

Information booklet for patients having an Implantable Cardioverter Defibrillator (ICD) Wythenshawe hospital



SPECIALITY	DEPARTMENT	NUMBER
Remote monitor, downloads Changing Out- Patient appointments	Cardiac Physiologists	0161 291 4615 for appointments 0161 291 4640 for downloads after a shock
Medicines, symptoms, driving licence enquiries, general enquiries	Cardiac Rhythm Management Team	0161 291 5076
Appointments, driving licence	Secretary to Dr Fox	0161 291 2743
forms	Secretary to Dr Ainslie/Dr Schmitt/Dr Reid	0161 291 2390
	Secretary to Dr Campbell/ Dr Skene	0161 291 2388
	Secretary to Dr Williams	0161 291 2624
	Secretary to Dr Brown/ Dr Temple/ Dr Nikolaidou	0161291 4152
Enquiries about waiting time for procedures	Waiting List co- ordinators Wythenshawe	0161 291 2882 0161 291 4947
Physiotherapy	Cardiac Rehab Wythenshawe	0161 291 2177

Types of ICD

St Jude ICD



Medtronic ICD



Boston Scientific



Biotronik



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Introduction

This booklet has been written to provide information to you and your family about a device called an Implantable Cardioverter Defibrillator (ICD). It explains what an ICD is, how you are prepared for having an ICD implanted, your recovery and living with your ICD at home. Since the COVID 19 pandemic there may be some changes to what is written here.

Section A - The ICD

What is an ICD?

An ICD is a small slim box which contains a pulse generator, a computer, a long-life battery and electrical leads which are connected to your heart. It looks for and treats dangerous, fast heart rhythms if they occur. Your Consultant Cardiologist will decide which ICD is best suited for you. The ICD can also act as a pacemaker to beat your heart for you if it goes too slow. Some people may need an ICD with a built-in special pacemaker, which co-ordinates the heart pumping function. This is called a Cardiac Resynchronisation Therapy Pacemaker or CRT-D.

Why do I need an ICD?

You have had, or are at risk of having a dangerous, fast heart rhythm. These kind of heart rhythms are life threatening. You can read more about guidelines for having an ICD from the National Institute for Health and Care Excellence (NICE).¹

There are a few reasons why you need an ICD. Some people are admitted to hospital after they have had a dangerous, fast heartbeat unexpectedly. They have needed cardio-pulmonary resuscitation (CPR) and have been given a shock from a defibrillator. This is called an Out of Hospital (OOH) Cardiac Arrest. An ICD will usually be implanted before you go home. This can be quite traumatic for some people. There is more information about this further on in this booklet.

Other people may have had investigations and have been found to have a poor functioning heart pump or short episodes of a dangerous heart rhythm which has made them feel poorly. Others may have been diagnosed with a heart condition such as cardiomyopathy.

Will an ICD make me feel better?

No. An ICD only provides treatment for dangerous, fast heartbeats. It will not make you feel better or worse after it has been implanted. It will not stop you from having a heart attack.

What will an ICD do?

An ICD has several functions. It can: -

- watch for dangerous, fast heartbeats
- give a shock to the heart if it detects a dangerous, fast heartbeat
- give a burst of fast pacemaker beats to try to stop a dangerous, fast heartbeat (anti-tachycardia pacing or ATP)
- act as a pacemaker when the heartbeat goes too slow (anti-bradycardia pacing or ABP).

Section B - Preparing to have an ICD

What are the risks of the procedure?

About 5% of people may have one of the following complications, however all the risks listed below are treatable. If one of these complications occurs, this may delay your discharge home, depending the complication.

- The leads of the ICD may puncture the lining of the lung. A tube called a chest drain will need to be inserted into the chest wall to re-inflate the lung.
- The leads of the ICD may puncture the wall of the lung causing blood from the lungs to leak into the lining of the lung. A chest drain will need to be inserted into the chest wall to re-inflate the lung.
- The leads can accidentally damage the blood vessels when being moved into position causing discomfort, bruising, and swelling.
- A blood clot can form in the brain causing a stroke or in the lungs causing a pulmonary embolism.
- The ICD leads move from the area in which they were originally placed and require repositioning.
- The leads may puncture the heart muscle and cause blood to enter the outer sac (pericardial effusion). You will need a pericardial drain inserted under your breastbone where your ribs join to drain the fluid.

How am I prepared for implantation of my ICD?

You will be contacted by the Waiting List department at Wythenshawe hospital who will offer you a date to come in for your procedure and have a Pre-Operation (Pre-Op) appointment, usually the week before. Since the COVID 19 pandemic, there may be additional instructions regarding obtaining a COVID swab and isolation, which you will be required to follow.

A letter will be sent to you containing details on the date of your procedure, your hospital admission, instructions on obtaining a COVID swab, isolation and what you need to bring with you. Please read this letter carefully as it contains

important information on when to stop eating and drinking (including chewing gum) and any special instructions you need to follow.

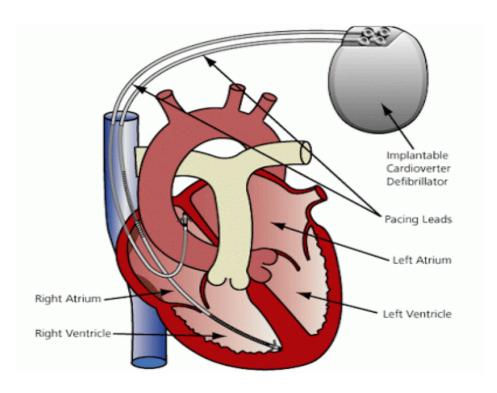
On the day you are admitted one of the doctors involved in implanting your ICD will explain the risks and benefits of having the device implanted and they will ask you to sign a consent form. If you have any questions about the procedure or its risks and benefits, please ask your doctor at this time. You can also call the Cardiac Rhythm Management (CRM) Nurses on one of the telephone numbers at the beginning of this booklet on pages 2 and 22. You can seek a second opinion at any time if you wish. The consent form may be signed at your Out-Patients' Appointment (OPA) or on the day of your procedure.

When you come in for the procedure your ward nurse will complete a checklist and prepare you for your procedure. A hollow tube called a cannula will be inserted into your arm so that medicines can be given. Gentlemen with a hairy chest will need to have this shaved to reduce the risk of infection. Your nurse will escort you to the Catheter Laboratory (Cath Lab) recovery area. You will be welcomed by a member of the Cath Lab team who will then ask you some questions to complete the checklist. You may be given an anti-biotic through your cannula as a preventative measure against infections.

How is my ICD implanted?

You will be attached to equipment which monitors your heartbeat, blood pressure and oxygen levels. Your upper body will be cleaned with a cold solution and covered with sterile towels so that the risk of infection is minimised. The doctor will inject medicines into your cannula to help you feel relaxed and sleepy. This is called conscious sedation.

You may also have analgesia in a drip through your cannula (usually paracetamol infusion). Then a local anaesthetic will be injected underneath the collar bone area (usually on the left side) to make it numb. Some people say this is like a tiny sting, but it is not painful and acts quickly to numb the area.



Position of an ICD²

Your doctor will make an incision approximately three to four centimetres in length underneath your collar bone and create a pocket under the skin. You can see pictures of your ICD on page 3. If you are having a sub-pectoral pocket, the doctor will place the pocket under your muscle. A vein will be made accessible so that your doctor can pass one or two leads into the heart.

Once the leads are in place, they will be tested to ensure they are positioned well and are functioning correctly. They will be connected to the ICD box, which is then placed inside the pocket. The ICD box contains the computer and battery generator. The wound is then closed with dissolvable sutures underneath your skin and glue is placed on top of your skin.

A dry dressing may be applied to your wound. Occasionally a tight bandage called a pressure bandage will be applied to ensure swelling and bruising is kept to a minimum.

What happens after my ICD has been implanted?

Once the procedure is completed, you will spend a short time in the recovery area of the Cath Lab. You will be taken back to the ward where your nurse will continue to take care of you. Your wound and observations will be checked regularly until you have fully recovered from the procedure. This varies with each individual patient, but you will need to remain in bed for approximately four hours. It is important that you tell your nurse if you feel unwell or have pain, swelling and/or bleeding from your wound straight away. Your nurse can give you simple

analgesia as prescribed and you may eat and drink as soon as you feel well enough.

Section C - Your recovery

When can I go home?

You should be able to go home later the same day or the day after providing your Consultant Cardiologist and nurse are happy that your treatment is complete, you have fully recovered, there are no complications, your wound is satisfactory and your ICD has been checked by the Cardiac Physiologists. They will provide you with a remote monitor (see page 14) and an ICD Identification (ID) card. The ID card should always be with you.

Will I feel any pain after my ICD has been implanted?

You may feel some pain and discomfort in the first week or two after your ICD has been implanted. This can be unpleasant, but it is to be expected. Simple analgesia such as paracetamol should help to reduce pain and swelling. Make sure no other medication you take has paracetamol in it. Always read the label, take the dose as prescribed and do not take medication you know you are allergic to. Consult your General Practitioner (GP) if you have any concerns. If you have a sub-pectoral implant (under the muscle) it may be more uncomfortable than if you have a sub-cutaneous (under the skin) implant. If you are experiencing severe pain at any time you should consult your GP and contact the CRM team.

How do I care for my wound at home?

Any dressing should be removed within two days. The glue is water resistant, so it is fine to have a bath or shower the day after your device has been implanted. However:

- Try not to get the glue too wet for any length of time.
- Do not soak the wound for the first two weeks.
- Do not apply any creams or lotions to the wound.
- Gently wash around the wound with warm water and pat the area dry with a clean towel.
- Leave the wound open to the air underneath loose-fitting clothing.
- Ladies can wear their usual undergarments if it is comfortable to do so.
- Your skin should heal in two or three weeks, however the tissues underneath your skin may take up to six weeks to fully heal.
- The glue may fall off gradually or all in one piece. Do not be tempted to pick off parts of the glue.
- The wound may be itchy, which is a normal part of wound healing. Do not scratch the area around your wound.
- Avoid heavy lifting for the first four to six weeks.

What do I do if my wound looks infected?

Some discomfort, bruising and swelling is normal in the week or two after your procedure. However, if your wound looks infected you may have:

- Pain
- Swelling
- Redness
- Oozing of pus, blood, or fluid
- Inflammation
- High temperature (pyrexia)
- Offensive odour from the wound
- Wound breakdown.

You should contact your GP and CRM team straight away. Your GP may wish to assess your wound and prescribe an anti-biotic. It may be appropriate to bring you back to clinic earlier than planned to assess your wound. The CRM Nurse will assess your symptoms over the phone and will decide on further management accordingly.

It is extremely important that you seek advice and treatment for suspected infection promptly. Wound infection may have serious health complications and you may require hospital admission for intravenous antibiotics and removal of your ICD.

If your wound opens up and you can see the leads or the generator box you must go to your nearest hospital straight away. If this occurs there is an increased risk of infection and you must seek medical attention on the same day.

How can I help my recovery after my ICD has been implanted?

It is important that you stay active after your ICD has been implanted. However, you should take it easy for the first week or two while your wound heals. You can wash, dress, and move around the home as normal on the day after your procedure. Try to avoid lifting your arm on the side of the ICD above shoulder height or lift anything heavy with that arm for the first four to six weeks. However, you should move your arm normally to prevent your arm from becoming stiff.

What about physical activity and exercise with an ICD?

You should be able to return to most usual activities, exercise, sports, and hobbies. It is important to work at moderate intensity, where you feel that you are breathing harder but feel comfortable to continue and you can speak without gasping for breath. Activities where you are working harder than this may not be suitable (e.g. squash). You should always start and finish any activity slowly so that you incorporate a warm-up and cool down in whatever you are doing. For example, if you are going out for a walk, start off and finish at a slower pace. Do not continue exercising if you have any symptoms, such as pain, dizziness, and

palpitations or if you feel unwell. If symptoms persist, you should speak to your CRM Nurse or GP.

Your heart rate will increase when you exert yourself. This is normal. The ICD is programmed to be able to tell the difference between a normal increase in heart rate associated with exercise and dangerous, fast heart rhythms so the ICD should not give you a shock. You should take care with hobbies or sports which involve repetitive, vigorous above-the-shoulder movement on the side of the ICD, such as golf and racquet sports, particularly if you hold the club or racquet on that side. Good technique may help to minimise the risk of straining the leads of the device.

Take care when performing dangerous lone activities such as outdoor swimming or climbing ladders. It will depend on your underlying cardiac condition as to whether swimming is suitable for you. Breaststroke is the recommended stroke. A goal of at least 30 minutes of moderate intensity activity most days of the week plus avoiding long periods of being sedentary will help keep your heart healthy. If you are unable to do 30 minutes in one go, perhaps due to another health condition, you can break the 30 minutes into three bouts of 10 minutes.

Depending on your underlying health condition you may be limited in the type or level of activity you can do. Before attempting any new physical activity or if you have any questions about physical activity and exercise with an ICD, speak to you CRM Nurse or doctor.

Any sport which involves bodily contact such as football, rugby, boxing, kick boxing or cage fighting are not usually recommended as there is a risk of damaging the ICD or its leads. Sports such as golf, tennis and indoor swimming should be played with consideration to your ICD. You should take care when participating in these sports and try to avoid direct impact to your ICD and the leads whenever possible. You may need to adjust your golf swing technique to ensure you are not straining the leads by keeping your arm close to your body during the swing.

What medicines do I take after my ICD has been implanted?

You should continue to take all the medicines you were taking before your ICD was implanted unless you have been told otherwise. You can discuss this with your CRM Nurse if you have any questions. Some of your medicines will help to reduce the risk of dangerous, fast heart rhythms occurring, however they do not guarantee that you will never have a dangerous, fast heart rhythm in the future.

It is important you do not stop taking any of your medicines without the knowledge of your doctor or Consultant Cardiologist. If you are struggling to cope with the side effects of any of your medicines, you should discuss them with your GP. Your GP and Consultant Cardiologist will regularly review your medications to ensure you are taking the correct dose and type. Always bring a list of your medicines to every clinic appointment. If you are having a telephone consultation, have the list ready.

You can write a list of your medicines here if you wish.

NAME OF MEDICINE	DOSE	TIME TAKEN	WHAT THEY ARE FOR

Section D – Living with your ICD

How am I monitored after my ICD has been implanted?

You will be closely monitored on a regular basis after your ICD has been implanted. Your first Outpatients Appointment (OPA) will be about 6 to 8 weeks after your ICD was implanted and this will be delivered to your home address. If you will be staying with a family member for a while after your procedure, please ensure you tell the Cardiac Physiologists where to send the OPA to. This is an important appointment as it gives the team an opportunity to check your wound is healing well, that your ICD is set at the right settings for you and to interrogate your ICD for any activity or "therapy" since it was implanted. From then on, you will have regular remote downloads from home and clinic review once a year. This may be performed on the telephone.

How will I feel emotionally after my ICD has been implanted?

Having an ICD implanted can be a major turning point in your life. No two people will feel the same and you may experience many emotions during the whole time you have your device. There is no right or wrong way to feel about having an ICD implanted. You may feel a sense of security, safety, and reassurance that you have your ICD.

You may feel sadness, anxiety, anger, a sense of loss, low in mood or vulnerability but it is recommended that you focus on the positive aspects of having your ICD to help you come to terms with the negative. It is important that you recognise your thoughts and feelings and talk to your family, significant others, and friends about it. The Consultant Cardiologist, CRM Nurse, ICD Support Group, Cardiac Physiologist, Cardiac Rehabilitation Physiotherapist and GP can also provide support.

If you would like to talk to someone who has an ICD, contact the CRM team and we will put you in contact with someone from the Support Group. We will need your permission to provide your name, contact details and a brief outline of your heart condition and concerns.

What does it feel like to receive a shock?

Everyone will experience a shock differently. Some people barely feel a shock, some describe it as a thump or a kick to the chest and some feel a "sense of impending doom". You may feel intense discomfort when your ICD gives you a shock or it may make you cry out. You may fall down (this may be because you are fainting or because your ICD is delivering a shock). You may injure yourself. You may feel minor muscle aches for a short time after. If you lose consciousness immediately or if you are asleep, you may not feel the shock. It is important to recognise and accept that however unpleasant the experience was

for you, it has just treated a dangerous, fast heart rhythm. It has just saved your life.

It is important that you don't spend your time worrying about the ICD. Get out and about, enjoy your life and do things which bring you joy and happiness!

What is a remote monitor?

Medtronic MyCarelink monitor ©



St Jude Merlin monitor ©



Boston Scientific
Latitude monitor ©



Biotronik ©



A remote monitor is a way we can monitor your ICDs activity and life span instead of asking you to come to hospital for an OPA. Remote monitoring equipment is free to you. All new ICD devices now use wireless (Wi-Fi) technology like a mobile phone signal. Wi-Fi signals are used to connect with your ICD at home and almost all the information that is required can be obtained. Remote monitoring can see how well your leads are working, how long the battery has left before it is depleted and if the ICD has given any therapy or shocks. There are newer remote monitors in use now, which use an Application (App) on your phone.

When you go home, you should set up the remote monitor as instructed by the Cardiac Physiologists. You can follow the advice booklet which accompanies your remote monitor and perform a "test download". This links your ICD with the remote monitor. You should then telephone the Cardiac Physiologists and tell them you have done a test download. This is important because it tells you that your remote monitor is ready and working.

The Cardiac Physiologists will discuss remote monitoring with you, either at your box check after your ICD has been implanted or at your first OPA. Having this equipment installed in your home has many advantages:

- Your ICD can be checked periodically via the remote monitor from home. You will receive a letter of confirmation from the Cardiac Physiologists to say they have received an automatic remote monitor download. Your ICD will then be checked annually or six monthly in clinic. This is particularly suitable for those patients who live a long distance away or have trouble getting to hospital.
- You can do a download at any time and call the Cardiac Physiologists if you think your ICD has delivered a shock or therapy. They will examine your download and analyse the results. You can also contact your CRM Nurse or Cardiac Physiologist for advice. A member of the team will call you back when the results are available and advise you.
- You can do a download at any time and call the Cardiac Physiologists if you think you have damaged your ICD, or you have received a shock. A download may detect a loose, broken or "fractured" lead which has confused the ICD into thinking that you are experiencing a dangerous, fast heart rhythm. This is rare but can occasionally happen if your ICD has recently been implanted, been damaged or has been in for a long time. This will need urgent attention. A member of the team will contact you and advise you.

What do I do if my ICD fires/goes off/gives me a shock?

All the above mean the same thing. Your ICD has delivered a shock to your heart because it has detected a dangerous, fast heart rhythm. If you have had a shock, you must not drive. The driving restriction for an appropriate shock (ie, the ICD has recognised and treated a fast, dangerous heart rhythm) is six months. The driving restriction for an inappropriate shock (ie, the ICD has incorrectly recognised a rhythm which it thinks is a dangerous, fast heart rhythm) is one month after the fault has been identified and corrected. This is the law.

Try to remain calm.

Try to sit down or if you feel unwell, lie down. You may be outdoors when this happens. Find a safe place to sit or lie but you may not always have time to do so. If you are in a chair or in bed, stay where you are.

If you felt well before the ICD fired and you feel well afterwards, call your CRM team or Cardiac Physiologist, and let them know. They will advise you on what to do. If you have a remote monitor, do a download, and then call the Cardiac Physiologists. Please bear in mind, this is not an emergency 24-hour service, but the answer machines are always on. Leave a message, stating your name and hospital number (this starts with 0 and is unique to you at Wythenshawe hospital) with a brief message. We will return your call the next working day.

If you feel very unwell after your ICD has fired, call 999 and ask for an ambulance to take you to the nearest Emergency Department (ED). If you come to Wythenshawe hospital, where your device was implanted, we will "interrogate" your ICD at the earliest opportunity to see what your ICD has done. Make sure you bring your ID card with you.

If you go to another hospital, make sure the doctors are aware you have an ICD and show your ID card to them. They may wish to contact us at Wythenshawe hospital. It may be possible for the doctor to "interrogate" your ICD if this technology is available at their hospital.

If you have had several shocks in close succession, you should ask someone to drive you to your nearest hospital or dial 999 and seek medical attention. Remember, if your ICD has fired, it is most likely because it has recognised and treated a dangerous, fast heart rhythm.

When can I drive again?

It depends on why your ICD was implanted. You can obtain detailed information from the Driver & Vehicle Licencing Agency (DVLA).⁶ If you **HAVE HAD** a dangerous, fast heart rhythm then you cannot drive for six months.

If you are **AT RISK OF HAVING** a dangerous fast heart rhythm, then you cannot drive for one month. The ICD has been implanted for preventative reasons. The CRM team or Consultant Cardiologist will be able to advise you on driving restrictions. Make sure you understand how long you should wait to drive again before you leave hospital. The DVLA have strict guidelines on driving and it is against the law to drive your vehicle while you are banned. It is your responsibility to inform the DVLA. This applies for everyone with a Group 1 licence (for example if you drive a car or motorcycle). Anyone who holds a Group 2 driving licence (for example you drive an articulated lorry) can no longer drive a Group 2 vehicle and you must inform the DVLA. This is life-long.

Can I do anything to stop my ICD from firing?

No. Your ICD is there to treat dangerous, fast heart rhythms. So, if it detects these rhythms, it needs to treat them. You can help reduce the likelihood of having these rhythms by taking the medicines your Consultant Cardiologist has prescribed for you. It is important you continue to take these medicines unless a doctor or your Consultant Cardiologist says so. Taking your medicines will not guarantee you will never get a shock though.

You should always carry your ICD ID card with you and inform any doctor, dentist, or medical/nursing staff that you have an ICD. Some people also wear a bracelet or neck chain with "I have an ICD" engraved. If you lose your ID card, or change address please call the Cardiac Physiologist for a replacement.

Can my ICD harm others if they are touching me when it fires?

No. Some people describe a feeling of pins and needles around the contact points between their bodies. Some people are more surprised at the suddenness of you receiving a shock, but they will not come to any harm.

Do I need to avoid any electrical equipment now I have an ICD?

Yes. You can find a more detailed list of items later in this booklet. Please see "What can I do and not do after my ICD has been implanted?" on page 17 and Appendix A.

You may not be able to have a Magnetic Resonance Imaging (MRI) scan once you have a standard ICD implanted. However, most of the ICD's which are now implanted are "MRI compatible". You should check if your ICD is MRI compatible before you leave hospital. When you go to any airport, show your ICD ID card to the security guards, and follow their instructions. When you enter shops, walk through the entrance at a normal speed and do not linger near the security equipment at the entrance.

How long will my ICD last?

It depends on how active your ICD has been. Most ICDs last for approximately six to ten years give or take a year! Generally, the more shocks an ICD delivers, the more battery it uses and the shorter it will last. You will be reviewed regularly, either in clinic or by doing a download at home from your remote monitor. If your battery life is coming to an end the Cardiac Physiologists will monitor you every three months. You will also be placed on the waiting list to have the battery replaced when your ICD has between 3 to 6-months' battery remaining. This is called a "box change". When appropriate, you will be admitted to hospital as a day case to have your battery replaced.

Some ICDs have a built-in alarm or a vibration device which is activated when the battery is running low. Please ring the CRM team **or** the Cardiac Physiologist and they will advise you on what to do if you hear an alarm or vibration coming from inside you. We may ask you to do a download or arrange to bring you to clinic to switch the alarm off while you are waiting for your box change. We may also demonstrate what this feels like when you are in clinic, so you know what to do if you hear an alarm or vibration.

What can I do and not do after my ICD has been implanted?

All ICDs have a protective shield so most items which you come into contact with will not affect the normal functioning of your ICD. However, some items which generate or use electricity, or transmit wireless signals have electromagnetic fields around them. Examples of these are portable generators, power drills, or mobile phones. Electromagnetic compatibility is the relationship between these electromagnetic fields and your ICD.

If items with electromagnetic fields are too close to your ICD and your ICD detects these fields, they may affect the normal function of your ICD temporarily. This may also occur if the items are in poor working order or improperly wired.

There is a risk that your ICD delivers a shock when it is not needed and withholds a therapy when it is needed. It is recommended that you only use equipment in good working order and at a specified minimum distance from your ICD.

If you feel dizziness, light-headedness, changes in your heartbeat or receive a shock while using equipment with an electromagnetic field, stop what you are doing immediately and move away from it. Any temporary effect is unlikely to cause reprogramming or damage to your ICD. If you still feel unwell after removing yourself from the electromagnetic field you should contact your doctor as soon as possible or if you are extremely unwell, call 999. You should also call the Cardiac Physiologists **or** CRM team for advice.

A list of the most common equipment inside and outside the home and specific advice on their risk can be found in Appendix A on page 20.

They are listed in categories:

- Household and hobbies
- Tools and industrial equipment
- Communications and office equipment
- Medical and dental procedures.

Can I have cardiac rehabilitation (cardiac rehab) after my ICD has been implanted?

Yes. Cardiac rehab is considered to be an essential part of the management of your heart condition. People who have had a heart attack or who have heart failure and need an ICD afterwards are already offered cardiac rehab. If your ICD is implanted because you have had an OOH cardiac arrest or are at risk of having dangerous, fast heart rhythms, you can also have cardiac rehab.

After your ICD has been implanted you will be asked if you would like cardiac rehab. You will then be referred to your nearest programme. If your local hospital does not offer cardiac rehab, you can have one session at Wythenshawe hospital. You can find a list of the cardiac rehab providers at cardiac-rehab.net⁷. You will be assessed by a member of the cardiac rehab team and a programme of physical activity, exercise, education, good lifestyle practices and psychological support will be devised dependent on your individual goals and diagnosis.

Is there a support group for people who have an ICD?

Yes, there is.

The Wythenshawe ICD Patients Support Group⁸ was set up in 2001 at Wythenshawe hospital to provide communication, education, and support for patients with ICDs. There is a Chairman, Secretary, Treasurer, and committee members, all of whom have or have had an ICD implanted.

They produce a newsletter called The Defibber News three times a year and this is sent to all patients with an ICD. Patients are encouraged to write about their own experiences with living with their device and the Support Group welcomes stories from new and existing patients. There are also interesting articles which are relevant to people with ICDs.

Shortly after the Defibber News is published, patients and their families can come to an informal meeting, either at Wythenshawe hospital or at a venue outside of the hospital. At these meetings, patients can meet other people with ICDs from 1 pm. A guest speaker will give a presentation on current topics for patients with ICDs at 2 pm. The Chairman, CRM Nurses and Cardiac Physiologists like to be there too so patients can have a chat with them if they wish. Since the COVID pandemic, they have not been able to hold meetings, but it is hoped that these can resume once it is safe to do so.

Wythenshawe hospital also has a team of male and female patient volunteers, all of whom have or have had an ICD. In their spare time they will chat to new patients who have or need an ICD. This can be done either by telephone, email, or face to face. They will offer support and will share their experiences of living with an ICD. You can ask the CRM team if you would like to speak to a volunteer. Volunteers cannot offer medical advice but are a great source of support and advice on living with an ICD. This can only be arranged by the CRM team.

The ICD Support Group is completely funded by donations which are always gratefully received. If you would like to contribute towards the newsletter, please contact the Chairman or the Treasurer of the Committee. Their details can be found on every newsletter and on the website. Further details are below.

If you move to a new house or if the person who receives the Defibber News has passed away, please let us know. You can call the CRM team or the Cardiac Physiologists on the numbers at the front of this booklet or on page 22.

The Support Group also has a website. Go to Google, type in wythenshaweicd.wixsite.com/icdsupport. You can also find the website by typing in Wythenshawe ICD support group. On here you can find information on past newsletters, details of the next ICD Support Group meeting, important contact numbers, the Committee members, and your type of ICD. You can also find this booklet if you lose it!

When can I resume sexual intercourse?

Sexual intimacy for most people does not pose a medical risk. You should be able to resume sexual relations when you and your partner feel ready. It is completely normal for one or both of you to feel anxious about this. Talking to each other and being open and honest about your fears and anxieties will help you both. Acknowledging and understanding each others' worries and needs is an important part of "getting back to normal".

If you get a shock during sex, your partner will come to no harm. Some people describe a feeling of pins and needles around the contact points between their bodies, but the shock will not hurt them. They may be taken by surprise by the shock that is given to you, as indeed, you may be too. This can be distressing to you both but talking about the experience will help you to cope with the incident.

You can also talk to the CRM team in strict confidence if you need support or advice.

What if I want to deactivate my ICD?

To deactivate an ICD means turning off the shock lead of your ICD. You can choose to have the shock lead switched off. If the shock lead is switched off your ICD will no longer monitor for and treat dangerous, fast heart rhythms. There are several reasons why you might want your ICD to be deactivated.

These include:

- You are at the end of your life and the delivery of a shock may delay a natural death.
- You do not want to experience a shock during the last stage of your life.
- You no longer wish for an ICD to be part of your care and treatment.

Whenever possible, the discussion to deactivate your ICD should be planned. It should take place between you, your Consultant Cardiologist/doctor/GP and your family or significant others with support from your CRM team and the Cardiac Physiologists. You must fully understand the implications and benefits of switching off the shock lead of your ICD. Support will be available to you and your significant others whenever you have questions and concerns.

Deactivating the shock lead of an ICD does not end a person's life but will allow for a natural death when the time comes without the risk of unpleasant and unnecessary shocks⁹. The process of deactivating any part of your ICD is quick, totally painless, and completely reversible. All functions can be switched back on again at any time in your life.

You may feel uncomfortable discussing deactivation of your ICD with your family and significant others and this is perfectly understandable. It is a sensitive issue

and talking about death when so much focus has been around improving your life can be confusing.

However, if you know what you want and when you want it to happen, your family will be comforted by this and be spared the fear of making the wrong choices at the end of your life. It is YOUR ICD, YOUR BODY and YOUR DECISION. At the end of life, it is not usual to have a life-threatening arrhythmia, but it can sometimes happen. Deactivating the shock lead of your ICD will remove the possibility of receiving a shock which may cause you pain and distress in your final hours or days. However, the ICD will not treat these rhythms which are life threatening. The pacemaker part of your ICD will still function.

The action of deactivating an ICD will neither bring about death, nor prolong life.

Who do I call if I need help?

SPECIALITY	DEPARTMENT	NUMBER
Remote monitor, downloads Outpatient appointments	Cardiac Physiologists	0161 291 4615 for downloads 0161 291 4640 for appointments
Medicines, symptoms, driving licence enquiries, general enquiries	CRM Team	0161 291 5998 0161 291 5443 0161 291 5076
Appointments, driving licence	Secretary to Dr Fox Secretary to Dr	0161 291 2743 0161 291 2390
forms	Ainsle/Dr Schmitt/Dr Reid	
	Secretary to Dr Campbell/ Dr Skene	0161 291 2388
	Secretary to Dr Williams	0161 291 2624
	Secretary to Dr Brown/ Dr Temple/Dr Nikolaidou	0161291 4152
Enquiries about waiting time for	Waiting List co- ordinators	0161 291 2882 0161 291 4947
procedures.	Wythenshawe hospital	
Physiotherapy Wythenshawe	Cardiac Rehab	0161 291 2177

Appendix A

HOUSEHOLD AND HOBBIES – providing the item is used as intended and in good working order

ITEM	RECOMMENDATION
Abdominal stimulator	Not recommended
Antenna for radio-controlled items	Minimal risk – maintain at least six inches or 15 centimetres (cm) from ICD
Back massager handheld	Minimal risk – maintain at least six inches or 15 cm from ICD
Battery powered shaver	No known risk
Car/motorcycle components of ignition system	Special consideration – maintain at least 12 inches or 30 cm from ICD
Casino slot machines	No known risk
CD/DVD/VHS player or recorder	No known risk
Charging base of electric toothbrush	Minimal risk – maintain at least six inches or 15 cm from ICD
Corded electric shaver	Minimal risk – maintain at least six inches or 15 cm from ICD
Dishwasher	No known risk
Electric blanket	No known risk
Electric fence	Special consideration – maintain at least 12 inches or 30 cm from ICD
Electric grocery cart motor	Minimal risk – maintain at least six inches or 15 cm from ICD
Electric guitar	No known risk
Electric pet containment fence – buried wire and indoor antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD
Electronic body fat scale	Not recommended
Electronic weighing scale	No known risk
Garage door opener	No known risk
Golf cart motor	Minimal risk – maintain at least six inches or 15 cm from ICD
Green transformer box in yard	Special consideration – maintain at least 12 inches or 30 cm from ICD
Hair drier – handheld	Minimal risk – maintain at least six

	inches or 15 cm from ICD
Handhald kitchen appliances (alcotric	Minimal risk – maintain at least six
Handheld kitchen appliances (electric	inches or 15 cm from ICD
mixer, knife)	
Heating pad	No known risk
Hot tub	No known risk
He saladil affect days	Nic Lorenza 251
Household battery charger	No known risk
Induction stove	Special consideration – maintain at
	least two feet or 60 cm from ICD
Ionized air filter	No known risk
Iron	No known risk
Kitchen appliances, small and large-	No known risk
blender, can opener, refrigerator,	
stove, toaster	
Low voltage residential power lines	No known risk
Manager (Colored and Laborator Laborator)	NAC de la contraction de la co
Magnet (fridge, household)	Minimal risk – maintain at least six
1 / 11/	inches or 15 cm from ICD
Magnetic mattress pad/pillow	Not recommended
Magnetic therapy products	Minimal risk – maintain at least six
	inches or 15 cm from ICD
Massage chair/pad	No known risk
Medical alert necklace	No known risk
Metal detector (beach comber) from	Special consideration – maintain at
search head	least two feet or 60 cm from ICD
Microwave oven	No known risk
Wildrowave over	140 Kilowii flok
Remote control for CD, DVD player,	No known risk
television, VHS	
Salon hair drier	No known risk
Caron man arren	THE INTERNATION
Sewing machine motor	Minimal risk – maintain at least six
	inches or 15 cm from ICD
Speakers	Minimal risk – maintain at least six
2,530.0	inches or 15 cm from ICD
Tanning bed	No known risk
Television	No known risk
Tue o due illus at a s	Minimal viale
Treadmill motor	Minimal risk – maintain at least six
I literatura de la contractiva di co	inches or 15 cm from ICD
Ultrasonic pest controller	Minimal risk – maintain at least six

	inches or 15 cm from ICD
Vacuum cleaner motor	Minimal risk – maintain at least six inches or 15 cm from ICD

TOOLS AND INDUSTRIAL EQUIPMENT- providing the item is used as intended and in good working order

ITEM	RECOMMENDATION
Air compressor (bench mounted or	Special consideration – maintain at
free-standing tools for motors with 400	least two feet or 60 cm from ICD
horsepower or less)	
Callipers (battery powered)	No known risk
Circular saw	Minimal risk – maintain at least six inches or 15 cm from ICD
Drill press	Special consideration – maintain at least two feet or 60 cm from ICD
Drills (battery and electric powered)	Minimal risk – maintain at least six inches or 15 cm from ICD
Electric chainsaw	Minimal risk – maintain at least six inches or 15 cm from ICD
Flashlight	No known risk
Gas powered tools – from components	Special consideration – maintain at
of ignition system – lawn mower, snow	least 12 inches or 30 cm from ICD
blower, weed whacker, chain saw	
Generators with 20 kW or less	Special consideration – maintain at least 12 inches or 30 cm from ICD
Grinder	Special consideration – maintain at least two feet or 60 cm from ICD
Grinder (handheld)	Minimal risk – maintain at least six inches or 15 cm from ICD
Hedge trimmer – electric powered	Minimal risk – maintain at least six inches or 15 cm from ICD
Jumper cables	Special consideration – maintain at least two feet or 60 cm from ICD
Laser level	No known risk
Pressure washer	Special consideration – maintain at least two feet or 60 cm from ICD
Sander	Minimal risk – maintain at least six inches or 15 cm from ICD
Screwdriver (battery powered)	Minimal risk – maintain at least six inches or 15 cm from ICD
Soldering gun	Minimal risk – maintain at least six inches or 15 cm from ICD

Soldering iron	No known risk
Stud finder	No known risk
Table saw	Special consideration – maintain at least two feet or 60 cm from ICD
Weed whacker (electric powered)	Minimal risk – maintain at least six inches or 15 cm from ICD
Welding equipment with current over 130 amps	Not recommended
Welding equipment with current under 130 amps	Special consideration – maintain at least two feet or 60 cm from ICD

COMMUNICATIONS AND OFFICE EQUIPMENT- providing the item is used as intended and in good working order

ITEM	RECOMMENDATION
Amateur radio	Minimal risk – maintain at least six inches or 15 cm from ICD
Amateur radio (3 to 15 watts) from antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD
Bluetooth technology	Minimal risk – maintain at least six inches or 15 cm from ICD
Computers	Minimal risk – maintain at least six inches or 15 cm from ICD
Cordless headphone sending unit (TV ears)	Minimal risk – maintain at least six inches or 15 cm from ICD
E readers (Kindle)	Minimal risk – maintain at least six inches or 15 cm from ICD
E tablets (iPad)	Minimal risk – maintain at least six inches or 15 cm from ICD
Fax machine	No known risk
Global Positioning Machine (GPS)	No known risk
Ham radio	Minimal risk – maintain at least six inches or 15 cm from ICD
Ham radio (15 to 30 watts) from antenna	Special consideration – maintain two feet or 60 cm from ICD
Ham radio (3 to 15 watts) from antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD

Headsets	Minimal risk – maintain at least six inches or 15 cm from ICD
Home wireless electronics – from antenna	Minimal risk – maintain at least six inches or 15 cm from ICD
Infra-red scanner	No known risk
iPod (digital music player – non transmitting)	No known risk
iPod (digital music player - transmitting)	Minimal risk – maintain at least six inches or 15 cm from ICD
Laptop/computer	No known risk
Marine radio	Minimal risk – maintain at least six inches or 15 cm from ICD
Marine radio (15 to 30 watts) from antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD
Marine radio (3 to 15 watts) from antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD
Mobile phone three watts or less – from antenna	Minimal risk – maintain at least six inches or 15 cm from ICD
Modems	Minimal risk – maintain at least six inches or 15 cm from ICD
Pager (receiver only)	No known risk
Photocopier (copying machine)	No known risk
Printer	No known risk
Radio (AM/FM)	No known risk
Remote car starter	Minimal risk – maintain at least six inches or 15 cm from ICD
Remote keyless entry	Minimal risk – maintain at least six inches or 15 cm from ICD
Routers	Minimal risk – maintain at least six inches or 15 cm from ICD
Scanner	No known risk
Security badge wall scanner	Minimal risk – maintain at least six inches or 15 cm from ICD
Smart meters (utility companies)	Minimal risk – maintain at least six inches or 15 cm from ICD

Smart phones	Minimal risk – maintain at least six inches or 15 cm from ICD
Walkie talkie (15 to 30 watts) from antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD
Walkie talkie (3 to 15 watts) from antenna	Special consideration – maintain at least 12 inches or 30 cm from ICD
Walkie talkie three watts or less – from antenna	Minimal risk – maintain at least six inches or 15 cm from ICD
Wireless communication devices (computers, modems, routers, headsets, smart phones, Bluetooth)	Minimal risk – maintain at least six inches or 15 cm from ICD
Wireless controllers (video game consoles)	Minimal risk – maintain at least six inches or 15 cm from ICD

MEDICAL AND DENTAL PROCEDURES – if used as intended and in good working condition

	RECOMMENDATION
ITEM	
Acupuncture – no electrical stimulus	Acceptable risk
Acupuncture with electrical stimulus	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant /cardiologist
AED (Automated External Defibrillator)	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Bone density test – x-ray	Acceptable risk
Bone density ultrasound – on heel or hand	Acceptable risk
Capsule endoscopy	Acceptable risk
Catheter ablation (microwave and radio frequency)	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Cauterisation (or any electro-surgery which use an electric probe to control bleeding, cut tissue or remove tissue)	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant

	Cardiologist
CT (Computerised Axial Tomography) scan	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Dental drills	Acceptable risk
Dental ultrasonic scaler/cleaner	Acceptable risk
Diathermy (high frequency, short wave and microwave)	Not recommended
Digital hearing aid transmitting loop	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
ECG (electro-cardiograph)	Acceptable risk
Echocardiogram	Acceptable risk
Elective cardioversion	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Electrolysis	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
External defibrillation	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Fluoroscopy (diagnostic x-rays)	Acceptable risk
HBOT (Hyperbaric Oxygen Therapy)	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Hearing aid (in or behind the ear)	Acceptable risk
Heart monitor	Acceptable risk
Laser surgery	Acceptable risk

Lithotripsy	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Mammogram	Acceptable risk
MRI (Magnetic resonance Imaging) scan with standard ICD implanted	Not recommended if ICD is not MRI compatible
MRI scan with MRI compatible ICD implanted	Inform your consultant Cardiologist and Cardiac Physiologist so that ICD settings can be adjusted immediately prior to and after MRI scan
Muscle stimulators and other devices sending current into your body	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
NMES (Neuro Muscular Electrical Stimulation)	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
PET scan (positron Emission Tomography)	Acceptable risk
PH capsules	Acceptable risk
Radiotherapy (including high energy radiation therapy	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Sleep apnoea machine	Acceptable risk
Stereotaxis	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
TENS (Transcutaneous Electrical Nerve Stimulation)	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
Therapeutic ultrasound	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist
TUNA therapy (Transurethral Needle Ablation	Acceptable risk with precautions – inform your physician that you have an ICD and/or inform your consultant Cardiologist

FURTHER READING

If you want further information about ICDs and heart conditions, the following websites are good places to visit.

Arrhythmia Alliance (www.heartrhythmcharity.org.uk)
Patient.co.uk (www.patient.co.uk)
National Institute for Health and Care Excellence (www.nice.org.uk)

If you have been diagnosed with a heart condition and need an ICD, the following websites can provide further information.

Arrhythmia Alliance (www.heartrhythmcharity.org.uk)

- Atrial fibrillation
- Brugada syndrome
- Long Q-T syndrome
- Sudden cardiac arrest

British Heart Foundation (www.bhf.org.uk)

- Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)
- Atrial fibrillation
- Brugada syndrome
- Cardiac arrest
- Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)
- Dilated Cardiomyopathy
- Hypertrophic Cardiomyopathy
- Long Q-T syndrome
- Progressive Cardiac Conduction Deficit (PCCD)

The Brugada syndrome website (<u>www.brugadadrugs.org</u>) can provide a list of medicines you should avoid when you have Brugada syndrome.

The Cardiac Risk in the Young website (www.c-r-y.org.uk) can provide information on sudden cardiac death in young people.

The Sudden Arrhythmic Death syndrome website (<u>www.sads.org</u>) provides further information on rarer heart conditions which affect the electrical functioning of the heart.

Wythenshawe hospital is not responsible for the quality or accuracy of any information or advice provided by other organisations.

REFERENCES

- 1. https://www.nice.org.uk/guidance/ta314/chapter/1-Guidance
- 2. http://www.azheartrhythmcenter.com/procedures/defibrillation-implantation
- 3. http://www.medtronic.com/us-en/patients/treatments-therapies/remote-monitoring.html
- 4. http://www.bostonscientific.com/en-US/products/remote-patient-monitoring/latitude.html
- 5. https://www.sjmglobal.com/en-int/patients/arrhythmias/our-solutions/remote-monitoring
- 6. https://www.gov.uk/guidance/cardiovascular-disorders-assessing-fitness-to-drive
- 7. http://maps.cardiac-rehabilitation.net
- 8. https://www.uhsm.nhs.uk/services/specialist/cardiology-cardiothoracic-surgery/heart-rhythm
- 9. http://www.gmccsn.nhs.uk/files/8113/6983/8277/ICD_Deactivation_PolicyFinal_V1.0.pdf

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