries
- blood tests. These will usually include tests to check the state of your general health, how your kidneys are functioning and the levels of certain salts and minerals in your body (electrolyte balance).



For more information, see our booklet **Tests** or our DVD **The road ahead – your guide to heart tests and treatments**.

If you've had a cardiac arrest, you'll usually have your ICD fitted while you're in hospital. If you're having the procedure as a day case, or day patient, you might be seen at a pre-assessment clinic and you should have counselling with a specialist nurse or doctor.

Whether you have your ICD as an emergency or by appointment, a nurse or doctor will discuss any concerns you may have and explain the procedure, along with the pros and cons of having an ICD.

If your ICD isn't fitted as a day case, you might need to stay in hospital overnight or for a few days. The procedure takes place in a cardiac catheter lab, or cath lab. It can take from one hour to three or more hours, depending on the type of device you're having. You won't be able to eat or drink for a few hours beforehand, and you'll normally be given a sedative and a local anaesthetic, so you'll be relaxed and not in any pain.

Your ICD will be fitted under sterile conditions and you'll be given antibiotics before, and sometimes after, the procedure to reduce your risk of infection.

There are two stages to fitting an ICD:

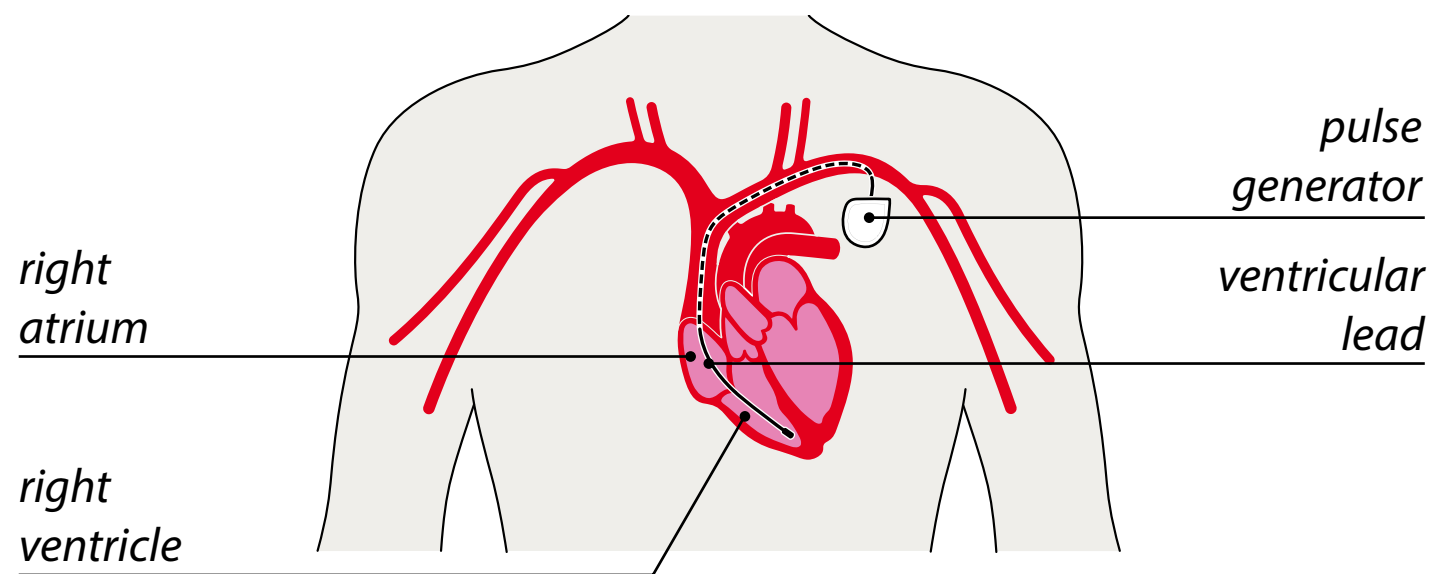
- the leads are inserted first, then
- the pulse generator is implanted.

Inserting the leads

If you are having an ICD, a small cut is made in the skin under your left collarbone. The lead (or leads) is then fed through a vein into the lower right chamber (ventricle) of your heart. This process is known as transvenous implantation. Many people also have a lead inserted into their upper right chamber (atrium).

Implanting an ICD with a single lead

A single lead is placed in the right ventricle.

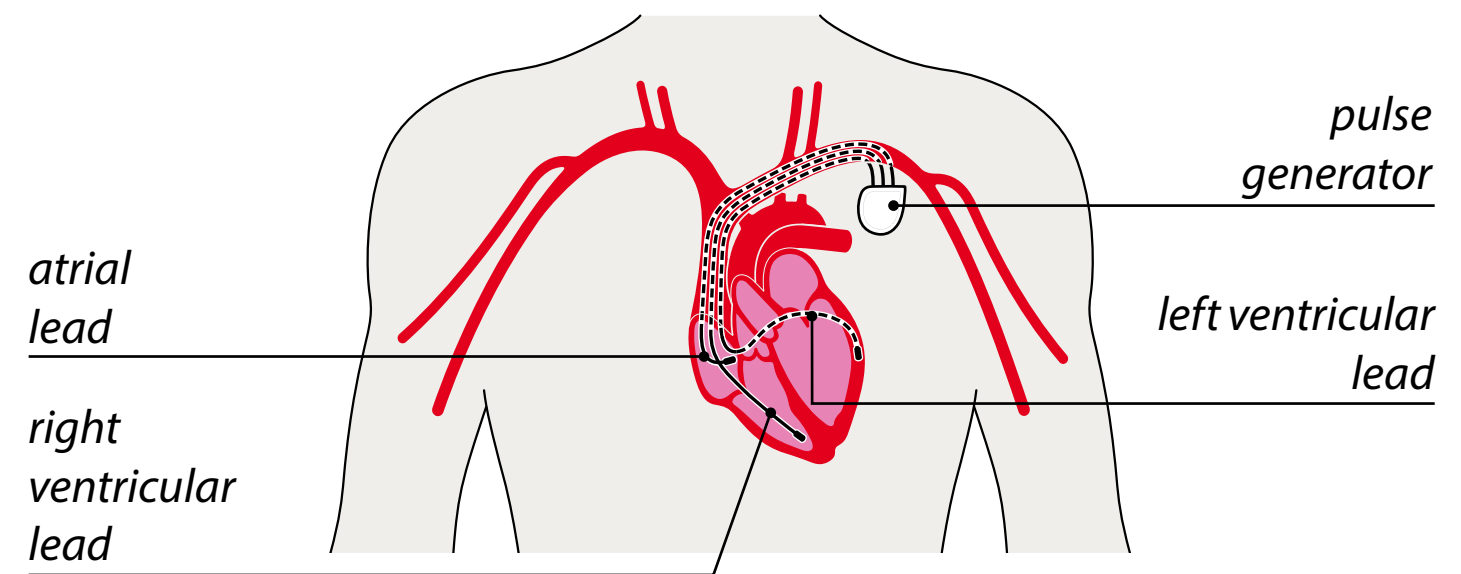


If you're having a CRT-D (see the illustration below), one lead is inserted into the upper right chamber of your heart (atrium), one into the lower right chamber (ventricle) and the third is placed on the far side of the left ventricle.

The position of the lead (or leads) is checked on an X-ray and they're then secured in place.

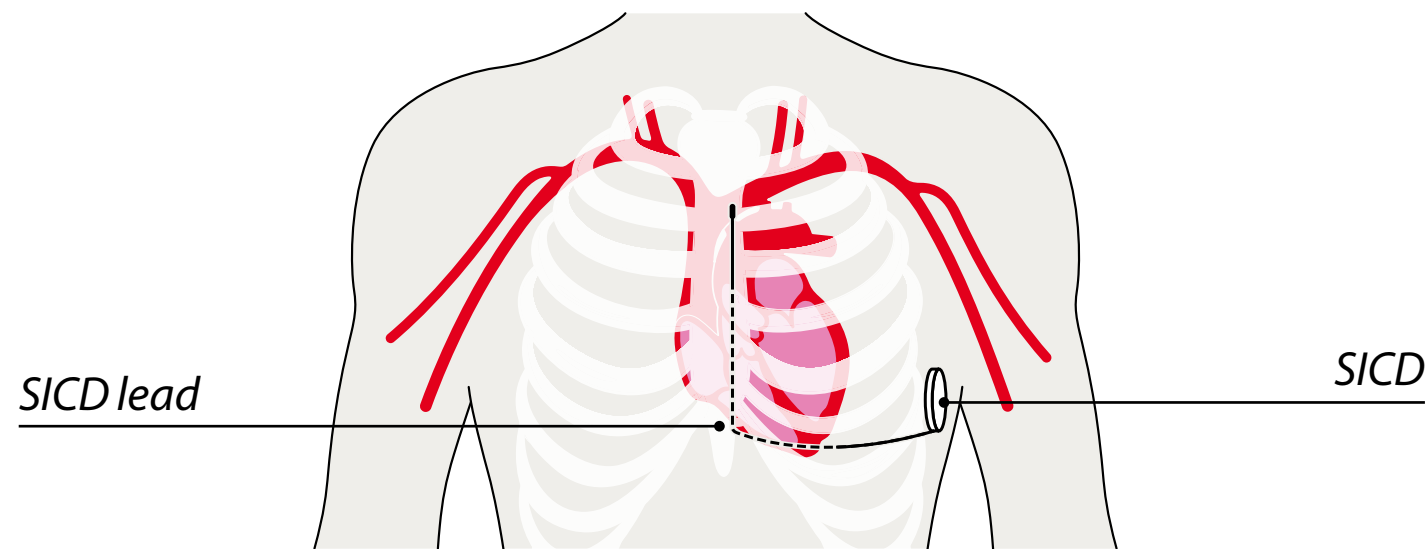
Implanting an ICD with two or three leads

If two leads are used, one is placed in the right ventricle and the other in the right atrium. If a third lead is used, it may be placed in the left ventricle.



If you're having a SICD, a single lead will be passed through the skin on your chest rather than into your heart (subcutaneous implantation). The box is bigger than an ordinary ICD and can usually be seen under the skin.

Implanting a SICD



Implanting the pulse generator (box)

Once the leads are in place, the cardiologist makes a small 'pocket' under your muscle or skin, usually below your left collarbone (see pages 20 and 21). If you're having a SICD, the pocket will be on the left side of your chest, below your armpit. The cardiologist then attaches the pulse generator to the leads and places it in the pocket and the wound is closed with stitches or glue.

Occasionally, the team may put the heart into an abnormal rhythm to check that the ICD is working correctly. You'll be sedated while they do this.

When you get back to the ward, the nurse will check your blood pressure, heart rate and rhythm, and also examine your wound for any bleeding or swelling.

You'll need to stay in bed for a short while. Once the sedation has worn off, you'll be allowed to eat and drink. The nurse will tell you the best way to sit up and when you can walk around. You'll usually be able to get out of bed quite soon and this will help to build your confidence for when you go home.

You may feel some discomfort and there can be quite a lot of bruising around the ICD site but this won't usually last long. A doctor will prescribe painkillers if you need them.

You must take care not to put too much pressure on the arm nearest the ICD (usually the left), or to lift your arm above your shoulder, so that you don't disturb the leads as they settle into place. For more on this, see page 27.

The cut will be about 4 to 7 centimetres (2 inches) long. You'll have a dressing over the wound and may have padding to help stop any bleeding.

It's important to keep your wound dry for the first few days while it heals, particularly if you have stitches that need to be removed. If your wound has been glued, you can shower straight away, but you should gently pat the area dry rather than rubbing it.

Before you leave hospital

You may have a chest X-ray before you go home to make sure that the leads haven't moved. A doctor will also check the ICD and the settings and, if necessary, make some adjustments using a computer. All these checks are painless.

Information about your ICD

The cardiac physiologist will also explain any special features of your particular type of ICD. For example, some can be programmed to make a sound or vibrate when the battery is getting low or if there are problems with the leads.

You'll be given the phone number of your ICD clinic and will probably be asked to contact them if your ICD delivers a shock. See page 35.

You'll also be given an **ICD identification card**, which has details of your type of ICD. Always carry this with you in case of an emergency.

Stitches

The incision (cut) will probably be closed with stitches that dissolve, but you might have stitches that need to be removed. If so, the nurse at your local GP practice can do this for you. Sometimes, special glue is used instead of stitches. This, like the soluble stitches, will slowly dissolve.

Before you leave hospital, you may be given a letter for your GP, explaining that you've had an ICD fitted, and the hospital will also write directly to your GP about it.

Arrhythmia nurses

Many hospitals now have specialist cardiac (heart) nurses, including arrhythmia nurses. You'll see one of these nurses at the hospital and at your follow-up appointments. They sometimes make home visits, too.

TOP TIPS...

on moving your arm in the first four to six weeks

- 1 Don't lift your arm on the ICD side above your shoulder for the first six weeks.
 - 2 When you're washing or combing your hair, move your arm slowly, as any sudden stretching may disturb the lead or leads.
 - 3 Avoid lifting heavy objects with the arm on the ICD side.
- These above steps help to prevent the leads moving (**lead displacement**) while they're healing securely into place.
- 4 Gently rotate your shoulder and move your head from side to side to avoid stiffness in your neck, shoulder and arm.

It's important that you return to your normal daily activities gradually and don't disturb the lead or leads as they settle into place but by six weeks they should be firmly embedded in place.

HELEN'S STORY

Helen had a cardiac arrest in 2011 and was diagnosed with cardiomyopathy. She had an ICD fitted soon after.

“Having the ICD was quite scary at the outset but then I thought, ‘Well, if it saves my life then I have to go with it, I can’t take that risk’.

It took me a while to go out on my own in case anything happened, but once I got my confidence back I realised life can go on. You learn to accommodate a little. I used to run and now I walk instead. I can’t raise my left arm high for very long, but the scarring is minimal. My ICD has never given a shock. I manage my condition with medicines and I’m sensible about what I can do. I know when it’s working and I know when I need to slow down.

You learn to live with it. Actually, I think of it as living with me – it’s like a tenant.”



Find out more about Helen's story at
bhf.org.uk/helens-arvc



Serious complications from having an ICD fitted are extremely rare, however, there's always a small risk with any heart procedure. Your doctor or nurse will discuss this with you beforehand.

Infection

There's a small risk of infection at the site where the ICD is implanted. If, after you get home or at any time, your wound or the area around the ICD becomes redder or more swollen, or if you notice pus coming from the wound or you develop a high temperature, contact your ICD clinic **immediately**.

If you do get an infection, your doctor will prescribe antibiotics. It's important that you take them as your doctor advises and that you finish the course. Occasionally, if the infection doesn't clear up, the ICD might have to be replaced, but this is very rare.

Bruising

Bruising is common after having an ICD fitted and it may affect your chest and arm for some weeks. If you're concerned that the bruising is getting worse, contact your ICD clinic or your GP.

Bleeding

As with any procedure that involves an incision (cut), there will be some bleeding. Sometimes the bleeding takes longer than usual to stop, which can cause more bruising. If this happens, the nurse might apply pressure dressings. This is more likely to happen if you are taking warfarin, aspirin or other medicines that affect how your blood clots. In rare cases, a person might need to go back to the cath lab for the doctor to control the bleeding.

Lead displacement

There's a small risk that the lead, or leads, may move (lead displacement). To reduce the chances of this happening, you should avoid strenuous physical activity, heavy lifting, or raising the arm nearest the ICD (usually the left) above your shoulder until after your first check-up – usually about four to six weeks later. For more on this, see 'Top tips on moving your arm in the first six weeks' on page 27.

Collapsed lung

There's a small risk of a collapsed lung (pneumothorax) during or after the procedure. This is when air leaks from your lungs into your chest. Your doctors will check for this on an X-ray before you leave hospital. If it does happen, it may get better without any treatment but sometimes a chest drain, or tube, is put in to allow the air to escape.

Technical problems

Technical problems – such as the battery or the leads not working properly – are extremely rare. However, this is one reason why regular follow-up checks at your ICD clinic are important.

Other types of abnormal heart rhythm

Some people with an ICD also get abnormal heart rhythms from the upper chambers of their heart (the atria). These aren't life-threatening but they can cause your heart to beat very fast. If this happens, your ICD might deliver a shock when it isn't needed because it's detected that fast heart rhythm.

If this happens, your clinic may re-programme your ICD to try to prevent it happening again. That's one of the reasons why it's so important to report all shocks to your clinic.

Occasionally, the ICD might read the heart rhythm wrongly and deliver a shock when it isn't needed. See page 35 for what to do if your ICD delivers a shock.

In rare cases, the ICD might not give the correct treatment when needed. If you feel unwell and think your ICD may not have responded correctly, call 999 for an ambulance.

If you have a cardiac arrest (see page 65) and your ICD doesn't seem to have worked, you might need to have **external defibrillation**. This is when your heart is given an electric shock manually by someone using a device called a **defibrillator**. You may also need a procedure called **cardiopulmonary resuscitation** (CPR), see page 66. Both defibrillation and CPR can be given in the usual way to people with an ICD.

Will I be able to feel my ICD?

Most people are aware of their ICD but they get used to it quickly. You might be able to feel it under your skin and its outline may show.

How it might feel when the ICD delivers its treatment

This varies greatly from person to person, but here's a rough guide to what you might expect.

If an ICD is delivering pacing impulses (ATP, or fast pacing, see page 13), you may feel palpitations or 'fluttering' in your chest.

If you have an abnormal heart beat (arrhythmia) that triggers the ICD to deliver an electric shock, either as cardioversion (see page 14) or defibrillation (see page 15), it's possible that you may collapse or become unconscious. If this happens, you might not feel the shock. However, if you're conscious, the shock might feel like a sharp thump or kick in your chest or back. Some people say it feels like being kicked by a horse, but there's no pain or discomfort afterwards.

Each shock is over in less than a second, but you may need more than one shock to restore your heart's normal rhythm. Many people find the shock unpleasant or distressing, especially the first time it happens. However, some people don't feel it at all, or describe it as barely noticeable.

Warning symptoms before an electric shock

Some people don't get any warning, while others have symptoms such as dizziness or heart 'flutterings' (palpitations). If your rhythm is seriously abnormal, you could collapse before the shock is delivered. If you notice any warning symptoms, sit or lie down so that you don't fall and hurt yourself.

After the ICD has delivered an electric shock

Once the shock has been delivered and your heart is back to a normal rhythm, you may want to rest for a while.

Most clinics ask you to let them know if your device delivers a shock. Ask the staff at your clinic about this as the advice can vary from one clinic to another.

If you felt unwell before the ICD delivered its shock, or feel unwell after recovering from the shock, you should call an ambulance or ask someone to take you to your nearest accident and emergency department. The staff can then assess you and monitor your heart. They'll contact your ICD clinic if necessary.

What if someone is touching me when my ICD delivers an electric shock?

If someone is touching you, they may feel a slight tingling sensation, which isn't dangerous, but most people won't feel anything.

You might jump or cry out when you feel the shock and this could frighten anyone with you. It's important that they stay calm, stay with you and reassure you. Relatives and friends need to know what might happen and understand that it's safe for them to be there and that you can find it very comforting to have them with you. Give your friends and relatives the phone number of your ICD clinic so that they know who to contact if they are there when your ICD delivers a treatment.

Will I still have to take heart medicines?

Most people with an ICD still need to take medicines to help prevent any abnormal heart rhythms. You may also need to continue taking medicines for any other heart or other medical conditions that you might have, such as angina, heart failure or diabetes.

Travelling abroad with an ICD

You can go abroad but always remember to carry your ICD identification card as it contains important information about your particular ICD. Your clinic may be able to give you details of a medical centre in the country you're visiting in case of an emergency. See page 60 for information about going through airport security systems.

Occasionally, people with an ICD have problems getting travel insurance. If this happens, we can give you a list of companies that may agree to insure you.



Download our **Insurance** information sheet at
bhf.org.uk/insurance-information

People experience a range of feelings, both in hospital and when they go home. Everyone differs in how long it takes them to adjust to having an ICD and to come to terms with the events that may have led up to them needing one. Eventually though, most people are reassured knowing that the device is in place to treat their condition.

At first, you may find that your sleep pattern is disturbed and you may feel more aware of your heartbeat. It might take time to adjust, but most people feel back to normal after a few weeks. Your arrhythmia nurse or cardiac physiologist will be able support you through this.

It's normal to feel low or anxious after the ICD delivers a shock treatment. You may find it helpful to discuss how you're feeling with your GP, practice nurse or at the ICD clinic.



See our booklet

Heart to heart – heart disease and your emotional wellbeing.

Support for you and your partner

This varies from one hospital to another. Ask at your clinic what services are available. There might be a **cardiac rehabilitation programme**, for example, which helps people to recover after a heart emergency or procedure (see page 40). There might be a **counselling clinic** where you and your partner can talk through any concerns with a specially trained health professional or there might be a **support group** where you, your family or carers can meet other people who have ICDs and share your experiences.

Reassuring your partner and family

It's usual for people to worry about their loved one when they have had an ICD, particularly when they're going back to their normal life. If your partner or your family are worried, or are being overprotective, your nurse might be able to reassure them. They might also find it helpful to read our booklet *Caring for someone with a heart condition*. Call our **Heart Helpline** on **0300 330 3311** to see if there's a support group in your area.

Cardiac rehabilitation programme

You should be invited to go to a cardiac rehabilitation programme, which you can start a short while after you get home from hospital. This is a programme of exercise and information sessions that will help you to get back to everyday life as quickly as possible and keep your heart healthy.

To find your nearest cardiac rehabilitation programme, ask your GP or at your clinic, visit www.cardiac-rehabilitation.net, or call our Heart Helpline on 0300 330 3311.

Follow-up appointments

It's very important to have regular follow-up appointments at your ICD clinic so that your device can be checked. How often you'll have to attend depends on your particular type of ICD and what treatment, if any, it has delivered. Usually though, you'll need a face-to-face appointment once a year and you will have these for the rest of your life.

At each clinic visit, your ICD will be 'read' for information about any irregular heart rhythms you have had and any treatments the ICD has delivered. The battery will also be checked. A small device called a programmer is placed on your skin, over your ICD. It not only reads the information that the ICD has stored but it can also re-program the ICD if necessary. You won't feel any pain while this is done.

You can also discuss any questions you have and you can contact the clinic team at any time in the future with any problems or concerns.



For more information, see our booklet
Cardiac rehabilitation.

Remote monitoring

Some of the latest ICDs can be followed up from your home with a home monitor. This allows the hospital team to keep a close eye on your ICD without you having to go into hospital, which is particularly useful if you live a long way away or if you need to be followed up frequently. However, this is fairly new technology and isn't yet available with all ICDs.

You'll be given a transmitter about the size of a small radio to plug into an electric socket. It sends information from your ICD by phone, or over the internet, to your clinic or to a monitoring centre.

If there are any problems, the centre will tell your clinic. Remote home monitoring is done in addition to your follow-ups at the clinic – it doesn't replace them. Your clinic will tell you if your ICD can be monitored from home.

Battery life and leads

An ICD battery lasts on average between four and eight years, depending on the type of ICD you have and how often it has delivered pacing or electric shocks. The battery will not be allowed to run out – when it runs low, the ICD will either bleep or vibrate to warn you that it needs to be changed. This means having the whole box, or pulse generator, replaced. This is usually done as a day case. The new incision (cut) will usually be made over the old scar.

The lead, or leads, will be tested at the same time and if they're showing signs of wear they'll also be replaced.

Having a new battery or lead is usually a straightforward procedure, similar to when your ICD was first fitted, as described on page 19.

Deactivating the ICD

There may come a time when your ICD needs to be turned off (deactivated). This may only be temporary – for example, if you're having a procedure called diathermy that involves electricity, or if your ICD is delivering shocks when you don't need them. Your heart will be closely monitored while your ICD is off.

There may also come a time when you decide that you no longer want shock therapy. People who are nearing the end of their lives, for example, sometimes feel that this is the right course for them. A specialist member of your ICD team will be able to support you and your family in making this decision and will arrange for your device to be switched off if this is what you want.

Your specialist nurse or doctor will also discuss this with you and your partner before or just after your ICD is fitted.

For most people having their ICD switched off is a big decision, so it's useful to know that if you change your mind it can be turned on again (re-activated) at any time.



Download our leaflet **Deactivating the shock function of an implantable cardioverter defibrillator towards the end of life**, available at bhf.org.uk/publications

CARL'S STORY

Carl was diagnosed with arrhythmogenic right ventricular cardiomyopathy (ARVC), a rare disease of the heart muscle, when he was 29. He had an ICD fitted in 2009.

"I've had two ablation procedures to try to correct my heart rhythm, and I also take beta-blocker medication. When I was offered an ICD, I was reluctant at first. Even the fear of sudden death couldn't change my mind. But my cardiologist convinced me. He said, 'You enjoy life so much, why not extend it?'

Sometimes it's a bit uncomfortable, such as when I lie on my left side in bed. And it's strange to have a metal battery inside you. I've had two 'shocks' but you might argue it's a small price to pay for my life. My condition doesn't define me. I travel when I can, pursuing my passion for natural history. My heart condition does not, and will not, prevent me from continuing to go out and see the world."



Watch Carl talk about his ICD and his love of spiders at bhf.org.uk/spiders



Your ICD has been designed to allow you to lead as normal a life as possible. However, you might need to make some changes to your lifestyle.

When can I return to work and take up my hobbies again?

This depends on the type of work and hobbies you do. Most people are advised to be off work for four to six weeks to ensure that the ICD leads are firmly in place. Your ICD clinic will be able to give you more detailed advice.

When can I resume sex?

You can resume sex whenever you wish, but in the first few weeks you should avoid sexual positions that may put strain on your upper body or accidentally move the leads. Sex aids such as vibrators are usually safe to use.

It's very rare for people to get a shock from their ICD during sex. If this happens, your partner may feel a slight tingling sensation, but this isn't dangerous for them.

You might find it reassuring for you and your partner to discuss this with a member of the ICD clinic team.

Driving

You must tell the Driver and Vehicle Licensing Agency (DVLA) that you have an ICD. You can contact them at:

DVLA

Swansea

SA99 1TU

Phone: 0300 790 6806

Website: www.gov.uk/defibrillators-and-driving

You must also tell your insurance company.

The rules about driving can be complicated. There are different restrictions depending on why you need an ICD, any treatments that your ICD has delivered, and the type of licence you hold.

The following page includes some general guidance but contact the DVLA or your ICD clinic if you have any queries.

If you have an ordinary driving licence (Group 1 car and lorry drivers)

If you have an ordinary licence you'll need to complete a DEFIB1 form and might have to send your licence back to the DVLA.

If you have a passenger-carrying vehicle (PCV) licence or a large goods vehicle (LGV) licence (Group 2 bus and lorry drivers)

If you have an ICD, you won't be able to hold a PCV or LGV licence. You'll need to complete a VOCH1 form and send it to the DVLA.

Ventricular fibrillation or ventricular tachycardia

If you have had either of these conditions (see pages 9 and 10) you won't be allowed to drive for at least six months after you've had your ICD.

After six months you may be able to drive again provided during that time:

- your ICD hasn't delivered any electric shocks or pacing treatment
- you haven't had any symptoms caused by your abnormal heart rhythm or by the ICD
- you have been to regular follow-up sessions at your ICD clinic, and
- you don't have any other condition that disqualifies you from driving.

If your ICD delivers any treatment after you've received your licence back, you might have to stop driving again, this time for either six or 24 months. Your licence will then be reviewed once more.

It's very important that you report any symptoms to your doctor or ICD clinic in case they're due to your heart condition. If so, your driving could be affected, which could put your life and those of other people at risk.

A few people who have had a ventricular arrhythmia and have an ICD may be able to drive again after one month. For more information about this, talk to your doctor or the DVLA.

If you haven't had a ventricular arrhythmia, but have been given an ICD because you're at risk of having one, you'll only have to stop driving for a month after you've had your ICD fitted.

You shouldn't drive for a week after you've had your ICD battery changed, and if you have a lead repositioned or replaced, or your anti-arrhythmic medicines are changed, you must stop driving for a month. You don't need to inform the DVLA in this instance.

Not being able to drive is a big lifestyle change for many people, so before you have your ICD fitted, you might want to think about how you'll get around. For more information about the regulations visit www.gov.uk/defibrillators-and-driving or call 0300 790 6806.

Physical activity with an ICD

Building physical activity into your everyday routine will help with your recovery and also keep you and your heart healthy.

Your doctor or nurse will advise you about the activities you can do, but it's important to avoid doing anything strenuous for about four to six weeks.

Don't lift the arm on the same side as your ICD above your shoulder, or carry anything heavy with that arm in case you disturb one of the leads while it's settling into position. However, keep your shoulder mobile during the first few weeks by gently moving the arm on the ICD side. You may need pain relief for this.

You can usually resume your normal activities within a few weeks of having your ICD fitted. Start slowly and build up both the time and intensity. Again, your doctor, specialist nurse or cardiac rehab professional can advise you about the level of exercise that's safe for you.

Most people with an ICD can do moderate intensity activity; that is, activity that makes you feel warmer, breathe harder and speeds up your heart rate, but still allows you to carry on a conversation. Warm up before you start your activity and allow yourself time to cool down afterwards. Don't stop suddenly.

Stop exercising if you feel any pain or if you feel dizzy, sick or unwell in any way. If the symptoms don't go or if they come back, see your doctor or go to your nearest accident and emergency department.

If you play contact sports such as football, rugby or martial arts, it's important to avoid a collision as this could damage your ICD. Your doctor or nurse may advise you to wear a protective pad over the site of the device, or they may recommend that you avoid these sports.

You should also avoid activities that could be dangerous if your ICD were to deliver a shock while you're doing them; for example, scuba diving or swimming on your own. You might find it difficult to get insurance cover for some activities such as skiing or extreme sports.

Most of the abnormal heart rhythms (arrhythmias) needed to trigger an ICD electric shock are much faster than your normal heart rate, even when you're doing strenuous exercise. However, occasionally an ICD needs to be programmed to recognise the difference between a normal and an abnormal fast heart rate. If you're concerned about this, ask at your ICD clinic.

Some people are limited in the type or level of activity they can do because of the underlying health condition that caused them to need an ICD in the first place. If you think this might apply to you, talk to your doctor or nurse.

LEADING THE FIGHT...

against heart disease

The BHF is the largest independent funder of cardiovascular research in the UK. Some highlights of our life saving research into ICDs and abnormal heart rhythms include:

- 1** Improving the quality of life for people with ICDs. Researchers are looking at how ICDs can assess dangerous heart rhythms more accurately so that fewer shock treatments are needed.
- 2** Understanding the role of calcium in abnormal heart rhythms. BHF Professor Alan Williams leads a team at Swansea University that's studying the underlying causes of life-threatening arrhythmias.

Our life saving research is powered by your support. If you'd like to make a donation, please see the inside front cover for more details.



For more information on the BHF's research into arrhythmias, see bhf.org.uk/research

CAN EVERYDAY EQUIPMENT INTERFERE WITH AN ICD?

57

Problems with everyday equipment are rare. ICDs have a metal casing to shield them from interference and a special circuit to detect and remove unwanted electrical activity. For more information, read the booklet about your type of ICD that you were given when your device was fitted.

If you have any questions about what you can and can't do, contact your ICD clinic or the manufacturer.

At home

Electrical equipment that you use at home – such as hairdryers and microwave ovens – will not be a problem, as long as they're at least 12 centimetres (5 inches) from your ICD. You should also be able to use household tools such as drills, mowers and electric screwdrivers, as long as they're in good condition. For more details, contact your ICD clinic or the manufacturer.

If you use an induction hob for cooking, keep the appliance at least 60 centimetres (2 feet) from your ICD, as these cookers generate an electromagnetic field that may interfere with your device's settings. However, if you're of average height or above, this won't be a concern.

Phones and computer equipment

Mobiles, cordless phones, tablets, iPods and MP3 players

You can use mobiles, cordless phones, tablets, iPods and other brands of disk-based or solid-state MP3 players, as long as you don't place them directly over your ICD. If you keep them at least 12 centimetres (5 inches) away from your ICD, you avoid any possible risk of interference.

Avoid having headphones within 3 centimetres (just over an inch) of your ICD, so don't put them in a pocket near the ICD or let them dangle around your neck when you're not using them.

When using a mobile or cordless phone, always use the ear on the opposite side to your ICD, and don't put the phone in a shirt pocket over your ICD.

For more information, see the booklet you were given when your device was fitted.

Hands-free kits and Bluetooth

There's no evidence that these devices affect ICDs, but some manufacturers recommend that you use the ear on the opposite side to your ICD.

WiFi, wireless LAN and 3G/4G networks

There's no clear evidence that these interfere with ICDs.

Games consoles

There's no clear evidence that devices such as the Wii, PlayStation or Xbox affect ICDs, but some games manufacturers advise you to contact your ICD manufacturer for more guidance.

TENS machines and body-toning equipment

TENS machines (used for pain relief – for example, for arthritis) and body-toning equipment rely on fast, short, high-voltage electrical pulses. Contact your ICD clinic or manufacturer for more information about using these devices. A TENS machine will probably need to be tested at the clinic to make sure it doesn't interfere with your ICD.

Airport security systems

Airport screening systems rarely cause problems with ICDs. Carry your ICD identification card with you to show the security staff. They may do a hand search or check you with a hand-held metal detector. Make sure the metal detector isn't placed directly over your ICD.

Some countries still insist that you go through the security system. If so, it's unlikely that your ICD will be affected. Just walk through without lingering.

Security systems in shops

Many shops have anti-theft detectors in their doorways. As with airport security, walk steadily through and don't linger – your ICD shouldn't be affected.

Some stores have 'trolley-ators', which are similar to escalators but secure your trolley while you go from floor to floor. There's a theoretical risk that these could have a temporary effect on your ICD, so avoid them if possible.

Metal detectors

Metal detectors can affect ICDs, so speak to your ICD clinic before using one.

Magnetic devices and fasteners

There is a very small, theoretical risk that small magnetic devices – such as the fasteners on a tablet computer case – could affect your ICD. So while normal use is fine, it's sensible to avoid 'hugging' these devices against your ICD.

At work

Some workplaces have strong electromagnetic fields that can interfere with your ICD – for example, where arc-welding equipment is used. If you're concerned about any equipment at your workplace, your ICD clinic will be able to advise you. The MHRA (Medicines and Healthcare products Regulatory Agency) can also help with this. You can find their contact details on the next page.

Medical and dental tests

Most medical and dental tests won't affect your ICD but some equipment may cause interference, so remember to tell the person treating you that you have an ICD.

Most scans are safe, including X-ray and CT scans. In the past, MRI scans weren't used on people with ICDs, however, some of the new models can withstand MRI scanning. Ask at your ICD clinic if your device is suitable. If so, this may be shown on your ICD ID card.

If you have an accident or go to a hospital accident and emergency department for any reason, tell the doctors and nurses that you have an ICD in case it needs to be checked.

For more information

Each ICD manufacturer gives detailed instructions about the sources of electromagnetic interference you should avoid. If you have any questions about this, ask your clinic staff. For more information, you can also contact the MHRA at:

Medicines and Healthcare products Regulatory Agency (MHRA)

Devices Division
151 Buckingham Palace Road
London SW1W 9SZ.

Phone: 020 3080 6000

Email: aic@mhra.gsi.gov.uk

Website: www.mhra.gov.uk

WHAT'S THE DIFFERENCE BETWEEN A HEART ATTACK AND A CARDIAC ARREST?

A **heart attack** is when there is a sudden interruption to the blood supply to part of the heart muscle. It is likely to cause chest pain and permanent damage to the heart. The heart is still sending blood around the body and the person remains conscious and is still breathing.

A **cardiac arrest** happens when the heart suddenly stops pumping blood around the body. Someone who is having a cardiac arrest will lose consciousness and will stop breathing or stop breathing normally. This always leads to death within minutes, unless the person is immediately given CPR (cardiopulmonary, resuscitation) and, in some cases, defibrillation.

A person who is having a heart attack is at high risk of having a cardiac arrest.

Both a heart attack and a cardiac arrest are life-threatening medical emergencies and the person will need immediate medical help. Call 999 if you think you or someone else is having a heart attack, or if you see someone having a cardiac arrest.

CARDIAC ARREST? THE SYMPTOMS... AND WHAT TO DO

65

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.

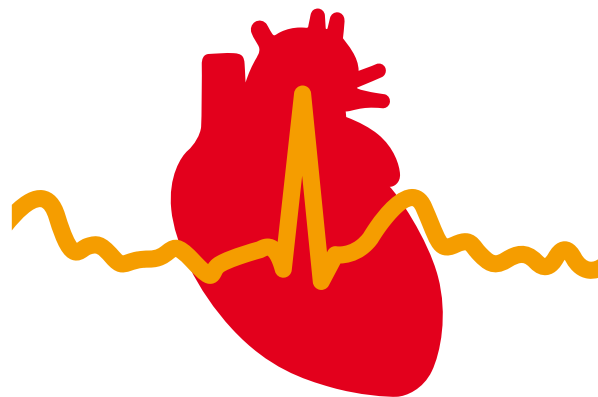
There are now **public access defibrillators** – or **PADs** for short – in many workplaces, shopping centres, train stations, leisure centres and village halls. It's very easy to use a PAD. The machine gives clear, spoken instructions and you don't need training to use one.

Once switched on, the PAD will instruct you 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**

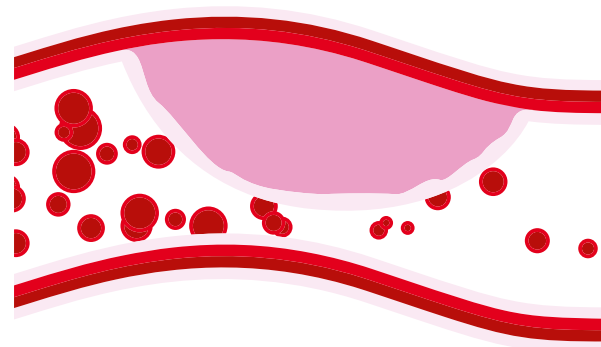
The most important thing you can do to help save a person's life is **CPR – cardiopulmonary resuscitation**. This, along with defibrillation, can double someone's chance of survival in some cases. We explain how to do CPR on the next pages.

CARDIAC ARREST is an **ELECTRICAL** problem



The person will be **UNCONSCIOUS**
■ Call 999 ■ Start CPR

A HEART ATTACK is a **CIRCULATION** problem



The person will probably be **CONSCIOUS**
■ Call 999 ■ Keep them calm

CALL PUSH RESCUE

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**

CALL...

Call for help.

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.



PUSH...

Push hard and fast on the centre of the chest.



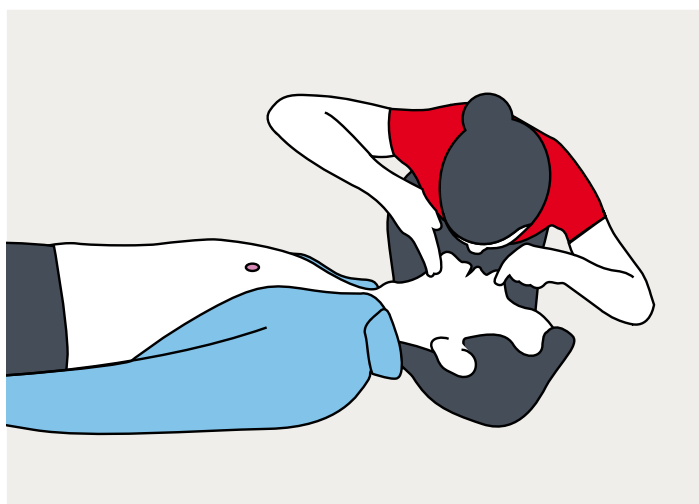
Start chest compressions.

- 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 each second.

RESCUE...

Give 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 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 ambulance crew arrives and takes over, or
- 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](https://www.bhf.org.uk/handsonly)

**British Heart
Foundation website****bhf.org.uk**

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

**Genetic
Information Service****0300 456 8383**

(A similar cost to
01 or 02 numbers.)
For information and
support on inherited
heart conditions.

Online community
community.bhf.org.uk

Share your experiences,
stories, tips and ideas
with other people
like you in our
online community.

Heart Helpline**0300 330 3311**

(A similar cost to
01 or 02 numbers.)
For information and
support about your heart
condition and keeping
your heart healthy.

Twitter**@TheBHF**

Get our latest news and
views directly into your
Twitter feed.

Facebook**facebook.com/bhf**

Join the conversation
and get our latest
news and updates
on Facebook.

For more information on heart health**Living with an inherited heart condition**

A series of booklets for people with an inherited heart condition and their families, describing how and why the condition develops, and how it's diagnosed and treated, including:

- Dilated cardiomyopathy
- Hypertrophic cardiomyopathy
- Sudden arrhythmic death syndrome
- Inherited abnormal heart rhythms

Other booklets and DVDs:

- An everyday guide to living with heart failure
- Heart to heart: heart disease and your emotional wellbeing
- The road ahead: your guide to heart tests and treatments

To order our booklets or DVDs:

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

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

Heart Information Series

This booklet is part of the *Heart Information Series*. The booklets in this series are:

- Angina
- Atrial fibrillation (AF)
- Blood pressure
- Cardiac rehabilitation
- Caring for someone with a heart condition
- Coronary angioplasty
- Diabetes and your heart
- Heart attack
- Heart failure
- Heart rhythms
- Heart surgery
- Heart transplant
- Heart valve disease
- Implantable cardioverter defibrillators (ICDs)
- Keep your heart healthy
- Living with a pacemaker
- Medicines for my heart
- Peripheral arterial disease
- Reducing my blood cholesterol
- Returning to work
- Tests

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 has a vision to create a nation of life savers. As part of that vision, we're doing everything we can to make sure the UK public know CPR and can use public access defibrillators. Join the fight for every heartbeat and help us save the lives of thousands of people across the UK every year. Find out more at **bhf.org.uk/cpr**

- **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 **0300 330 3300**, 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 **0300 330 3311**.

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 helping us to make new resources to informing our research. Visit **bhf.org.uk/heartvoices** for more information and to sign up.

abnormal heart rhythms	03, 05, 32
activity	53
arm exercises	27, 53
arrhythmias	03, 07, 08, 10, 55
ATP	13, 34
battery life	43
bi-ventricular pacemaker	16
bruising	24, 30
card: ICD identification card	25, 37, 60
cardiac arrest	09, 10, 18, 64, 65
cardiac resynchronisation therapy	16
cardiopulmonary resuscitation	10, 33, 64, 66
cardioversion	10, 14, 34
catheter ablation	11
complications	30
CPR	10, 33, 64, 65
CRT-D	16, 21
deactivation	44
defibrillation	10, 14, 15, 33
external defibrillation	33, 64
from an ICD	15, 34
driving	49, 50, 51, 52
electrical interference	57, 58, 59, 60, 61, 62, 63
electrical shock	65
electrode leads	03
everyday life	48

exercise	53
feelings	38
flying	60
follow-up	26, 32, 40
heart attack	08, 11, 64
heart failure	04, 08, 16
heart rhythm	05
abnormal heart rhythms	03, 05, 32
normal heart rhythm	05, 06
ventricular fibrillation	09, 10, 12, 14, 50
ventricular tachycardia	09, 10, 13, 14, 50
identification card	25, 37, 60
implanting the ICD	19, 20, 21, 22, 23
inappropriate shock	32, 33
infection	19, 30
interference	57, 63
leads	03, 12, 13, 19, 31, 43
Long QT Syndrome	08
LQTS	08
medicines	37
mobile phones	58
MRI scan	62
normal heart rhythm	05
pacing	13, 14, 34
phones	58
pre-assessment clinic	18

pulse generator	03, 12, 13, 19, 23, 43
recovery after the implantation	24, 53
rehabilitation programme	39, 40
remote monitoring	42
resynchronisation therapy	16
security systems: interference from	60
sex	48
shock: electrical shock	65
shock therapy	13, 14, 44
SICD	15, 22, 23
sinus node	05, 06
sports	53, 54
subcutaneous ICD	15, 22, 23
support groups	39, 76
technical problems	32
testing the ICD	23, 25, 41
tests	17
transvenous implantation	20
travelling	37
ventricular arrhythmias	07, 08, 10, 11
ventricular fibrillation	09, 10, 12, 14, 50
ventricular tachycardia	09, 10, 13, 14, 50
VF	09, 10, 12, 14, 50
VT	09, 10, 13, 14, 50

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**. Or, write to us at:

BHF Customer Services
Lyndon Place
2096 Coventry Road
Birmingham B26 3YU.

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THANK YOU

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**



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.

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

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HIS19/1117