

Addendum

Extravascular* ICD (EV-ICD) see image on page 14.

An EV-ICD lead is implanted under the skin just below your rib cage, the tip sits next to your heart, it is connected to the ICD device which is implanted on the left side of your chest under your armpit.

The EV-ICD monitors your heart continually, it has a pacing function for too-fast and too-slow heart rhythms, the ICD will send a small electrical signal to try to correct your heart rate called pacing (for a slow heart rate) or anti-tachycardia pacing or ATP (for a fast heart rhythm).

If the fast heart rate continues despite ATP, the ICD will defibrillate the heart (deliver a small electrical shock to the heart) to restore it to a normal rhythm.

The EV-ICD's battery life will depend on several things including how often it sends signals to your heart but can last up to 10 years.

After your EV-ICD has been implanted you might experience some discomfort or pain and bruising this usually improves within 1-2 weeks. It might take a few weeks to get used to your ICD, and you will be recommended to wear loose tops, not lift anything heavier than 15 pounds, push or pull anything heavy or twist your upper body suddenly.

You will be given an EV-ICD card, always carry it with you as it has important information about your ICD.

*Extravascular= outside of the veins

All about devices

A guide to having an implantable cardioverter defibrillator or cardiac resynchronisation device for cardiomyopathy



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

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

i Words highlighted in bold can be found in the summary of terms on page 53

We are particularly grateful to the following people for allowing us to share their experiences, Hugh, Bill, and Aaliyah.

We are very grateful to Dr Robert Cooper, Consultant Cardiologist at Liverpool Heart and Chest Hospital for reviewing and approving the ICD section of this booklet and to Jamie Walton Head of Cardiac Implantable Devices – Cardiology University Hospitals Birmingham for his work writing the CRT section of this booklet.

Images on page 14 were provided by Medtronic Limited, images on page 26 were provided by Mindray Limited, images on page 52 were provided by Abbott Laboratories.

Contents

About devices	4
ICDs	6
Who needs an ICD?	9
Types of devices	12
What do ICDs look like?	14
Deciding whether to have an ICD or not	15
Bill's story - Pipe dreams and peace of mind	16
How are ICDs implanted?	18
What are the risks of implantation?	21
ICD shocks	24
Your ICD identification card	27
The emotional impact of having an ICD	28
Aaliyah's story - Getting used to my S-ICD	30
Living with an ICD	32
ICDs at the end of life	37
CRT devices	38
Why do I need a CRT device?	40
What are the benefits of a CRT device?	41
What are the risks of CRT implantation?	42
Hugh's story - Getting used to an ICD	44
Remote monitoring of your CRT device	51
CRTs at the end of life	52
The emotional impact of device implantation	52
Summary of terms	53

About devices

There are many treatment options for people with cardiomyopathy. Some therapies treat the symptoms, and some treat the condition itself to reduce its long-term impact on the heart. There are also treatments aimed at reducing the risk of dangerous cardiac events.

Many people with cardiomyopathy take medication. This includes medications aimed at improving the efficiency of the heart's pumping function such as beta-blockers (to reduce the rate and force of the heart's contraction), ACE inhibitors (reduce the workload on the heart), Angiotensin Receptor-Neprilysin Inhibitors (reduce the workload on the heart), or SGLT2 inhibitors (regulate the heart's use of energy). There are also categories of medications that are aimed at reducing fluid build-up (diuretics), stabilising the heart's rhythm (antiarrhythmics) or thinning the blood to prevent clots and strokes (anticoagulants).

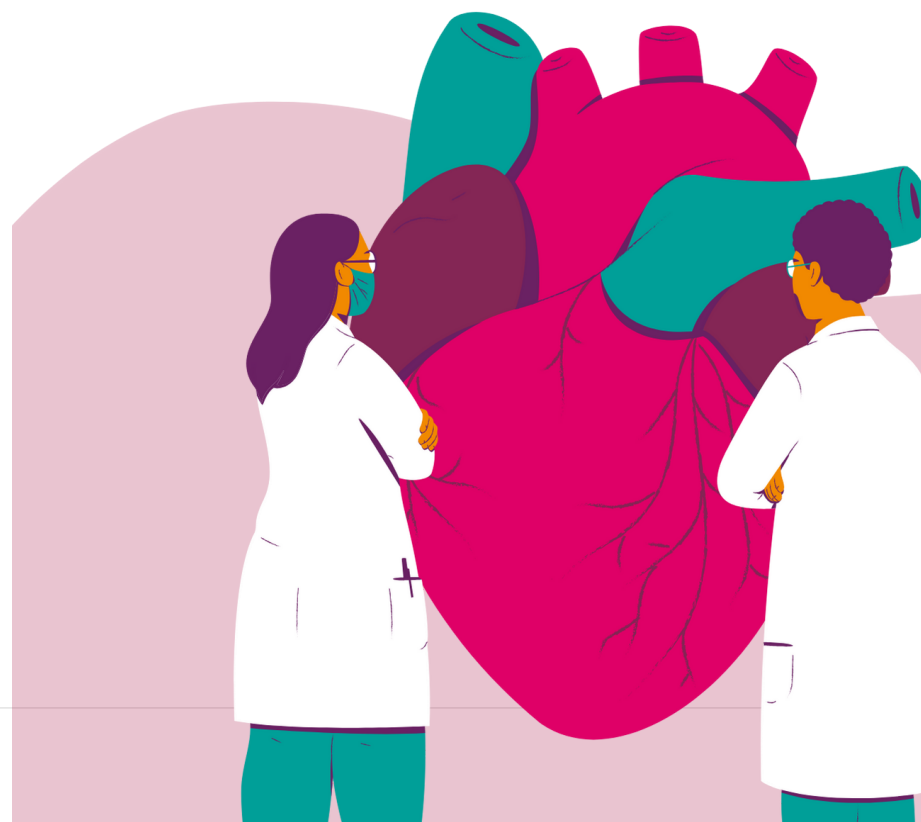
Some people will have medical devices to treat their cardiomyopathy. These are types of implanted technology to support the heart, either by monitoring the heart rate and treating any abnormal rhythms, or by taking over the control of the heart rate to synchronise its contraction in a more effective manner.

This booklet is for you if you are considering having an **ICD** (Implantable Cardioverter Defibrillator) or **CRT** (Cardiac Resynchronisation Therapy) for your cardiomyopathy, or if you have already had a device implanted and would like to know more. It explains what **ICDs** and **CRTs** 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** or **CRT**, to share what it is like to live with one. The glossary at the end of the booklet explains all the phrases marked in bold.

What types of device are there?

There are different types of device, each with a slightly different function. They fall into three categories, **ICDs**, **CRTs** (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 in a more efficient manner, 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 **heartbeat** 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.

Arrhythmias (abnormal heart rhythms) happen when the electrical signals that control the **heartbeat** 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**. If the **arrhythmia** is originating from the **ventricles** and poses a threat to the patient's life the **ICD** will treat this.

Arrhythmias treated by ICDs

Ventricular tachycardia (VT) is a type of **arrhythmia** that originates in the **ventricles** and causes the heart to beat too quickly. This is caused by abnormal electrical activity within the **ventricles** which causes it to beat over 100 times per minute, out of synch 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 **anti-tachycardia 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 to stop the **arrhythmia** and 'convert' the heart back into **sinus rhythm**. Not all **ICDs** have this pacing function (see **S-ICD** information below), but all are capable of **cardioversion**.

Ventricular fibrillation (VF) is caused by a series of abnormal impulses, coming from many parts of the **ventricle**, 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** will cause **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 prolonged **VF** which, if left untreated, will become fatal.

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.

i ICDs can help to 'pace' a heart if it is beating too slowly.



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**. 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 are thickened) there are guidelines from the European Society of Cardiology (ESC) available to help clinicians 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**.

Several risk factors are considered, which include the following:

- A family history of **cardiac arrest**;
- A history of syncope (blackouts);
- Episodes of 'non-sustained **ventricular tachycardia**' (periods of temporary too-fast rhythm in the left **ventricle**)
- The amount of left ventricular hypertrophy (how thick the left **ventricle** wall is)
- The amount of extra pressure in the heart building up as result of 'obstruction'
- The size of the receiving chamber in the left heart, the left atrium

This information is used to determine an individual's risk of a life-threatening **arrhythmia** and therefore whether a device is recommended. Each person's condition and symptoms will be reviewed by their clinical team so that any recommendations are appropriate for them.

Clinicians in some centres may use additional information from scans and exercise tests to inform consultations regarding **ICDs**. A Magnetic Resonance Imaging (MRI) scan can allow your team to understand the presence and volume of heart scar tissue which can increase the risk of dangerous events. Assessing heart rhythm and blood pressure response during exercise can also help in some circumstances.



NICE guidelines about ICDs

NICE (the National Institute for Health and Care Excellence) is an independent organisation that provides 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** (cardiac resynchronisation therapy) for **arrhythmia** and **heart failure** (called 'TA314') and **S-ICDs** for preventing **sudden cardiac death** (called 'IPG603').

You can go on the NICE website at www.nice.org.uk and search for 'TA314' or 'IPG603' for more information:

TA314 - Implantable cardioverter defibrillators and cardiac resynchronisation therapy for **arrhythmias** and **heart failure**; Technology appraisal guidance.

 www.nice.org.uk/guidance/ta314

IPG603 - Subcutaneous implantable cardioverter defibrillator insertion for preventing **sudden cardiac death**; Interventional procedures guidance.

 www.nice.org.uk/guidance/ipg603

Types of Devices

There are three main types of cardiac devices:

- **Transvenous ('through a vein') 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 (deliver a small electrical shock to 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 breastbone to the heart. The leads do not sit within the heart (unlike a transvenous 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 transvenous ICD.

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

There is a third type of device, called a CRT - Cardiac resynchronisation therapy devices are available in two sub-types; a CRT-P includes a pacing function, and a **CRT-D** has the ability to defibrillate the heart.

You can learn more about Cardiac Resynchronisation Therapy on our YouTube channel. Go to:

 www.bit.ly/cardiomyopathy-UK-CRT

Which device would I need?

Which device you would need depends on your medical needs. A transvenous **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. In the unlikely event that 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 can be difficult to extract. However, this device is suitable for anyone who may need a pacing function and provides the option of **anti-tachycardia pacing** which the **S-ICD** cannot do.

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 fine coated wires, with special electrodes on the end, which are connected to the generator. The 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 these examples:



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 of whether to have an **ICD** is yours, and it is important you feel you have enough information and support to make this decision.

The decision can be difficult, and it can feel overwhelming. 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 clinicians and the **ICD** clinic, and with those close to you.

If you would like to talk to someone with experience of having an ICD, you can speak to one of our specialist nurses, chat with a Heart to Heart volunteer, or join a support group:

 www.cardiomyopathy.org/support



Bill's Story

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 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 or very little scope for any research into DCM or ICDs, it made the decision very simple for me.

Within a week of initial diagnosis I was discharged from 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 or how to react to my new life.

After a few weeks I had my first shock from the device (which turned out to be entirely appropriate, although I found it 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 were a few minutes of 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 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 third ICD box change three 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 third 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!



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



How are ICDs implanted?

ICDs are usually implanted by a cardiologist specialising in heart rhythm disorders. Transvenous devices are usually implanted on the left side as this is closer to the heart for the leads to be placed. You can ask your hospital for further information about the procedure, as it may vary from one hospital to another.

You would usually have the device implanted while you are under a local anaesthetic, and sedation is offered if required. Some implants are performed under general anaesthetic. Many centres now implant **ICDs** as a day case procedure without the need to stay overnight. You will have an X-ray to ensure that the **ICD** is correctly in place and you have no complications from the surgery, and a device check to ensure it is working appropriately.

With transvenous **ICDs**, the leads are inserted first, through a small (5-6cm long) incision under the collarbone. They are fed through a **vein** in the chest down into the right side of the heart. An X-ray camera 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 **atrium**. The leads are attached to the heart muscle to keep them in place.

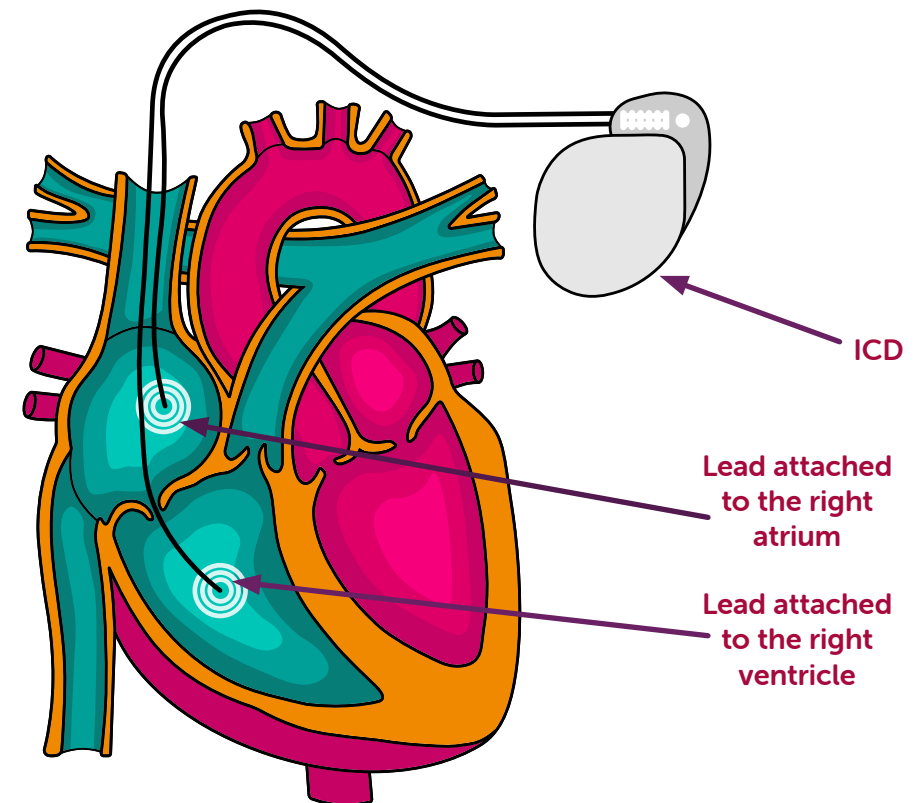
The generator is then implanted. This is usually located in the left side of the upper chest, and sits in a small space under the skin or muscle (sometimes referred to as a 'pocket'). The generator is then connected to the lead (or leads).

Once the generator and leads are in place and connected, the device will be 'programmed'. 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 skin glue, then covered with a dressing.

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

Representation of ICD lead placement in the heart:

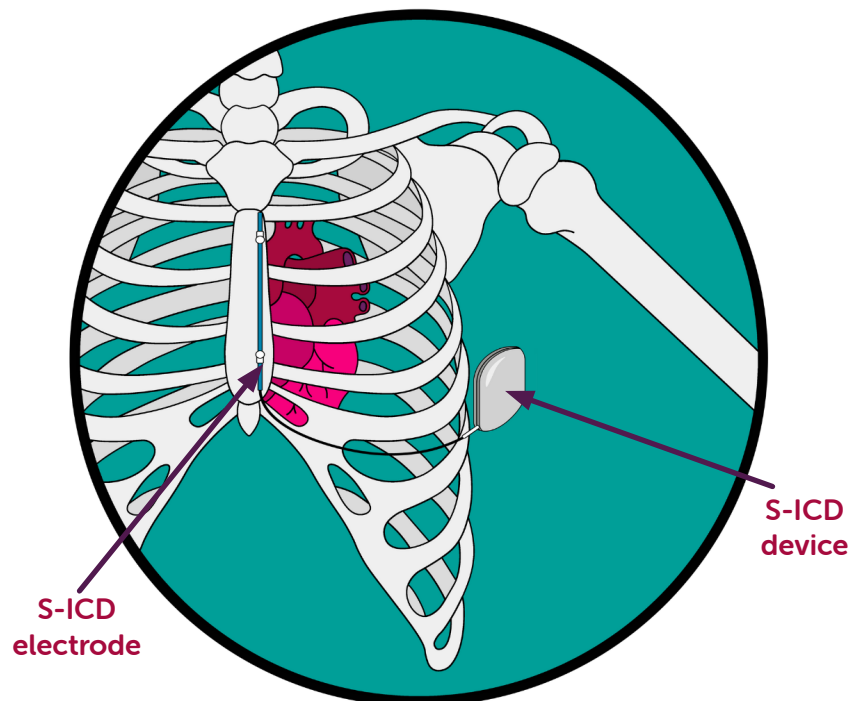


If implanting the battery on the left side would be difficult (for example, if you are left-handed) you can talk to your clinician about whether you could have the implant on the right side (although the wires would still go into the right side of the heart).

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 left side of the chest wall, and the leads go under the skin (rather than along a blood vessel).

Representation of S-ICD lead placement in the heart:



What are the risks of implantation?

As with any surgical procedure, there are some risks to having an **ICD** implanted. Your clinician will discuss these risks with you before any procedure, so you can talk through any concerns you have. **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 clinician 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 reprogrammed 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**.

Moving around after an implant operation

You will be advised to limit the movement of your left arm for a few weeks following the procedure. 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 predominantly to give your wound time to heal properly, and also gives the leads time to become firmly attached to the heart muscle, lessening the chance they will move.

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 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 (see page 14) 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 **ICD** 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 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 device battery will be checked, so you have plenty of warning before 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 (Home Monitor) or smart phone app. This app or Home Monitor use a wireless connection to download information from your **ICD**, which it sends via a mobile phone network to your **ICD** clinic. This remote monitoring may mean you don't have to attend a clinic as often. It can also be reassuring if you have any symptoms you are worried about.

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 **heartbeat** they may be aware of it, and may feel faint or dizzy. The **ICD** monitors the heart to see if it corrects itself. Some people may be aware that their heart is beating quickly prior to delivery of a therapy shock, or may be aware that their **ICD** is pacing their heart prior to a shock being delivered. Some 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 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 clinicians 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 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 may feel a small shock themselves. This is a bit like a static shock and is harmless.

How long does an ICD last?

The battery on an **ICD** usually lasts around five to ten 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 procedure 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 cardiologists may make the incision over the top of the last one to reduce any new scarring.

Should an AED be used for someone who has collapsed and/or is not breathing, or has no detectable pulse but has an ICD implanted?

If a situation arises where it looks like CPR and/or a defibrillator (**AED**) is required, you should prepare to use it straight away just as you would for anyone else. It is possible that the **ICD** will do its job before the **AED** is necessary. If the **AED** detects a normal rhythm, it will not deliver a shock. If someone is giving CPR and a person's **ICD** issues a shock at that time, this will not harm or hurt the person giving CPR.



Image: Mindray BeneHeart C2 Fully Auto AED

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)
- 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), clinicians will have access to your information. It is also helpful for any routine medical appointments, and for things like going on holiday (see page 34).

Some people with medical conditions carry a form of medical identification (or 'medical ID'). This might be a bracelet, watch or necklace. Some mobile phones also offer a medical ID function which can be accessed from the lock screen (check your phone settings). 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).

For a copy of our free 'I have cardiomyopathy' ID card. Go to:

 www.cardiomyopathy.org/information-resources

The emotional impact of having an ICD

Considering having an **ICD**, or having an **ICD** implanted, 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 have already 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 their 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. It's worth remembering that how you feel may change over time.



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.

- Sue Jones, former Pacing/ICD Service Manager



If you want to speak to someone who understands what it is like having an ICD, our Heart-to-Heart network offers you 1-1 support with someone who understands what you are going through. Go to:



www.cardiomyopathy.org/heart-to-heart



Aaliyah's Story

My name is Aaliyah, I have DCM and I got my S-ICD when I was 17. I did have arrhythmias when I was first diagnosed, but the medication I take has stabilised my heart.

My doctors had been mentioning having an ICD for a year or so beforehand; they described it as like 'having a seatbelt'. I agreed to have the operation during the COVID pandemic, so things weren't running like they normally do. I had to go in a couple of days before the operation to have blood tests and a COVID test, which came back clear and meant I was allowed to go ahead.

I had to go into the hospital on my own on the morning of the appointment, and I wasn't allowed to eat anything beforehand. I went into the Cath Lab awake. They did an ECG whilst I was laying on the table and they put a cannula in my wrist (which was one of the worst parts). I was under general anaesthetic and, when I woke up, I spent 24 hours in a ward recovering. The pain I felt wasn't so much from the wound on my chest, but it came from my back. There is also a tiny scar on the front of my chest, where they positioned the wires.

On the way home in the car, it felt really sensitive when we went over bumps or around roundabouts. My family kept



asking to see where the device was. You can see the scar under my left armpit,

but you can't really see the box. It was hard to get to sleep at first, because it felt painful in my back. After about a month, I didn't feel any more pain. I told some of my close friends that I'd had the operation. The trickiest thing was finding bras. I had to wear sport bras for a few months after.

I have a little machine that has to be plugged in 24/7. Every Monday morning I stand next to it so it can connect with my S-ICD and send an update to the hospital. If there are any problems, the hospital always gives me a call.

I have to go to a pacing clinic every six months. You go in, it's literally five minutes. They put a device on my chest, press a few buttons and it checks that the S-ICD is working properly. I've had my S-ICD for about three years now, it lasts about six years. I spotted something on my clinic letter recently that surprised me, it said 'Aaliyah's device is at 67% battery'.

I'm aware of my S-ICD. It's not a nice thing, but I just think it makes you live a bit differently. Every day is a gift and you have to live it to the fullest. Do everything you want to do, don't wait. The time might not come. There aren't really any downsides, apart from when my nan hugs me too tight and sometimes it hurts. The upside is that I go to the gym now and I know that if something was to happen, it wouldn't be such an emergency now.



Every day is a gift and you have to live it to the fullest. Do everything you want to do, don't wait.



Living with an ICD

ICDs control **arrhythmias** and reduce the risks associated with this so 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.

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. In some devices, magnets can activate a switch that stops them from working (your device should turn back on when the magnet is removed). Electromagnetic fields can cause damage to or deactivate **ICDs**.

It is worth knowing that most day-to-day electrical appliances are safe to be used by people with **ICDs**. If your device is affected by an electromagnetic source, you may feel dizzy or light-headed, or experience **arrhythmias**.

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 clinician or device clinic.

Join our online support group for those with/due to have ICDs (Implanted Cardioverter Defibrillators) fitted:

 www.cardiomyopathy.org/icd-online

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 may not be able to have an MRI. This is for some devices which are not 'MRI compatible' because the MRI could damage or affect the settings of your device. Some centres can offer MRI scans for non-compatible devices, so it is worth checking with your clinicians. 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 clinician knows that you have an ICD. To find out more visit:

 www.mrimypacemaker.com

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 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.

For more information about travel and holidays, visit:

 www.cardiomyopathy.org/travel

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 program 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). **ICDs** also have extra programming features that help to discriminate between normal fast heart rhythms and dangerous **arrhythmia**. 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.

Playing contact sports with an **ICD** can present some problems. This should be discussed with your clinicians. Damage to the leads and box are possible with high impact, but measures such as protection vests can help reduce the risk. If you are keen to play contact sports, this should be discussed before **ICD** implant with your clinical team so that this can be considered when deciding which type is appropriate for you.

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. However, it is important to consider your underlying cardiomyopathy and whether this may have an impact on your physical activity; advice from clinicians varies according to the type and severity of your cardiomyopathy.

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

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.

For more detailed information about driving standards, visit:

 www.cardiomyopathy.org/driving

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.

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 20). 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 cardiologist 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 dangerous, ventricular **arrhythmias** you have 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.

CRT Devices

Cardiac Resynchronisation Therapy or **CRT** is a type of pacemaker that is implanted into the body to treat the effects of **heart failure**.

Heart failure is a condition which affects the ability of the heart muscle to pump blood around the body. **Heart failure** is caused by damage to the heart muscle in the lower chambers of the heart, called the **ventricles**. **Heart failure** can have many different causes and sometimes a combination of causes. The impact of **heart failure** can vary depending on the cause, and the cause can also determine what treatment is used. Possible causes are coronary artery disease, heart valve problems, heart rhythm disorders, high blood pressure, pulmonary hypertension, congenital heart disease, inflammation of the heart muscle (myocarditis) and all types of cardiomyopathy. Generally, medications are used to treat or improve the symptoms of **heart failure**.

However, for a select group of patients a **CRT** device may also help; these are patients with dysynchrony or disorganised contraction of their **ventricles**. The device aims to restore the synchronisation of the **ventricles** and improve the overall pumping ability of the heart.

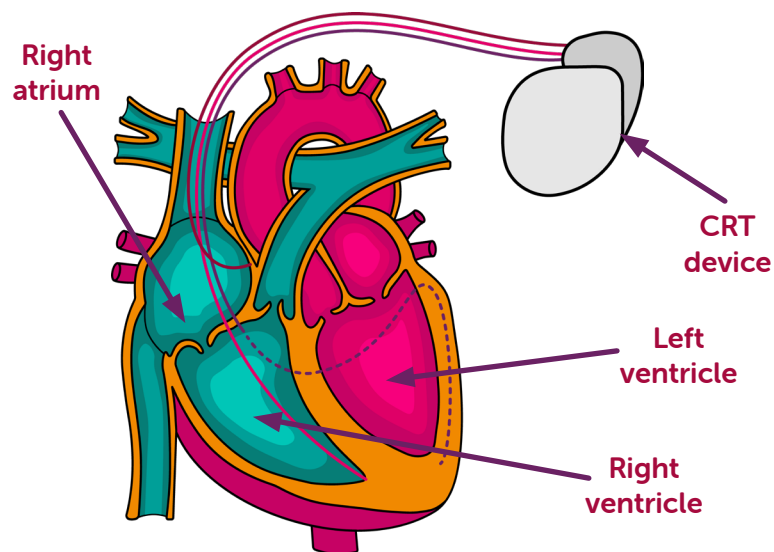
There are two types of **CRT** device: a **CRT** pacemaker (**CRT-P**) and a **CRT defibrillator** (**CRT-D**). Both devices have the pacemaker function and the ability to deliver an electrical pulse to restore heart contraction. However, some patients are also at a higher risk of potentially life-threatening **arrhythmias**, which originate from the bottom chambers of the heart (the **ventricles**). This is sometimes due to scarring within the heart muscle. The defibrillator part of

the implanted device will send a small electrical shock (or shocks), called **cardioversion**, to the heart to try to stop the **arrhythmia** and 'convert' the heart back into **sinus rhythm**.

How does a CRT work?

A **CRT** device is effectively an advanced type of pacemaker. A pacemaker is a small metal box which houses electronics and a battery. This is surgically implanted beneath the skin, typically on the left or sometimes right side of your chest just below the collarbone. The pacemaker unit is attached to electric leads which are fed through your **veins** directly into your heart. For a **CRT** device you would need two or three leads into your heart, one to the right bottom chamber (right **ventricle**), one to the left bottom chamber (left **ventricle**) and possibly one to the right upper chamber (right **atrium**).

These leads transmit a small electrical pulse from your pacemaker box to the heart muscle. This electrical pulse causes the heart to contract or beat. This electrical pulse is not normally felt by you. The pacemaker is programmed to specific timing to synchronise or organise the beat of your heart to improve the heart's pumping ability. Both a **CRT** pacemaker and **CRT defibrillator** work in this way, however a defibrillator **CRT** has the defibrillator function in addition to the pacemaker. Information regarding defibrillators is covered in the **ICD** section of this booklet.



Why do I need a CRT device?

'A **CRT** device may be advised for you once your **heart failure** team has reviewed your investigation results and consulted with NICE **heart failure** guidance' (National Institute for Health and Care Excellence).

NICE guidance recommends **CRT** implantation for patients diagnosed with **heart failure** who have a reduced heart pumping function, or who experience symptoms of **heart failure** such as breathlessness and reduced exercise tolerance as a result of this breathlessness. This is despite appropriate treatment with a combination of **heart failure** medications as well as evidence of a disorganised **heartbeat** on an electrocardiogram (ECGs provide a recording of the heart's electrical activity). This criterion has been set by NICE, who provide guidance for treatments and clinical care within the UK. The guidance is generated from reviewing several research studies that have identified the patients most likely to benefit from this treatment.

What are the benefits of a CRT device?

A **CRT** device is designed to improve your life expectancy and quality of life following a diagnosis of **heart failure**. The devices are designed to help the heart beat in a more efficient "synchronous" manner and therefore improve the blood flow around the body.

Research has shown that, for many patients, the heart pumping function (or **ejection fraction**) improves following implantation. This may help to relieve symptoms of breathlessness and fatigue. These benefits may not be seen in everyone with a **heart failure** diagnosis, or even everyone who receives a **CRT** device. Some patients' heart function may improve, but this may not translate into an improvement in their symptoms. Some patients may not see any benefit, but the device may prevent their **heart failure** from getting worse.

The main benefit seen across the majority of patients is the improvement in life expectancy (or 'prognosis'). A beneficial response to **CRT** devices is seen in around 80% of patients. At the moment, we do not fully understand why 20% do not respond, but there is a lot of research ongoing to try and improve this.

Patients with a defibrillator component will also have the benefit of protection from sudden, fast heart rhythms and **sudden cardiac death**. This is described in more detail within the **ICD** section of this devices booklet. Other benefits of modern **CRT** devices are the wide range of diagnostics. The devices are able to detect and record **arrhythmias** or abnormal heart rhythms which can be treated and managed by the clinical team more efficiently than without a device.

The devices also record information on heart rate as well as some other clinical signs, which can enable clinicians to detect worsening **heart failure** and prevent the need to come to hospital; improving your quality of life.

Risks of CRT implantation

As with any surgical procedure, there are some risks associated with the implantation of a **CRT** device. The majority of these risks are low and highly unlikely. These include:

- Infection of the device site
- Damage to the lungs caused by air or blood in the chest
- Damage to the blood vessels or heart.

On rare occasions following the implantation of the **CRT**, leads can move out of position and require another procedure to reposition them. Patients can also experience some swelling or bruising around the surgery site, especially if they take blood thinners. Your clinical team will discuss these risks with you before any procedure so you can talk through any concerns you have.

Patients commonly report a “twitching” sensation in their stomach, which feels like the hiccups, after or sometimes during the procedure. The pacing lead goes to the left side of your heart, sitting very close to the phrenic nerve. Sometimes the electricity delivered through this lead to pace your heart catches the nerve and causes the diaphragm to twitch. This is not harmful, but can be quite uncomfortable. If this does happen, let your device team know and they can usually program the device to prevent this from happening. There is a low chance that if the team cannot program around the twitching, you may need another operation to

move the lead to a place where this doesn’t happen. Modern technology has helped make it easier to program around it and prevent the need for an additional procedure.

Implantation of CRT- procedure

The implantation of a **CRT** will generally happen in a Cardiac Catheter Lab, which is a specialist theatre designed for implantation of these devices, among other cardiology procedures. A **CRT** procedure will usually take around an hour, but can take a bit longer than this on occasion. You will be made comfortable on an operating table and the procedure will usually be performed under local anaesthetic rather than a full general anaesthetic. This reduces the risks that can come with a general anaesthetic, and some of the after-effects following surgery. The team will make you as comfortable as possible and typically give you some sedation to make you feel more relaxed.

A small cut is made below the collarbone, typically on the left-hand side of your chest. At this stage you should not feel any pain, but feeling some pushing and pulling is normal. The **CRT** leads are fed through small ports into your **veins** and positioned within your heart in the correct chambers. Most people will have three leads put in, but some may only have two if they are in **atrial fibrillation (AF)**. X-ray cameras will move around you to take pictures of the heart and leads, guiding the operator to place them in the correct positions. In most cases, an X-ray dye is used to picture your blood vessels in better detail. When this happens, you may feel a warm sensation around your body and in your groin: this is completely normal. Once the leads are in place, they are connected to a pulse generator (small box), which will be placed just under your skin.

Hugh's Story

Getting used to an ICD

I had my first ICD implanted in 2003. I generally take everything in my stride, but I did find it hard to get used to the idea of needing the device. It was almost as hard to come to terms with as my diagnosis of dilated cardiomyopathy several years earlier.

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 already had a cardiac arrest or a life-threatening arrhythmia it wouldn't have seemed such a big step to take. Even though the doctor's advice was quite clear, it felt like signing up for an invasive procedure with no obvious short-term benefit and the possibility of serious long-term implications. The need for it seemed 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 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 a few seconds later. I didn't feel groggy, no gradual recovery – I was instantly 'back in the room'. I felt exhausted, but strangely 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 that wouldn't be 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 – 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. All the time I have had an implanted device I have been very well looked after – my health professionals have always made time to see me and reassure me.



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.



Graduating to a CRT-D

In 2012, when my first ICD was nine years old and running out of battery life, it was replaced with a CRT-D. This meant two additional wires into the heart, but the procedure was easy – completely painless, just like the first implant. I am now on my second CRT-D (the third device in all), and another box change is on the horizon.

At first, the CRT-D felt very odd. After years of living with a heart that was beating out of sync, I was suddenly firing on all cylinders, properly coordinated, nicely tuned and working well. But it wasn't what I was used to – so I had a couple of weeks of feeling rather wobbly, as if my head and my feet were on different planets, or in different time zones. The strange sensation soon passed, though, and I adjusted to my new normal. I am paced almost 100% of the time, but I am usually completely unaware of it.

Has the CRT-D made a difference to my heart health? That's a hard question to answer. I know that for many people the resynchronisation makes a huge difference, and some see dramatic improvements in ejection fraction and symptoms. That hasn't happened for me. But maybe it has slowed what would otherwise have been a more rapid decline. Am I glad I have it? Absolutely!



After the procedure- hospital stay/checks

Following the procedure, you will usually go back to the ward to recover and allow the sedation to wear off. An X-ray will be performed to confirm that the pacing leads and box are in the correct place before you go home. Most patients go home the same day, although some may be required to stay overnight. This can vary from hospital to hospital.

Following the procedure, you will be instructed to limit your arm movements on the side of the device. This is to prevent unintentionally moving the pacing leads until they have settled in position. This is only for the first six weeks following the procedure. You should continue to move your arm to prevent a frozen shoulder, but not perform anything too strenuous such as heavy lifting, movements above shoulder height or pushing yourself up from lying down.

The hospital team will give you dressings and advice for wound care following the procedure; this may vary from hospital to hospital. You should keep an eye on the wound site – if there are any signs of swelling, redness (signs of infection) or severe discomfort at any point following the implantation, call your device team straight away. You are likely to have some pain and discomfort following the surgery, and this can be managed using over the counter painkillers. This should start to ease with time.

You will receive an appointment with a device clinic typically four to six weeks after your procedure. This will be a clinic run by Cardiac Physiologists who will manage your **CRT** device moving forward. They will check your surgery site has healed and perform checks on the **CRT** device using a specialist machine to ensure it is working as it should be.

They may also perform an electrocardiogram (recording of the heart's electrics) or echocardiogram (ultrasound scan of the heart) to assess whether the CRT device is having the desired effects. The specialist Physiologists are experts in managing cardiac devices and will be able to help with any questions you have.

You will also receive an identification card which provides details of your cardiac device. This is useful if you come into hospital or go travelling, as it allows clinicians to know what you have.

Advice post implantation

Your **CRT** device will be followed and managed by the device team for as long as you have a device. They are experts in managing patients with these devices and a great source of advice. If you encounter problems, especially relating to the wound site, then do not hesitate to contact them.

A **CRT** battery will generally last around five to eight years, although the battery technology is continually advancing and more modern devices may reach up to ten years. The battery is continuously monitored by your device team, typically using remote monitoring in modern devices. Remote monitoring allows clinicians to accurately and safely predict when a replacement device will be needed. When this occurs, your clinical team will guide you through the process, which will involve a further procedure to replace the device with a new one. The whole unit is replaced as the battery is housed within it. This is usually a quicker and more straightforward procedure than the initial implantation.

Following the procedure, things will generally start to settle after a week or so. Some people can return to work at this

point, depending on what their work entails. You will generally be fully recovered after four to six weeks and be able to use your arm normally again. Your device team will provide advice specifically for you.

Recovery - Driving Restrictions

The main restriction with these devices is in regard to driving. For a **CRT** pacemaker you are unable to drive for a week following the procedure and will only need to stop again if you have another procedure. For patients with defibrillators, you will not be able to drive for at least a month following the procedure, but this may be up to six months in some cases.

There are other driving restrictions with a defibrillator, which are covered in more detail by separate Cardiomyopathy UK information resources. Your device team will support you with applications/correspondence with the DVLA.

For more detailed information about driving standards, visit:

 www.cardiomyopathy.org/driving

Lifestyle changes/restrictions

Most people can live a relatively normal life following a **CRT** implantation. There are very few restrictions with an implanted device. Most household items are safe to use with a device, as long as they are in good working order and are at least six inches away from the device. Contact sports (e.g., rugby or martial arts) or dangerous sports (scuba diving) are not recommended due to your safety and risk of damage to the device. It is recommended that mobile phones are not placed in a pocket over the device or used within six inches

of the device. Sex is also perfectly safe with a **CRT** device once you feel up to it.

To learn more about staying active with cardiomyopathy, visit our YouTube Channel: @cardiomyopathyUK

 www.youtube.com/@cardiomyopathyuk

Having an MRI

There may be a need for you to have an MRI scan in the future. The majority of **CRT** devices and leads these days can be scanned by an MRI under certain restrictions. Your device team will be able to advise on whether you can undergo an MRI with the specific device you have implanted.

 **Find out more at:** www.mrimypacemaker.com

Travelling with a CRT device

Travelling with a **CRT** device should ideally be discussed with your device team who can advise you. General advice on travel can be found on our website.

For more information about travel and holidays, visit:

 www.cardiomyopathy.org/travel

Remote monitoring- home monitor/mobile phone support app

The follow up for CRT devices has typically been performed in an outpatient clinic. Nowadays the devices have the ability to be monitored remotely in place of, or in conjunction with outpatient appointments. To facilitate this you will be provided with a monitor or an app on your smartphone, which you can use to send information through to your hospital. Modern remote monitoring machines are mostly automated, but you may be required to press a button and follow a simple process in order to send information.

Remote monitoring can provide the device team with most of the same information collected from the monitoring machines in a clinic. The benefits of this are the convenience of not having to attend the hospital regularly and the ability to detect and deal with problems quickly, preventing potential hospital stays. The devices can automatically test themselves, measure the battery life and report the findings daily. Diagnostic information about the device itself is also available through remote monitoring. The devices have pre-set alerts and can advise the hospital automatically if a problem is detected with the device or your condition; this may be before you even become aware. Your team will be able to advise you further on remote monitoring for your device.

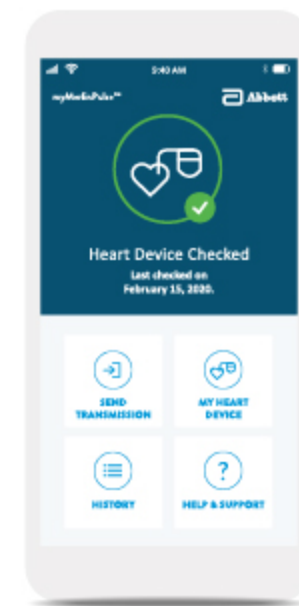


Image courtesy of Abbott

CRTs at the end of life

When it comes to end-of-life care, you may need to consider whether your **CRT** 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** part 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 you want to discuss in advance with your family and healthcare team.

The emotional impact of device implantation

Having a device implanted can have an impact on emotional wellbeing for some people. Mental health support is an important aspect of care for people advised to have/who have a device implanted.

For some people, device implantation can indirectly impact their quality of life; for others, a device improves their quality of life and provides reassurance.

To watch a video recorded at the Cardiomyopathy UK 2022 Conference, where Dr Anne-Marie Doyle discusses the psychological impact of cardiomyopathy, visit:

 www.youtube.com/watch?v=E6k5CbehWUU

Summary of terms

AED - Automated External Defibrillator - used to help those experiencing cardiac arrest. It's a sophisticated, yet easy-to-use medical device that can analyse the heart's rhythm and, if necessary, deliver an electrical shock, or defibrillation to restore a normal heart rhythm.

Anti-tachycardia pacing - when an ICD uses fast electrical impulses to try and restore the heart to a normal rhythm.

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 (singular atrium) - the top two chambers of the heart.

Atrial fibrillation - a heart condition that causes an irregular and often abnormally fast heart rate.

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).

Ejection Fraction - a measurement used to calculate the percentage of blood that leaves your heart each time it contracts.

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.

Heartbeat - 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.

Sinus rhythm - the normal rhythm of the heart.

S-ICD - Implanted under your skin rather than through your veins. It can help prevent sudden cardiac death in people with abnormally fast heart rhythms.

Sudden cardiac death - when the heart is no longer beating efficiently to pump blood around the body

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).

The information provided in this document is based on academic peer-reviewed journal articles and the experience of our subject expert authors. Source materials can be provided on request:



contact@cardiomyopathy.org

Cardiomyopathy^{UK}

the heart muscle charity

Contact us:

-  75a Woodside Road, Amersham, Buckinghamshire, HP6 6AA
-  01494 791 224
-  Helpline: 0800 018 1024
-  contact@cardiomyopathy.org
-  www.cardiomyopathy.org

Keep in touch:

-  facebook.com/cardiomyopathyuk
-  [@cardiomyopathyuk](https://www.instagram.com/cardiomyopathyuk)
-  [@cardiomyopathy](https://www.twitter.com/cardiomyopathy)
-  youtube.com/cardiomyopathyuk

We rely on donations to fund our work supporting people affected by cardiomyopathy. For details about supporting us, go to our website: www.cardiomyopathy.org

Every effort is made to ensure that information is accurate. This information is not intended as a substitute for advice from your own clinicians. Cardiomyopathy UK does not accept responsibility for action taken after reading this information. Please note that information may change after date of printing and is intended for a UK audience.

© October 2023. Registered charity no 1164263.