



British Heart
Foundation

Your guide to pacemakers and ICDs



**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

The devices

Pacemaker
2cm(w)x4cm(h)



**Implantable
cardioverter
defibrillator (ICD)**
2cm(w)x7cm(h)



About the BHF

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



Little Hearts Matter

Offering support and information to anyone affected by single ventricle heart disease, half a working heart. Contact us 0121 455 8982 info@lhm.org.uk

-
- 03** Why do I need my device?
 - 06** How does a normal heart work
 - 10** What is my device, and what does it do?
 - 18** How is my device fitted?
 - 19** How does it feel?
 - 22** Is there anything I can or can't do?
 - 23** Everyday life
 - 26** What happens at follow-up appointments?
 - 27** What about how it looks?

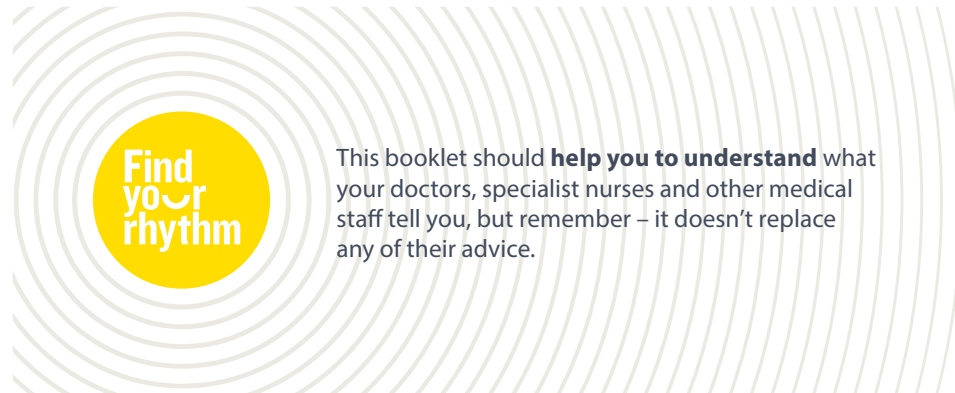
About this booklet

Aged 13–19?

Do you have a pacemaker or an implantable cardioverter defibrillator (ICD), or about to have one fitted? This booklet's for you, and it's packed full of useful information.

It can be difficult to completely ignore you have a device, but over time you'll get used to it being there and hardly notice it at all.

Modern devices are comfortable and reliable, so if you follow some simple rules and go to all your appointments you can feel more confident in your everyday life with your device.



This booklet should **help you to understand** what your doctors, specialist nurses and other medical staff tell you, but remember – it doesn't replace any of their advice.

Why do I need my device?

Sometimes, the electrical signals in your heart might not work properly, or can become blocked.

This can lead to abnormal heart rhythms (arrhythmias) that can sometimes be very slow (bradycardias), and very fast (tachycardias).

Some heart rhythms might even be extremely fast and life threatening, and lead to cardiac arrest. This is when your heart isn't pumping blood around your body any more.

These rhythms are:

- Ventricular fibrillation (VF) – where the ventricles are quivering extremely quickly, and aren't able to pump blood around your body, and
- ventricular tachycardia with no pulse (pulseless VT) – where the ventricles are beating so quickly that not enough blood can fill them to be pumped around the body.

A cardiac arrest is the most serious medical emergency. If you, or someone you are with, has a cardiac arrest it's vital that someone dials 999 immediately and starts cardio-pulmonary resuscitation (CPR).

- If you suffer from very slow or very fast heart rhythms, you will most likely have a pacemaker.
- If you are at high risk of, or have already had an extremely fast, life threatening heart rhythm, you will most likely have an ICD.

Some ICD's will also have pacemaker functions too, we explain more about this on page 14.

Living with a
device means:

NO MORE

BLACKOUTS

How does a normal heart work?

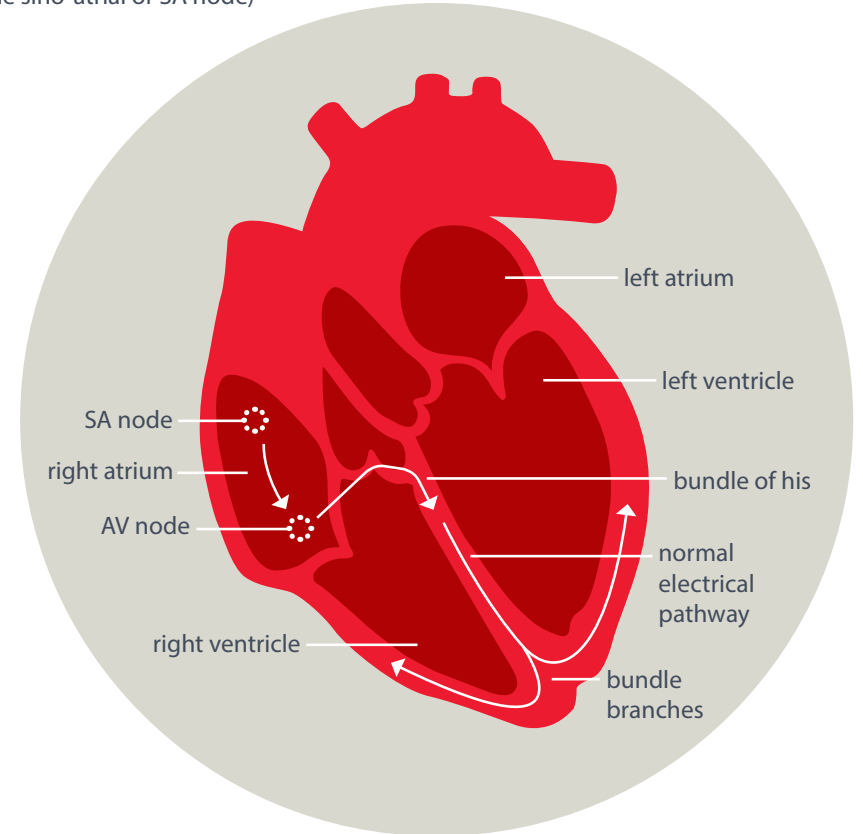
To help you understand more about your heart, it's important to know how a normal heart works. Your heart is a pump that relies on electrical signals to work properly, and deliver blood to your heart, brain, lungs and the rest of your body.

The sinoatrial (SA) node is your heart's natural pacemaker, and is in charge of how fast or slow your heart beats. At the very start of a heartbeat cycle, the SA node will fire an electrical signal or impulse to begin the heartbeat cycle. This impulse will cause the top two chambers of your heart (the atria) to contract and squeeze blood out and into the bottom two chambers of your heart (the ventricles).

The impulse travels to the atrioventricular (AV) node, which acts as a gateway between the atria and ventricles. The AV node will briefly hold the impulse, and then send it down through the Bundle of His and the bundle branches - these are parts of the electrical pathway that conduct the impulse to make sure the heart beats regularly and in sync.

A regular heart rhythm

Each regular heartbeat begins in the natural pacemaker of the heart (the sino-atrial or SA node)





Katie's story

I'm Katie, I'm 17 years old and I have congenital complete heart block, PDA and tricuspid regurgitation.

I had my first pacemaker fitted when I had just turned four years old and my second one in when I was 16.

When my first device was fitted I don't really remember a lot about it, but having my second one put in, I was a lot more aware which was quite scary but at the same time I found it very interesting to learn about what was happening.

Before the procedure I was worried about missing out on things that my friends were doing whilst I was at home recovering. Having to take time off from sixth form when I was supposed to be studying for my exams was a concern too. I also didn't know what to expect pain wise when I woke up.

I didn't want to worry all the time about what would happen, so I read a few leaflets and spoke to my mum. I found that not thinking about the procedure that much helped rather than focusing on it.

Now I have a pacemaker I don't even realise it's there! I've had a few problems in science lessons when my teacher forgets and brings out a giant magnet sending me in to a panic! I've also found that driving for me will be slightly different than when my friends start because of the extra couple of forms that need filling out and having to explain my condition to driving instructors and the DVLA.

Having a pacemaker makes me different to my friends but that means I have an interesting story to tell! It has improved my fainting and tiredness and I generally feel healthier.

I can now spend the whole day out without fainting which means I don't have to spend the whole next day recovering.

“My advice to anyone about to have a pacemaker fitted is to ask as many questions as you want and write them down before your appointments or surgery.”

Don't rush your recovery, everyone is different and you will know when it's time to go back to normal completely and don't push yourself too much.

What is my device, and what does it do? Pacemakers

A pacemaker is a small, battery powered device, which paces your heart by sending an electrical impulse telling your heart when to pump.

The battery and pacemaker box itself usually sit under your left collarbone. Occasionally it can be placed in your abdomen. 1, 2 or 3 leads will be attached to the box and be fixed either within your heart's chambers or just outside. Battery life is usually 6 - 10 years (see page 26) but, it might be shorter or longer depending on how often your heart needs pacing.

You might have a problem with:

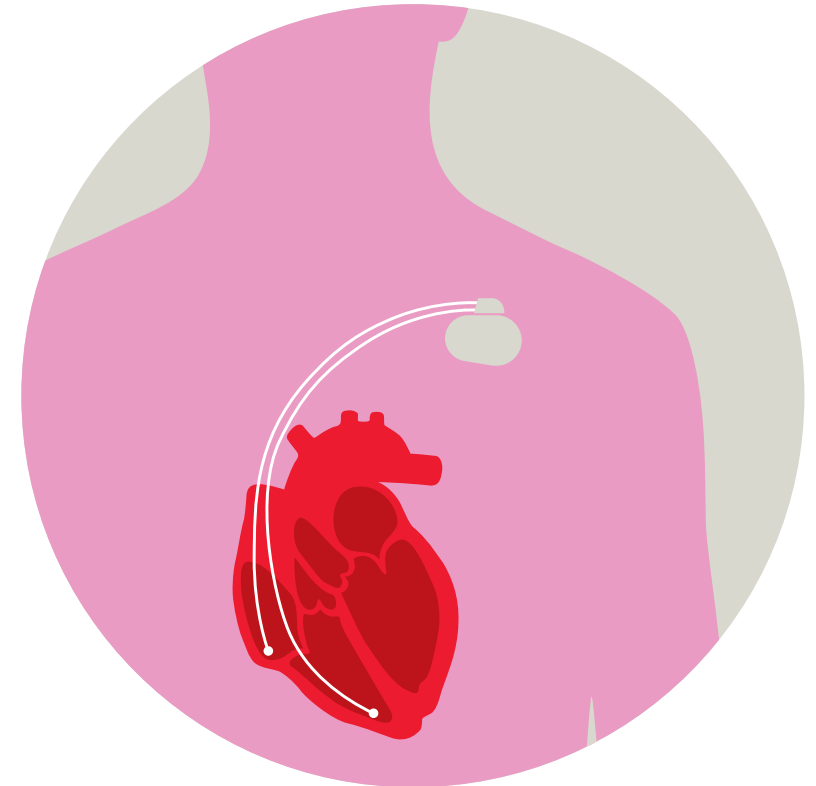
- Your SA node (your heart's natural pacemaker), which means that your heart beats too slowly, too quickly, or irregularly.
- Long pauses between heart beats, sometimes causing dizziness, light headedness and sometimes blackouts.
- Your AV node, meaning that signals from the SA node are either partially or completely blocked.

If your heart rate is constantly too slow, your pacemaker will work all the time. We call this fixed rate pacing.

If your heart rate is only slow some of the time, or you have long pauses between some of your heart beats, your pacemaker will only provide beats where they are needed. We call this demand pacing.

Some pacemakers are also set to change the pacing speed depending on what you're doing, for example, they will pace your heart faster when you're exercising and then slow down again when you stop.

Whichever type of pacemaker you have, it will constantly be monitoring your heart, even when it's not pacing.



Living with a device
means having more:

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G
Y**

What is my device, and what does it do? ICDs

Similar to pacemakers, an ICD is a small battery powered device. Most will also have full pacemaker functions (see page 10), and be implanted under your left collarbone with 1, 2, or 3 leads. Battery life is usually 4–6 years (see page 26), but might be shorter or longer depending on how often it delivers treatment, such as shocks and pacing, which we explain next.

An ICD is designed to treat extremely fast, life threatening heart rhythms (such as VF and VT) in these ways:

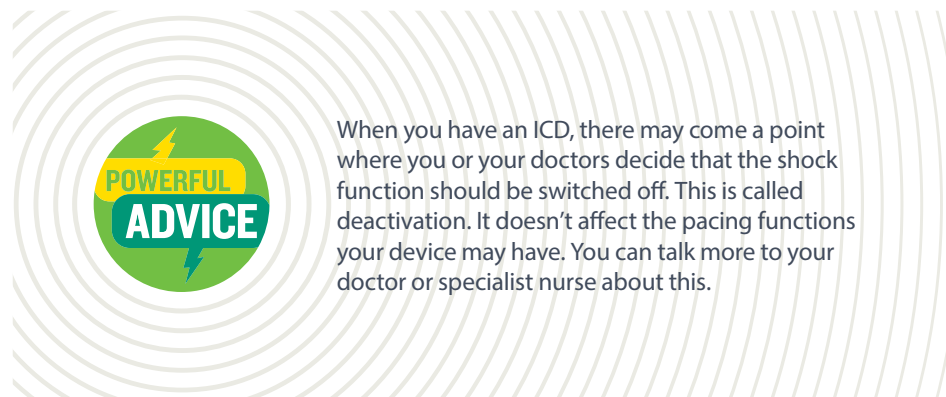
- Anti-tachycardia pacing (ATP) – during VT, your ICD tries to pace your heart even faster than the life threatening rhythm, and then gradually slow it down again.
- Cardioversion – if ATP fails, your ICD will deliver a small electrical shock to your heart to help restore its normal rhythm.
- Defibrillation – if cardioversion fails, or if you're in VF, your ICD delivers a larger electrical shock to your heart to help restore it to a normal rhythm. You may only need one shock, but sometimes several shocks are necessary if the rhythm doesn't go back to normal straight away.

Your ICD will constantly monitor your heart for abnormal heart rhythms. Sometimes people know when their device is about to shock them, as they get certain symptoms such as palpitations, feeling faint, sweaty and dizzy.

However, many ICD shocks happen when there are no warning symptoms. Some people are unconscious when their ICD shocks, but others are awake and aware of what's going on. This is something to talk about with your specialist nurse or doctor, they can give you advice and support on what you most likely can expect with the condition that you have.

If your ICD shocks you, don't panic, wait a few moments to recover and see how you're feeling. Make sure you then call your clinic for some support and arrange an appointment. If you still feel unwell after the shock or get any more shocks you need to dial 999.

Your ICD stores information about the treatment it's given, and this needs to be downloaded (see page 26) and checked to see exactly what happened and decide if you need any other treatments or changes to medication.



When you have an ICD, there may come a point where you or your doctors decide that the shock function should be switched off. This is called deactivation. It doesn't affect the pacing functions your device may have. You can talk more to your doctor or specialist nurse about this.



Joe's story

I'm Joe, I'm 18 and I was born with transposition of the great arteries. I now have Pulmonary Stenosis and I had my pacemaker fitted when I was 14 years old.

I was dizzy and collapsing all the time so I was in hospital for a few months while the medical team were trying to find out why this kept happening. I was ok when I was in hospital so my doctor fitted a Reveal device which can be activated when I had an episode and records my hearts rhythm. I can remember that I left hospital on a Friday and I went back to school on the Monday and I ended up collapsing at lunch time. I was rushed into hospital and I was told after they had analysed the data that I needed a pacemaker.

I felt strange and scared because I thought it was only older people that have pacemakers and not young people. Since then I have realised that they are very common in children with heart conditions.

Before I had the pacemaker implanted the doctor told me everything about it. He explained how long it will last,

and that I will need the battery and wires changing every now and again. At the time I thought he meant changing every year. But he meant when the battery runs low, but that would be years away because I'm not using my pacemaker all the time it only kicks in when it needs too.

“Since I've had the pacemaker, I don't even realise it's there.”

I get asked all the time by friends if I can feel it but I can only feel it if I touch it. I probably wouldn't even know it was there if I couldn't see the outline of the box under my skin.

I'm glad I had the pacemaker fitted because it means that I don't go dizzy or collapse anymore, which used to be all the time. It now means I can go about my daily business without having the fear of whether I'm going to collapse today or not. The fear was really restricting and lowered my confidence because I wouldn't do anything, and I was scared to even walk too quickly in case anything happened.

I would advise anyone to have it if they need it because it gives you more confidence knowing that there isn't the risk of anything happening to you.

How is my device fitted?

Most pacemakers and ICD's are implanted under your left collarbone. Occasionally, it might be implanted on the right hand side if the left side is unsuitable.

Some ICD's are now fitted subcutaneously, this mean that instead of a lead inside your heart, the lead will sit just outside. The ICD box will also be in a different position – most commonly on the left side of your upper abdomen.

Your device will usually be implanted in a cardiac catheter lab (cath lab). The skin where your device will sit will be cleaned, and then a sterile drape will be put over your entire body.

This keeps the area as clean as possible to help prevent infections. Usually, a metal frame or similar is used to keep the drape off your face so you can breathe normally and speak clearly if you need to.

The procedure is usually done under local anaesthetic, which means you'll be awake throughout. The area where your device will sit is made numb, and then the doctor will make a cut and a pocket for your device. However, you may have a general anaesthetic which means you will be asleep during the procedure.

Using a vein, the device leads are then guided with an x-ray machine into your heart and secured into place. Once these leads are tested, your box will be attached and sewn into place, and then the pocket will be closed using either stitches or glue.

During the procedure, it's important you say if you're in pain or distressed. A doctor or nurse can give you pain relief and medication to help you relax if you need it, so don't be afraid to ask.

If you're having an ICD fitted, the shock function may need to be tested before you leave cath lab. You will be sedated while this is done, so you normally won't feel or remember anything during the test.

How does it feel?

When your pacemaker or ICD is fitted, the area should be completely numb. It's important that if you feel any pain or discomfort you tell someone so you can be given more pain relief or more local anaesthetic.

You might feel some pushing and pulling, but this shouldn't hurt. Once your device is fitted, there might be some bruising and a bit of swelling but this usually goes down within a week.

The devices are much smaller and lighter than they used to be, so they're usually comfortable. At first, you might really notice but once you get used to it most people forget it's even there.



Driving restrictions with an ICD are more complicated. After your device is fitted you have to be shock-free for 6 months before you can drive again. If you get a shock from your ICD, it's a minimum of 1-6 months before you can drive again depending on what actually happened (like if your shock was appropriate or not). The DVLA website is the best place to start, and have a chat with your cardiologist too.

Living with a
device means:

YOU FEEL
LESS DIZZY

Is there anything I can or can't do?

Having a pacemaker or an ICD won't affect many areas of your life. During the first couple of weeks there are some things to be careful of, but otherwise you should be able to live a normal life.

Here's a few do's and don'ts to keep in mind:

Do:

- keep your pacemaker or ICD site clean and dry for as long as your doctor tells you, and keep any dressings in place until you're told to take them off
- make sure you have contact details for your device clinic in case you need to speak to someone

- watch out for signs of infection – redness, swelling or pain that's getting worse, hot skin or oozing from your pacemaker or ICD needs to be seen by a doctor
- tell a healthcare professional if you're worried about anything at all.

Don't:

- raise your arm above shoulder height for at least the first six weeks on the side where your device is
- lift, push, pull or put a lot of strain on your arm
- drive for a week if you've had a pacemaker fitted, or had a box change for a pacemaker or ICD
- play any rigorous or contact sports like rugby or martial arts
- ignore any symptoms you're having, always report back to your doctor or nurse.

Everyday life

ID card

When you have a pacemaker or ICD implanted, you'll be given an ID card. Make sure you always carry this with you; it has important information about your device not only medical professionals but for places like airports too.

Everyday items

Whilst most things shouldn't affect how your pacemaker or ICD works, you should be cautious – be cautious and keep at least six inches away from your device, anything that has a magnetic field and certain electrical equipment.

This includes:

- hairdryers
- stereo speakers
- induction hobs (at least 2 feet away)
- mobile and cordless phones, iPods, MP3 players and tablets (use phones on opposite ear to your device, and also don't keep anything in a pocket near your chest)

- TENS machines and body toning equipment
- any magnetic jewellery or clothes fastenings that sit near your device.

Airport security - always carry your device ID card as security systems will detect the metal box. It's fine to pass through the large scanners, but any hand-held scanners should not go near or come into contact with your pacemaker or ICD.

Shop security systems – your device may or may not set this off. If needed, show your ID card to shop staff and make them aware. Walk through the scanners normally but don't dawdle or linger.

MRI scans – unless you have a specific 'MRI-safe' device, you won't be able to have an MRI scan as it involves very strong magnets.

Theme parks - leisure facilities and theme parks have their own guidelines for heart patients and the rides or equipment they can safely use, so check with them if you are planning a visit.

Lindsay's story

I'm Lindsay, I'm 21 years old and I have Long QT Syndrome. My heart condition links with Periodic Paralysis to create the genetic condition Andersen-Tawil Syndrome. I was 12 years old when I had my pacemaker fitted.

When it was time to have my pacemaker fitted, I felt okay, as my mum and sister made sure I knew what was happening and that it was for the best. Whenever I had a hospital appointment my mum would buy me a book or something else nice so I would associate hospitals with nice things (as I was 10 when I first started going).

I've recently had my battery changed in my ICD and I was in the adult ward. The thought of not being asleep under general anaesthetic for the procedure panicked me. I worried I would be awake and possibly feeling what they were doing. However this was wrong I felt nothing and was quite heavily sedated for it (completely at the end so they could test if it would shock.) It really helped talking to my sister who had a similar procedure done and the nurses in the hospital quickly put my mind at rest.

In the hospital there was a lovely nurse who was a children's nurse when I had my first defibrillator (she's now a transition nurse for those going from the children's ward to the adult ward.) She provided my mum with information, and along with my sister, they both talked through everything with me and answered any questions.

“Whilst you may be scared or nervous, just remember that this is there too keep you safe.”

The only printed information available then was for adults so it was good to have someone to go through it all with me to make sure I understood. Also the consultant was very helpful discussing with me before, during and after the procedure and answered even the silliest of questions. He also arranged for my device to be monitored via the telephone line to allow for more checks if the device was having problems without me having to travel to the hospital.

The positive things about having an ICD is the knowledge that I am safe when I go out on my own or with friends, if anything happens the hospital can find out what it was and help accordingly. Due to my condition I get tired more quickly than a regular person, and I try to avoid things like close contact sport, so I exercise in the form of walking my dog.

My advice to someone about to have an ICD fitted is whilst you may be scared or nervous, just remember that this is there too keep you safe. Also as you grow older, and need to tell people that you have a defibrillator fitted, don't be afraid to tell them and be prepared to answer any question.

Many people have never heard of an ICD before, to them you look 'normal' as you don't have anything visibly wrong with you.

Find out about disability living allowance or disability student allowance if you go to university. It's not just financial support that's available, there is help you can get which is really useful such as you can have someone to take your notes if you are absent due to your defib/heart condition or if it causes a lot of stress for you. When I started university the amount of help I could get made a big change.

Now I have an ICD, I can drive (although it did take the DVLA a few months to decide if I was allowed to have a licence, so be prepared for a wait). Although I do not drive far or for a long time as I get tired quite easily and it's important to be responsible. My mum is happier to let me go out on my own without fear that something will happen (as we live in a rural area, sometimes you go out and don't see another person).

What happens at follow-up appointments?

You will have regular follow-ups for the rest of your life when you have a pacemaker or ICD. Routine appointments are usually every 3-12 months depending on what sort of device you have and if you have any on-going symptoms or problems.

You will need to be seen in clinic following an ICD shock, whether you are due a routine appointment or not.

Your battery life will also be checked. If the battery needs to be changed (usually when there is less than 6 months battery life left), you'll have an appointment given to you to come back to the hospital. The procedure is much quicker for a battery change. Usually, they will cut open the pocket where your pacemaker sits, remove the box – leaving the leads in place – and just attach a new box with a fully charged battery.

Your device stores information about the treatment it's delivered and can record electrical activity in your heart – this information can all be downloaded quickly and painlessly from your pacemaker or ICD by using a small device that's placed over your skin.

You should also make an appointment if you have any worries or concerns about your device, sometimes it might be something that you can be advised about over the phone or you may need to attend a clinic.

What about how it looks?

As time goes by, pacemakers and ICDs are getting much smaller. It may even be that by the time you're due your battery change, the next device that's implanted might be smaller than the last one you had.

Depending on where your device is implanted and how much body fat you have around that area can affect how much other people might notice. If you're very slim and have a small build, your device might be easier to see. This can sometimes take some getting used to, but over time most people forget that it's there.

There might also be a small, thin scar where the cut was made to implant your device. This will gradually fade and get smaller over time. If you're more likely to get keloid scarring, have a chat with your doctor before the procedure and get some advice.



It can help to have a really positive and outgoing attitude towards having a device implanted. If you see anyone noticing your device, try smiling at them and telling them what it is – they're normally just really curious!

For more information

Meet@teenheart

BHFs meet@teenheart programme for 13–19 year old heart patients and is here to help you. Whether you come along to our events, read the newsletters we send you or simply engage with us through social media - meet new people and gain new skills.

For more information visit yheart.net

Picture your journey

A resource for 13–19 year old heart patients to help them make the journey from child to adult care. This pack is a place to keep all your medical contacts, appointments and health care information together in one place. Three booklets inside offer information and support as you become an adult and start to take responsibility for your own health. G690

Revealing the facts about your condition series

14 information leaflets in this series for 13–19 year olds provide information and support on different heart conditions.

Titles include:

- ICD (C9T)
- Pacemaker (C8T)
- Arrhythmias (C14T)

For more information on titles available visit bhf.org.uk/publications

Straight from the heart

A resource for young people who are going into hospital for a heart procedure. It's called straight from the heart because all the tips have come from young people who have been through the experience. G562

The BHF card

An ID card for young people who have an ongoing heart condition to be shown at times when their condition is questioned. The card is only available to order by health care professionals who will fill out the information and give to their patients. G486



**British Heart
Foundation**

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

But so many people still need our help. From babies born with life-threatening heart problems to the many Mums, Dads and Grandparents who survive a heart attack and endure the daily battles of heart failure.

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

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk