



Information for patients following your Implantable Cardioverter Defibrillator (ICD) or Cardiac Resynchronisation Therapy Defibrillator (CRT-D) procedure

Information for patients from the Heart Failure Team

This leaflet aims to provide you with all the information you will need to care for your device at home but should you have any further questions or concerns please do not hesitate to ask.

Please bring this leaflet with you on the day of your procedure, so that staff can complete the relevant sections for you.

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Why have I been recommended for a cardiac device?

Your doctor has recommended that you are fitted with a cardiac device. This means that you may be suffering from heart failure and / or may have experienced or may be at risk of experiencing an abnormal, fast heart rhythm.

CRT devices are used to help treat heart failure (when the heart does not pump as well as it should) by acting as a pacemaker, stimulating the heart chambers to pump at the same time. The defibrillator function sends impulses (fast pacing) to your heart muscle when your heart beats too quickly (which could be life threatening). These life threatening rhythms (dangerous heart rates and rhythms) are treated by delivering a shock to your heart.

What happens when I arrive at the hospital?

The doctor (or nurse) will explain the procedure to you, including the risks and benefits. You will then be asked to sign a consent form to confirm that you are happy for the procedure to go ahead. Please use this time to ask any questions about the procedure.

You will need to change into a hospital gown for your procedure. A small plastic tube (a cannula) will be inserted in your arm for medication to be given.

If you have any concerns or questions do not hesitate to ask as we would like you to be as relaxed as possible about your procedure.

What happens during my procedure?

You will be asked to lie on your back on a narrow firm table which is positioned under an x-ray camera; this is used to help guide the doctors during the implantation. It is important that you lie still during your procedure, so if you feel like you need to move please just let the staff know.

You will be connected to a heart monitor and you will be closely monitored to keep you safe.

Your skin will be cleansed with an anti-septic solution, which may feel cold and wet. Your chest will be covered with drapes to keep the wound as clean as possible. You will be given local anaesthetic (like at the dentist) under your skin below your collarbone on the side the device is being placed. This may sting at first, but will soon go numb. You may be offered sedation that will make you relaxed and sleepy, but not fully asleep. If you have any concerns or questions do not hesitate to ask as we would like you to be as relaxed as possible about the procedure.

The device will be implanted in a pocket that the doctor will make under your skin which may feel uncomfortable or even painful at the time. This will leave a visible scar and there will be a small bump where the device is placed.

The device will then be connected to your heart with flexible leads that pass through a vein under your collarbone. The doctor will insert the leads into your heart using x-ray images to guide them. Moving the leads inside your heart is completely painless.

When the device has been implanted (and tested if necessary) the wound will be closed and covered with a dressing.

How long does the procedure take?

The procedure is mostly done as a day case and the chances are high that you may go home the same day. It is, however, highly recommended that you do bring an overnight bag to hospital with you in case you do have to stay overnight for observations.

Are there any risks to the procedure?

As with any procedure, there are risks that need to be considered. Most problems are usually related to the following.

- The site of your cardiac device **may bruise and appear swollen**, this normally settles down but there is a chance that a collection of blood under your skin does not dissolve on its own; this is called a haematoma. This could be removed if needed to help with healing.
- There may be **slight bleeding** at your wound site. If it becomes a problem, please let the Pacing Clinic know and they can help you.
- There is a small risk of **infection** in your wound site. You may be offered antibiotics to reduce the risk of infection.
- One or more of the **leads may move and become displaced**, it will then become necessary to reposition it, but the doctor will explain this to you if needed at the time.

- Very rarely, **one of your lungs may be perforated**; this is called a pneumothorax. It will be identified by x-ray once your procedure has taken place. Most of the time nothing needs to be done as this may settle on its own accord or a small drain may be inserted to treat it.
- Very rarely, **a small leakage of blood around the heart may occur** called a cardiac tamponade, as a result of a small hole being made to the lining of your heart during your procedure. This often needs no treatment as it may settle on its own or it may need a small drain inserted to drain away the blood collection.
- There is a small chance that you may receive **inappropriate shocks from your defibrillator**. This means the device may deliver a shock when it was not necessary. It will not always be known whether or not it was an inappropriate / appropriate shock until your device has been checked. Always follow the instructions given later in this booklet on what to do when the device shocks (see **What should I do in the event of a shock?**).
- There may be other risks unique to your case. These will be discussed when you sign the consent with your doctor.
- There is a small risk that **you may not have an improvement in your symptoms** from the CRT-P function of the device.

Discharge Summary

(to be filled in on day of your procedure by the nursing staff)

Your procedure was:

Your device is: (manufacturer)

ICD / CRT-D device with (one, two, or three) leads in your heart and will be positioned on the *left / right side of your upper chest (*delete as appropriate)

Your procedure consultant was:

Your follow-up consultant is:

Your GP will be told of your procedure via the hospital's Electronic Discharge Notification (EDN) system.

Will I need a follow-up appointment?

The device is checked at the time of implantation, and then checked, typically a few hours later. Occasionally, we may ask you to come back the following day for this check.

You will be sent a follow-up appointment for a device check within four to six weeks of your procedure, where, if you consent, you may be offered a home monitor system in order for remote monitoring to take place.

If you do not receive this appointment through the post within four weeks of your procedure, please call the Pacing Clinic on one of the numbers below.

- Pacing Clinic, William Harvey Hospital, Ashford
Telephone: 01233 616193

- Pacing Clinic, Queen Elizabeth the Queen Mother (QEQM) Hospital, Margate
Telephone: 01843 234461

Further follow-up checks will depend on the type of device you have been given. You will be given information by the Pacing Clinic regarding your follow-up.

If for any reason you do not receive your appointment, please contact the Pacing Clinic using the numbers above.

What if I need help getting to my appointment?

If you are in need of transport to get to your follow-up appointments, please call the Patient Transport Service on 0800 096 0211. They will ask you a set of clear, confidential questions that will determine if you can use this service.

If for any reason you do not qualify, the patient transport service can also provide further advice on transport options.

More information on the Patient Transport Service is available through their web site. (<https://www.km-pts.co.uk>)

How does the remote monitoring system work?

Remote monitoring systems connect with your cardiac device securely through a wireless transmitter and receiver. This allows your healthcare team to receive regular updates to monitor your heart condition and your heart device, and access information from your cardiac device if needed.

This remote monitoring has many benefits - it may reduce the number of visits you make to your device clinics, help your healthcare team to detect abnormal rhythms, improve your quality of life with fewer disturbances, and may give you a sense of security.

This information will be used at your regular device clinic appointment in order to help with your management plan.

It is important to remember that it does not call anybody or dial 999 when you are feeling unwell or in emergencies.

What should I do when I get home?

After your procedure you should rest quietly all evening. You may eat and drink as normal but avoid alcohol as this may make you less aware of your actions, potentially causing accidental damage to your device. It could also cause potential arrhythmias.

The next morning you can have a wash, but it is very important to keep your wound completely dry for the first five days.

As you have been given sedation or local anaesthetic for your procedure, we advise that you should not drive, operate any heavy machinery, make important legal decisions, or sign any legal documents for the next 24 hours.

How will I feel after my procedure?

You will experience pain from this procedure. We strongly advise that you take regular painkillers (such as paracetamol) to help with this. We will not supply painkillers for you to take home, but we will provide you with painkillers if needed during your stay in hospital.

When can I remove my wound dressing?

Any dressing covering your wound should be left in place for five days. Any top dressing can be gently removed after five days by dampening it with water.

Do I need to have my stitches removed?

No. Your wound will be closed using either absorbable stitches or glue. Please follow the advice below depending on which method was used.

Absorbable stitches

- These are slowly dissolved by your body, so should **never normally be removed**.
- Your stitches need to be kept dry for the first five days, after which you can gently wash the area with water for a further five days. After this time you can wash as normal.
- Occasionally you may find that a small part of a stitch has not fully dissolved. If this happens contact the Pacing Clinic.

Glue

- Your wound needs to be kept dry for the first five days, after which you can gently wash the area with water, and the glue will start to dissolve or fall off.
- **Do not pick or try to remove the glue from your wound.**

Can I move around as normal once the device has been fitted?

To reduce the chance of the implanted lead(s) being moved out of position it is important that you **do not**:

- raise your arm on the side of the CRT-D or ICD device above shoulder level for the first two weeks
- use your arm to lift heavy weights (such as shopping bags or garden rubbish); or
- do any strenuous activity for the first six weeks.

Should I be aware of any potential problems to look out for?

It is rare for serious complications to occur after these procedures. The most common problem is bruising of the skin around your wound site. This may be uncomfortable for a few days; you can take your normal painkillers (for example paracetamol) to help with any pain.

If you experience any of the following problems please contact the Pacing Clinic, Monday to Friday, 8am to 6pm. If outside these hours please attend your nearest urgent treatment centre (formerly known as minor injury units), call your GP, or dial 111 if you are unable to get to the urgent treatment centre.

- Worsening pain around your wound site
- Swelling around your wound site
- Pus and / or oozing around your wound site
- Pain and / or swelling down your arm that is the same side of device.

If you receive medical treatment for any of the above out of hours please tell the Pacing Clinic the next working day between 8am and 6pm.

- Pacing Clinic, William Harvey Hospital, Ashford
Telephone: 01233 616193
- Pacing Clinic, Queen Elizabeth the Queen Mother (QEQM) Hospital, Margate
Telephone: 01843 234461

How can I help myself when I return home?

The following is a list of advice that you should stick to during the first few weeks after leaving the hospital. It is essential for your wound and device to heal and embed itself properly before starting your normal activities.

On the affected side

- Keep your upper arm close to your side as much as possible for 10 days.
- Do not raise this arm above shoulder level for two weeks.
- Do not lift with this arm for six weeks.
- Do not push up out of a chair with this arm for six weeks.
- Do not pull on the stair bannister with this arm for six weeks.
- Do not carry anything heavy with this arm for six weeks.
- Put this arm into your clothes first for six weeks.
- Keep your wound dry for five days.
- Check your wound morning and evening for any signs of infection / swelling / discharge.
- Do not wear tight clothing over your wound for seven to 10 days (for example no bras, vests, or braces).
- The dressing can be removed after five days.
- Build up the use of your arm gradually over the next month, but do nothing strenuous with it until you have had your first device check after six weeks.
- Take your prescribed course of antibiotics.

- It is advisable to sit behind the driver when in a car as this would avoid the seat belt coming in to contact with the device if it is on your left side and vice versa. If you cannot avoid the seat belt over the device then place a sponge over the device under the seat belt to protect it whilst healing is taking place and the device is settling in.
- If you use a walking stick, please use it with your unaffected arm for the first six weeks.
- If you are using crutches, please speak to a healthcare professional in the Pacing Clinic for advise regarding the use of crutches before you go home.

When can I start driving again?

Do not drive yourself home on the day of discharge, ask someone to take you home.

Driving restrictions vary depending on your medical history and the reason for your device.

Ask your nurse what restrictions you may face, according to the DVLA guidelines, as this varies depending on why you had the device fitted and what type of device you have.

Please check the DVLA website regarding up to date information, however, the following gives general guidelines.

- If you were given the device as a precautionary measure (prophylactic and not associated with incapacity) you may not drive for four weeks after your implant. You must tell your insurance company that you have had this procedure.
- After having an ICD or CRT-D implant for sustained ventricular arrhythmia associated with incapacity, you may not drive for six months. You must tell the DVLA and then reapply for your licence, unless you have decided to give up driving.
- After an ICD / CRT-D / CRT-P box change you may not drive for one week. You do not need to tell the DVLA or your insurer.

If you drive professionally, you will be unable to carry on with this after the implant.

If the DVLA suspend your driving licence following your implant of an ICD or CRT-D, you will need to reapply for your licence. The DVLA will provide the relevant paperwork upon your request and will let you know when you can return to driving.

The DVLA contact number for medical issues is 0300 790 6806 or you can access the DVLA website (<https://www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency>).

What should I do in the event of a shock?

If you receive a shock from your device or have symptomatic anti-tachycardia pacing (that will feel like palpitations/flutter), do not drive. If you feel unwell, suffer with any symptoms such as palpitations (where you feel like your heart is beating too fast or fluttering), or receive a second shock or more, please call 999 immediately and go to your nearest Emergency Department.

Let the Pacing Clinic know about any shocks you get from your device, even if it was just one shock, as your ICD or CRT-D will need to be checked. Please do not drive again until you have spoken with the Pacing Clinic and DVLA, if required.

- Pacing Clinic, William Harvey Hospital, Ashford
Telephone: 01233 616193
- Pacing Clinic, Queen Elizabeth the Queen Mother (QEQM) Hospital, Margate
Telephone: 01843 234461

When do I start taking my usual medication again?

Before your procedure, please refer to your current list of medications for instructions on how and when to stop and restart your medication if you are on any of the following:

- NOAC (Apixaban, Dabigatran, Rivaroxaban, Endoxaban)

Date to restart:

- Antiplatelets (Aspirin, Clopidogrel, Ticagrelor)

Date to restart:

- Warfarin

Date to restart:

Why have I been sent a device identity (ID) passport?

The device identity passport is useful to have at your regular checks to make sure the correct information is given in an emergency.

Before your first device check you should receive your identity passport through the post.

The identity passport has all the information about your device, including its make, model, and serial number plus information regarding the leads and device settings.

It is important that you keep a copy of your passport on you at all times.

It is advised that you take a photocopy of the passport and store the original safely at home.

When you go for your device checks or are travelling abroad please take the original ID passport with you.

Important information to remember regarding your device

- **Mobile phones** should be used on the opposite side to your device. Do not store your mobile phone in a shirt top pocket on the same side as your device.
- No **magnets** should be passed over the area of your device. If using small magnets, these should be kept at arms' length.
- No **MRI's** unless your device is compatible; this could be confirmed by your Pacing Clinic. If it is compatible, you must not have an MRI for six weeks after implant. You will need to be seen in your Pacing Clinic before having the scan.

- The **security barriers at the entrance to shops** should be treated with caution. You should walk briskly through these and not linger in between them as there is a small chance of interference of your device.
- When **going abroad**, you must not go through the security scanner at the security desks. You must show them your device passport and they will advise you on where to go. They will use a wand to pass over your body but you must ask for it to not go over the ICD / CRT-D area.
- Avoid **induction cookers** as these use magnets.
- **Magnetic fields** may interfere with the device so please be cautious of this.
- **Try to avoid knocking the site of the device**, as this may dislodge the device itself or the leads.

What happens if I decide to deactivate my device?

Deactivation simply means the shock function of your ICD is turned off (deactivated). It may be important to consider this if you develop a terminal illness, become very frail, or decide you no longer wish to receive shocks from your ICD. This does not mean that all other treatment plans will end.

This could be discussed with your specialist nurse, cardiac physiologist, cardiologist, or GP.

It is important that you and your family or close friends have the opportunity to discuss this so everyone understands what is involved and you can make your own personal wishes clear. This decision is usually made by you, supported by your healthcare team or family members or close friends.

Please remember that deactivation of the ICD is reversible, that means the ICD shock function can be turned back on (reactivated) if you change your mind or your condition improves.

Sometimes a decision to deactivate an ICD has to be made in a matter of urgency by the doctor responsible for your care. This will usually be necessary if you suddenly become very ill and are unable to make choices about treatment yourself. Any such decision will be made in your best interest 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.

Deactivation of an ICD is:

- completely painless
- will make no difference to how you feel, other than making sure you do not receive shocks that may be painful; and
- 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 shock.

Contact information

If you have any concerns or questions about your procedure, please contact the Pacing Clinic at your relevant hospital.

- Pacing Clinic, William Harvey Hospital, Ashford
Telephone: 01233 616193
- Pacing Clinic, Queen Elizabeth the Queen Mother (QEQM) Hospital, Margate
Telephone: 01843 234461

If you have an urgent query which is out of office hours, please contact your local **cardiology ward** and they will do their best to help you, or dial 111. Please remember if it is an emergency then dial 999.

- Cardiology Ward, William Harvey Hospital, Ashford
Telephone: 01233 616869
- Cardiology Ward, QEQM, Margate
Telephone: 01843 234579

Further information

This booklet is designed to give you as much information as possible about this type of procedure, what to expect afterwards, and how to look after your wound and device.

Further information is available from other sources regarding this topic. Please have a look at the following websites for further information.

- Pumping Marvellous (<https://pumpingmarvellous.org/heart-failure-guide/crt-devices/>) is a charity that has lots of good information and videos online (please note, the videos do not have any sound). Please visit the website below that will take you directly to their page on devices.
- Arrhythmia Alliance (<https://heartrhythmalliance.org/aa/uk/>) is another website that has good information on devices. Please visit the following website and click on the 'for patients' tab and then click on 'treatments' where you will find information on ICD.

This booklet has been produced with grateful acknowledgment to the patient information available from Pumping Marvellous and Arrhythmia Alliance.

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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