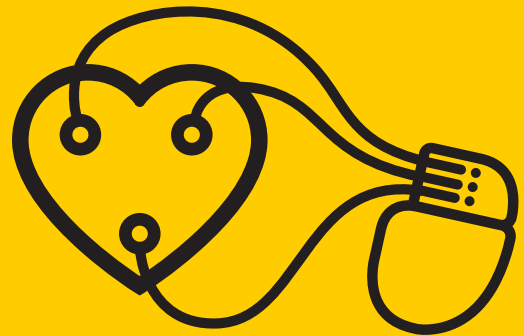


# **A Marvellous Guide to Having a Cardiac Device Fitted**

*A Patient's Story...*



# WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



A number of heart failure patients now live with complex cardiac devices. This Marvellous Guide has been created by the Pumping Marvellous Foundation (PMF) and Patient Educators who all live with a cardiac device. The aim of the guide is to give you the information that we HOPE will be helpful when you are about to have your cardiac device fitted. There is technical information here in 'patient speak' and discussion around the various emotions that you may be experiencing at this time.

We feel this is one of our more technical toolkits, but the Patient Educators feel we have explained it sufficiently in their language so that you will understand it. If you require help then please do not hesitate to call us on **01772 796542** or email [hearts@pumpingmarvellous.org](mailto:hearts@pumpingmarvellous.org).

If you are on social media we also have two Facebook groups [www.facebook.com/heartfailureaware](https://www.facebook.com/heartfailureaware) and [www.facebook.com/groups/helpforhearts](https://www.facebook.com/groups/helpforhearts).

A big thank you goes to our Patient Educators who formed the PMF device team and the patients who have reviewed the successive versions. The team came together to share their stories, experiences and knowledge, and guided the production of this Marvellous Guide. A thank you also to Clare from Boston Scientific who provided technical support. We would also like to thank Boston Scientific for continuing to fund this very useful and widely used guide in the NHS.

**Nick Hartshorne-Evans**  
Founder and CEO of the Pumping Marvellous Foundation

**Angela Graves**  
Chair and Consultant Nurse in Heart Failure

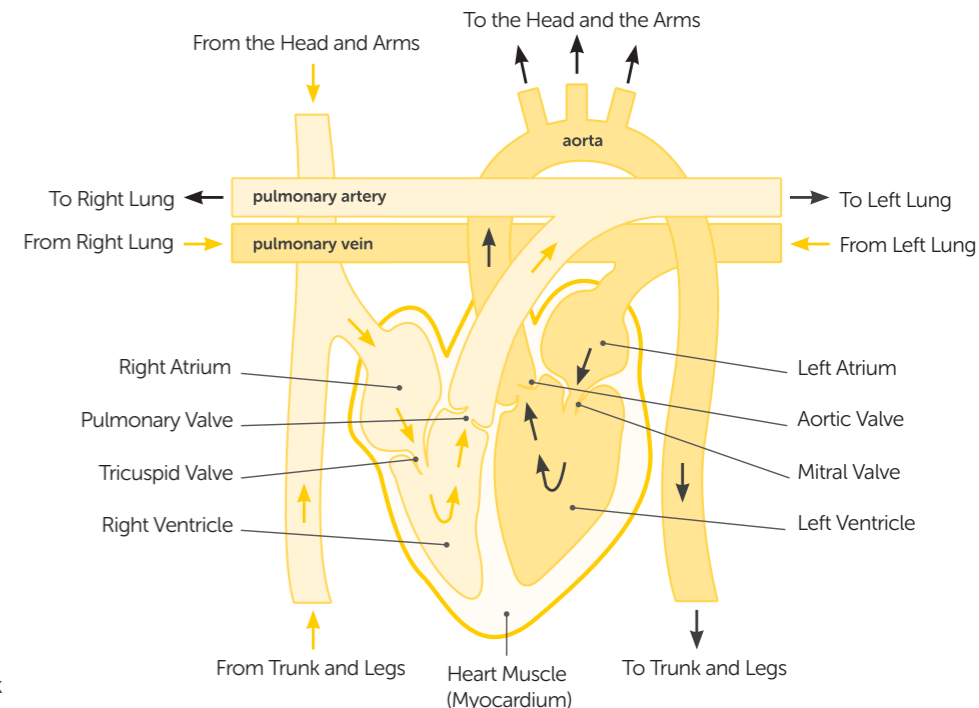
The development and reprint of this booklet has been supported by hands off educational grant from Boston Scientific.

**PLEASE NOTE:** This guide should not replace or substitute the interactions you receive from your Healthcare Professionals. If you have any concerns regarding your condition, you should discuss these with your Healthcare Professional at the earliest opportunity.

## What are they and how do they work?

Cardiac devices are very clever, almost as clever as your body! To understand how a cardiac device works, it's necessary to understand how the heart works.

The heart is a pump that ensures that blood containing oxygen and nutrients is delivered to all parts of the body. When the heart is unable to do this efficiently, we call it heart failure. The heart is made up of four chambers (see diagram) the right and left atrium and the right and left ventricle. The diagram explains how the blood that delivers oxygen to the rest of the body returns to the heart and is sent to the lungs to pick up more oxygen. It then returns to the heart and is pumped out of the left ventricle (LV), which has the most work to do of all the chambers. Blood is then sent around the body. In heart failure, we particularly relate to how efficiently the LV is working. You may have heard this referred to as the ejection fraction (EF), thus you will see it written as LVEF. We expect a normal LVEF of approximately 60% to 65%. In heart failure this is usually below 45%. However, it is often not how low your LVEF is that tells us how effectively your heart is working, but how you are feeling. This we assess via the New York Heart Association Scale (on the next page).



# The New York Heart Association Scale

You can assess how you are feeling with your heart failure by looking at the table below.

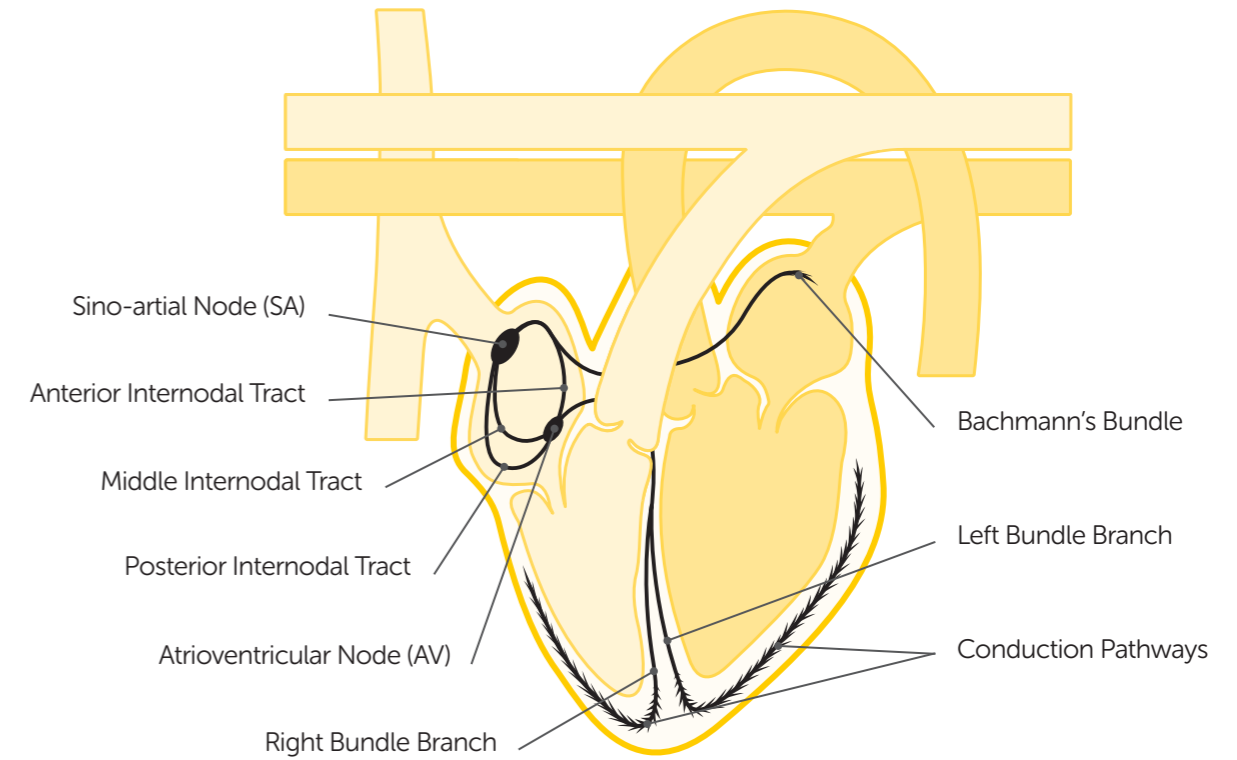
NYHA Class	Symptoms
NYHA Class I	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations or shortness of breath.
NYHA Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations or shortness of breath.
NYHA Class III	Comfortable at rest, but less than ordinary activity causes tiredness, palpitations or shortness of breath.
NYHA Class IV	Unable to carry out any physical activity without discomfort and tired and short of breath even at rest. If any physical activity is undertaken, discomfort is increased.

Your heart needs to be told when to pump. This is what we call a beat. The heart has its own electrical system in order for the heart to beat. The electrical system of the heart starts at the top in the right atrium, this is called the sino-atrial node or SA. This sends a signal down from the top two chambers, which causes those chambers to contract and pump blood. The signal then travels down to the bottom chambers, the ventricles, via the atrio-ventricular node or AV, and makes them contract to pump blood. As the chambers empty, the heart will relax and fill up with blood in order for the action to reoccur. Normally this happens between 60 to 80 times a minute - this is our heart rate. The heart does this more frequently if required, such as when we exercise and require more oxygen.

If an abnormality of the heart's electrical system takes place we call this an arrhythmia. This is when devices are employed in order to correct any problems. This may be because signals are not getting through and the heart does not beat enough (heart block), or there is misfiring taking place as in Atrial Fibrillation. The cardiac device will ensure a signal is delivered so the heart continues to work efficiently, called pacing.

In heart failure, the bottom chambers of the heart, the ventricles, may not be receiving a sufficient signal which means that instead of contracting together they are out of synchrony. A cardiac device is fitted to correct this, which is called either a biventricular (bi meaning two) device or resynchronisation therapy, abbreviated to CRT-P (cardiac resynchronisation therapy pacemaker). It makes sense to think that if the ventricles are not contracting efficiently, they will not help your heart to function properly.

Occasionally we have problems with the electrical system of the heart, which means that the electrical system is so poor it will lead to the heart misfiring and stopping (asystole) or entering a really fast, abnormal rhythm (ventricular fibrillation). This can be due to an inherited problem, a heart attack, or heart failure, and can be treated with a cardiac device called an Implantable Cardiac Defibrillator (ICD). This type of cardiac device will either pace or send a shock to the heart to ensure that the heart returns to beating effectively. On occasions we are able to combine a CRT-P device and an ICD, this then is called a CRT-D. A lead is placed into your right atrium, right ventricle, and a third lead wraps around your left ventricle.

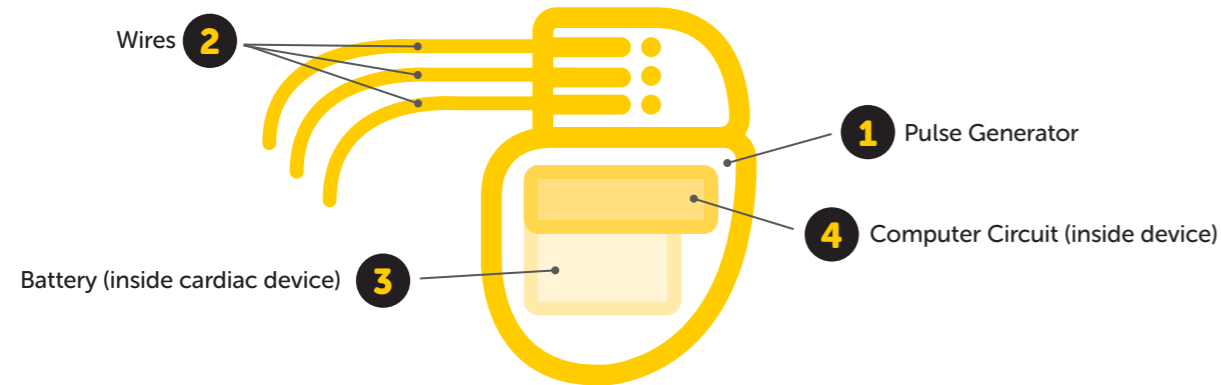


# Cardiac Devices/Pacemakers

Cardiac devices have become a lot more sophisticated and malfunctioning issues have reduced considerably over the last number of years. We suggest that you ask to see what a cardiac device looks like, so that you have a visual image of what is to be inserted into your body. Patients say that this really helps and some even give their cardiac device a name. They are the size of a matchbox and weigh approximately 20 to 25 grams.

A cardiac device contains four elements:

- 1 A pulse generator.
- 2 The wires which will run from the cardiac device into your heart.
- 3 A battery which will last anywhere up to 6 to 10 years, depending how much your cardiac device has to do. Your battery life will be assessed on a regular basis so that your Clinician knows when you may require another one.
- 4 A minute computer circuit which converts energy produced by the battery, travels down the wires and thus stimulates your heart to beat.



# Why do I need one?

Your Cardiologist will have conducted a number of tests in order to assess if a cardiac device will be of any help to you. These will have included an Echocardiogram or ECHO, a scan of your heart, various ECGs, tracings of your heart and possibly a cardiac monitoring device which you may have been wearing for one, two, or even a number of days. Clinical guidance has been published by the National Institute of Health and Clinical Excellence (NICE) [2014] regarding the most appropriate patients who would benefit from a cardiac device based on clinical research. The guidance is based on what NYHA status the patient is, their previous experiences of having cardiac arrhythmia problems, or their risk of problems, or if their heart is out of synchrony which is identified on an ECG reading.

QRS Interval	NYHA Class			
	I	II	III	IV
<120 milliseconds	ICD if there is a high risk of sudden cardiac death			ICD and CRT not clinically indicated
120–149 milliseconds without LBBB	ICD	ICD	ICD	CRT-P
120–149 milliseconds with LBBB	ICD	CRT-D	CRT-P or CRT-D	CRT-P
>150 milliseconds with or without LBBB	CRT-D	CRT-D	CRT-P or CRT-D	CRT-P

LBBB, left bundle branch block; NYHA, New York Heart Association

# Patients' Experiences

## For the patient

You are no doubt experiencing a wide range of emotions at present and these differ from person to person. Some patients express how they are pleased and positive that there is a treatment which they HOPE will relieve their symptoms of heart failure. For others, they express feelings of shock, being emotional, frightened, concerned and apprehensive. Many speak of the speed of what is suddenly being proposed and are desperate for information to understand what is going to happen. Sometimes patients are attending a routine appointment when cardiac device treatment is recommended and it is not always possible for them to have time to reflect on what is being proposed. Ask to actually see a dummy cardiac device so that you understand what they are going to insert. Remember that this therapy is being recommended by your Cardiologist because they feel that it will help you, so ask them exactly why they feel this is the best option for you and what are its implications. Ensure that you are given contact details, so that when you go home and if you think of any concerns, you are able to contact your Cardiologist and further discuss the procedure with them.

# Benefits of having a Cardiac Device

Our Patient Educators tell of the HOPE that many of them experienced when they had their cardiac device fitted. The cardiac device is there to improve your symptoms and/or prevent a life-threatening arrhythmia. You may experience an improvement in your symptoms of heart failure if you have had a CRT device fitted almost immediately, however, some patients say it may be a gradual improvement which can take a number of weeks. Symptoms relating to severe palpitations and dizziness may be improved quite quickly after insertion of your cardiac device.

For some patients, particularly women who are of a slender build, their cardiac device may appear quite prominently in their chest. Some find this disconcerting and this may affect their self-esteem while others see this as their 'badge of honour'. Initial swelling does settle and many talk of the benefits of the cardiac device outweighing any body image issues they may experience.

## For the carer

A carer of someone with heart failure may be very different things to different people. It could be a close member of the family, a friend, neighbour or a professional carer. Whoever that significant other is in your life, we suggest that you show them this guide so that they have an understanding of the proposed cardiac device, what it entails, the effect that it may have on you and some of the emotions that you may currently be feeling.

Some carers have expressed how they HOPE that the procedure will bring relief of symptoms or if an ICD will potentially save the patient's life; they find this both hopeful and reassuring. Discuss your emotions, hopes and concerns with your carer, and if they have any questions ensure that you discuss them with your Clinician.

# Pre-assessment Check

You are generally called for a pre-assessment before the actual insertion of your cardiac device. This occurs approximately two weeks before the procedure. This appointment is often conducted by a Nurse who will take a number of routine blood samples, ensure that none of your medication will need to be adjusted for the procedure (e.g. Warfarin, Clopidogrel) and ensure that you have a good understanding of what the procedure entails. You will then be asked to sign a consent form. This is also a very good opportunity to ask any outstanding questions or discuss any concerns that you may have. Some hospitals may wish you to have nothing to eat or drink for 4 hours before the procedure due to the sedation you will receive.

## Risks of the procedure

As with any procedure there are risks to be considered and your Cardiologist or Nurse should explain these in detail, however, most problems are usually related to the following:

- The site of your cardiac device may bruise and appear swollen. This usually settles, however, your cardiac device may appear prominent.
- There may be slight bleeding at the site.
- There is a small risk of infection at the site.
- One of the leads may move or become displaced, it will then become necessary to reposition this.
- Very rarely one of the lungs may be perforated. This is called a pneumothorax (identified by an X-ray when the procedure has taken place). This may settle of its own accord or require a small drain to be inserted.
- The procedure may lead to a very rare complication called a cardiac tamponade, whereby one of the arteries surrounding the muscle of your heart (coronary artery) is accidentally punctured. This rare occurrence would lead to major complications in the procedure.

See our section on our website under "Heart Failure Guide/CRT Devices" for information in regard to specific issues relating to these cardiac devices.



# What happens on the day?

On the day itself, you will be admitted to the unit where the procedure is to take place. Generally complex cardiac devices will require an overnight stay in hospital. The procedure usually takes place in a mini theatre, often referred to as the CATH lab. Don't let this worry you, it ensures that the procedure is undertaken in a very clean environment to prevent infection and it will no doubt have a number of X-ray screens and monitors. You will be given a theatre gown too and during the procedure you are likely to be covered with sterile towels. Male patients may be asked to shave their chest prior to the procedure and ladies asked to remove any nail varnish.

You will find a number of people in the room who all have a vital role to play. You may wish to introduce yourself and ask who they are and what their role is. A general anaesthetic is not required, but you will be offered a sedation and a local anaesthetic. This will ensure that you feel no pain and are relaxed. You will be monitored closely, a monitor will measure your heart rate, you will have a cuff on your arm to measure your blood pressure and you may be given oxygen via a face mask. A needle will be placed into a vein in your arm and will stay there so that the sedation and pain relief can be delivered through the vein and topped up if required. You can expect the procedure to take a number of hours, particularly if you are having a CRT device fitted. Getting the third lead into place can take longer than planned and you may feel a little pulling and tugging, which is normal. You may be asked to take some deep breaths. Some Clinicians like to have music playing in the background, so don't let that surprise you. Do tell the team if you are in any discomfort or if you have any questions as your procedure is taking place.

You may be given a course of antibiotics before and after the procedure has taken place as a precaution against infection.



# How is the Cardiac Device fitted?

**You may wish to visit the Pumping Marvellous website to watch a video on a cardiac device being inserted.**

Having had your sedation you will feel relaxed and even sleepy. You will feel a cold solution (which is an antiseptic) placed on the area where the procedure is to take place, this is in order to clean the skin. A small injection is then administered to the site area (which is a local anaesthetic), this will numb the area. Using X-ray guidance, the Cardiologist will make a very small incision into one of the blood vessels below the collarbone on the left side of your chest in order to feed the wires into the heart. For a CRT device, a lead will be placed in the top chamber of your heart (the atrium), another lead in the bottom chamber (right ventricle) and the third lead goes into a vein and wraps around the left ventricle. Occasionally this can take a little time. The leads are connected to the cardiac device which is then placed in the pocket. The leads and cardiac device are then tested and the wound is stitched up. If you have an undissolved stitch called a suture, this will need to be removed a week after the procedure. Once your Cardiologist is happy with the working of your cardiac device, you are generally taken to a ward to rest. Your heart rhythm will continue to be monitored for a number of hours and then you will be allowed to sit up, eat, drink and walk around. You will be given painkillers for any discomfort you may have. If you do experience any discomfort make sure that you tell the ward staff.

If you have had an overnight stay you should be able to go home, dependent on your cardiac device being rechecked. This will involve an ECG of your heart. A Specialist Cardiac Physiologist or Specialist Nurse will perform this and will adjust any settings on the cardiac device that are required. Whenever you have your cardiac device settings altered in order to optimise its capacity, you may find that this may result in you feeling uncomfortable for a few seconds. You will also have a chest X-ray in order to ensure the leads are in the correct position. Do ask any questions or raise any concerns you may have with the specialist team.

Scan me!



For more information, go to:  
[www.pumpingmarvellous.org/heart-failure-guide/crt-devices/](http://www.pumpingmarvellous.org/heart-failure-guide/crt-devices/)

# Follow-up Arrangements

You should ensure that the site of your cardiac device is kept clean and dry until the site has healed which is usually six weeks. Avoid having a shower for three or four days after your procedure and ask for a waterproof dressing. Ensure that you are aware of the follow-up arrangements should you have any concerns regarding your cardiac device site, particularly any redness, heat, pain or oozing. You can expect the site to be swollen, which should settle with time. If, however, the swelling does not settle or it becomes sore, then contact the number you have been given in case of any problems. Expect to feel the cardiac device under your skin and even the wires, this is normal.

You will be given a further appointment to see your Cardiologist, this is usually in approximately two weeks' time, so you can have your cardiac device retested.

You will be given a card with all the details of your cardiac device on it. Ask the staff on the ward to explain to you exactly what your card says. You should carry this with you at all times.

You may also have a home monitor that works via your telephone line or cellular network, which downloads recordings of your cardiac device, and can then be assessed by cardiac device technicians. A full explanation will be given by your cardiac team.

At any time in the future the battery of your cardiac device will need to be changed - this will only involve changing the unit and not the leads.

Any additional information relating to your device and its manufacturer can be obtained from their website. The makers of your specific device can be found on the documentation you should receive post procedure. If you have not received that then ask your team.

# Dos and Don'ts

You will be given some general advice about living with your cardiac device, however, here is some information that you may find helpful at this stage:

- **Arm Movements** - until you have had your first follow-up appointment you should be careful not to raise your arm above shoulder level and avoid any contact sports. This will ensure that the healing process can take place and that the leads will be embedded which will prevent any movement of them.
- **Physical Activity** - please discuss this with your Healthcare Professional first. Physical activity can be undertaken usually after a period of three or four weeks, however, avoid contact sports. It is better to gradually build up your exercise regime. Ask if there is a cardiac rehabilitation programme that you can be referred to.
- **Mobile Phones/Cordless Phones** - there is some evidence to suggest that a mobile phone may interfere with your cardiac device. It is suggested that you do not keep your phone in a garment pocket that would cover your cardiac device. It is also recommended that you hold your mobile six inches away from your cardiac device, preferably using it in the hand opposite to your cardiac device.
- **Sexual Activity** - care should be taken for a period of six weeks so that excessive strain is not placed on the cardiac device site. If you have an ICD fitted then no harm can be caused to your partner if the cardiac device delivers a shock.
- **Medical Cardiac Devices** - always inform your Healthcare Professional of your cardiac device card, which will indicate the type of cardiac device you have and if medical equipment, such as MRI scans which have magnetic fields, would interfere with your cardiac device. If you require surgery then an ICD will be turned off by alteration of the settings whilst surgery takes place.
- **Magnets** - avoid placing any form of magnet over your cardiac device as this will interfere with your cardiac device. In an emergency a medical team may need to switch off an ICD. They may do this by holding a magnet over your cardiac device.
- **Medication** - your Cardiology team will no doubt review your medication and you may find that some things will be stopped, added or current medication increased.
- **Security Systems** - you will need to inform airport security that you have a cardiac device as again they employ a magnetic field.
- **Cardiac Device Shock** - should you experience a shock from your cardiac device (activation of your ICD) then do contact your cardiac device centre. If it is at a time of day when the unit will be closed then attend A&E in order to receive a check-up and receive reassurance and an explanation as to what has happened.

# Cardiac Devices and the DVLA

We believe this section is relevant to you understanding the impact of having a cardiac device, concerning the restrictions that may be applicable as designated by the DVLA. Do discuss with your health team before you have your procedure any concerns or confusion around this issue.

You must inform the Driver and Vehicle Licensing Agency (DVLA) that you have had a cardiac device fitted. You can visit their website on:

[www.gov.uk/guidance/cardiovascular-disorders-assessing-fitness-to-drive#cardiac-resynchronisation-therapy-crt](https://www.gov.uk/guidance/cardiovascular-disorders-assessing-fitness-to-drive#cardiac-resynchronisation-therapy-crt)



## For an ordinary driving licence and non-ICD pacemaker

You will be able to drive a week after fitting your cardiac device, as long as:

- You have no symptoms such as dizziness or fainting which may affect driving.
- You attend regular check-ups in the pacemaker clinic.
- You have not recently had a heart attack or heart surgery.

## For a large goods vehicle (LGV) or passenger-carrying vehicle (PCV) licence

- You cannot drive these vehicles for six weeks after the cardiac device is fitted.
- You can apply for another licence when you no longer have any symptoms that would affect driving - e.g. dizziness or fainting.
- A current licence is replaced with a three-year licence and you will have to go to a pacemaker clinic regularly.



# Driving and ICDs

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

## Associated with incapacity

- You cannot drive until six months after the procedure.
- You cannot drive for a further six months after any shock therapy and/or symptomatic anti-tachycardia pacing.
- You cannot drive for a period of two years, if after cardiac device implantation incapacity results. This could be from the cardiac device or an arrhythmia, unless:
  - It is proven to be an inappropriate shock (e.g. atrial fibrillation); or
  - The shock was appropriate but measures to prevent it have been undertaken (then you can drive after six months).
- You cannot drive for one month after any alteration of the leads or change to anti-arrhythmics.
- You cannot drive for one week following a change of the ICD box.

## Not associated with incapacity

- You cannot drive after one month if stable, non-sustained VT provided LVEF is less than 35%, no inducible fast VT and any induced VT is terminated (needs to be shown twice).
- If, subsequently, the ICD provides a shock then the driving rules revert to the same as those 'associated with incapacity'.
- For ICDs inserted as a precaution, you cannot drive for one month after implantation - if, however, they subsequently receive a shock then they too fall under the 'associated with incapacity' rules.

Group 2 drivers (e.g. lorry or bus drivers) - there are no subdivisions that apply and they are permanently barred.



# Top tips from patients

Here are some top tips from the Pumping Marvellous Patient Educators on having had a cardiac device fitted:

- Make sure you sleep on the opposite side from your cardiac device to avoid discomfort.
- On the day, it's not as frightening as you think.
- If it's a cold day wear an extra T-shirt or sweater as you feel the cold more on the site of your cardiac device.
- Remember to rest and listen to your body.
- Front fastening pyjamas and front fastening bras help when you have had your cardiac device fitted.
- Take your nail varnish off when you go to have your cardiac device fitted.
- When having your cardiac device fitted don't be afraid to ask your Healthcare Professional any questions.
- It can take time to have your cardiac device fitted, so don't panic as it can be fiddly.
- When driving use a baby sponge under your seat belt over the site of the cardiac device.
- Your cardiac device site takes some time to settle down, so don't panic.



# Concerns on activation of an ICD

Having an ICD fitted is a major decision that you may wish to discuss with your Doctor, Nurse and family. Its capacity to prevent you experiencing a life-threatening event cannot be underestimated, however, it can impact on your lifestyle. It may have a direct bearing on the work you undertake, you will not be able to drive certain vehicles or be an arc welder as the magnetic field will interfere with your cardiac device. Some patients are concerned at first of the possibility of their cardiac device giving them a shock (activated). Patients feel this settles as your confidence grows in living with a cardiac device. One patient put it as "better my cardiac device goes off than dying".

Patients ask what will it feel like to receive a shock from their cardiac device. Our Patient Educators described it as receiving a blow to their stomach which passes quickly. It is natural to feel very emotional afterwards. This may impact you psychologically as you may wonder if this is likely to occur again. Remember the cardiac device has done its job, discuss your feelings with your Healthcare Professional or give us a call on **01772 796542**.

One aspect that is not often discussed is what happens should you reach the end of your life, something that will happen to all of us. Having an ICD in does not mean that you will never die, it may prevent you from dying of a life-threatening arrhythmia. Some patients may reach a point whereby their heart failure has resulted in their heart now being too weak to continue or a patient may develop a terminal condition. As a consequence they may wish to die without their cardiac device being activated. For such patients a discussion can be had with their Consultant, GP or Nurse into having the shock aspect of their ICD turned off (deactivated). This can be performed quite easily by the settings being changed by the cardiac device specialist team.

# Remote Monitoring

Some cardiac devices may have remote monitoring systems. Remote monitoring systems connect with your cardiac device securely through a wireless transmitter and receiver. The cardiac device then transmits regular updates securely to a monitoring system that your healthcare team can access.

## What it does

It helps your healthcare team to:

- Manage your heart condition.
- Monitor your heart device.
- Access information from your cardiac device.

## Why is this important for patients and their families?

- It may reduce the number of visits you make to the device clinic.
- It helps your healthcare team detect abnormal heart rhythms.
- This means a better quality of life and less disruption for you.
- It may help you have a sense of security and safety around your device.

## What you need to know

- The remote monitoring system can come in all different shapes and sizes depending on who the manufacturer is and generally sits at the side of your bed, or is a wand style device that looks like a computer mouse. Downloads may take place at night when you are asleep. You won't know this is happening.
- The remote monitoring system does not change anything with your cardiac device.

- What it does do is report to your healthcare team how your heart is working with your cardiac device.
- It transmits data that helps your healthcare team understand your condition.
- It doesn't call anybody or 999. All it does is transmit important data that helps your healthcare team make the best decisions for you.
- The information transmitted from your device will be used at your regular device clinic appointments, so your healthcare team can make the best decisions for you.
- Depending on your device, the data will be sent to your healthcare team automatically or prompt you to send information at a scheduled time to your healthcare team.

## Simply

**Scheduled** – Download of information is scheduled.

**Send** – Your device sends information securely to your remote monitor.

**Transmit** – Your remote monitor sends information to a secure website.

**Healthcare team** – Your team review the information.

For more detailed information you will get an information pack from the manufacturer of your device.

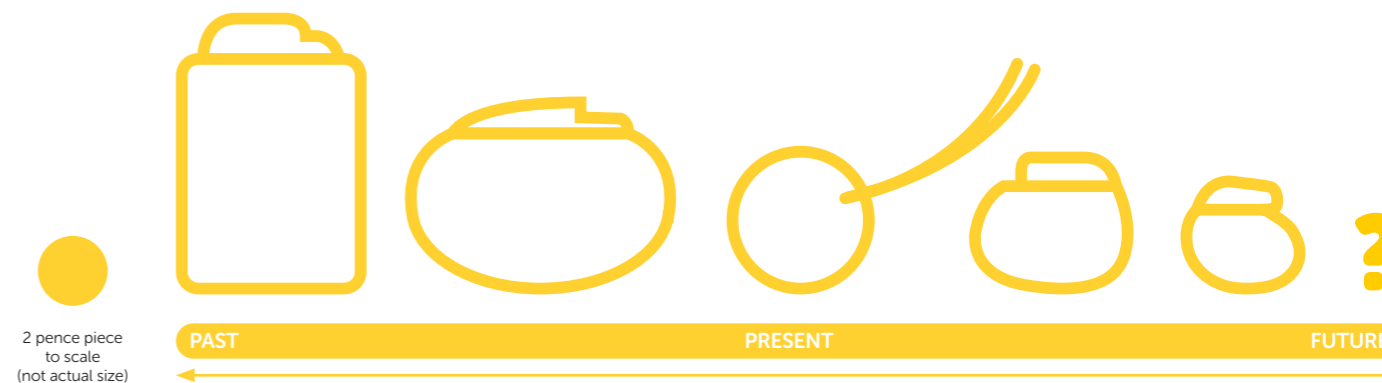
# What does the future hold?

By the time we have written and printed this "Marvellous Guide to a Cardiac Device" the technology surrounding cardiac devices will have moved on. So how do we see what's in the future?

Devices are getting smaller, battery life is lasting longer and overall devices are much smarter. It has been known for some time that cardiac devices can do much more than the initial role they were intended for. Some devices are now able to monitor deterioration of your condition long before you may experience symptoms. This means that Clinicians can monitor remotely and notify you to alter your medication or give advice, avoiding you experiencing distressing symptoms and possibly avoiding a hospital admission. Expect your marvellous device to play a much more significant role in the management of your heart failure.

## Examples of this could be your device being able to

- Detect higher pressures in your lungs which is a very early indication of you heading to worsening symptoms long before you are aware of this.
- Detect fluid beginning to build up in your lungs, again, before you are aware of this taking place.



# One step at a time

We hope that our Marvellous Pocket Guide has triggered thoughts around some of the questions you may have. We know this is not a position you want to be in but it's about taking small steps which is a good thing. You may never have had to deal with something like this but if you want to then self-management can be the key to a better life and enable you to find your normal again. This maybe the start of your journey so if you need help do seek out further advice from your Healthcare Professional or visit our website:

[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)

# The Wonders of Social Media

At Pumping Marvellous we know how important it is for patients to get support from other people who have heart failure, to share experiences, knowledge, feelings and emotions, the negatives and positives of heart failure, and yes there are positives. People find successes in heart failure as they learn to manage the challenges of heart failure. Pumping Marvellous has looked at using new and exciting ways of providing patient to patient support. Why don't you give some of them a try! Search "help for hearts" on Facebook, or visit PMTVLive on YouTube as well as the Pumping Marvellous website. In everything we do you will find rich veins of support to help you manage your heart failure better.

**Good luck, good health and keep those positive pants on!**



01772 796542

Twitter - @pumpinghearts

Web - [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)

Facebook - Search "Heart Failure Aware"

Email - [hearts@pumpingmarvellous.org](mailto:hearts@pumpingmarvellous.org)

Facebook Support Group - Search "Help for Hearts"

YouTube - Search "Pumping Marvellous"

Instagram - Search "Pumping Marvellous"

# Useful Contacts - Patient Organisations and Related Services

[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)

The UK patient led heart failure charity, the go-to-site for both patients with heart failure and carers looking after them.

[www.cardiomyopathy.org](http://www.cardiomyopathy.org)

Website to support patients with heart muscle disease.

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Website with a range of information and services for the older person.

[www.carersuk.org](http://www.carersuk.org)

Website of organisation for carers.

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Organisation website that supports not just those with cancer but for those requiring palliative care services.

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Information on a wide range of issues and details of local branches for appointments.

[www.gov.uk/apply-blue-badge](http://www.gov.uk/apply-blue-badge)

Details as to how to apply for a blue badge, enabling free parking.

[www.relate.org.uk](http://www.relate.org.uk)

Organisation that provides information and counselling services for couples.

[www.nhs.uk/Pages/HomePage.aspx](http://www.nhs.uk/Pages/HomePage.aspx)

Link to various NHS services.

[www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11](http://www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11)

Information for carers.

[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

Information in regards to current information benefits.

[www.acas.org.uk](http://www.acas.org.uk)

Information for both employers and employees for training and mediation.

[www.gov.uk/pensions-advisory-service](http://www.gov.uk/pensions-advisory-service)

Pension advice, both state and private.

[www.gov.uk/contact-jobcentre-plus](http://www.gov.uk/contact-jobcentre-plus)

Employment advice and opportunities.

[www.samaritans.org](http://www.samaritans.org)

Agency providing immediate support and crisis management.

[www.moneyadviceservice.org.uk/en](http://www.moneyadviceservice.org.uk/en)

This is an independent body set up by the government to provide information and support on a range of financial matters.

[www.gov.uk/current-medical-guidelines-dvla-guidance-for-professionals-conditions-g-to-i#advice-for-the-general-public](http://www.gov.uk/current-medical-guidelines-dvla-guidance-for-professionals-conditions-g-to-i#advice-for-the-general-public)

Driving information from the DVLA.

## Useful Contacts - Medical Organisations and Further Information:

[www.bhf.org.uk](http://www.bhf.org.uk)

Website to support those with a range of conditions in relation to heart disease.

[www.bsh.org.uk](http://www.bsh.org.uk)

The Clinicians' organisation for those who specialise in heart failure.

[www.nice.org.uk](http://www.nice.org.uk)

NICE (National Institute for Health and Care Excellence)  
NICE's role is to improve outcomes for people using the NHS and other public services. They do this by:

1. Producing evidence based guidance and advice for health and public health and social care practitioners
2. Developing quality standards for health, public health and social services
3. Providing a range of informational services across the spectrum of health and public health services

NICE Chronic Heart Failure Guidelines -  
[www.nice.org.uk/guidance/ng106](http://www.nice.org.uk/guidance/ng106)

NICE Acute Heart Failure Guidelines -  
[www.nice.org.uk/guidance/cg187](http://www.nice.org.uk/guidance/cg187)

[www.heartfailurematters.org](http://www.heartfailurematters.org)

European Society of Cardiology website, Clinician organisation but does have patient information.

[www.drinkaware.co.uk](http://www.drinkaware.co.uk)

Information on alcohol intake.

[www.alcoholics-anonymous.org.uk](http://www.alcoholics-anonymous.org.uk)

Support organisation for alcohol-related issues.

[www.nhs.uk/livewell/drugs/pages/drugtreatment.aspx](http://www.nhs.uk/livewell/drugs/pages/drugtreatment.aspx)

Support organisation for drug-related issues.

[www.mind.org.uk](http://www.mind.org.uk)

Mental health charity.

[www.england.nhs.uk](http://www.england.nhs.uk)

Health commissioning organisation for the NHS.

[www.cqc.org.uk](http://www.cqc.org.uk)

Regulatory body for the NHS.

## Useful Contacts - Other Charities and Nonprofit Groups

Here at Pumping Marvellous we are enthusiastic about working with other charities who, like us, are aiming to help individuals and their carers by providing information and support to manage their health and general well-being. Please find the list below:

**Atrial Fibrillation Association**

[www.atrialfibrillation.org.uk](http://www.atrialfibrillation.org.uk)

**British Cardiovascular Society**

[www.bcs.com](http://www.bcs.com)

**British Heart Foundation**

[www.bhf.org.uk](http://www.bhf.org.uk)

**British Heart Valve Society**

[www.bhvs.org.uk](http://www.bhvs.org.uk)

**British Society for Heart Failure**

[www.bsh.org.uk](http://www.bsh.org.uk)

**Cardiomyopathy UK**

[www.cardiomyopathy.org](http://www.cardiomyopathy.org)

**CRY**

[www.c-r-y.org.uk](http://www.c-r-y.org.uk)

**Heart UK**

[heartuk.org.uk](http://heartuk.org.uk)

**Heart Failure Matters (European Society for Cardiology)**

[www.heartfailurematters.org](http://www.heartfailurematters.org)

**SADS**

[www.sads.org.uk](http://www.sads.org.uk)

# Useful Contacts

## Government

NHS Choices  
[www.nhs.uk](http://www.nhs.uk)

NICE  
[www.nice.org.uk](http://www.nice.org.uk)

## General Information

Patient  
[www.patient.info](http://www.patient.info)

Driving with a medical condition  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/491028/aagv1.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/491028/aagv1.pdf)



## Mental Health Charities

Mind  
[www.mind.org.uk](http://www.mind.org.uk)

Rethink  
[www.rethink.org](http://www.rethink.org)

# Other 'Marvellous Guides' available in the series:

Please scan this QR code with your smartphone:



### Patient's Guide to Being Told You Have Heart Failure

<https://pumpingmarvellous.org/wp-content/uploads/2021/01/Pumping-Marvellous-HOPE-Booklet.pdf>



### The Marvellous Big Pocket Guide to Heart Failure

<https://pumpingmarvellous.org/wp-content/uploads/2019/08/Pumping-Marvellous-Big-Pocket-Booklet.pdf>



### A Marvellous Guide to Medicines for Heart Failure

<https://pumpingmarvellous.org/wp-content/uploads/2018/05/Heart-Failure-Medicine-Guide.pdf>



### More information for patients can be found here

<https://pumpingmarvellous.org/heart-failure-toolkit/>



### My Marvellous Guide to Walking A Day In My Shoes

<https://pumpingmarvellous.org/wp-content/uploads/2021/01/Pumping-Marvellous-Walk-in-My-Shoes-Booklet.pdf>



### Pumping Marvellous Traffic Light Symptom Checker

<https://pumpingmarvellous.org/wp-content/uploads/2019/08/Heart-Failure-Symptom-Tracker.pdf>



### My Marvellous Guide to Travelling with Heart Failure

<https://pumpingmarvellous.org/wp-content/uploads/2019/09/Pumping-Marvellous-Heart-Travel-Guide.pdf>

## My Team:

Your Carer's Name:

Your GP's Name:

Your Cardiologist's Name:

Your Heart Failure Nurse's Name (if applicable):

Your Practice Nurse's Name:

Your Pharmacy's Name:

Your Carer's Telephone Number:

Your GP's Telephone Number:

Your Cardiologist's Telephone Number:

Your Heart Failure Nurse's Telephone Number (if applicable):

Your Practice Nurse's Telephone Number:

Your Pharmacy's Telephone Number:

## Your device details:

Device Type:

Manufacturer:

Serial Number:

Device Clinic Tel Number:

Other details:

If you have any concerns or questions, get in touch with  
**Pumping Marvellous Foundation.**



*Another Midi Toolkit by The Pumping Marvellous Foundation  
Crowdsourced information from REAL patients.*

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**Dr Martin Thomas** Consultant Cardiologist, Clinical Lead for Heart Failure St Bartholomew's & UCLH  
**Clare Brooke** Boston Scientific  
**Patients** who helped to create this guide

# Contact Us



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Web - [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)

Email - [hearts@pumpingmarvellous.org](mailto:hearts@pumpingmarvellous.org)

YouTube - Search "Pumping Marvellous"

Twitter - @pumpinghearts

Facebook - Search "Heart Failure Aware"

Facebook Support Group - Search "Help for Hearts"

Instagram - Search "Pumping Marvellous"



Interested in getting involved in medical research in heart failure go to [CardioTrials.org](http://CardioTrials.org)

## Can you help us by donating or fundraising?

This resource has been supplied free of charge by The Pumping Marvellous Foundation. We rely on contributions to help us provide this vital service. Thank you!



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