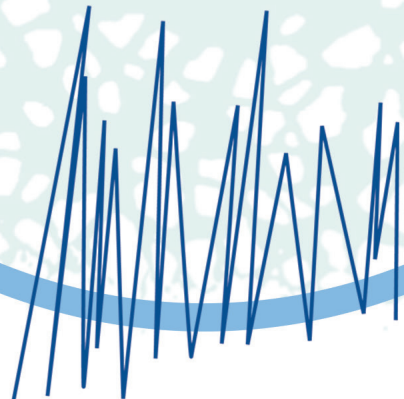


Implantable cardioverter defibrillators

A patient's guide



Introduction

This leaflet has been written to provide information about the follow-up care arrangements for the implantable cardioverter defibrillator (ICD) device that was implanted to help correct abnormal heart rhythms.

We hope it answers some of the questions or concerns you may have about your living with an ICD and follow-up care arrangements. It is not intended to replace talking with medical or nursing staff.

After the procedure

There are some things you may need to consider after your operation. Here are a few rules you should follow:

Do:

- Always carry your ICD ID card and the Trust's helpline numbers with you.
- Keep your mobile phone on the other side of your body at least six inches away from your ICD, and use the opposite ear to your ICD.
- Be careful with anti-theft devices in shops (often hidden near the entrance). Walk through them at a normal pace and don't stop in the middle or too close either side.
- Tell your cardiologist, cardiac physiologist or arrhythmia specialist nurse of any worries or anxieties you might have.
- Keep your appointments with your cardiologist and cardiac physiologists.
- Tell your doctor, dentist and other clinicians about your ICD as it may affect your treatment.
- Ask for help if things are difficult. Our contact details are in this leaflet. Please don't hesitate to get in touch.
- Enjoy life!

Don't:

- Don't get too close to a strong magnetic field, e.g. spot or arc welding.
- Don't touch the ICD site, particularly soon after the procedure. You will be advised about how to look after your wound.
- Don't put small magnets near your ICD (e.g. the magnets cats wear to activate cat flaps or magnets to hold scarves in place).
- Don't have an MRI scan unless you have been specifically advised it is safe to do so (CT scans are safe for your ICD).
- Don't change your heart medications (particularly beta blockers and antiarrhythmic drugs such as amiodarone) or stop your heart medication without checking with your cardiologist, cardiac physiologist or arrhythmia specialist nurse.
- Don't take part in any contact sports that could result in a blow to your ICD without discussion with your cardiologist, cardiac physiologist or arrhythmia specialist nurse.
- Don't be afraid to ask questions.

Back at home

Most people adapt fairly quickly to having an ICD implanted and are able to lead a relatively normal life after making a few adjustments. However, many people find they have some questions when they get home.

Some common questions are listed here:

How can I care for my ICD wound?

The dressing over your wound is waterproof so you may shower as usual. You should remove the dressing yourself after four days and leave the wound uncovered. The stitches are under the skin and are dissolvable so there is no need to have them removed.

It is normal to have some bruising, and this should resolve within two to three weeks. However, if you have any signs of infection such as increased pain, redness, swelling or discharge around the wound, or if the wound area feels hotter than the surrounding skin or you have a raised temperature, contact the arrhythmia specialist nurses for advice and support.

How much can I move my arm?

It is important to allow time for the device to settle in. We advise that you should not lift the arm nearest your ICD above your head or stretch behind your back for the first month. However, do keep your arm mobile to avoid shoulder stiffness by doing normal activities such as washing, dressing and eating.

Once the first month is over, gradually increase your activity and arm movements over the next few weeks.

Can I exercise?

Other medical conditions you have may limit your exercise but the ICD will not. It is important to build up your level of exercise over several weeks. Your cardiologist, cardiac physiologist or arrhythmia specialist nurse will be able to advise regarding safe exercise limits.

Activities involving repetitive arm exercise such as swimming, rowing and golf should be avoided for two to three months. It is advisable not to play contact sports as these may damage the ICD. Please discuss specific sports or activities with the arrhythmia specialist nurse as sometimes special protection is possible.

How soon can I drive after implantation?

The regulations regarding driving are complex and subject to change. You will not be able to drive for a period of time after your ICD implantation. This could be either one month or six months depending on the reason the ICD was implanted. Your cardiologist or arrhythmia nurse will be able to advise you which ban applies to you.

You must contact the DVLA to notify them you have had an ICD implanted. When you notify the DVLA they will ask your cardiologist for medical details, which are given with your permission. Depending on these, the DVLA will contact you about resuming driving.

You must also inform your insurance company.

Special conditions apply for professional drivers. Your cardiac physiologist will be able to advise you about the rules related to your situation.

If you find a seatbelt uncomfortable, we recommend placing extra padding over the ICD site. As a passenger, try sitting behind the driver, so the seatbelt crosses to the other shoulder.

Is it normal to feel anxious about life with an ICD?

Yes - you may experience a whole range of feelings. You may have experienced a stressful situation which is life-threatening and it is natural to feel anxious. Your condition may have changed your thoughts about your life.

Feelings of sadness, denial or anger are common. Some people feel vulnerable because of the device, while others feel positive because it treats their condition. The negative feelings usually disappear with time.

If you would like to talk to someone, the arrhythmia specialist nurses are available to help.

Will having an ICD affect my physical contact with others?

Many people worry about receiving a shock from their ICD when in close physical contact with people or pets. There is no need for you or other people to worry about this. If the ICD shocks you, the other person may be startled and feel a tingling sensation. This is completely harmless.

Can I go on holiday or travel abroad?

The ICD will not restrict you with any form of travel, although your cardiologist may advise against this if your general condition is likely to cause problems.

Take with you details of your device, and sufficient supplies of your medication. It is very important that your medication is carried in your hand luggage in case of delays or problems during your travel.

It is essential that your holiday insurance company is aware of your ICD.

Your clinic or ICD manufacturer will be able to give you a list of ICD clinics in any country you are visiting. Please contact the arrhythmia specialist nurses if you have any queries or concerns about spending time abroad.

If you are due a follow-up soon we would advise you arrange to have this before you go away (please contact us if you need to change an appointment).

Can I go through security gates and metal detectors?

Anti-theft systems in shops and airports can interfere with ICDs, but they are safe provided that you go through at a normal pace.

Sometimes these systems may set off the alarm, therefore please advise airport security staff that you have an ICD before going through the archway detector. We recommend that you carry your ID card as you go through security to highlight the reason for the alarm.

Can I use a microwave oven, computer and other domestic electrical equipment?

Most household appliances are not a problem as long as they are well maintained and regularly serviced. Although it cannot be categorically ruled out, any CE marked domestic electrical appliances are unlikely to affect an ICD. Computers should not affect your ICD. As a rule, do not place anything containing strong magnets over the ICD site.

Are there any restrictions regarding special environments?

Modern ICDs are rarely affected by common electrical environments. However, if you work closely with high levels of electro-magnetic radiation it is important to discuss this with one of the cardiac physiologists.

Visiting hospital

If you are spending time in hospital, let hospital staff know that you have an ICD. Usually this will not affect your treatment, but in some instances, we may need to adjust the settings of your ICD before or after your procedure.

You must not have an MRI scan (body imaging scan) unless you have an ICD especially designed to be compatible (please contact us if you are not sure about your device). This is because the MRI scanner uses strong magnets, however, other scans are safe.

ICDs may not be compatible with therapeutic radiation dosing, TENS machines and lithotripsy. Please ask your cardiac physiologist for advice before having these treatments.

Will I know when my ICD is working?

Most ICDs do not affect the symptoms of a heart condition on a day to day basis, it is there purely to correct an abnormally fast heart rhythm if this occurs.

You may or may not be aware when your ICD detects and corrects your heart rhythm. This often depends on the type of therapy you are receiving and how you feel when you have a fast heart rhythm.

Some types of ICD are also designed to synchronise the pumping chambers of the heart in people suffering from heart failure. This is called cardiac resynchronisation therapy with defibrillation (CRT-D).

The CRT-D device completely takes over the stimulation of the heart, so every impulse comes from the device rather than from your heart's natural pacemaker. If you have a CRT-D device, although you may not be aware of the device pacing your heart, you may see a change in your heart failure symptoms. This action is in addition to the shock provided by the device if you have an abnormally fast heart rhythm.

What should I do if I receive a shock?

You may feel that you have been thumped hard in the chest. This can be momentarily painful and a bit frightening. Try to stay calm. The ICD has done its job and therefore you should not need to visit hospital as an emergency.

If you feel unwell after a shock, you should phone 999 and ask to be taken to the hospital to be assessed. It may not be your implant or ICD follow-up hospital, but they will be able to stabilise your condition and transfer if needed.

If you feel well after your shock and do not require to urgently attend hospital, please phone your ICD department within 24 hours (within working hours). They may need to arrange a device check and/or medication review.

If you have already received medical advice and receive further shocks in a week or experience multiple shocks in short time frame you should seek urgent advice from your cardiac physiologist or the arrhythmia nurses as you may need your medication or ICD settings adjusted.

Please also remember that if you receive therapy and/or shocks from your ICD there may be a driving restriction depending on the reason. Please check with your consultant or DVLA for further information as the regulations regarding driving are complex and subject to change.

How can I avoid my ICD firing?

Often there is no obvious cause for your fast heart rhythm. Always take your prescribed medication. Some people feel that some kinds of physical or mental stress can set their heart beating erratically. If this is the case, try to avoid these situations.

How long will the battery in my ICD last?

This depends on use, but your battery is likely to last several years. Battery life is monitored at every ICD check. When the time comes that we need to consider changing the ICD, we will review and discuss exactly what course of action is best for you. We will most commonly arrange a procedure to replace it with another identical one, but at some point, we may need to discuss changing it for a different device without the

shock function, or not changing it at all. This will be the case when the shock function is no longer indicated or required, or when you decide that you no longer want shock therapy.

What if I no longer want to be resuscitated?

There may come a point in your life when you would prefer not to have a shock to correct a life threatening heart rhythm. This may be if your heart condition has deteriorated or you have another medical condition which cannot be cured.

The ICD can be deactivated so it will no longer deliver a shock. Turning off the ICD does not cause death nor will it cause any pain or deterioration in your condition.

Once it is deactivated, should you change your mind, it can be reactivated at any time. The choice to deactivate your ICD is entirely yours and there are people to advise and support you with your decision.

If you would like to discuss this possibility, please talk to the arrhythmia specialist nurses.

What are my follow-up care arrangements?

It is important that you attend regular check-ups at an ICD clinic. These may be at three to twelve month intervals depending on the type and age of your ICD.

Some devices can be monitored remotely. If this applies to your device, the procedure will be explained by a cardiac physiologist at the ICD clinic.

Routine follow-ups are specifically to check your ICD and do not replace your normal medical management in any way.

Remote monitoring

Remote monitoring is not an emergency monitoring service. If you become unwell and require urgent care we advise you to contact A&E, 111 or your GP practice, as you deem appropriate.

You may have been given a remote monitor that pairs with your ICD. The physiologist will have explained how this works and how it can be used for your routine follow-up of your device, which includes battery and lead function.

The data from your ICD is sent securely to a website. This is reviewed by the cardiac physiologist within working hours (Monday - Friday 9:00 - 16:00).

Data will be sent for review if any of the automatic checks go out of range or if you receive shock therapy and you are in range (usually three meters) of your home monitor.

The main limitation of remote monitoring is that we are unable to perform programming changes through the system. Any programming changes require an appointment and need to be carried out in clinic.

What are working hours and what to do out of hours.

Working hours and phone lines are Monday-Friday 9:00 – 16:00. We do not provide any service outside of these hours.

During out of hours, if you have a shock and/or feel unwell, you should contact A&E, 111 or your GP practice, as you deem appropriate.

What is the ICD registration card or form?

This is identification ID for your device: it has the make, model and serial number of your device as well as details of the original settings. This will be sent to you following your implantation - please carry it with you at all times and show it to any doctor or dentist who may treat you.

Always bring your ICD ID to your appointments.

How can I book and change my follow-up appointments?

It is important that you have an ICD check at least once a year. If you have not had an ICD follow-up within the past year, please contact us to book an appointment.

Please inform us if you are unable to attend your appointment so that your slot can be made available to another patient and your appointment can be rescheduled.

If you change your contact details please let us know so that we can keep our records up to date.

Who do I contact if I have concerns about my care at Royal Papworth Hospital?

The Patient Advice and Liaison Service (PALS) is an independent office based at Royal Papworth Hospital who offer a confidential service to help you sort out any concerns you may have about the care Royal Papworth Hospital provides.

PALS

Royal Papworth Hospital NHS Foundation Trust
Cambridge Biomedical Campus
Cambridge CB2 0AY
Telephone: **01223 638896**

Who can I contact for advice and support?

The arrhythmia specialist nurses, Royal Papworth Hospital NHS Foundation Trust
Cambridge Biomedical Campus
Cambridge CB2 0AY
Telephone: **01223 638947**
Email: **phn-tr.arrhythmia-nurses@nhs.net**

My ICD details:

For appointment bookings

Pacing and ICD department office
Royal Papworth Hospital NHS
Foundation Trust
Cambridge Biomedical Campus
Cambridge CB2 0AY
Telephone: **01223 639945**
Working hours: Monday – Friday
09:00 – 16:00

My appointment details:

Are there other organisations that offer advice about ICDs?

Arrhythmia Alliance

The heart rhythm charity
PO Box 3697
Stratford-Upon-Avon
Warwickshire CV37 8YL
24hr helpline: **01789 450787**
Email:
info@heartrhythmcharity.org.uk
Website:
heartrhythmcharity.org.uk

British Heart Foundation BHF

Greater London House
180 Hampstead Road London
NW1 7AW
Heart helpline **0300 330 3311**
Email:
supporterservices@bhf.org.uk
Website: **bhf.org.uk**

DVLA

Drivers Medical Group DVLA
Swansea SA99 1TU
Telephone: **0300 7906806**
Email: **eftd@dvla.gsi.gov.uk**
Website: **dft.gov.uk/dvla**

Further information about health issues that affect driving
direct.gov.uk/driverhealth

Royal Papworth Hospital NHS Foundation Trust

A member of Cambridge University Health Partners



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royalpapworth.nhs.uk



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View a digital version of this leaflet by scanning the QR code.



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