

Having an internal cardiac defibrillator (ICD) implanted to regulate your heart rhythm

The aim of this leaflet is to answer any questions you may have about having an internal cardiac defibrillator (ICD). It will explain what an ICD is and how it works, as well as the benefits and risks of the procedure.

You should have already spoken with your cardiologist or specialist nurse about having an ICD. This booklet is not meant to replace these discussions, but we hope it will make you feel more comfortable with your decision to have this procedure.

Your nurse or cardiologist will answer any questions you may have after reading this booklet. We encourage you and your family to ask questions and are more than happy to talk through any concerns you may have.

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The healthy heart

What does the heart do?

The heart's job is to move blood around the body. Blood contains oxygen and other nutrients that the body needs to do its work. Blood cells pick up oxygen in the lungs and the pumping action of the heart moves this oxygen-rich blood to the rest of the body.

What does the heart look like?

The heart has four chambers – the top chambers are the left and right atrium and the larger, bottom chambers are called the left and right ventricles. The heart has large blood vessels called veins that bring blood to the heart and large blood vessels called arteries that take blood away from the heart.

How does the heart normally beat?

In order for your heart muscle to contract and pump blood around your body, it needs an electrical signal. In a normal heart, the electrical signal that tells the heart to pump comes from a special area called the sino-atrial node or SA node. This is sometimes called the heart's natural 'pacemaker' and can be found at the top of the heart in the right atrium. The electrical signals from your SA node travel through the top two chambers (atria) causing the heart muscle to contract (pump). They then pass through a second node called the atrio-ventricular node or AV node, and down to the lower two chambers (ventricles), making them contract. The contraction (heartbeat) pumps the blood out of the atria and ventricles and around the body. Between each heartbeat, when the heart is at rest, blood flows into the atria and ventricles, ready for the next heartbeat.

Normally, a heart beats 60 to 100 times each minute. When a heart's rhythm is normal, this is called sinus rhythm. When you exercise, become excited or experience stress, your body needs more oxygen and your heart beats faster to keep up with this demand.

Information about the heart is available from the British Heart Foundation (BHF) – ask your nurse for more information or contact the BHF using the details on the back page.

Abnormal heart rhythms (arrhythmias)

What is an arrhythmia?

Sometimes people develop an abnormal heartbeat, also called an arrhythmia. The heart may beat too fast, too slow, or it may beat in response to an electrical signal that does not come from the SA node. An abnormal heartbeat can interrupt the usual pumping action of the heart. It may be as short as one or two beats, or it may continue for several minutes or even hours. In a very small number of cases this can cause cardiac arrest. This happens when the heart is beating so fast that there is no time for the ventricles to fill and pump blood around the body.

What causes arrhythmias?

Arrhythmias can be caused by many things. These include:

- coronary heart disease and previous heart attacks

- abnormal heart muscle function, including cardiomyopathies or heart failure
- congenital (inherited/present at birth) heart problems such as Brugada Syndrome and long QT Syndrome.

Having any one of the problems listed above does not mean that you will have an arrhythmia, but your doctor will assess the individual risks for you.

How are arrhythmias diagnosed?

To assess your heart rhythm we will need to do an electrocardiogram (ECG). This involves putting small sticky pads on your arms, legs and chest, which are connected to an ECG machine. It is not painful. The machine then measures and records the electrical activity of the heart and gives us a printed record. Sometimes we need to leave this on for 24 hours or more, to record the electrical activity in your heart over a longer period of time. In these cases, the sticky pads are connected to a small portable recorder that you can carry around with you.

Types of arrhythmias

Unusually fast heartbeats (tachycardia)

Sometimes the heart beats too fast. This is called tachycardia.

If the tachycardia is caused by an electrical signal coming from one of the top chambers of the heart (the atria), it is known as supra-ventricular tachycardia (SVT – meaning ‘above the ventricles’). In the majority of cases a supra-ventricular tachycardia is not dangerous. It may cause palpitations (awareness of your heartbeat), shortness of breath or dizziness. Usually this kind of tachycardia can be managed with medicines or a procedure called ablation, which burns away or blocks the abnormal electrical signals.

If the tachycardia is caused by an abnormal electrical signal coming from one of the bottom chambers of the heart (the ventricles), it is known as a ventricular tachycardia (VT) or ventricular fibrillation (VF).

Ventricular tachycardia (VT)

During VT, the heart beats so fast that its chambers cannot completely fill with blood between beats. This means less blood and oxygen are pumped to the body. If you have VT, you may have palpitations, feel dizzy, faint, or collapse.

Although VT is a serious, life-threatening arrhythmia, it can sometimes stop by itself without any form of treatment. If not, it can be treated with medicines or by delivering an electric shock to the heart to stop the abnormal electrical signals.

Ventricular fibrillation (VF)

The most serious kind of arrhythmia is ventricular fibrillation (VF). This is where lots of electrical signals fire off at once from the heart’s lower chambers. This causes the heart to quiver rather than beat normally. No blood is pumped out to the body, so a person in VF loses

consciousness very quickly. An electrical shock is needed to stop the abnormal signals and bring back the normal heart rhythm.

Unusually slow heartbeats (bradycardia)

Sometimes, due to disease or ageing, the electrical signals in the heart slow down or fail to work properly and your heart rate slows. This is called bradycardia.

A person with bradycardia may feel very tired, because the body is not getting enough oxygen. They may also feel short of breath, light-headed or dizzy, or may have had blackouts.

Treating your arrhythmia with an ICD

What is an internal cardioversion defibrillator (ICD)?

An ICD is an electronic device used to treat patients who have fast heart rates caused by ventricular tachycardia (VT) and ventricular fibrillation (VF), as these are the two most dangerous kinds of arrhythmias. The ICD also contains a 'pacemaker' device that can treat any episodes of bradycardia.

It is made up of two main parts: the generator (box) and the leads. The generator is implanted under the skin, below your collarbone. It is small enough to fit into the palm of your hand and weighs about 90 grams (three ounces). It contains electronic circuitry, which is powered by a small battery. The soft, flexible leads of the ICD pass through a vein to connect the generator to your heart.

There are many different types of generators and leads available. Your cardiologist and cardiac physiologists will decide which model of ICD will best treat your arrhythmia and will discuss this with you.

What does an ICD do?

The three main functions of an ICD are to:

1. continually monitor your heart, to detect any arrhythmias;
2. treat any arrhythmia, and bring your heart back to a normal rhythm. This includes both bradycardias and tachycardias (slow and fast abnormal heart rhythms); and
3. store data each time an arrhythmia occurs, which can be reviewed at the hospital during your check-up.

If the arrhythmia does not last more than a few seconds and your heart returns to its normal rhythm, the ICD will not give any treatment and will go back to monitoring your heart's rhythm. Your ICD will decide how to treat any arrhythmias based on how it has been programmed. This is different for everyone, and is done once the ICD has been inserted (see page 5 'How will the ICD know what treatment to give?')

Anti-tachycardia pacing (ATP)

During VT, the heart beats very fast, but in a regular rhythm. Depending how fast it is, you may feel dizzy or light-headed but may not pass out completely. The ICD will try to bring your heartbeat back to normal by sending out a series of short electrical signals to your heart. This is known as anti-tachycardia pacing, or ATP.

If the pacing does not work the first time and you are still in VT, it may be repeated several times, depending on how the ICD is programmed. It may try using more pacing impulses each time, or pace slightly faster each time.

You probably won't feel the electrical impulses being delivered. However, if you continue to have VT after the repeated pacing, the ICD may go on to use shock therapy. Sometimes the ICD tries shock therapy first if your heart rate is very fast.

Shock therapy

Unlike ventricular tachycardia, during ventricular fibrillation the heart beats extremely fast and irregularly. You will feel very dizzy and may pass out. Pacing cannot be used to stop an irregular rhythm. Therefore, the ICD will charge up to deliver an electric shock. The electric shocks do not damage your heart, but are just strong enough to stop all of the electrical signals in your heart for no more than a second or two. This allows the normal electrical signals in your heart to take over again, and puts your heart back into a normal rhythm.

If the shock does not work and you are still in VF, the ICD can give more shocks. It is usually programmed to give a maximum of five to eight shocks. Each time it delivers a shock, it checks to see what rhythm your heart is in before giving another shock. It may send out a smaller amount of energy for the first shock, and then give bigger shocks if your heart's rhythm has still not returned to normal.

Having a shock is unpleasant and can be frightening for you and anyone with you at the time. You will feel a sudden jolt in your chest, although different patients feel it in different ways. Many patients describe it as a big thump or blow to the chest. Anyone with you will see you twitch or jump when the shock is delivered. The shocks can be painful although the pain only lasts a few seconds. As patients are sometimes unconscious when they receive a shock they may not feel anything.

It is important to know that anyone touching you when you have a shock may feel it, but will not be harmed. It can be comforting or reassuring to have someone put their arm around you when you have a shock.

Bradycardia pacing

As well as treating the dangerously fast heart rates, your ICD can treat bradycardias or slow heartbeats (see page 4). You will not have an ICD inserted just for bradycardias as there is a smaller and simpler device called a pacemaker that can do this. Bradycardia pacing is just an extra function of your ICD. Sometimes this is needed after having shock therapy, while the normal electrical signals in your heart recover and take over again. Your ICD will sense if your heart rate is too slow (usually below 60 beats per minute, but this is adjusted for each person),

and will speed it up by sending small electrical signals to the heart, making it contract. These signals are very small and cannot be felt.

How will the ICD know what treatment to give?

The type of treatment the ICD is programmed to give you depends on what type of arrhythmia you have had and how you felt when it happened. Your ICD will be programmed to deliver the best therapy for you. This is done using a special computer called a programmer. The ICD is programmed after it has been implanted. If your doctor wishes to change the programming later, this can be done at any time using the programmer - you do not need to have another operation. It is done by placing a wand (small device) over your skin that sends information between the programmer and your ICD.

Benefits, risks and alternatives

What are the benefits of having an ICD?

An ICD regulates your heartbeat.

If your fast heart rate is very dangerous, such as in fast ventricular tachycardia or ventricular fibrillation, this treatment can save your life. Many patients feel that their ICD gives them peace of mind. They feel safer because it automatically treats their fast heart rate. Also, many patients find that symptoms such as light-headedness, dizziness, and fainting decrease after they have an ICD.

What are the risks of having an ICD?

It is important to note that the ICD may not stop all the symptoms of your arrhythmia. You may still feel light-headed or dizzy, or you may faint before the ICD has a chance to deliver therapy. This will depend on how fast your heart is beating and how well your heart copes when it beats extremely fast.

As with any operation, there are risks in having an ICD implanted. A very small number of people will develop a complication because of the surgery. The risk of you developing any kind of complication is about one in 100.

The potential risks are:

- **Infection.** You may develop an infection. However, you will be given antibiotics before the procedure to reduce this risk. If you develop an infection after you have left the hospital, you must return to St.Thomas' for evaluation. About two in every 100 patients develop an infection. You might have an infection if:
 - you develop a high temperature, or
 - your wound becomes red and inflamed or warm and painful, or
 - your wound starts to ooze.
- **Reaction to medicines.** We try to reduce the risk of this by carefully recording any known allergies that you might have. It is not always possible to know if you will react to a medicine that you have not used before.

Reactions to medicines can vary from developing a rash, or feeling sick or unwell, to a drop in your heart rate or blood pressure that needs treatment, problems with breathing, or even death. Our staff are trained to act on any emergency, should you have a reaction to the medication we give you.

- **Haematoma** (collection of blood in the tissues causing swelling and bruising). There is a risk of severe bruising or swelling around the site where the ICD is implanted. This is more common in people who are taking the blood thinning medicine warfarin before their procedure. If this does happen, we may need to take you back to theatre to re-open your wound and drain it. About three to four in every 100 patients have severe bruising.
- **Pneumothorax** (air in the spaces around the lungs also known as a collapsed lung). The ICD wires are inserted into the heart, through a vein in the upper chest area. When this happens, there is a risk that a small puncture may be made in the top of the lung. This can cause air to leak into the spaces around the lungs and partially collapse your lung. If the leak is small, it may be left to heal by itself. Sometimes we have to insert a chest drain to remove the air and allow your lung to fully inflate again. This happens in about one in every 100 patients.
- **Pericardial effusion** (blood leak around the heart). When the leads are positioned in the heart, they can damage the heart wall and the sac surrounding the heart (pericardium) may fill with blood. This may heal by itself, or you may need a small drain put in to remove the blood. This happens to about one in every 500 patients.
- **Lead displacement.** There is a risk that the leads we put in will move after the procedure. If this happens, your ICD will not work properly and you will probably need another procedure to have the leads repositioned. You can help to lower the risk of this by following the instructions on limiting your arm movements after the procedure (see 'When can I go back to my normal activities?' on page 10). This happens in about four to five in every 100 patients.
- **Blockage in the veins.** Sometimes when we put more than one lead through a vein into your heart, there can be problems with the flow of blood through that vein. If this causes a problem for you, the doctors might consider starting you on the blood thinning medicine warfarin or even removing one or more of the leads if necessary. You would need to come back in for another procedure for this, and the leads would be replaced using a different vein.
- **X-rays.** Your examination and/or treatment involves a period of X-ray scanning that will give you a relatively small X-ray dose. In some cases where we need to do more extensive investigation and treatment, there is a small chance that you will get a skin

reddening reaction like sunburn which will fade after a few days. Please talk to the radiographer if you need more information.

The vast majority of patients undergoing ICD implantation will survive. The approximate risk of death is very rare (one in every 1,000). Some people are more at risk than others depending on their general health and well-being.

The cardiologist will discuss the risks with you in more detail before asking you to sign a consent form. Please feel free to discuss all your questions and concerns with him/her.

What are the alternatives?

An alternative to having an ICD could be managing your arrhythmias with medicines. Usually your cardiologist has considered this before recommending that you have an ICD, but has decided that the safest treatment for you is to have an ICD fitted. If you would like more information on this option, please feel free to talk with your cardiologist.

Asking for your consent

We want to involve you in all the decisions about your care and treatment. If you do decide to go ahead, you will be asked to sign a consent form to confirm that you agree to have the procedure and understand what it involves. It is your right to have a copy of this form. You should be given the leaflet, **Helping you decide: our consent policy**, which gives you more information. If you are not given this leaflet, please ask us for one.

Having your ICD implanted

Will I have a local or general anaesthetic?

Inserting your ICD can be carried out under local or general anaesthetic. Your doctor will talk with you about which one would be best for you. You should be given the leaflet, **Having an anaesthetic**, which explains what to expect when you are given the anaesthetic. If you are not given this leaflet, please ask a member of staff caring for you.

What will happen before the procedure?

You will usually remain in hospital while you are waiting to have your ICD inserted. If you are taking warfarin, you will need to discuss when you should stop taking it before your operation.

If you are taking warfarin or an antiplatelet medicine (for example aspirin, clopidogrel, prasugrel or dipyridamole) you should discuss with your doctor or nurse whether you will need to stop taking it before your operation.

Please let your doctor know if you are taking any other medicines, including anything bought over the counter, and any herbal/alternative preparations. They will let you know if you need to stop any of these before having the procedure.

You will not be allowed to eat or drink anything for six hours before your operation because of the anesthetic. A nurse will give you an oral sedative an hour or so before the procedure. This will help you relax, but will not send you to sleep.

If you are having the surgery under general anaesthetic, the anaesthetist (doctor specialising in anaesthesia) will come to see you on the ward before your operation. He/she will ask you questions about your general health and about any previous operations that you have had under general anaesthetic.

What will happen during the procedure?

All our staff are fully trained for these procedures and will be monitoring you closely at all times. In the theatre, the nursing staff will check your details, such as any allergies and when you last ate. They will then help you onto the operating table. A number of staff will be present, including nurses, doctors, radiographers and cardiac physiologists.

A technician will connect you to an electrocardiogram (ECG) machine, which will monitor your heart rhythm during surgery. A nurse will put a cuff around your arm to monitor your blood pressure and a clip on your finger to measure your oxygen levels. These are not painful.

If you are having the procedure under local anaesthetic and have not yet had a needle put into your hand or arm, one will be put in now. All medicines will be given through this needle. We will then assess you and give you a painkiller (morphine) and sedation to help you to relax and become drowsy. Sedation will be 'topped-up' throughout the procedure. Information about having the procedure under general anaesthetic, is given overleaf.

The ICD is usually put in on the opposite side to your dominant arm. For example, if you are right handed, it will be put in on the left side. This is usually because the leads will be under less strain on this side. The doctor will then clean the relevant side of your chest with an antiseptic liquid. After this, you will be covered with drapes to make sure the whole area is kept sterile throughout the operation.

The doctor will warn you before they inject the local anaesthetic. At first, the local anaesthetic will sting, but soon the whole area will go numb. You should not feel any pain during the procedure, but you may be aware of pressure in the area where the doctor is working. Please let us know if you feel uncomfortable.

Depending upon the type of ICD you are being given, the doctor will put one or two wires into your heart through a vein. In some cases, up to four wires may be put in. The wires will be put in under X-ray guidance. Once in place a cardiac physiologist will test these wires to make sure they have good contact with your heart muscle. The wires either have small prongs or a tiny screw to hold them in position against your heart wall. After the wires are in position, the doctor will make a small pocket under the skin to fit the battery (generator), and will then connect the wires to this.

Once this has been done, your ICD will be tested. Your heart will be put into its fast rhythm, to test that the ICD is able to shock you back into normal rhythm. Further sedation and pain relief will be given to help you sleep through this phase. You should not feel any pain during this part of the procedure but you may be aware of a jolt. Extra pain relief can be given if any part of the procedure is painful for you.

When this test has been completed, the doctor will close your wound with dissolvable stitches. It will then be sprayed with an antiseptic solution that will help to protect it from infection and will be left uncovered. The cardiac physiologists will make sure that your ICD is programmed correctly and switched on. You will then be ready to return to the ward.

What if I am having a general anaesthetic?

If you are having a general anaesthetic, you will have the same procedure as above, but you will be asleep throughout the surgery. Once you are connected to the monitoring equipment, you will be put to sleep by your anaesthetist. A tube will be passed into your windpipe and connected to a machine called a ventilator. This will control your breathing during the operation. You will have extra monitoring of your blood pressure through a special needle in your wrist because of this, which will be put in once you are asleep.

You will wake up in theatre when the procedure is over and the tube will be removed from your windpipe. When the anaesthetist is happy that you are fully awake, you will be taken back to your ward.

What happens after my surgery?

After the operation, you will return to the ward. You may need to be attached to a heart monitor to keep an eye on your heart rhythm for 12 to 24 hours. Because of the anaesthetic (local or general) and sedation, you may need an oxygen mask for a few hours to help your breathing. Your nurse will also check your blood pressure and wound regularly for the first few hours.

You can expect to feel drowsy for a few hours following the procedure. As you will have had nothing to drink for a few hours before your surgery, you may need a drip of intravenous fluid. You will need to stay in bed for a few hours while the sedation wears off. Your nurse will allow you to eat and drink when it is safe.

You will have a chest X-ray to check the positioning of the ICD leads in your heart. This is usually done the following morning.

Will my ICD be checked before I go home?

Yes. You will be taken down to the Cardiac Outpatient Department to have your ICD checked by the cardiac physiologists. This is to make sure that your defibrillator is working as it should be and that it has been programmed correctly before you go home. You will not receive a shock from the ICD during this check. The cardiac physiologists will give you your ID card with all the technical details for your ICD. This gives useful information for anyone needing to treat you or your ICD, wherever you are. You will also receive information on how often your ICD will need to be rechecked (usually every three to six months), and how to contact the hospital if you have any problems or concerns. Your cardiac physiologist will let you know if your future ICD checks can be done at a hospital closer to where you live. Be sure to ask questions if anything is unclear or confusing.

Recovering after your operation

Your wound and the shoulder where the ICD has been implanted will be uncomfortable for the first few days. You will be given painkillers by the nursing staff to help with this. For more information on your wound and its care, please see our leaflet *Living with an internal cardiac defibrillator (ICD) to regulate your heart*. If you do not have a copy please ask your doctor or nurse for one or contact the Cardiac devices information line (see back page for details).

When can I go back to my normal activities?

You should be able return to your normal activities as soon as you feel up to it. On the side of your body where the defibrillator has been inserted, you must not lift your arm above shoulder height for at least four weeks. You will also have to avoid lifting, pushing or pulling heavy objects for the first four weeks. Do not be afraid to move your arm normally, as this will prevent your shoulder from becoming stiff. You may feel a little tired or sore at first, so build up slowly to your normal routine.

There are rules that regulate whether you can drive with your implant, and you will also need to take some precautions before you travel. For more information on driving and travel, please see our leaflet *Living with an internal cardiac defibrillator (ICD) to regulate your heart*. If you do not have a copy please ask your doctor or nurse for one or contact the Cardiac devices information line (see back page for details).

Useful contacts

The Cardiac devices information line – for any questions or concerns you may have about having an ICD.

t: 020 7401 9249

m: 07770 581 872 (text messages only)

e: heartdevices@gstt.nhs.uk

You can also contact:

- your cardiac physiologists on 020 7188 1058
- the Nurse Case Managers on 020 7188 0978
- the Cardiac Rehabilitation Team on 020 7188 0946

They are available on weekdays from 9am–5pm. If no-one is available to take your call, please leave a message on the answerphone. Messages are checked s daily. You will be contacted as soon as possible. Out of hours, for **urgent** help only, call your local Accident & emergency (A&E) for advice.

British Heart Foundation - for more information on issues relating to heart disease. Address: Greater London House, 180 Hampstead Road, London, NW1 7AW
t: 0207 554 0000 (Monday to Friday, 9am to 5pm). **w:** www.bhf.org.uk

PALS - To make comments or raise concerns about the Trust's services, please contact our Patient Advice and Liaison Service (PALS). Ask a member of staff to direct you to PALS or:

t: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Knowledge & Information Centre (KIC) - For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.
t: 020 7188 3416 **e:** kic@gstt.nhs.uk

Language support services - If you need an interpreter or information about the care you are receiving in the language or format of your choice, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953 **e:** languagesupport@gstt.nhs.uk

NHS Direct - Offers health information and advice from specially trained nurses over the phone 24 hours a day.
t: 0845 4647 **w:** www.nhsdirect.nhs.uk