University Hospitals Bristol NHS
NHS Foundation Trust

Patient information service
Bristol Royal Hospital for Children

Defibrillator advice

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Introduction

The aim of this booklet is to provide advice to patients who have recently had a defibrillator fitted or who are about to have one fitted.

The information contained in this booklet is drawn from research and provides simple details about the device and how it works. The booklet is intended to be used in addition to talking to doctors and cardiac physiologists about the defibrillator. If you find that you still have questions about your particular needs, please ask a cardiac physiologist or doctor. If they do not have the answer, they will be able to find out for you.

Over 4,000 people in the UK have an **ICD** (**implantable cardioverter defibrillator**).

What is an implantable defibrillator?

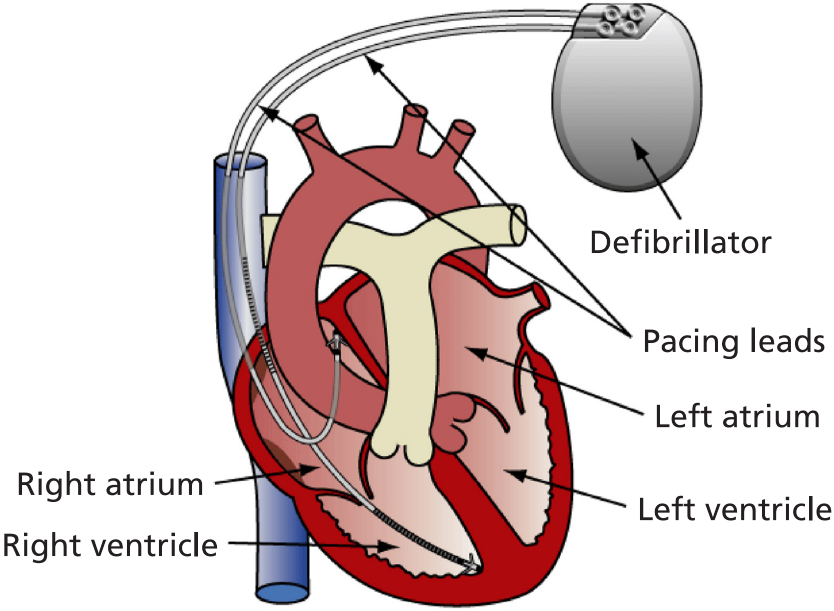
A defibrillator is a rounded metal box that senses when your heart is beating too fast and delivers an electrical shock.

The defibrillator box has a battery and electronic circuits.

The defibrillator can also function as a pacemaker if your heart beats slowly.

The defibrillator is connected to your heart by one or more wires (which are often called leads). The leads are passed along a blood vessel to the heart, either to the top chamber and bottom chamber, or only to the bottom chamber. The defibrillator box is usually implanted under the skin in your upper chest near your collarbone, but maybe implanted elsewhere if necessary (this would be discussed with your cardiac consultant).

Some patients with heart failure may have a defibrillator fitted that has two leads (one to each ventricle) to help the heart beat more effectively. A third may be attached to the atrium.



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What does a defibrillator do and why do I need one?

There are several different reasons why people need defibrillators. Your doctor and other members of staff at the hospital will explain why you need one.

The defibrillator can stop fast heart rhythms that occur in the chambers of the heart called the ventricles. These rapid rhythms are called **ventricular tachycardia (VT)**.

VT can often be treated successfully with drugs, but if it cannot then a defibrillator may be recommended because VT is a potentially serious condition.

Some patients have a more rapid and irregular heart rhythm called **ventricular fibrillation (VF).** This is life-threatening if it is not treated quickly with an electrical shock. A defibrillator is recommended if patients are at risk of having an attack of VF.

Some patients may have tests to check the electrical pathways in the heart to find out whether a defibrillator is required. These may include electrophysiology tests (EPS) or being fitted with a monitor to record the rhythm of the heart over a day or so. Some patients may be fitted with an internal loop recorder.

How is the defibrillator fitted?

Before the procedure starts, we will give you some medicine to make you more relaxed. When you arrive into the cardiac catheter lab you will be given a general anaesthetic. This will make you sleep; you will not feel or remember anything during the procedure.

During the procedure, the doctor will make a small cut in your upper chest and pass the lead(s) along a vein into the heart. The lead(s) are connected to the defibrillator, which is placed under the skin in your chest. This area is then closed with dissolvable sutures (stitches).

We may try to make your heart go faster during the procedure in order to test that the defibrillator works properly.

What happens after the operation?

You will be able to eat, drink and move around a couple of hours after the procedure.

The wound will probably feel bruised and sore, but you can be given painkillers for this. These are particularly recommended for the first 24 hours.

You will be asked to try to not lift your arm until you have had your check six weeks after the procedure. This is to let the lead settle into position in your heart.

You should keep the wound clean and dry until it is properly healed.

Most people leave hospital one or two days after the procedure when all necessary checks have been made.

Going home

It is natural that you and your parents or guardians might feel a little unsure when leaving the technical experts behind to return to life at home. However, we try to make sure that you get the help you need to return to as full and active a life as possible. Please read through the information in this leaflet and feel free to ask any questions to help you.

How will having a defibrillator affect my day-to-day activities?

Arm movements

Try not to lift the arm on the same side as your defibrillator lead above shoulder height until you have had your outpatient clinic check. However, do keep using your arm to stop it becoming stiff.

Extra tissue grows around the lead in your heart, and this holds the lead in place. Until this tissue has grown (which takes about four to six weeks) there is a slight risk of the lead wire moving.

The wound site

Your wound site should heal up within about six weeks. Dissolvable stitches are used, and any external threads from these will drop off when they are ready (approximately one to two weeks, although they may take longer).

As well as feeling the defibrillator box beneath your skin, you may feel other lumps nearby. These are the lead(s) that are curled up beside the defibrillator.

Do not prod, push or try to move the defibrillator, as this can damage both your skin and the leads. Please talk to staff at the clinic if these continue to bother you.

It is better to avoid tight clothing over the wound site until it is completely healed because constant rubbing over the area may interfere with healing. Report any soreness, redness, swelling or new tenderness immediately to the cardiac physiologist or the cardiologist, as these may be signs of wound infection.

What does the defibrillator treatment feel like?

The defibrillator is adjustable; the settings and treatments that you need can easily be programmed in to the defibrillator by a cardiac physiologist, who you will see in the defibrillator clinic.

The defibrillator can usually give the following treatments, but not all of them may be programmed or be required by you.

Bradycardia pacing pulses

Defibrillators can give small pulses to the heart to help it if it starts beating too slowly (bradycardia).

Sometimes, after treatment for rapid heart rhythms, the heart beats rather slowly for a short period of time and these pulses are often required then.

Bradycardia pacing pulses are usually not noticed and are not painful.

Tachycardia pacing pulses

This is a different sort of treatment, which can help to stop the heart from beating too fast (tachycardia). The defibrillator can recognise tachycardias and deliver these pulses so quickly that some patients are completely unaware of this happening. Other patients notice brief palpitations or a brief dizziness.

Cardioversion shocks

These shocks are used to treat some tachycardias and, although they give a smaller shock to the heart than defibrillation shocks, they can be slightly painful. Some patients have reported that they feel as if they have been punched in the chest when they get these shocks, and others are not aware that they have occurred. All treatments can be detected when you come to the technical follow-up clinics.

Defibrillation shocks

Defibrillation shocks are used to treat life-threatening ventricular tachycardias and episodes of ventricular fibrillation.

Sometimes patients report that they feel as if they have been suddenly punched or kicked in the chest with these shocks and they can be painful, although the pain only lasts a few seconds. As patients are sometimes unconscious when they receive shocks, they may not feel anything.

If someone is with a person when they have a shock, they will probably notice that the patient gives a jolt. No harm will come to anyone who is touching someone when they receive a shock. Indeed, it can be very comforting and reassuring to have someone put their arm around you as you experience a shock.

What do I do if I have a shock from the ICD?

Often, patients will have some warning that their ICD has been triggered such as feeling dizzy, light-headed or sensing palpations and be able to take the following steps.

If you think that you are about to receive treatment you should:

- **lie or sit down on the ground**
- **let someone else know how you are feeling.**

In either case, you should recover quickly afterwards. If you remain feeling unwell, or if your device gives a second shock, please dial 999 for an ambulance. This will make sure that you are brought into the hospital so that you and the device can be checked.

If you receive a shock for the first time, it can be upsetting, so we ask that you let the cardiology department know and come in for reassurance and to check that the shock was appropriate.

Sometimes you will have no warning that the device has been triggered and has delivered a shock. We will be able to look at these episodes when you attend the defibrillator pacemaker clinic.

You will be asked to contact us (cardiology department by telephone) after a shock that you or your parents/guardians are aware of. It is important for you to keep your ICD card with you at all times so that technical information is available for anyone who may need it, wherever you are.

Number of shocks or other treatments from your ICD

Because people have ICDs fitted for many different reasons, the amount and type of treatments you may experience can vary quite a lot from person to person. Many people never receive a shock, while others may have several.

Some people worry when they talk to others with an ICD and find out that they have had more than one shock, and think this means they are sicker than the other person. This is not necessarily the case; each person's ICD treatments are programmed individually, often at the same time as changes to medicines.

ICDs are an advanced technology; however, it is a programmable device. In the very unlikely event of having an inappropriate shock, you will need to call the cardiology department so we can check and see why it delivered it inappropriately.

Returning to previous activities

After a short recovery period, you should be able to return to your usual activities – for example, returning to school. Although having an ICD fitted can be viewed as quite a big event in your life, over time and with appropriate help and support, most people learn to adapt.

Physical activity

Similar concerns have been expressed about undertaking physical exercise. Individual concerns can be discussed, but generally speaking, exercise in some shape or form is encouraged to keep your heart healthy. Caution is advised regarding contact sports and swimming alone. If you usually swim regularly, please discuss this with your doctor.

For older patients who are thinking of driving or already driving

There are driving restrictions after this procedure too, but usually only for one month instead of six. This time depends on how often you have been having ICD shocks or other treatments. Please talk to staff at the hospital about this.

The exact length of time you must stop driving for will depend on why your ICD was fitted (DVLA guidelines 2004).

A useful website for detailed information is:

www.gov.uk/defibrillators-and-driving

You are obliged to inform the Driver and Vehicle Licensing Agency (DVLA) that you have had an ICD fitted, and failure to do so may invalidate some insurance. Contact DVLA direct or via a Post Office.

Safety advice

Travel

Patients with a defibrillator can safely travel abroad. However, we would recommend you do not pass through the security gates at the airport. You should show your identification card and request to be searched by hand.

If you wish, you can be given addresses of the defibrillator clinics in the area that you are visiting. Please contact the cardiac physiologists at the clinic a few weeks before you intend to travel to allow us time to collect the information.

Travel information for devices is available on the internet (these web addresses are on page 14).

Electrical interference

Defibrillators have been designed with modern life in mind and are usually not affected by common electrical gadgets. Providing your household appliances are in good working order, ordinary radios, cookers, fridges, televisions, computers and microwave ovens do not affect defibrillators.

If you ever experience sudden symptoms such as dizziness or palpations whilst using an electrical appliance, you should move away from the appliance and inform the pacemaker clinic.

If you are thinking of going into a job or hobby that involves the use of very powerful magnetic or electrical equipment, please contact the cardiology department for advice.

Mobile phones

Mobile phones can be used, but it is recommended that you use them on the side opposite your ICD site. Do not keep them in a pocket directly over the ICD site when not in use.

Avoid contact with the antenna of older models.

Magnetic fields

There are a few situations that should be avoided by defibrillator patients:

Magnets

Do not place a magnet over the defibrillator as this may affect the technical setting. If your child has a toy with a magnet we suggest you bring in the toy to clinic and we can test and monitor the toy to see if it has any effect on the device.

Stereo speakers or hi-fi speakers

Please avoid carrying these and standing near them – for example at a concert – as they contain strong magnets and there is a risk of interference.

Game consoles

Game consoles (such as Xbox and PlayStation) are safe. Handheld game consoles are safe to use, but please keep a safe distance of approximately 15cm from the device. If you are concerned, please contact the pacemaker clinic and we can test the handheld console while checking your device. You can also find more information regarding game consoles on the manufacturers' websites (see page 15).

Radio controlled toys

Radio-controlled cars, boats, and flying objects are not advisable in close proximity.

CB amateur radios (citizen band)

These can produce electromagnetic interference. Interference from the antenna to your pacemaker is dependent on many factors. These include the transmitter power, frequency and type of antenna. If the transmitter power is very high, greater distances may be needed.

If the antenna can be directed very specifically, you may need to be further away.

Type of amateur radio	Minimum distance
Portable	1ft / 30cm
Car	3ft / 90cm
Home	10ft / 3m

Electronic ignition systems

Please avoid leaning directly over the alternator in car engines whilst the engine is running. Some patients with an ICD have successfully continued jobs as mechanics, so it is worth discussing this point with the cardiac physiologists and your doctor. If required we will involve the device manufacturer representatives.

Shop/library doorway security systems

As there is a very small risk of interference from these systems to the ICD, avoid waiting in shop or library doorways. Just walk through and wait in or out of the shop.

Other hospital treatments

Always take your information/identification card with details about your device with you when you go for any hospital visit or treatment.

If you ever go into hospital as a patient for treatments not connected with your defibrillator, please make the staff aware that you have an ICD, as technical support may be required before some treatments. In particular, this applies if you need general anaesthetic, electrocautary diathermy, certain treatments in a physiotherapy department, dentistry or certain scans in the X ray department.

ICD clinic visits

ICD clinics are held in the cardiology department on level 3 of the Bristol Royal Hospital for Children. They are run by the cardiac physiologists with cardiologists, and occasionally representatives from the device manufacturers, on hand for advice.

Your ICD should be checked regularly and, as previously mentioned, visits may be necessary more often after the ICD is first fitted. Information such as individual settings on your ICD, information stored of treatments given and estimated battery duration are all taken through a computer and stored in your records at each visit.

Eventually, you will come back every two to six months for these technical checks.

Please don’t hesitate to ask questions; we are there to help and assist.

Changing the defibrillator

This depends on how much you use the device for pacing and therapy. As you grow, we also will keep a close eye on the length of the lead(s). If at any point we feel they may be a little tight, we can ‘advance’ the lead to help give it more slack. If the life of the battery looks as though it may be low, then at the same time as ‘advancing’ the leads, we can also change the defibrillator.

By having your defibrillator checked regularly, the staff at the clinic will be able to predict when to change the defibrillator and it will not be allowed to run down completely.

When the defibrillator battery box needs changing, you will be admitted to hospital. The procedure may be similar to when your ICD was first fitted, except that this time you probably only need the defibrillator box (device) changed, not the leads.

Contacting the ICD/pacing clinic

The clinic is open: **Monday to Friday 9am to 4.30pm.**

You are welcome to telephone the cardiology department any time for advice or if you are worried.

For help and advice outside these hours, it may be better if you contact your GP first, who can then contact the on-call paediatric cardiac consultant. Your GP can contact the hospital or cardiologist via the hospital switchboard **0117 923 0000** and contact the on-call consultant.

The telephone numbers of the department are:

0117 342 8722 / 0117 342 8181 / 0117 342 8473.

Tell the cardiac physiologist that you are a defibrillator patient or the parent/guardian of a patient with a defibrillator, and we will help with your enquiry.

Patient support information

- **www.arrhythmiaalliance.org.uk**
- **www.stars.org.uk**
- **www.bhf.org.uk**
- **www.chfed.org.uk**

Where to get further information

In addition to the above, you can access some helpful information via the following web sites:

- **www.sjm.com**
- **www.guidant.com**
- **www.medtronic.co.uk**

Glossary of technical terms used

Arrhythmia - when the heart is beating in an unusual rhythm.

These essentially are:

Ectopic beats – extra beats.
Tachycardia – the heart is beating quite quickly.
Bradycardia – the heart is beating quite slowly.

Contact numbers

Cardiac physiologists	**0117 342 8181** **0117 342 8722** **0117 342 8473** **0117 923 0000**	 **bleep 2538**

On-call paediatric

Cardiologist ask to bleep the on-call cardiologist (for the weekends and after 4.30pm weekdays)	**0117 923 0000**
Dr Graham Stuart (Secretary)	**0117 342 8852**
Dr Rob Martin (Secretary)	**0117 342 8855**
Ward 32	**0117 342 8332**
Outpatients	**0117 342 8440 / 8441**
Cardiac liaison nurses	**0117 342 8286**

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **Smokefree Bristol** on **0117 922 2255**.

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While your child is under our care, you may be approached about them taking part in research. To find out more please visit: **www.uhbristol.nhs.uk/research-innovation** or call the research and innovation team on **0117 342 0233**.

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital switchboard: 0117 923 0000

Minicom: 0117 934 9869

www.uhbristol.nhs.uk

For an interpreter or signer please contact the telephone number on your appointment letter.

For this leaflet in large print, audio or PDF format, please email patientleaflets@uhbristol.nhs.uk.

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