

Endocardial pacemaker

Information for patients, parents and guardians

A pacemaker is used to treat heart rhythms that can cause your heart to beat too slowly or to miss a beat. This leaflet will help answer some of the questions you might have about your child having a pacemaker. If you have any other questions that aren't covered in this factsheet, please contact the cardiac nurse specialist team on 023 8120 4659.

Why does my child need a pacemaker?

Your child's heartbeat is too slow or irregular. This may be because your child:

- was born with a problem with the electrical signals in their heart.
- is taking medication to prevent a fast heartbeat, which is causing the electrical pathways to work too slowly.
- had an illness that damaged the electrical pathways of the heart.
- had heart surgery that damaged the electrical pathways of the heart.

Your child may feel breathless or tired because of a slow heartbeat, but some children will have a pacemaker fitted even if there are no symptoms in order to prevent future complications.

What is a pacemaker?

An artificial pacemaker is a small metal box, which is placed under the skin or muscle of the chest (or occasionally the abdomen). Attached to it are one or more electrode leads, which carry electrical impulses from the pacemaker to

the heart to regulate its beat.

When the leads pass from the metal box through the veins to reach the heart, this is called an endocardial pacemaker.

The pacemaker is programmed to sense when your child's heart rate is too low or skips a beat. It sends an electrical impulse from the battery, along the wire to the heart to make it contract and produce a beat.

How should I prepare my child for the procedure?

Preparing your child for the procedure will help them to understand their treatment better. Talking to your child in advance will give them time to talk about any questions or concerns. Children tend to be more co-operative and at ease when they understand what is happening to them.

What to say:

- give truthful, factual information such as "your heart is not beating as well as it should".
- explain the reason for going into hospital.
- explain the tests your child may have such as blood tests, an x-ray, a heart scan. Our play specialist team can help guide you about what to say. You can contact them by calling the cardiac nurse specialist team on 023 8120 4659.
- explain that they will have a deep sleep

while the doctor fits the pacemaker and that they won't feel anything during the operation. There is an excellent video on YouTube called "A little deep sleep" on the UHBristol channel which might help you to prepare them:

www.youtube.com/watch?v=BWsQTPyLiMk

- explain they may have some discomfort but not pain when they wake up, this is from where the lead was inserted and around the wound.
- They will need to take some oral medication for pain relief (Calpol, for example) and antibiotics for a few days.

What happens before the procedure?

Most children will come to the ward on the morning of the procedure. They may require a chest x-ray, an ECG, blood tests and an ultrasound of the heart (echocardiogram).

We will also need to put a small tube (cannula) into a vein in your child's arm or hand to give them medicine during the operation.

Your child will not be able to eat or drink for six hours before the operation. You should receive instructions about this in your appointment letter.

The cardiologist will meet with you before the procedure to discuss the risks in detail before asking you to sign a consent form. Please feel free to discuss all your questions and concerns with them.

The procedure will take place in the cardiac catheter laboratory at Southampton General Hospital. Your child will be given a general anaesthetic which means they will be asleep during the procedure.

You can be with your child until they have the anaesthetic and are asleep. You can then wait on the ward whilst they have the procedure and then join them in the recovery room when they

wake up.

What happens after the procedure?

Once the operation is complete your child will be taken to the recovery area and you will be able to join them there once they're awake. You'll both be taken back to the ward where the nurses will check your child regularly for the first few hours after the procedure.

We'll give your child antibiotics through their cannula during the procedure. You will not need to take any antibiotics home with you unless advised to do so by the medical team.

After the procedure, your child will need to have a chest x-ray to check the position of the pacemaker and leads, as well as a pacemaker 'box' check where a special scanner (similar to a computer mouse) is placed over the site of the pacemaker to read and/or change the settings and check the battery. You will also be given an implant card at this time which contains important information about the pacemaker.

Your child may feel sore around the pacemaker. The nurse can give your child paracetamol to relieve this.

Some children will be able to go home on the day of their procedure. Others may need to stay overnight. If your child needs to stay on the ward overnight, one parent or guardian can stay with them.

Important post-operation advice

It is very important that your child does not make any large movements of the arm on the side the pacemaker was inserted until your first follow-up appointment (four to six weeks post procedure).

This will allow the leads time to settle into their heart muscle. They should avoid motions that stretch the chest muscles on the side of your pacemaker.

They should not:

- lift heavy objects
- lift their arm above shoulder height
- stretch their arm back behind their body
- use strenuous pushing or pulling motions

It's important to encourage them to still use their arm for light activities to maintain movement in the shoulder joint.

Six weeks after the procedure, you will be asked to bring your child back to the hospital to check the pacemaker and review the wound. You will have the opportunity to ask us any questions that you might have. Following this, your child will need to come to the hospital every six months so we can monitor the pacemaker and their health.

How to care for your child's wound

In your child's operation, they had a surgical cut to insert the device. You should keep the dressing on the wound for five days and keep it clean and dry. The dressing can be removed at home after the five days. Generally there are no stitches which need to be removed; your child's nurse will advise you what to do and where to go if there are stitches.

The top layer of your child's wound may have been closed with steristrips (also known as butterfly or paper stitches) underneath the main dressing. These are narrow adhesive strips that help close the edges of small wounds.

Keep the wound clean and dry, until the steristrips are ready for removal. The strips can be removed between 5-10 days after application. When removing the steristrips, remove them slowly and if the strips are difficult to remove, it may help to moisten them with warm water, before attempting to remove them again.

If you are finding it difficult to remove the steristrips or have any concerns, please contact

the cardiac nurse specialists on 023 8120 4659 or contact your GP.

Once the dressing has been removed, keep the area clean and dry until the wound has healed and monitor for signs of infection which include:

- soreness
- redness
- swelling
- discharge
- high temperature
- sudden severe pain in the wound site.

If you are worried about the wound, contact the cardiac nurse specialists on 023 8120 4659. Our opening hours are 9am to 5pm, Monday to Friday. Outside of these hours, contact E1 Ocean ward on telephone: 023 8120 6470.

When can my child go back to their normal activities?

Your doctor or nurse will talk to you before you go home about when your child can return to their normal activities. Your child should be able to go back to school within a few days but should avoid carrying a school bag on the pacemaker side for six weeks.

Energetic activities, such as gymnastics and jumping on a trampoline, and forceful arm movements on the side of the body where the pacemaker is should be avoided for six weeks. This is to help prevent the leads from moving.

After six weeks, the leads should be firmly held in place by body tissue and most activities can be resumed. However, full contact sports such as rugby, boxing and karate should be avoided now that your child has a pacemaker.

Care should also be taken when engaging in activities which involve forceful arm movements on the side of the pacemaker, for example shotput throwing, butterfly swimming stroke and competitive (fast) front crawl, and swinging from monkey bars.

Our cardiac nurse specialist team can give you information to take to school about the pacemaker and the advice for school activities.

What everyday items can affect the pacemaker?

Modern pacemakers are protected from outside interference from most everyday electrical items. However, some precautions include:

- MRI scanning is not allowed for people with certain types of pacemakers. Check with your child's cardiologist whether their pacemaker is MRI compatible.
- The pacemaker may set off airport alarm detectors. Your child should show staff their implant card and walk quickly through the detector without pausing. Security scanning wands should not be held over the pacemaker as they can disrupt the signal from the box to the leads.
- Antitheft detectors such as those found in shop doorways, can interfere with the pacemaker if your child stands still inside them. It is best to walk through briskly.
- Mobile phones should not be placed over the pacemaker site. It is best to use the phone in the opposite hand.
- Magnets placed over the pacemaker site can change and interfere with the settings until removed. This can make your child feel uncomfortable and should be avoided.
- Laser tag guns and vests can contain magnets. You will need to discuss with the manufacturer whether this activity is safe for your child.

How long will the pacemaker last?

Modern pacemakers can be expected to last for about four to eight years. The length of time the battery lasts depends on the pacemaker settings chosen and how much the pacemaker

is used. If only the pacemaker needs changing, this is a quicker procedure and your child may be discharged the same day. Occasionally the wires will need replacing. This is more complicated and your doctor will discuss this with you if necessary.

What is a home monitor?

Some pacemakers are compatible with a home monitor which can be used to send information through to the rhythm management department at the hospital. Your child's cardiologist will decide which pacemaker is right for your child.

Travelling abroad

When travelling abroad you should always:

- take your child's pacemaker implant card and show airport security officers
- research where the nearest hospital is
- take out travel health insurance
- take your child's clinic letters and last pacemaker check letter
- take a good supply of your child's medication and a prescription.

Who can I contact for more advice at home?

Children's cardiac nurse specialists
Monday to Friday, 9am to 5pm
Telephone: 023 8120 4659

Ocean ward
24 hours, 7 days a week
Telephone: 023 8120 6470

Cardiac rhythm management department
(for home monitor transmissions)
Monday to Friday, 9am to 5pm
Telephone: 023 8120 6404

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone **023 8120 4688** for help.

www.uhs.nhs.uk/childrenshospital