

Living with an endocardial pacemaker



A pacemaker keeps your heart beating correctly. This leaflet explains about endocardial pacemakers and why you might need one. It also explains how one is inserted, and the effect it will have on your life afterwards. There is another sort of pacemaker called an epicardial pacemaker – this is covered in another information sheet.

Information for young people

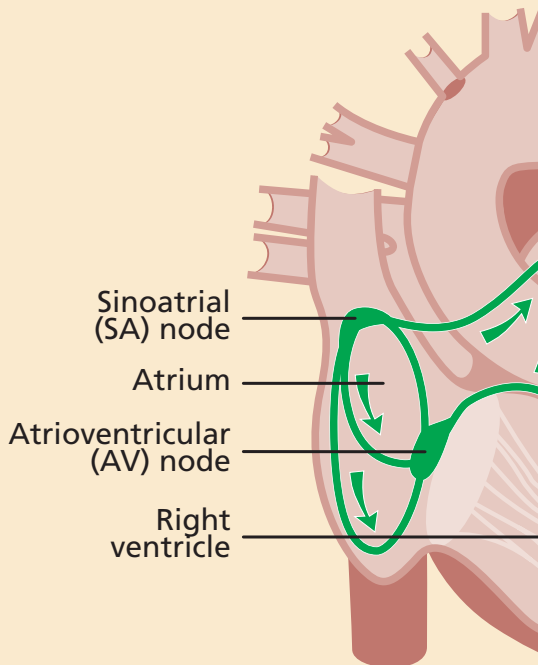
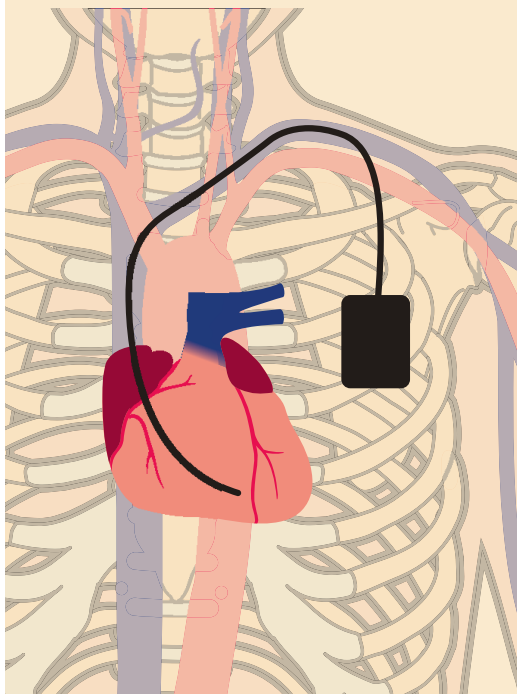
What is a pacemaker?

A pacemaker is a device implanted under the skin on your chest that releases electrical pulses to keep your heart beating normally. The pacemaker is about the size of a matchbox. It is composed of a pulse generator (pacemaker box) and can be connected to up to three 'leads' (thin insulated wires) placed inside your heart. These are used to deliver electrical pulses to the heart. The pacemaker box is powered by a battery. It contains special software to monitor and record your heart rate.

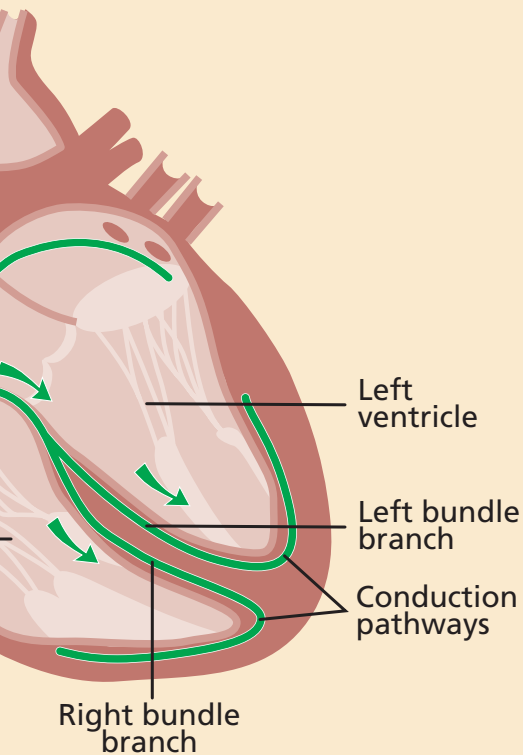
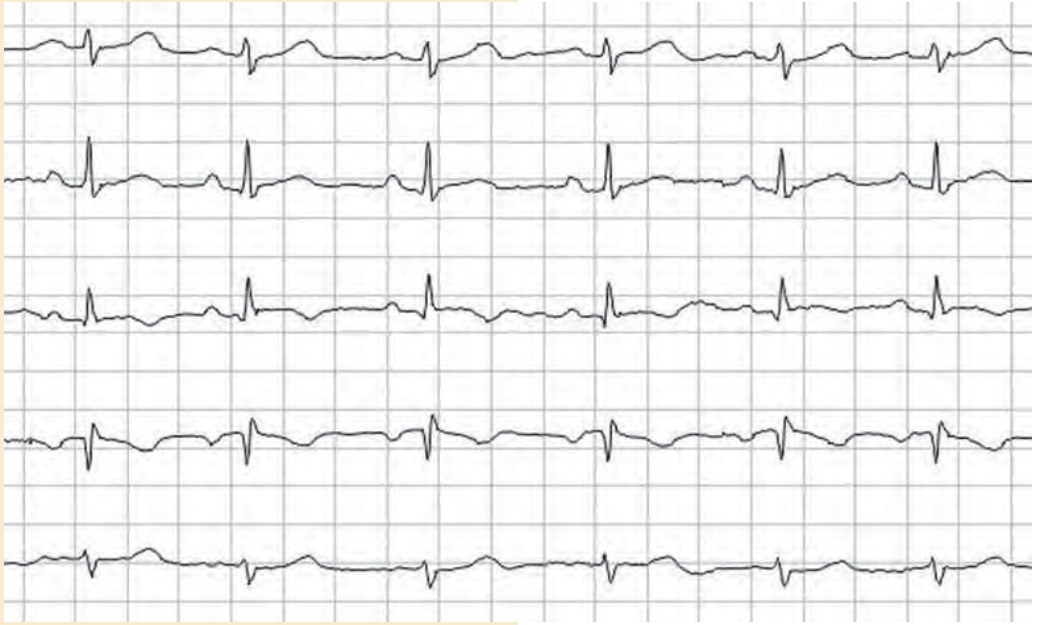
There are three types of endocardial pacemaker – your surgeon will explain which type you need:

- **Single chamber** – this contains a single wire that is fed into either the right ventricle or right atrium of your heart
- **Dual chamber** – this contains two wires, fed into the right ventricle and the right atrium
- **Biventricular** – this contains three wires, fed into the right ventricle, right atrium and left ventricle of your heart

The pacemaker will be programmed to suit your particular heart rhythm problem. It can automatically increase the pulses released when you are exercising. If your heart rate becomes irregular, it will generate a series of electrical pulses to ensure your heart beat does not fall too low.



On an ECG trace, a normal heart beat looks like above



How does the heart beat normally?

The heart has an electrical system that makes it pump. An electrical impulse starts in a specialised area of heart tissue in the right atrium called the sinoatrial (SA) node. It then passes from the right atrium through to the ventricles via the atrioventricular (AV) node. As the impulse passes through the atrium it makes it pump blood into the ventricle. It has the same effect when it passes through the ventricle. This electrical impulse is something that happens naturally. You can't feel it and the electrical impulses travel through the heart each time it beats.

Why do I need one?

Pacemakers correct abnormal heart rhythms, which may be caused by conditions such as heart block or sinus node disease. Your doctor might have suggested one if you have had symptoms resulting from a slow heart rhythm or you are at risk of a very slow heart rate. You may have had tachycardia, where your heart beats too fast. Irregular heart rates can make you feel very unwell and can be dangerous because the heart can't pump blood around the body properly while it's beating too fast or too slow. A pacemaker is a good way of dealing with the slow heart rhythms or pauses before it causes any problems.

Pacemakers can also be implanted to improve the coordination of the heart chambers. In particular biventricular pacemakers can be used to improve symptoms in those patients with dilated heart chambers or weakened heart muscle.

What happens when I have a pacemaker fitted?

You will have your pacemaker fitted in a small operation while you are asleep under general anaesthetic. Your doctor will explain all about the operation and ask you and your parents to sign a form giving permission for the operation to happen. While you're under the anaesthetic, the doctor will put the pulse generator under your skin near your collarbone. The wire(s) are threaded through the veins into the heart and then connected to the generator. You will have an x-ray during the operation to check that the wire(s) are in the correct position. The doctor will then program the generator to suit your heart rhythm.



What happens afterwards?

You'll start to wake up in the recovery room a short time after the operation. The nurses will call your mum or dad when you start to wake up so that they can come to see you straight away.

Once you're a bit awake, you'll come back to the ward to wake up fully. The operation site will usually be closed with dissolvable stitches. Medical glue or steri-strips® are used for the skin. The wound will be covered with a small dressing. Your chest might feel sore from the operation, but the nurses will give you medicine to help to get rid of any pain. As you start to feel better, you can get out of bed and walk to the play room if you like. We like you to be out of bed the day after the operation.

Antibiotics are given through a drip at the time of the operation and the day following. You may be given oral antibiotics.

Before you go home, you'll have another check in the ECG department so the doctor can make sure that the generator is working well. The staff in the ECG department can download information stored on the device by holding a reader against the skin over the generator. You may also have another chest x-ray to confirm that the wire(s) are in the correct position.

When you go home

You will be able to go home when the doctor is happy that your pacemaker is programmed correctly and you are starting to feel better.

Your chest may still feel a bit sore when you get home, but this goes away in a few days. If it hurts, you can take pain medicine containing paracetamol. Before taking regular ibuprofen, please discuss with your doctor.

The operation site will be swollen and a bit red and it might also be bruised. Gradually, this will go down over the next three or four weeks. Once the swelling has improved, you might be able to feel or see the outline of your pacemaker, but this is normal. Since you know you have a pacemaker, you might feel like it is more noticeable to others. However, most people won't even notice that it is there. During the next few months, you will hopefully start to forget all about it.

The dressing should be changed before leaving the hospital. You can have a shallow bath two days after your operation, but try not to get your operation site wet. This could soften the scabs so they fall off too early. The dressing will be removed one week after the procedure. If you have steri-strips(R) under the dressing, these will be removed at the same time as the dressing. You can go back to having a normal bath or shower a week afterwards. Wearing looser clothing for a few weeks after the operation can help to protect the wound.

Getting back to normal

Until you see your consultant for your follow up appointment, you should avoid doing things where you are swinging your arms higher than your shoulders, such as golf, tennis, swimming or bowling. It will take some time for the tissue around the pacemaker to heal up and there is a very small risk that moving the arm in this way might cause the device to move slightly. You should still move the arm gently, as it will become stiff and sore if you do not use it at all. Once the tissue is fully healed, the pacemaker will be held in place securely and you will be able to move your arm more freely. You should also avoid lifting or carrying anything too heavy, like a school bag full of books. Other than this, you should be able to go back to doing most of the things you did before.

Exercise and sport

You should be able to do a similar amount of exercise as before. If you are planning to start a new exercise program, you should check with your doctor at GOSH first. You might need to do an exercise test just to check that the settings on your pacemaker are right for things where your heart has to pump harder than normal. You will have to avoid some sports, especially if they're contact sports, like rugby or judo. A direct hit to your chest could damage the pacemaker and more importantly,

you. If you are keen to play contact sports, you can discuss this with your cardiologist. If you are aware of the risks and take steps to protect the area, you can reach a joint agreement.

School

You can go back to school about a week after your pacemaker operation. You should be able to do all your usual lessons, but it may take a little longer before you are ready to do PE again. As a general rule, we advise you to wait six weeks before starting normal PE lessons again. The hospital can provide written information for your teachers about the pacemaker device. It is important that the school staff are aware that you have a pacemaker, so that they can make sure that you are kept safe and comfortable while you are at school. If they want to know more about it, they can ring the nurse practitioners or clinical nurse specialists for advice.

Going out

There's no reason why your pacemaker should get in the way of your social life. Concerts, clubs and going out should be fine, but if you have any questions, please ring the nurse practitioners or your clinical nurse specialist for advice.

How will you feel about your pacemaker?

Your pacemaker will take some getting used to, and it will probably feel strange at the beginning. It may feel uncomfortable when you lie in certain positions or wear certain clothes, but this will not damage the pacemaker or affect the way that it works. If you are at all worried about having a pacemaker, talk to your clinical nurse specialist. The important thing to remember is that your pacemaker is keeping your heart beating normally, so you are safer with it than without it.

Precautions

The pacemaker is powered by a battery and controlled by a computer chip, so strong magnetic fields or electric currents can affect how it works. So, there are some precautions you need to take but these shouldn't get in the way of normal life too much.

Tell people about your pacemaker

It's important that you tell people about your pacemaker if you are in hospital for something else. Some scans and treatments can stop the pacemaker working properly, so you need to avoid them completely. These include MRI scans that use a strong magnetic field, lithotripsy that uses sound waves and cautery that uses heat. Other procedures are less risky, but you should still tell the doctor about your pacemaker. These include radiotherapy that uses x-ray beams and diathermy that uses electricity to create heat. Some newer endocardial pacemakers can be taken into the MRI scanner. These pacemakers are MRI-compatible. You still need to inform the pacing clinic and the MRI department if you are due to have a scan.

If you are due to have an operation, the doctor should contact the doctors at GOSH for advice. You may need to have extra monitoring during the operation, or certain surgical techniques might have to be avoided.

We suggest that young people with a pacemaker wear a medical identity bracelet or necklace all the time. You can visit the following websites for more information: www.medicalert.org.uk or www.theidbandco.com. We will also give you an identity card saying that you have a pacemaker to show people. Make sure you always have this with you.

Mobile phones

Your mobile phone should not interfere with your pacemaker but we advise you to avoid carrying it in your breast pocket or the shoulder strap of your bag.

Security gates and checks

Most shops, libraries and airports have security gates these days. Walking through them at normal speed won't harm your pacemaker but try not to hang around near them. Security metal detectors, such as those in airports, may detect the pacemaker, so it is important to carry your identity card with you to show to the security guards. If you are going to the airport, you should not be searched with a handheld scanner, as it works using magnetism. Show the security guard your identity card and ask to be hand searched instead.

Microwaves and other household equipment

Your pacemaker is designed to cope with common household equipment, like microwave ovens, so they will not cause any problems. If you are likely to come into contact with any industrial strength equipment, it is a good idea to check with your doctor first.

Travel

Going abroad for holiday or work will not affect your pacemaker, but remember the precautions to take about airport security checks in previous paragraphs. If you have trouble obtaining travel insurance from your usual provider, the British Heart Foundation website contains a list of companies who offer insurance to patients with a range of different heart conditions. Before you go, find out the details of pacemaker centres near your destination and get in touch with them to warn them. You hopefully won't need them but carry the information with you all the time, just in case.

Follow up

We will arrange a clinic appointment for one month after your pacemaker is fitted. After that, you will still need to come to clinic appointments every three to six months so we can check how you're doing. The team in the ECG department will download the information stored by the generator by placing a handheld reader against the skin over the pacemaker. The information they download will help us to make sure your pacemaker is still on the right setting for you. Usually, you'll also need to have an ECG and we might ask you to have an echocardiogram too. If you have any questions, write down a list to bring with you so you remember to ask the ECG staff. We recommend a pacemaker is checked every six months. This needs to be done via a remote download every six months and a hospital check up every year.

Replacing your pacemaker battery

As your pacemaker is battery-powered, it will eventually need to be changed. At every clinic appointment, we will check how much power is left in the battery. If we think the battery might start running out soon, you will need to have a small operation to replace it. The operation will be under general anaesthetic as before, but it is shorter than the original procedure. You won't feel as sore as with the first operation, and where possible, the doctor will use the same operation site, so you only have one scar. Some children and young people need to have the wire(s) from the generator to their heart lengthened or replaced as they grow older and bigger. This will also involve an operation under general anaesthetic.



Places to go for further information

Arrhythmia Alliance

Tel: 01789 450787

Website: www.rrhythmiaalliance.org.uk

British Heart Foundation

Tel: 08450 70 80 70

Website: www.bhf.org.uk

Cardiomyopathy Association

Tel: 0800 018 1024

Web: www.cardiomyopathy.org

Driving Vehicle Licensing Authority (DVLA)

Tel: 0870 600 0301

Website: www.dvla.gov.uk

If you have any questions, please contact your clinical nurse specialist on extension 5646 or 5139, or the Bear Ward nurse practitioners on 020 7405 9200 extension 5774. Out of hours, please call Bear Ward on 020 7829 8829.



Notes

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