

All about devices - ICDs

A guide to having an implantable cardioverter
defibrillator for cardiomyopathy



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We are very grateful to Sue Jones, former Pacing/ICD Service Manager at St George’s University Hospitals NHS Foundation Trust for reviewing and approving this booklet.

Words in **red** are listed in the summary of terms on page 32.

Cover image and page 2: Stock photo. Posed by model.

About devices

There are many treatment options for people with cardiomyopathy. Some of which treat the symptoms, and some treat the condition itself to reduce its impact on the individual and lessen the symptoms.

Many people with cardiomyopathy take medication. This includes medication to thin the blood (anticoagulants), to reduce fluid build-up (diuretics), to reduce the rate and force of the heart's contraction (beta-blockers), reduce the workload on the heart (ACE inhibitors) or to control abnormal heart rhythms (anti-arrhythmic medication).

Some people will have medical devices to treat their cardiomyopathy. These are types of implanted technology to support the heart, either by monitoring the heart rate and treating any abnormal rhythms, or by taking over the control of the heart rate to keep a regular rhythm.

This booklet is for you if you are considering having an **ICD** (implantable cardioverter defibrillator) for your cardiomyopathy. It explains what ICDs are and what they are for, how they work and who needs them. We have also included the experiences of people who have an ICD, to share what it is like to live with one. This booklet is also for you if you have an ICD but have some questions about it.

Please note: this booklet contains pictures of ICDs, photos of people who have one, and descriptions of implantation procedures and people's experiences of having an ICD. We understand that some people may feel uncomfortable with these images and descriptions.

What types of device are there?

There are different types of device, each with a slightly different function. They fall into three categories: ICDs, **pacemakers** (including **CRT** or cardiac resynchronisation therapy devices), and **VADs** (ventricular assist devices). Generally, ICDs monitor and shock the heart when a dangerous arrhythmia occurs, pacemakers set the pace of the heart, CRTs synchronise both sides of the heart to beat together, and VADs help to support the function of the heart if it is seriously impaired.

Implantable cardioverter defibrillators

ICDs, or implantable cardioverter defibrillators, monitor the heart rhythm and respond to abnormal heart rhythms. When dangerous abnormal rhythms are detected an ICD works to restore the normal rhythm of the heart.

The normal heartbeat and arrhythmias

The heart normally beats in what is known as '**sinus rhythm**', which is controlled by regular electrical signals that travel through the heart. These signals make the chambers of the heart beat in sequence, which causes the blood to flow through the heart and to the lungs or to the body. The speed of the heart beat will depend on what the person is doing, and how much energy the body needs. For example, the heart beats more slowly when someone is sitting down quietly reading a book, and faster if they are walking quickly.

♡ *See page 34 for how the heart works.*

Arrhythmias (abnormal heart rhythms) happen when the electrical signals that control the **heart beat** are disrupted in some way, and the heart beats in an abnormal rhythm. There are many types of arrhythmias, some affect the **atria** (top chambers of the heart) and some affect the **ventricles** (bottom chambers of the heart). Some make the heart beat faster (**tachycardia**), some make it beat slower (**bradycardia**), and some cause the heart to beat erratically (**fibrillation**). Arrhythmias are often treated with medication (anti-arrhythmic drugs). However, some arrhythmias can be life-threatening (see below).

ICDs are devices that constantly monitor the heart's rhythm, and detect and monitor any arrhythmias in the ventricles. Depending on the type of arrhythmia, the ICD will treat this.

Arrhythmias treated by ICDs

Ventricular tachycardia (VT) is a type of arrhythmia that causes the ventricles to beat too quickly. This is caused by abnormal electrical activity within the ventricles which causes over 100 beats per minute,

out of synchrony with the atria. This means that the ventricle doesn't have time to fill properly so blood cannot be pumped around the body effectively. Although VT can be brief and not cause any problems, when it is more prolonged it can cause dizziness and light-headedness, and sometimes collapse. In extreme cases, VT can cause the heart's function to be so reduced that emergency resuscitation is needed.

If the ICD detects a too-fast rhythm it will monitor this. If the heart doesn't go back into sinus rhythm it will 'pace' the heart (take over the electrical signals controlling the heart rate) by giving fast electrical impulses to interrupt the arrhythmia. This is called anti-tachycardia **pacing** or 'ATP'. If pacing the heart doesn't restore a normal rhythm, and the heart is in VT, the ICD will send a small electrical shock (or shocks) to the heart (called '**cardioversion**') to try stop the arrhythmia and 'convert' the heart back into sinus rhythm.

Ventricular fibrillation (VF) is caused by series of abnormal impulses, coming from many parts of ventricle walls, that interrupt the electrical signalling in the heart. This causes the ventricles of the heart to contract in an uncoordinated way, and 'quiver' (or 'fibrillate') rather than contract normally. This means that the heart can't pump blood out of the ventricles (called the '**heart's output**'). Ultimately, VF can be a cause of **cardiac arrest** (when the output of the heart stops suddenly and the person collapses), which can be fatal.

If an ICD detects VF, it gives an electrical shock to the heart to interrupt the abnormal rhythm (literally 'de-fibrillating' or stopping the fibrillation) and restore sinus rhythm. This prevents VF leading to a cardiac arrest.

An ICD can only work if there is electrical activity in the heart. If the heart output has stopped and there is no electrical activity (called 'asystole') an ICD will not fire to 'restart' the heart. Emergency resuscitation would be needed (giving chest compressions) until medical help arrives to administer drugs to the heart.

Note: ICDs can help to 'pace' a heart if it is beating too slowly (like a normal pacemaker). This is called anti-bradycardia pacing or 'ABP'.

Who needs an ICD?

ICDs are used for people who have experienced abnormal or dangerous arrhythmias (for example that have caused them to lose consciousness or led to a cardiac arrest). They are also used for people who are considered to be at risk of having abnormal or dangerous arrhythmias (where they are used prophylactically or on an 'in case' basis). This may be the case for people with various types of cardiomyopathy, depending on how their condition affects them.

For people with hypertrophic cardiomyopathy (HCM, where areas of the heart muscle is thickened) there are guidelines from the European Society of Cardiology (ESC) available to help doctors decide for whom a device is appropriate. The guidelines help to predict the risk of a life-threatening arrhythmia that could lead to a cardiac arrest and sudden cardiac death. Several risk factors are considered, which include the following:

- a family history of cardiac arrest;
- a history of syncope (blackouts);
- blood pressure that either doesn't increase or decreases, on exercise;
- episodes of 'non-sustained ventricular tachycardia' (periods of temporary too-fast rhythm in the left ventricle); and
- the amount of left ventricular hypertrophy (how thick the left ventricle wall is).

This information is used to determine an individual's risk of a life-threatening arrhythmia and therefore whether a device is recommended.

Although there are no ESC guidelines to decide about ICDs for people with other types of cardiomyopathy, each person's condition and symptoms will be reviewed so that any recommendations are appropriate for them.

NICE guidelines about ICDs

NICE – the National Institute for Health and Care Excellence – is an independent organisation that gives recommendations on health and social care in England. It produces guidelines on how conditions should be treated and managed, which are developed using evidence-based research. NICE has guidance on the use of ICDs and CRT (a type of pacemaker) for arrhythmia and **heart failure** (called ‘TA314’) and S-ICDs for preventing sudden cardiac death (called ‘IPG454’).

You can go on the NICE website at www.nice.org.uk and search for ‘TA314’ or ‘IPG454’ for more information.

Hugh's story



"I did find it hard to get used to the idea of needing an ICD...getting used to the ICD itself was quick and easy."

Getting used to an ICD

I generally take everything in my stride, and I don't easily get upset by health issues, but I did find it hard to get used to the idea of needing an ICD. It was almost as hard to come to terms with as my diagnosis of DCM. It wasn't the fear of the procedure, but an unease about having an implant for the rest of my life – a sense of 'What on earth am I doing to my body?' It was implanted as a precaution. Maybe if I'd had a cardiac arrest or a life-threatening VT/VF it wouldn't feel like such a big step to take. What's difficult about a precautionary ICD is that it feels optional. It feels as if you are choosing to have something unpleasant done, which may have serious long-term implications, but the need for it seems remote and unreal.

On the other hand, getting used to the ICD itself was quick and easy. I had no psychological issues, and very few physical ones. My wounds healed quickly, with no problems. I was kept well informed throughout.

I have had three appropriate shocks over the years. When the first one happened it suddenly became really easy to accept that I needed the ICD! Twice I have been shocked while I was doing moderately strenuous exercise, but the third time I was simply having a shower.

I had one shock when I was unconscious: it was completely painless. I felt faint for a moment, and woke up on the floor 15 seconds later. I didn't feel groggy, no gradual recovery – I was instantly 'back in the room'. I felt exhausted and in need of some care, but euphoric. It was much more alarming for bystanders than it was for me. My friends wanted to rush me to A&E, but I insisted it wasn't necessary.

I have had two shocks while conscious. It was not pleasant, but it was over so quickly that I had no time to be worried by it. It felt like an electric shock from another source: a jolt in the chest. I have never been kicked by a horse, but I imagine that would be far worse!

After each shock I phoned the ICD clinic the next morning, and went in to be checked over (very reassuring). All the time I have had an ICD, I have been very well looked after – my health professionals have always made time to see me and reassure me.

Types of ICD

There are two types of ICD.

Regular ICDs – these are implanted under the skin on the upper chest wall, usually on the left side, and are connected via wires that pass through a blood vessel leading into the heart. These have a pacing function (for too-fast and too-slow heart rhythms) as well as being able to defibrillate (to ‘fire’ or ‘shock’ the heart).

Subcutaneous ICDs (or S-ICDs) – these are implanted on the lower left side of the chest towards the bottom of the ribs. The leads are fed under the skin (subcutaneously), across the ribs and along the breast bone to the heart. The leads do not sit within the heart (unlike a regular ICD) and so they deliver a shock to the outside of the heart (rather than within the heart). As S-ICDs do not sit within the heart they are not currently able to offer the same pacing function as a regular ICD.

Both ICDs record details of your heart rhythm, and any activation of the device, which can be useful for monitoring your condition.

 *If you are considering having an ICD you can ask your doctors whether they have any patient information (such as a booklet) from the device company that they can give you to read.*

There is a third device – called a CRT-D – which includes an ICD function. This is a type of pacemaker called ‘cardiac resynchronisation therapy’ device or biventricular pacemaker).

 *You can read more about CRT-D in our booklet on pacemakers.*

Which device would I need?

Which device you would need depends on your medical needs.

A regular ICD is smaller than an S-ICD, but it is more invasive as the leads feed through a **vein** and sit within the heart's muscle walls. If the leads need replacing this is a more complicated procedure than with an S-ICD as they can become securely embedded in the heart muscle and difficult to extract. However, this device is suitable for anyone who may need a pacing function.

An S-ICD battery is larger than a regular ICD, but the device is less invasive as the leads sit outside the heart rather than within the heart. If the leads need to be changed this is a more straightforward operation than for a regular ICD and so it may be considered an option for people who are likely to need more lead replacements during their lifetime (for example, younger people compared to older people). It may also be recommended for someone for whom a regular ICD is not suitable, for example if they have a condition that makes it difficult for the wires to be placed through a blood vessel into the heart. As S-ICDs do not have a pacing function they are suitable for people who do not need the additional pacing but are **not** suitable for someone who needs a pacing function.

Do I still need to take medication if I have an ICD?

ICDs are used to treat dangerous arrhythmias when they happen. They do not prevent arrhythmias, and they do not treat other symptoms of cardiomyopathy. If you take medication for symptoms from your cardiomyopathy you will most likely need to continue to take these medications. The ICD is an *additional* form of treatment, rather than an *alternative*.

What do ICDs look like?

ICDs consist of a pulse generator (which includes a battery), which looks like a small box, and a number of leads. These leads are like fine coated wires, with special electrodes on the end, which are connected to the generator. These leads are either fed into the heart through a vein, or sit outside the heart, (depending on the type of ICD) where they monitor the heart's rhythm. If needed, the leads deliver a shock from the generator to the heart to restore the heart's normal rhythm.

There are several companies that make ICDs so your ICD may look slightly different to the examples below.

Examples of what ICDs look like



*Left: image provided courtesy of Boston Scientific. © 2017 Boston Scientific Corporation or its affiliates. All rights reserved.
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Deciding whether to have an ICD or not

An ICD is only recommended when it is considered necessary for you, either because you have had, or are at risk of having, potentially life-threatening arrhythmias. However, the decision whether to have an ICD is yours, and it is important that you feel you have enough information and support to make this decision.

The decision can be difficult, and it can feel over-whelming. It may help to think about the risks and benefits of having, and of not having, the ICD. And it can help to talk through any questions or concerns you have, both with your doctors and the ICD clinic, and with those close to you.

♥ *If you would like to talk to someone with experience of having an ICD, call our helpline and ask to be put in contact with a peer support volunteer.*

Bill's story



"I tried to carry on as normal, not really knowing what to expect nor how to react to my new life."

Pipe dreams and peace of mind

I was diagnosed with dilated cardiomyopathy (DCM) in 1997, at the age of 36. My cardiologist decided that I should have an ICD immediately or the prospect of reaching 40 was considered remote. With such a stark message there was really very little to think about, especially as I had no idea what DCM was, nor the prognosis.

In some ways, when I look back at how the prospect of needing an ICD was thrust upon me, with no time for reflection nor very little scope for any research into DCM or ICDs, it made the decision very simple for me.

So, within a week or so of initial diagnosis I was discharged from my hospital complete with my new 'Guardian Angel', ready to face the world. At first I tried to carry on as normal, not really knowing what to expect nor how to react to my new life.

Within a few weeks I had my first shock from the device (which turned out to be entirely appropriate, although very painful). It happened when I was asleep: I awoke with a jolt when I felt a heavy punch-like sensation in my chest. There was a few minutes quiet and then I began to feel my heart start to race again, and a second shock happened. I was taken to hospital in an ambulance and, eventually, after several shocks became stable. The ICD had certainly saved my life and it had responded correctly to the series of heart arrhythmias I had gone through.

I have taken medications to help control my arrhythmias, as well as having the ICD. I am delighted to say that I have been shock-free since 1998!

Such has been my continued good health, that I had to seriously consider whether or not I wanted to have a 3rd ICD box change 3 years ago. Having been shock-free for many years, I seriously wondered if I wanted to go through the procedure again with the subsequent infection risks and so on. However, to ensure continued peace of mind I decided to have the 3rd ICD.

So whilst I occasionally contemplate life without an ICD, this will likely always remain a pipe-dream, for quite simply I would not be here to have a pipe-dream if it were not for my ICD!

How are ICDs implanted?

ICDs are usually implanted by an electrophysiologist (cardiologist specialising in heart rhythm disorders). They are usually implanted on the left side as this is closer to the heart for the leads to be placed.

i You can ask your hospital for further information about the procedure for this, as it may vary from one hospital to another.

You would usually have the device implanted either under a general anaesthetic, or while you are sedated and under a local anaesthetic. You will usually be in hospital overnight following the implant (to check on your recovery) and given an x-ray to ensure that the ICD is correctly in place and you have no complications from the surgery.

With regular ICDs, the leads are inserted first, through a small (5-10cm long) incision under the collarbone. They are fed through a vein in the neck down into the right side of the heart. An x-ray is used to guide the leads into place. If the device has a single lead, it will be placed in the ventricle. If it has two, one sits in the ventricle and one in the atria. The leads are attached to the heart muscle to keep them in place.

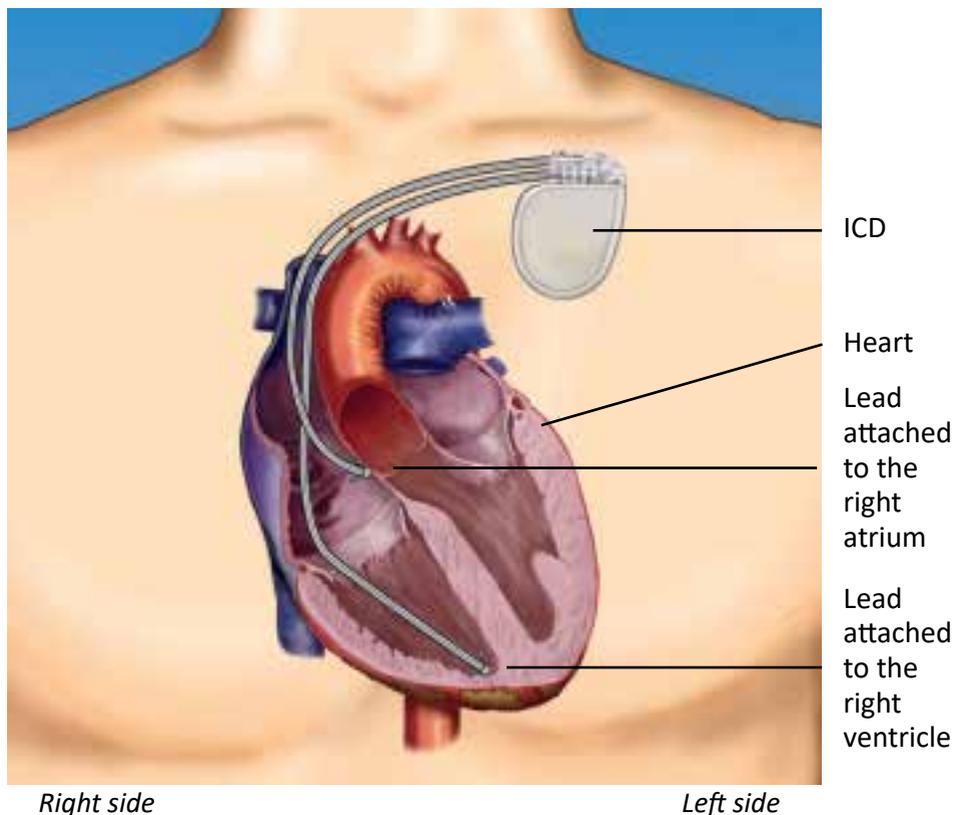
The generator is then implanted. This is usually located in the left side of the upper chest, and sits in a small space under the skin or muscle (sometimes referred to as a 'pocket'). The generator is then connected to the lead (or leads).

Once the generator and leads are in place and connected, the device will be 'programmed'. This involves testing that the device works by bringing on an arrhythmia using electrical impulses, and checking that the device responds to treat these arrhythmias. It will also be programmed to recognise natural increases in your heart rate, such as when you are active or exercising. This is important as it means that the device can be adjusted and programmed to meet *your* needs.

The wound is closed with stitches and covered with a dressing.

i The hospital will provide information about recovery, care of your wound and removal of stitches (which may dissolve or need to be removed - which can usually be done by your GP surgery).

Representation of where an ICD is placed in the body.



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If there is a reason why implanting the battery on the left side would be difficult (for example, if you are left handed) you might want to talk to your doctors about whether you could have the implant on the right side (although the wires would still go into the right side of the heart).

How are S-ICDs implanted?

The process for implanting an S-ICD is similar to having an ICD, with the leads being implanted, followed by the generator. However, the generator is located lower down on the body, and the leads go under the skin (rather than along a blood vessel).

What are the risks of implantation?

As with any surgical procedure, there are some risks to having an ICD implanted. These can include the following.

- Soreness and bruising around the implant site (this can be due to the procedure which includes implanting the device under the skin). Any bruising will usually disappear in a couple of weeks.
- Risk of infection from the wound site (your doctors will explain how to clean and care for your wound to minimise this risk).
- Damage to the blood vessels as the leads are put in place.
- Damage to the lungs, where either air or blood leaks out of the lungs and into the chest cavity (which can happen as the leads are put into place). This is called a 'pneumothorax' and may get better on its own or the air may need to be drained out.
- Blood clots due to the operation. You may be given anticoagulant medication to reduce any blood clot should this happen.

Following the procedure, complications may include the following.

- Risk of infection from the device, which can cause pain, swelling and a fever. This can happen during the first year of having the device implanted. This will usually be treated with antibiotics, and it may mean that the ICD needs to be replaced.
- Problems with the device, where it doesn't work properly. This could be due to a fault with the leads, or the generator or battery. This might mean that the ICD needs to be re-programmed or replaced.

Although these risks may sound worrying, the likelihood of them happening is small. It is also worth considering the risks of implantation against the benefit of the ICD which can monitor and treat dangerous arrhythmias.

i *Your doctors will discuss these risks with you before any procedure, so you can talk through any concerns you have.*

Moving around after an implant operation

You will be advised to limit the movement of your left arm for a few weeks following surgery. This means avoiding lifting your arm higher than shoulder height and avoiding strenuous activity or exercise, stretching or lifting heavy objects. Also, avoid any pressure directly on the wound or device. This is to give the leads time to become firmly attached to the heart muscle and lessens that chance that the leads will move. It also gives time for your wounds to heal.

After a couple of weeks, you can usually return to normal activities, including work, and most exercise and leisure activities. However, you may be advised to continue to avoid activities that could potentially damage the ICD (such as contact sports).

Can you see the device once it is implanted?

When you have an ICD you will have a small scar where it was implanted. This might be visible, depending on what you are wearing. Generally, devices are relatively small so, depending on your build, they may not be obvious. You may be able to feel where the device is, but again this will depend on your build. However, you may be aware of the device if you touch the area or lie in certain positions.

Some people may be aware of the device and keep touching it, even subconsciously. This is sometimes called 'Twiddler's syndrome' and may cause problems if the pacemaker moves position. Although this is very rare, in this case the device may need to be repositioned.

How is my device monitored?

If you have an ICD implanted, you will be given an appointment at an ICD clinic (often called a 'pacing clinic') a few weeks after the implant, to check your ICD and see how you are getting on. After this, you will need to have your device routinely monitored for as long as you have it. This is to check your ICD and whether it has treated any arrhythmias, and is a way of monitoring your condition. Your ICD contains software so that it can store information about your heart, and whether the ICD has been activated. This information can be downloaded and reviewed by the clinic. It is also when the battery of your device will be checked, so that you have plenty of warning for when it will need to be replaced.

Monitoring might be done at a clinic every six months or so (depending on how you are getting on). However, most ICDs can now be monitored with a remote device at home, which usually sits by your bedside. This remote device uses a wireless connection to download information from your ICD, which it sends via a mobile phone network to your ICD clinic. This may mean you don't have to attend a clinic as often as you would without remote monitoring. It can also be reassuring if you have any symptoms that you are worried about.

 *You can ask your doctors whether this is possible for you.*

How long does an ICD last?

The battery on an ICD usually last around 5 – 10 years (depending on the individual device and how much it is used). The battery life will be monitored during your routine clinic appointments. When the battery is low the ICD will need to be replaced. The surgery for this is similar to when you had the ICD implanted, but usually only the generator needs to be changed (the leads are kept in place and attached to the new battery). The surgeons may make the incision over the top of the last one to reduce any new scarring.

ICD shocks

An ICD is designed to respond to arrhythmias, either by ‘pacing’ the heart back into a normal rhythm or by giving a shock to the heart. This sounds scary, and many people with ICDs are anxious about the possibility of this happening. Although a shock is potentially life-saving, it can be distressing, and a sign that someone would otherwise have had a cardiac arrest. This in itself can be distressing.

If someone has a fast or irregular heart beat they may be aware of it, and may feel faint or dizzy. The ICD monitors the heart to see if it corrects itself. The person may be aware of a possible shock happening. People who have been awake when they received a shock have said it is like being thumped or kicked in the chest. This is a temporary feeling.

However, for most people their arrhythmia will cause loss of consciousness and so they will be unaware of the shock happening.

Most people recover quite quickly from a shock, and do not have any lasting physical symptoms, although it is often a good idea to rest before going back to normal activities. However, some people have an emotional reaction to having a shock, as it can be upsetting.

Your doctors will talk to you about what to do if you receive a shock. They may ask you to visit the ICD clinic for a check-up following a shock. You would usually only need an ambulance or to go to hospital if you continue to feel unwell, or you receive more than one shock.

What are inappropriate shocks?

An inappropriate shock is when an ICD gives a shock to the heart when it is not necessary. This can sometimes happen if the ICD detects a fast heart rhythm that is not dangerous. The ICD is programmed to reduce the possibility of this happening. If it does happen, your ICD will need to be checked to see why it has happened, and may need to be reprogrammed so that it doesn’t happen again.

What happens if someone touches me when I have a shock?

If someone is touching you when your ICD goes off, they will feel a small shock themselves. This is a bit like a static shock and is harmless.

Your ICD identification card

If you have an ICD you will be given an 'ICD identification card'.

This card carries important information about:

- your type of ICD (including the make and model);
- the type of leads;
- the settings (for example, what arrhythmias it is set to detect); and
- the reason for having the ICD.

It is important to carry this card with you at all times so that, should you be taken ill for any reason (including reasons unrelated to your cardiomyopathy), doctors will have access to your information. It is also helpful for any routine medical appointments, and for things like if you are going on holiday (see page 28).

Some people with medical conditions carry some form of medical identification (or 'medical ID'). This might be a bracelet, watch or necklace. Medical ID carries details of your medical condition, and some also have details of your treatment. You may like to consider having a form of ID that says you have a medical device. This may give added reassurance, alongside your identification card, should medical help need to be called for you (such as an ambulance).

♥ *See our factsheet 'Medical jewellery and ID'.*

♥ *Contact us for a copy of our free 'I have cardiomyopathy' ID card.*

The emotional impact of having an ICD

Considering having an ICD, or having an ICD fitted, can bring up a variety of different emotions. Some people come to terms with the need for an ICD easily, and feel reassured by having it, knowing that it could, potentially, save their life. However, other people find it difficult to come to terms with having an ICD, and this can be for many reasons.

- The reality of needing an ICD means that their heart is not working well, that this could be life-threatening, and that they are relying on a machine, which can be frightening.
- They may already have experienced a dangerous arrhythmia and this can be traumatic.
- Some people don't like the idea of having a device – a foreign object – implanted into the body.
- The implantation operation will leave a small scar, and the device might be visible (as a small bulge in the upper chest). Some people feel self-conscious about that.
- An ICD is a constant reminder of a condition. Some people may become preoccupied by their heart and any symptoms they experience.
- Some people are extremely anxious about the device giving a shock, including when they are awake or if it is an inappropriate shock.

All of these feelings are natural, and there is no right or wrong way to feel. And how you feel may change over time.

 *You might like to talk to your doctor about whether counselling is available to help you with some of these feelings.*

-  *See our booklet 'emotional wellbeing' for more about help and support.*
-  *If you would like to talk to someone with an ICD, call our helpline and ask to be put in contact with a peer support volunteer.*

"It is important to remember that an ICD is a backup in case you have a life-threatening heart rhythm. It shouldn't define your life: life should carry on as normally as possible depending on your heart condition."

Wendy's story



“By the time the ICD came along I was well prepared for it.”

Getting used to my ICD

I had my ICD fitted recently so it is all still very fresh to me. There was never any question in my mind about having this fitted: I saw it as a precaution and a preventative strategy. I have not had any need for it yet but as my condition deteriorates it will be the next stage for me.

To be honest I had such a difficult time emotionally dealing with the deterioration of my heart that I sought professional psychological help. By the time the ICD came along I was well prepared for it. My cardiologist had already explained that I might possibly need an ICD at my appointments in the past so it was not a surprise when the time came.

My question was which ICD to choose as I was eligible for two. My cardiologist talked me through the options and her explanation was very clear and easy to understand. I read through medical advice about how they work and asked people on the Cardiomyopathy UK Facebook group, who already live with them, how they feel (and the pros and cons). I made my choice based on both comfort (as an S-ICD is bulkier and not comfortable with a bra) and on medical grounds (as the ICD I have has a pacemaker function and, although I don't need that now, I would be prepared if that need should arise).

I was concerned about my mobility after surgery. But the heart failure nurses in hospital explained everything well and continued to do so at every opportunity before I was discharged. The ICD team also were very clear and understandable in their explanation.

Speaking to the consultants, nurses and device teams helped my husband come to terms with my cardiomyopathy: this was the first time he had a medical explanation of my condition and he was reassured by how the ICD meant I could be monitored round the clock.

The service overall was extremely thorough and I was well looked after. It took me the average time to recover, and it was painful as the wound recovered, but in the grand scheme of things it was a short time.

I am aware of the ICD but much more used to it. Time will tell how we get on together.

Living with an ICD

ICDs control arrhythmias and reduce the risks associated with this so that you can carry on your life and normal activities. However, it will not 'cure' your cardiomyopathy, and you will still have your underlying condition. The following information is about having an ICD, but there may be issues around your cardiomyopathy that are also important to consider. For example, your ICD may not affect your ability to exercise, but this may depend on your cardiomyopathy.

i *You might like to talk to your cardiologist, nurse or device clinic if you have concerns about any activities.*

Is it safe to be around magnets and electrical equipment?

ICDs are electromagnetic devices and have built-in protection (like a 'shield') that gives protection from magnets and electromagnetic fields. However, they can be affected by strong magnets and electromagnetic fields (produced by electrical equipment and wireless devices), or those too-close to your device. Magnets can activate a switch in some devices that stops it from working (although it should turn back on when the magnet is removed). Electromagnetic fields can cause damage to or deactivate ICDs, or cause them to give a shock.

It is worth knowing that most day-to-day electrical appliances are safe to be used by people with ICDs.

- Wireless devices (such as digital music players, e-readers, and headphones) should not cause any problems.
- Mobile phones can be safely used.
- Computers, laptops and tablets are considered safe. However, when use or carry a laptop or tablet do not hold it close to your chest. Photocopiers and printers are also considered safe.
- You may be able to use a TENS machine (for pain control), depending on where on the body you use it and how close this is to your device.
- Household items such as TVs, remote controls, microwaves, chargers and irons are usually safe.

However, there are some guidelines which are helpful to know.

- Avoid strong magnets or electromagnetic fields. If your work involves using technology or machines with electromagnetic fields, talk to your employer and doctors about whether this may be a problem for you.
- Avoid using any faulty or poorly-wired equipment that may cause an electric shock.
- If you go to a shop with a metal detector at the door, don't stand or linger in the area around the detector. Also, be aware that your ICD could set off a metal detector (and so having your ICD identification card can be helpful).
- Keep items such as electric shavers and toothbrushes, hairdryers, speakers and radio-controlled items at least 15cm from your device.
- Keep at least 60cm away from induction hobs.
- If you are due to have any dental or medical tests or procedures it is important that your healthcare professional is aware that you have an ICD so that they can take any necessary precautions. Some medical equipment could affect your device.
- It is a good idea to consult a gym instructor before using electrical gym equipment, or contact the manufacturer of the equipment for further information.

 *You can find more guidance in the patient booklet from your device company. You can also ask your device clinic for any specific guidance.*

If your device is affected by an electromagnetic source, you may feel dizzy or light-headed, or experience arrhythmias. It is possible that your device may fire. If you move away from the source, or let go of what you are holding (if it is a hand-held device), your device should return to normal. If you are concerned about your device working, or you have had prolonged contact with an electromagnetic source, you may want to contact your doctor or device clinic.

Can I have an MRI?

MRIs use strong magnetic fields to build up a picture of the body, and involve being inside a strong magnetic field. For this reason, for some devices you will not be able to have an MRI. This is for devices that are not 'MRI compatible' because the MRI could damage or affect the settings of your device. However, some devices are 'MRI-compatible' and so are considered safe in an MRI, under certain conditions.

Your ICD card should say whether your device is compatible with an MRI or not. If you are likely to need an MRI it is important that your doctor knows that you have an ICD.

What about travelling and airports?

If you have an implanted device you may have concerns about security checks at airports that include scanners which check for any hidden prohibited items. Although the Medicines and Healthcare products Regulatory Agency (the organisation that regulates the safety of medicines and medical devices in the UK) consider that you can safely use airport security scanners, the following may be helpful.

- Let the staff know that you have a device as soon as you approach the security desks, and show them your ICD identification card.
- If the scanner is a walk-through one (an archway scanner), walk at a normal pace and do not pause or stop in the scanner.
- If the scanner is an electronic wand (that is passed over your body) ask the staff to avoid passing it close to, or repeatedly over, your heart.
- If the scanner is a full-body one (where you have to stop inside it to be scanned) these use 'millimetre wave' technology, and are considered safe for people with medical implants.
- If you are concerned, you could ask to be searched by hand instead.

 *If you are concerned, contact your follow-up clinic before you travel.*

 *See our factsheet 'Travel and cardiomyopathy' for more information about travel and holidays.*

Can I exercise or do sports with an ICD?

Some people worry that a change in their heart rate, due to exercise, could cause their ICD to give them a shock. Generally, people with an ICD can exercise, and an ICD is no more likely to give a shock during exercise than at any other time. The arrhythmias detected by an ICD that trigger a shock are usually faster (higher heart rate) than what happens during normal exercise.

An exercise test can help to programme an ICD to recognise the person's normal heart rate, even when exercising, and only give a shock at the appropriate time (for heart rates above your normal exercising heart rate). For some people, regular exercise might help to reduce the risk of arrhythmias. It is also a good idea to warm up before, and to cool down after, exercise so that your heart rate increases and decreases gradually, and to reduce the risk of arrhythmias.

Once you have recovered from having an ICD implanted, your ICD should not limit your physical movement. However, over-stretching your arm and shoulder could affect the leads, and this could affect what exercise is suitable for you. Also, pressure on the ICD itself should be avoided, and this could also affect what exercise and activities you do. This may mean that you need to avoid contact sports or high impact sports.

However, it is important to consider your underlying cardiomyopathy and whether this may have an impact on your physical activity.

 *It is a good idea to talk to your doctor or device clinic about what exercise will be suitable for you.*

 *See our factsheet 'Cardiomyopathy and exercise' for more information about exercise.*

Can I drive with an ICD?

There are driving standards related to having a device implanted or a battery replaced, and what to do following a shock from an ICD, that mean you will have to stop driving for a period of time and may need to inform the DVLA. How this applies to you will depend on the type of device you have, and your driving licence (car or vocational licence). There are also driving standards for specific types of cardiomyopathy, and for specific symptoms, depending on your situation. However, once you meet the standards for driving you should be able to drive again.

♥ *See our factsheets 'Cardiomyopathy and driving' for more detailed information about driving standards.*

Is it safe to have sex when you have an ICD?

It is not unusual for people to be concerned about sex and whether it might trigger an ICD to fire if their heart rate increases. The increase in heart rate during sex usually happens gradually, and is still under the rate at which an ICD would normally fire. Your ICD will be programmed so that it will not fire at your normal heart rate or the rate during exercise or general physical activity. So once you have recovered from having the ICD implanted and your wounds have healed, you can normally have sex without any concerns. However, it is best to avoid positions that put pressure directly on the ICD itself.

Will having an ICD affect what I can wear?

A regular ICD usually sits underneath the collarbone, although an S-ICD sits lower down the body (see page 16-17). The placement of the device may vary slightly depending on your build and the type of ICD you are having implanted. However, this can mean that the device sits where your clothes, for example, a bra strap or straps on a rucksack, also sit. For some this might be uncomfortable, and using straps with padding might help this. You can talk to your surgeon before implantation to see where your device will sit, and how it might affect you, and discuss any concerns you have.

ICDs at the end of life

Having an ICD will treat any arrhythmias you have, and reduce any symptoms you have because of the arrhythmias. But it will not affect your underlying cardiomyopathy, or any other condition you have (or may develop during your lifetime).

When it comes to end of life care you may need to consider whether your ICD is still appropriate or whether to turn it off, so that it no longer paces your heart or gives life-saving shocks. In this case, the ICD can be deactivated, where it is programmed to stop working. The device itself will be left in place.

This can be a very difficult decision, and it may be something that you want to discuss in advance with your family, and with your healthcare team.

Summary of terms

Arrhythmia – abnormal heart rhythms, that are either too fast, too slow, or are uncoordinated. This affects how well the heart works, but can also have complications such as causing cardiac arrest.

Atria – the top two chambers of the heart.

Bradycardia – a type of arrhythmia where the heart beats too slowly.

Cardiac arrest – when the heart stops suddenly (is ‘arrested’) and does not pump blood around the body. This causes the person to collapse and eventually stop breathing.

Cardioversion – when electricity is used to try and restore the heart’s normal rhythm. This might be done internally (such as by an ICD) or by an external by a defibrillator.

CRT-P and CRT-D – types of pacemaker, cardiac resynchronisation therapy helps both sides of the heart to be together. CRT-P only has a pacing function but CRT-D has an additional defibrillator function.

Defibrillation – where a large shock is given to the heart to restore a normal heart rhythm (see also cardioversion).

Fibrillation – where the electrical signals that usually cause the heart’s chambers to contract are interrupted and cause it to be uncoordinated, and ‘quiver’ rather than beat normally. This can happen in the atria or the ventricle.

Firing (of an ICD) – when an ICD delivers a shock to the heart to restore the normal rhythm.

Heart beat – the ‘beat’ actually refers to the sound made by the heart’s valves as they shut. This term is usually used to refer to the contraction of the heart’s chambers, causing blood to flow around the heart.

Heart failure – when the heart is not able to pump enough blood, at the right pressure, to meet the demands of the body. This causes symptoms such as shortness of breath, fluid retention and fatigue.

Heart output – the blood that is being pumped out of the heart each minute. Also known as ‘cardiac output’, it is calculated as the number of beats per minute multiplied by the volume of blood pumped at each beat.

ICD – implantable cardioverter defibrillator – an implanted device that is used to monitor the heart rhythm and treat ventricular arrhythmias.

Pacing – when an ICD uses fast electrical impulses to try and restore the heart to a normal rhythm.

Pacemaker – an implanted device that sets the pace of the heart. Some pacemakers work continuously and some work just when the heart needs it.

Sinus rhythm – the normal rhythm of the heart.

Tachycardia – a type of arrhythmia where the heart beats too fast.

VAD – a ventricular assist device, an artificial pump that helps the heart to pump blood around the body.

Vein – a type of blood vessel that transports blood towards the heart (either from the lungs or from the rest of the body).

Ventricles – the bottom two chambers of the heart.

Ventricular fibrillation – a type of arrhythmia where the contraction of the ventricles is uncoordinated, and they ‘quiver’ rather than contract normally, so blood is not pumped out of the heart effectively.

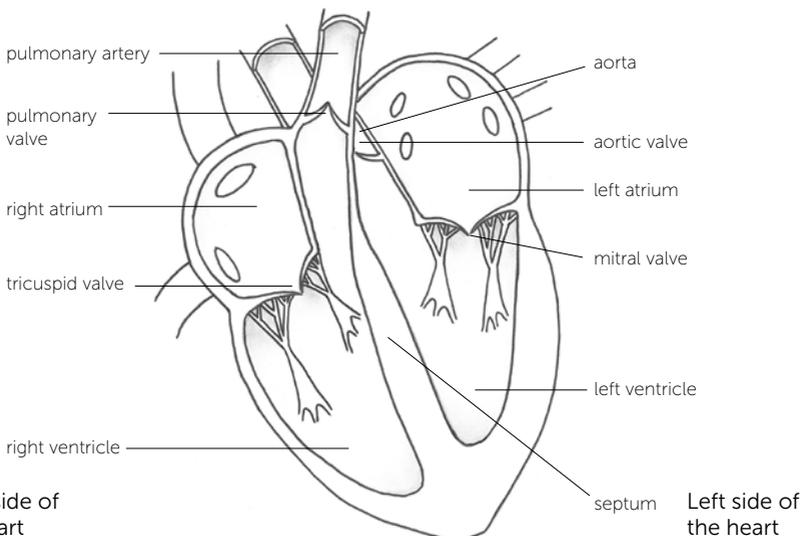
Ventricular tachycardia – a type of arrhythmia that starts due to abnormal electrical activity in the ventricles, where the heart contract abnormally quickly (over 100 beats per minute).

How the heart works

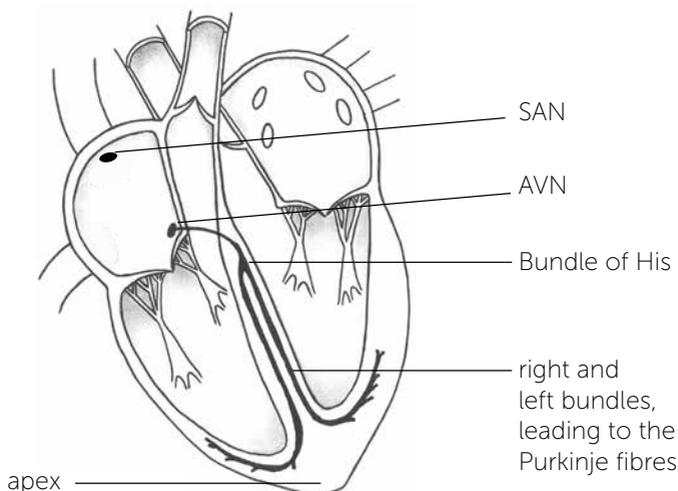
Blood flows around the body in 'double circulation': traveling through the heart twice on each complete cycle (from the heart to the lungs to pick up oxygen, then from the heart to the rest of the body to deliver oxygen to the body). This happens in the following way.

- Deoxygenated blood (that carries no oxygen) enters the right atrium and the chamber fills with blood.
- The atrium contracts, forcing the blood into the right ventricle.
- The ventricle relaxes and fills with blood.
- The ventricle contracts forcing the blood out of the heart through the pulmonary artery.
- Blood travels to the lungs where it picks up oxygen.
- From the lungs, blood flows into the left atrium of the heart.
- The atrium contracts, forcing blood into the left ventricle.
- The ventricle relaxes and fills with blood.
- The ventricle contracts forcing the blood out through the aorta.
- Blood travels to the body, where it delivers oxygen to the cells, tissues and muscles.

Although this describes the flow of blood through the heart in one 'circuit' of circulation, both sides of the heart are working at the same time (both atria fill and contract at the same time and both ventricles fill and contract at the same time).



How the heart works is controlled within the heart, from an area called the sinoatrial node or 'SAN'. The SAN generates and conducts electrical impulses which make the heart muscles contract and relax (or 'beat'). It also controls the rhythm and speed of the heartbeat (and is sometimes referred to as the 'pacemaker').



The cycle is generated in the following way.

- Electrical activity is spontaneously generated by the SAN.
- The electrical activity spreads through the muscle of both atria, making them contract.
- The electrical activity is stopped from spreading to the ventricles by a layer of connective tissue. Instead, the activity reaches a second group of specialised muscle cells called the atrioventricular node (or AVN), between the two atria and the top of the ventricles.
- The AVN passes the electrical activity down a group of muscle fibres called the Bundle of His, which sits in the septum - the muscular wall between the two ventricles.
- From the Bundle of His, the activity spreads into the left and right bundle branches and to the smaller muscle fibres (Purkinje fibres). This causes the ventricle walls to contract from the bottom point of the heart (the apex) upwards, pushing the blood out of the heart.

♥ *For more information about how the heart works, see our factsheet 'About the heart'.*

This guide is for anyone with cardiomyopathy who has, or is considering having, an ICD.

It includes experiences shared by people with cardiomyopathy who have experience of having an ICD.

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