



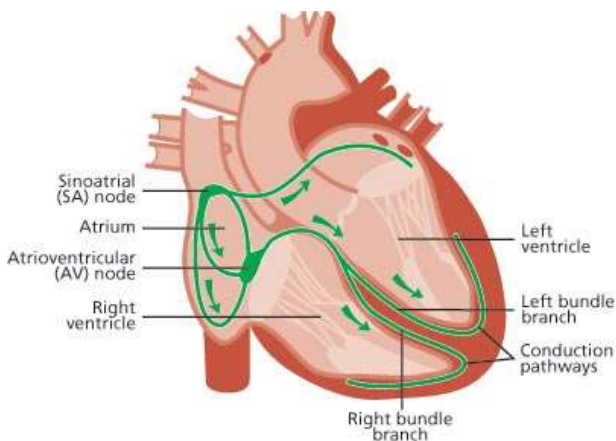
NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust

Living with a pacemaker: information for young people

A pacemaker keeps your heart beating correctly. This information sheet from Great Ormond Street Hospital (GOSH) describes the two sorts of pacemakers we use at GOSH and why you might need one. It also explains how one is inserted, and the effect it will have on your life afterwards.

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.

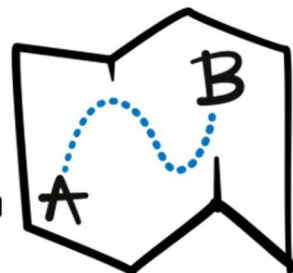
Why do I need a pacemaker?

Pacemakers correct abnormal heart rhythms, by sending out electrical impulses to keep your heart beating regularly. Pacemakers can also be used improve the coordination of the pumping chambers of the heart.

Your clinical team may suggest one if:

- You have had symptoms resulting from a slow heart rhythm called heart block or your heart is at risk of beating very slowly
- Your heart is beating too quickly or it is very irregular and medication has not helped
- Your heart muscle is weakened or dilated causing your heart to beat out of sync.

The clinical team will explain how they think a pacemaker will help you.



What is a pacemaker?

A pacemaker is a device implanted under the skin on your chest or abdomen that releases electrical pulses to keep your heart beating normally. The pacemaker is 4cm x 4cm x 0.7cm.

It is made up of a pulse generator (pacemaker box) and can be connected to up to three 'leads' (thin insulated wires). 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 pacemaker – your clinical team 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

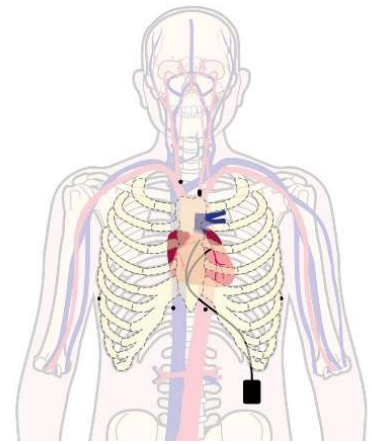
The pacemaker will be programmed to suit your particular heart rhythm problem. It can automatically sense how fast your heart is beating naturally and will send out impulses to keep your heart beating regularly. Pacemakers do not give your heart an electrical shock.

Your medical team will decide whether your pacemaker wires are placed inside your heart (endocardial or transvenous), or outside on the surface of your heart (epicardial). The difference between the two types is explained below.

Epicardial pacemaker

A small incision is made to make a pocket in the abdomen to insert the generator then the wires are guided

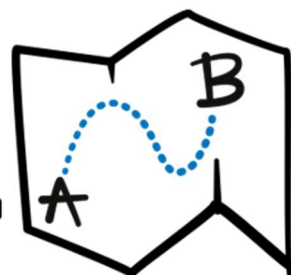
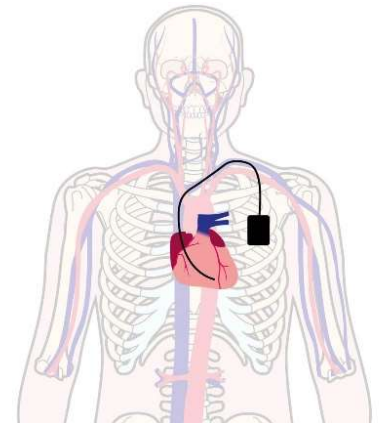
onto the outside of heart through a second incision on the chest. The incision sites need to be larger for this pacemaker. Sometimes a small wound drain is needed for a day or two and recovery can take a little longer. Epicardial pacemakers are generally used for smaller children at GOSH.



Endocardial (transvenous) pacemaker

A small incision is made in the chest to make a pocket to insert the generator then the wires are

guided into the heart through the veins. There is a slightly increased risk of endocarditis (infection inside the heart) due to the wires inside the heart. Usually patients spend a night in hospital to recover and go home the following day.



What happens when I have a pacemaker fitted?

A few days before the procedure you will need to come for a pre-admission appointment. They will check that you understand what will be happening, look at where to put your pacemaker, and when to stop taking your medicines.

You'll need to have a thorough shower the day before the procedure to make sure your skin is nice and clean. You will also need to stop eating and drinking for a few hours before the procedure is due to start so the anaesthetic is as safe as possible. We will tell you the last times you can have something to eat and drink during your pre-admission appointment.

The day of the pacemaker insertion

Your admission letter will tell you what time to come to Walrus Ward (Cardiac Day Care). If you haven't signed it already, a doctor will explain the procedure again and ask you and your parents for permission to carry out the procedure – this is called consent. An anaesthetist (specialist doctor) will also visit you to explain about the anaesthetic.

Your nurse will check that you are ready for the procedure and help you into a hospital gown before taking you to the anaesthetic room. The anaesthetist will give you anaesthetic medicine so you aren't aware of anything or feel anything with either a mask or a small needle in the back of your hand.

While you're under the anaesthetic, the doctor will put the pacemaker under your skin near your collarbone or abdomen. The wire(s) are threaded through the veins into the heart, or guided onto the outside of the heart. 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?

When you are awake from the anaesthetic, you will return to the ward. The nurses will be checking how well you are recovering by measuring your heart rate, temperature and breathing. They will also make sure you are not in pain and check your wound.

The operation site will usually be closed with dissolvable stitches. Medical glue and 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 pain medicine. 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 a course of oral antibiotics to take as well.

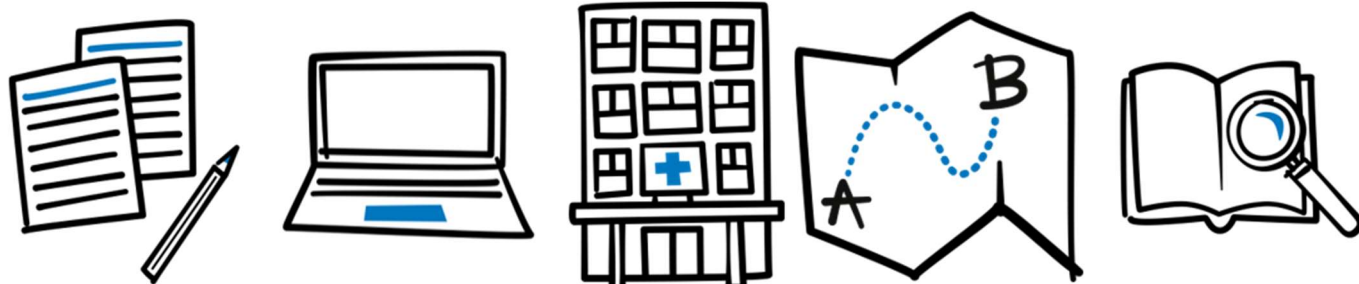
Before you go home, you'll have another check in the ECG department so the doctor can make sure that the pacemaker is working well. The staff in the ECG department can download information stored on the device by holding a reader over the skin above the pacemaker. You may also have another chest x-ray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

When you go home

The dressing should be changed the day after insertion, before leaving the hospital. 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. You will need to stay overnight for at least one night following your procedure.

The insertion site may still feel a bit sore for a few days when you get home. If it hurts, you can take pain medicine.

You should keep the dressing dry for seven days and make an appointment at your family doctor (GP) to get it taken off and your wound reviewed. Try not to soak the wound after you take the



dressing off and avoid scrubbing or soaking the wound. The glue will appear dry and clear – it is a bit like a scab so do not pick or fiddle with it.

If you have Steri-strips® 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 if the scar has healed. Wearing looser clothing for a few weeks after the operation can be more comfortable, make sure you wear a clean top every day.

Looking after your operation site

Keep your dressing on for the first seven days

Check your operation site every day

- Does it look red?
- Does it look angry and inflamed?
- Is it open?
- Is it oozing, fluid?

If you answer 'yes' to any of these questions, visit your family doctor (GP) to have it checked and let your Clinical Nurse Specialist know.

Telephone your Clinical Nurse Specialist if you have any questions about your wound or the device. Out of hours (nights or weekends), you can call Bear Ward.

Remember that your pacemaker site is slightly swollen and the scar is new – both will look better over time.

Once it has healed, you can wash your operation site gently with water, but pat it dry rather than rubbing it.

Scar healing

The operation site will be swollen and a bit red and it might also be bruised. Gradually, this will go down over the few 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 scar will get less red over the next few months, and eventually fade to a pale line. It can help to gently massage a simple fragrance-free moisturiser into the scar to make it less noticeable. You can start to do this when the scar has completely healed – about 6-10 weeks after the procedure.

Your follow up appointment will be planned and your wound will be reviewed at this time.

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.

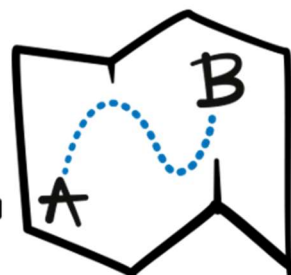
It will take some time for the tissue around the pacemaker to heal up and there is a very small risk that moving the arm in this way might cause the device to move slightly. You should still move the arm gently, as it will become stiff and sore if you do not use it at all.

You should also avoid lifting or carrying anything too heavy, like a school bag full of books. Other

Washing

Do not have a shower – have a shallow bath instead whilst the dressing is on

Wash your hair over the sink for the first week



than this, you should be able to go back to doing most of the things you did before.

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.

Exercise and sport

You should be able to do a similar amount of exercise as before when your pacemaker has healed. 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.

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 as a general rule, we advise you to wait six weeks before starting normal PE lessons and sports 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 team for advice.

Dealing with feelings 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 the team. 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 such as avoiding using strong magnets unless supervised as there is a theoretical risk of these affecting the pacemaker. While this does not mean you cannot use them, you should sit at a table and keep the magnets about 10 to 15cm away from your abdomen. The same rule applies for tablet or laptop devices as these also tend to have magnets within them.

Doctors

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.

Some newer 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 clinical team should contact GOSH for advice as you may need to have extra monitoring during the operation, or certain surgical techniques might have to be avoided.

Dentists

You need to make sure you are brushing your teeth morning and evening every day.

Dental hygiene is really important when you have a pacemaker because if germs and bacteria build up in your mouth it can lead to infections around your heart. This is known as endocarditis.



You should let your dentist know you have a pacemaker when you visit.

Endocarditis

Endocarditis is a serious infection of the inner lining of your heart. It is usually caused by bacteria or germs that have got into your blood stream from your mouth or another smaller infection. It requires weeks of treatment in hospital and may require your pacemaker to be removed until the infection has been treated.

Red flags

- Persistent fevers
- Tiredness
- Unexplained weight loss
- Night sweats
- Headaches and achiness
- Breathlessness or breathing difficulties

You should see a doctor if you get any of the red flag symptoms and contact your cardiologist.

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Lifestyle

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 contact the team for advice.

Body piercing and tattooing can put you at risk of infections and therefore increases your risk of endocarditis. For this reason we do not recommend piercing or tattoos if you have a pacemaker.

If you decide to go ahead against the advice this it is really important that this is undertaken in a place that practices high standards of hygiene including:

using aseptic technique and single use needles and single use piercing cassettes. You should follow any cleaning advice strictly and seek medical advice at any signs of infection: redness, swelling, odour, ooze, pain.

Identification

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

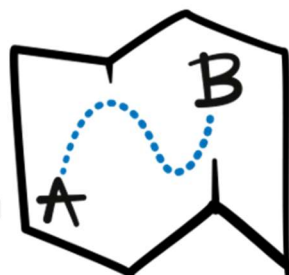
Mobile phones

Some of the newer smartphones and tablets contain magnets which when positioned near to a pacemaker, can result in temporary changes to function. These can be used but for safety must be kept 15cm away from cardiac devices, so that they will not affect cardiac device function.

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 move away from them when you have walked through.

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 strong magnets. Show the security guard your identity card and ask to be hand searched instead.



Work

You will need a safety assessment and to let your cardiologist know if you are considering jobs that involve working with strong magnets or generators.

Please be aware if you are considering a career in the army, RAF, navy or airline, there is a medical involved and they may not accept you with a pacemaker.

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 pacemaker by placing a

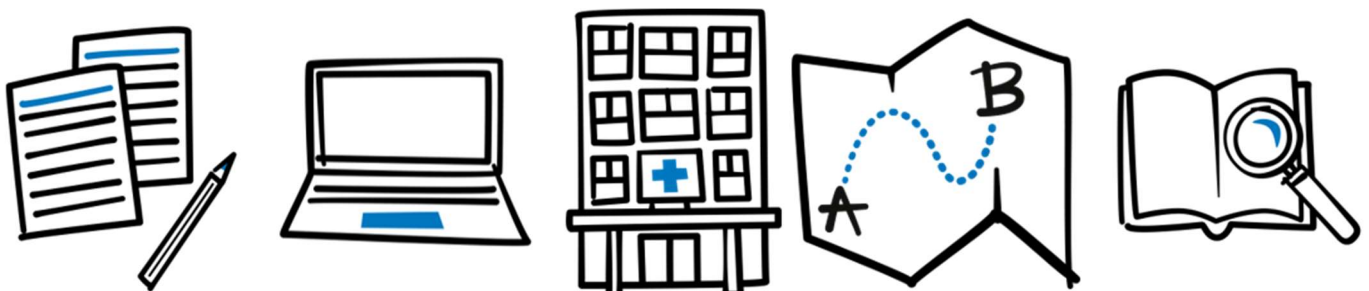
handheld reader against the skin over the pacemaker. The information they download will help us to make sure your pacemaker is still on the right setting for you. Usually, you'll also need to have an ECG and we might ask you to have an echocardiogram too.

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.



Any questions?

You can get in touch with the Arrhythmia Service on 020 7405 9200 extension 5298 or 020 7813 8568 during office hours or the ECG team on ext 1011. In the evenings and at weekends, call Bear Ward on 020 7829 8829.



You can also email the Arrhythmia Clinical Nurse Specialists at gosh-tr.ecg.gosh@nhs.net, the pacing team at gosh.pacing@gosh.nhs.uk or via MyGOSH once you have registered. More information is available at www.gosh.nhs.uk/your-hospital-visit/mygosh







Arrhythmia Alliance – call 01789 867 501 (24 hour helpline) or visit their website at www.heartrhythmcharity.org.uk

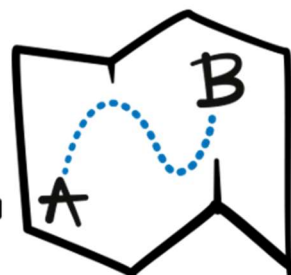
British Heart Foundation – call their Heart Helpline on 0300 330 3311 or visit their website at www.bhf.org.uk

Disclaimer

This is a general GOSH information sheet. If you have specific questions about how this relates to you, please ask your doctor. Please note this information may not necessarily reflect treatment at other hospitals.

Having a heart pacemaker

	If your heart beats very slowly, very fast or not very regularly, you might need a pacemaker.
	A pacemaker can check your heart and sort out how it is beating if it goes odd.
	You will need to have the device put in during a short operation.
	You will have a general anaesthetic for the operation. This means you will not feel anything or know what is happening.
	You will have the pacemaker under the skin on your chest or your tummy.
	The pacemaker is about the size of a matchbox with wires that go to your heart.

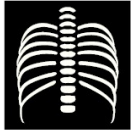




You might feel a bit sick or dizzy after an anaesthetic. This will not last long.



You will stay in hospital for one night to make sure the pacemaker is working properly.



The next day, you might have an x-ray to check the wires are in the right place.



You can then go back home.



Your chest or tummy where it was put in might feel a bit sore. You can take some pain medicine to help.



There will be a dressing on your chest or tummy. You can take this off 7 days after the operation.



You can have a shower when you have taken off the dressing. Do not rub your chest or tummy for a few days to let it get better.



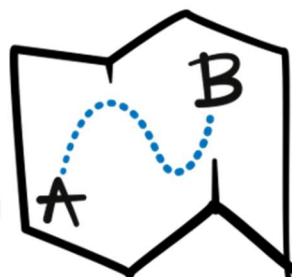
You can go back to school about a week afterwards.



Wait 6 weeks or so until you do sport again but avoid sports where you could get knocked in the chest.



Do not put your mobile phone in a pocket near your chest.

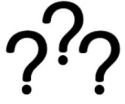




Your nurse will phone you about a week after the operation. They will ask how you are feeling.



You will need to come back to hospital for a check-up a few weeks later.



Please ask us if you have any questions.

