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Sherwood Forest Hospitals
NHS Foundation Trust

Living with your Cardiac Resynchronisation Defibrillator (CRT-D)

Information for patients



Living with your CRT-D

A cardiac resynchronisation therapy (CRT) device is a pacemaker used to help to treat heart failure.

It makes the lower heart chambers (ventricles) pump at the same time (synchronously) to help to improve the overall function of the heart. It may potentially help you to feel less breathless and to feel that you have more energy. Additionally your pacemaker will prevent your heart from beating too slowly.

In a CRT pacemaker an additional lead is placed on the left side of the heart to make the left ventricle beat at the same time as the right. Your device also has a cardioverter defibrillator (ICD) built into it.

If your heart beats in an abnormal dangerous fast rhythm, the ICD can give you a burst of extra beats at an even faster rate to help to return your heart rate back to a normal rhythm. This is called anti-tachycardia pacing (ATP).

If the anti-tachycardia pacing does not bring your heart back to a normal rhythm, or if the ICD senses a faster rhythm called ventricular fibrillation, the ICD can give one or more shocks. This is called defibrillation.

If the doctor has suggested that you need a defibrillator you may have experienced OR will be at risk of experiencing an abnormal, fast heart rhythm that can cause you to become unwell, unconscious, or your heart to stop beating.

The main thing that you need to be aware of is that the device can give you a shock. Usually the faster dangerous rhythms can cause you to faint before this happens and you may not be aware of the shock. However, people who have been aware have sometimes found it unpleasant and feel like they have suddenly been punched or kicked in the chest.

In the event of a shock

Before the device delivers a shock you may sometimes be aware of a fast heart beat or palpitations and you may feel light-headed or dizzy. You may be able to ask for help if possible and sit or lie down on the ground. However, sometimes this may happen so quickly that you have no warning at all.

Afterwards you should recover quite quickly. **However, if you feel well after the shock you should still contact the Pacemaker Clinic soon as you can to arrange a device check and medication review.** The number is at the end of this leaflet.

If you continue to feel unwell, if you black out or faint more than once, or if your device has given you more than one shock, you must dial 999 for an ambulance. Your ICD will be checked to find out why the shock was given.

Wound care

You may have had a pressure bandage applied over the top of the wound dressing and you may need to wear a sling to restrict all movement of the arm on the side of your pacemaker for 48 hours only. After this time it can be removed. You can sleep or lie on your left side if comfortable. Please avoid wearing a seatbelt on the same side as your implantable device for the first 10 days. Following this you can wear a seat belt on either side.

You will have received an appointment to have your stitches removed 10 – 14 days after your implant. Please leave your dressing in place until your first routine wound review at the Cardiac Catheter Suite. Your wound site should be kept clean and dry until it has fully healed. Do not get the dressing or device site wet until all scabs have fallen off naturally from the wound.

It can take up to six weeks until the wound is fully healed. Avoid wearing tight clothing over the area. **If you notice any weeping or oozing, pain or heat, excessive bruising or discolouration, or you can see the device please contact either the Cardiac Catheter Suite or Pacemaker Clinic as soon as possible. The numbers can be found at the end of this leaflet. Do not go to your GP with any problems with your pacemaker wound.**

Exercising/moving

Once your sling is removed, you need to restrict movement in the arm on the same side as your pacemaker for six weeks after the pacemaker is implanted. **Do not lift your arm above shoulder level and avoid heavy lifting.** This gives the tissue in the heart time to grow around the pacemaker leads to secure it to the heart wall and allows your wound site time to heal completely.

To avoid the risk of getting a frozen shoulder, small frequent general movements are beneficial. You are able to push up from a bed or chair as long as this movement does not require you to lift your arm higher than shoulder height. You can weight bear – use a walking frame or any other walking aid that doesn't require you to lift your arm up.

Exercising with an ICD is influenced by the cause and type of your arrhythmia and the type of exercise you perform. You may be offered cardiac rehabilitation or exercise testing to restore your confidence and get you back to normal.

The likelihood of an abnormal rhythm is no greater during moderate exercise than during resting. However, exercising hard from rest without a warm-up, or immediately stopping exercise without a cool down or active recovery period should be avoided to reduce the likelihood of an arrhythmia.

A certain level of exercise is good to stay healthy. It is advised however, to avoid strenuous activity in the first six weeks after the ICD implant before taking part in regular healthy exercise. Please talk to the team at the Pacemaker Clinic if you have concerns about physical activity. You can take part in most activities but it is advisable to avoid contact sports to minimise the risk of damaging your ICD.

ID information

You should have received a CRT-D identity card which has details of the make and model of your device **and you should always carry this with you.**

If you require any further medical treatment in the future it is important that you show this card to the healthcare professionals treating you. Take a photo of your ID card with your phone and store it on your phone. If you have not received this card please let a member of the pacemaker team know so that this can be either sent to you by post or given to you at the Pacemaker Clinic. Some people may like to purchase a Medic Alert and we have provided you with some information in this pack.

Mobile phones/portable music players

Some studies have shown that mobile phones and portable music players can affect the CRT-D if held within six inches of the device. It is therefore recommended that you do not keep them in a coat or shirt pocket over the ICD. Keep the handset more than six inches away from the CRT-D; ideally hold your phone over the ear on the opposite side to the device.

Medications

Medications are part of your treatment plan, so take medications exactly as instructed. Medications work with your CRT-D and help your heart pump regularly.

Keep records of what medications you take and **always bring a list of them to all hospital appointments.**

Alarms

Some ICDs have a safety warning sound programmed into them. In some devices this is an audible alarm and in others the device has a vibration alarm within it. This will alert you to the need to be seen earlier than previously planned in the ICD clinic. The alarms are programmed to sound when various parameters are met. This is for your safety and should not cause concern. However, if you hear your device alarming then contact the Pacemaker Clinic on the number at the end of this leaflet and a physiologist will call you back if they are not available.

Using household appliances and equipment with a pacemaker

Most mechanical and electrical devices that you use in your home will not affect your CRT-D. Household equipment such as ordinary radios, fridges, cookers, remote controls, televisions, electric razors, computers and microwaves etc. will not affect your CRT-D as long as they are in good working order.

In the case where you ever feel dizzy or experience palpitations while using an electrical appliance, you should move away from the appliance and phone the physiologist in Pacemaker Clinic for advice.

Driving with a CRT-D

The Driving and Vehicle Licensing Agency (DVLA) have guidelines in relation to patients who require an ICD and whether or not they are safe to drive. There will be some restrictions, but these will vary depending on why you have had your ICD fitted. It is very important that you discuss this with your nurse, physiologist or doctor at the Pacemaker Clinic who will explain this in more detail.

You must inform the DVLA and your insurance company that you have had an ICD implanted.

Medical equipment or other hospital treatment

It is important to always mention to any doctors, nurses or dentists that you have a CRT-D before undergoing any investigations or procedures. Please take your ID card with you whenever you go to hospital. It may also be useful to contact the Pacemaker Clinic for advice before you go into hospital for any investigations or operations that are not associated with your CRT-D.

Most equipment used by your hospital or GP surgery will not cause any problems to your CRT-D. It is safe for you to have x-rays, CT scans and mammograms.

Some CRT-Ds, are MRI conditional which means that they have been demonstrated to pose no known hazards in a specified MRI environment with specified conditions of use. If you have any concerns, please speak to your Pacemaker Clinic.

Some electrical nerve and muscle stimulators (TENS units) may cause interference with CRT-Ds but this depends on where they are being applied, and, if any of these treatments are suggested to you then the Pacemaker Clinic should be contacted for advice.

If you require an operation, you must tell your surgeon and anaesthetist that you have a CRT-D. It may be necessary to temporarily switch off (deactivate) the shocks on your CRT-D for the duration of the operation. This can be done through a programmer, but equally can be done using a magnet taped over your CRT-D. This will prevent unnecessary shocks being given during operations, especially when diathermy cautery (your healthcare professional will explain this) is used as this can be sensed by the CRT-D.

Electromagnetic interference

Electromagnetic interference will not damage your CRT-D but will stop it from delivering any treatment for the period of time that you are in contact with it. Most mechanical and electrical devices that you use in your normal daily activities will not affect your CRT-D. Ordinary radios, fridges, cookers, computers and microwaves will not affect your CRT-D as long as they are in good working order.

In case you ever feel dizzy or experience palpitations while using an electrical appliance, you should move away from the appliance and phone the physiologist in Pacemaker Clinic 4 for advice.

Magnets

Do not carry magnets or place a magnet over your chest. Avoid carrying stereo or hi-fi speakers as they contain strong magnets that can interfere with your CRT-D. CRT-D therapies may be temporarily disabled by magnets and, in some cases, this may be necessary if you received inappropriate shocks from the CRT-D. However, it is not recommended that you place a magnet over your device unless proper instructions have been given by your doctor.

Arc welding

This should be avoided.

Electronic ignition systems

Avoid leaning over the alternator in a car while the engine is running, otherwise it is generally safe to work as a mechanic.

CRT-D clinic visits

Your CRT-D should be checked regularly and you will be invited to attend the Pacemaker Clinic as required. You will need a check six weeks post-implant, then three months post-implant, then every six months. You may be asked to attend more often if necessary.

During each clinic visit, the physiologist will examine your CRT-D using a special programmer and your wound will be checked. The programmer will allow them to examine the settings and the battery life of your device as well as the state of the leads that connect the device to your heart.

Changes may be made to the CRT-D settings if necessary and you may sometimes require an ECG.

At these visits please also take this opportunity to ask any questions or let the medical team know if you have any problems or worries.

Home monitoring

At your six week check the physiologist will set you up on 'remote' monitoring. This means that we can monitor your heart and implanted device while you are at home.

You will need a special transmitter which automatically sends medical and technical information from your heart when it connects to your device. This allows the physiologists to monitor your condition based on accurate, up to date clinical information at any time, meaning that should you receive a shock and you are feeling well, the care team will be able to check your device and the cause of the shock without the need to attend the hospital.

Remote monitoring can also replace some routine clinic visits, saving you time, although we are available at the clinic should you need some advice or you need to be examined.

Changing the CRT-D

Normally a CRT-D battery lasts between five and seven years. Your battery will be checked at every visit to the clinic and staff at the clinic will be able to predict when you need a replacement.

Don't worry, it will not be allowed to completely run down. You will be seen more regularly and an appropriate time for replacement will be scheduled.

You will need to attend the hospital for the day for the procedure which is similar to having your first CRT-D fitted. It will not usually involve having new leads.

Travel

You can safely travel abroad with your CRT-D, but you are advised to show the security staff your identification card. The metal casing of the CRT-D may set off the airport security alarm. The detector will not cause any harm to your device provided you walk briskly through the arch.

You will need to make sure that your travel insurance company is aware that you have a CRT-D. Some insurance companies require written confirmation from your cardiologist that you are fit to travel.

The Arrhythmia Alliance Website has a list of travel friendly companies for people with CRT-Ds and this can be found with the links and phone numbers at the end of this leaflet.

Symptoms of anxiety, depression and post-traumatic stress disorder (PTSD)

After an ICD implantation, you may feel anxious or depressed. This is not uncommon. If you experience these feelings, or even anticipate them, consult with your doctor or healthcare team and get help. By asking questions and expressing your concerns about the ICD and your reactions to it, you might prevent or alleviate potential anxiety or depression.

Exposure to a traumatic life-or-death experience is a key to diagnosing PTSD. You having sudden cardiac arrest, multiple shocks or other near-death situations can certainly bring about PTSD symptoms. Do not hesitate to discuss your feelings regarding the trauma with your healthcare team. Your mental and emotional well-being is important to your physical well-being.

Deactivating the CRT-D

The pacemaker function, resynchronisation function and defibrillator (shock) function can be adjusted independently of each other. This will usually be done by a physiologist, using a similar programmer to the one used for routine checks at the pacemaker clinic.

The shock function of CRT-D can be deactivated towards the end of life.

It may be important to consider this if you develop a terminal illness, become very frail or decide that you no longer wish to receive shocks from your CRT-D.

It is important that you and your family, or close friends, can discuss this so that everyone understands what is involved and you can make your own personal wishes clear. Your cardiologist, specialist nurse or physiologist will be happy to discuss this.

Sometimes a decision to deactivate a CRT-D has to be made as a matter of urgency by the doctor responsible for your care. This would usually be necessary if you become very ill and are unable to make choices about your treatment yourself. Any such decision would be made in your best interests and would be handled with care and sensitivity.

Whenever possible, this would be undertaken with advice from your family or other people who know you well, unless you have stated that you do not want them involved. Discussing your views and preferences in advance will help to make sure that any decisions that are made for you are the ones that you would have wanted.

Whenever possible it is recommended that an CRT-D is deactivated at the Pacemaker Clinic. If you are too unwell to attend the clinic and you are in a nursing home, a hospice, community hospital or your own home it may be possible to arrange deactivation there. However, this would need to be planned carefully so that a physiologist can attend.

Deactivation of a CRT-D is completely painless and will make no difference to how you feel, other than making sure that you do not receive shocks that may be painful. It will not cause death but in time allows a natural death - it simply means that as you reach the last stages of your illness you will remain free from shocks.

This is a reversible process and if the situation changes or you wish to change your mind it can be turned on again (reactivated) If you decide that you do not wish to have your ICD deactivated it will be left active. The decision can be reconsidered and discussed at any stage as your condition changes or if you wish to change your mind.

To summarise

For the first six weeks DO NOT:

- Carry or lift anything heavy.
- Raise your arm/elbow above shoulder height.
- Fiddle with the device. This could move the leads which are inside the heart, which would then need to be repositioned.
- Stand in security gates in shops or airport security. However, if you have to go through security in airports/border controls please inform staff that you have a pacemaker and be prepared to show your pacemaker identity leaflet.

Do:

- Take the full course of antibiotics if these have been prescribed.
- Take all other medications as instructed by your doctor.
- Attend the Cardiac Catheter Suite for a wound check and suture removal on _____
- Leave your dressing in place until the appointment for your wound check.
- Restart warfarin/apixaban/rivoroxaban/edoxaban/dabigatran on _____
- dose of _____
with INR check _____
- Live a normal life and don't forget to keep your appointments with us in clinic.
- Refrain from driving until _____
- Remove your pressure dressing on _____
- If you receive a shock from contact the pacemaker clinic if you feel well or 999 if you continue to feel unwell.

Telephone numbers

- Pacemaker Clinic at King's Mill Hospital – 01623 672259.
- Cardiac Catheter Suite at King's Mill Hospital – 01623 672424.
- In an emergency contact the Pacemaker Clinic between 8am and 6pm Monday to Friday.
- Outside of working hours please call 999.

Useful links

- www.heartrhythmalliance.org/aa/uk/for-patients
- www.patient.info/dvla

Further sources of information

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them. If you require a full list of references (if relevant) for this leaflet, please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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