

WIRED UP

A pacemaker guide for Teenagers





A message from Dr Eric Rosenthal

- Consultant cardiologist at Evelina London

In the last 60 years pacemakers have become much smaller, much more reliable and for many, their best friend. Congratulations to Katie and Hannah for putting this brilliant booklet together. I am sure it will be a useful resource for many young people.

Dear Fellow Heart Buddy,

Congratulations on your new pacemaker! Or as we like to call it, 'battery pack'.

Our names are Hannah & Katie and due to our congenital heart conditions we both have pacemakers.

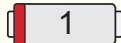
We are writing this letter to let you know that as scary as this process may seem, there are many others that have been on the journey that you are about to start.

You are not alone and we wish you the best of luck with your operation. We hope that it gives you back a more active and normal life.

Having fears and worries about your procedure is completely normal, it would be weird not to feel slightly scared! Don't forget there is lots of support for you at the hospital. You can also remember our wish for you:

"As you start this journey,
We wish that all your fear is behind you,
Better health lies in front of you,
& Bravery is by your side"

Hannah & Katie



Your Pacemaker



A pacemaker is a small battery device which is no bigger than a matchbox. It is put under your skin or muscle to help control abnormal heart rhythms. Your 'battery pack' can have between one and three leads which send electrical impulses to your heart. This helps it beat at a normal rate.

Katie and I need our pacemakers to work all the time, which means we are pacemaker dependent. Some of you will only need it to 'kick in' when your heart is playing up. This is known as 'on demand', much like TV on demand! If you want to see what a pacemaker looks like you can turn to page 15.

Why do I need a pacemaker?

There are many different reasons for why people will need a pacemaker. The main two reasons that you may require one are:

♥ Heart block

♥ Sick sinus syndrome

Other conditions that may sometimes require a pacemaker are:

♥ Fainting (Syncope)

♥ Heart failure

♥ Arrhythmia

For more information on each of these conditions, please see the glossary at the back of this manual. If you are unsure as to why you need a pacemaker, please ask your consultant for more information.

What to ask?

You may have lots of questions about your pacemaker and the procedure. We certainly did! Don't be scared to ask questions no matter how silly you think they are. Here are some examples of the questions that we asked:

How long is the procedure?

Is the procedure painful?

Will I be given pain relief?

Can I choose how I am put to sleep?

How long will it take for me to recover?

How long might I be in hospital for?

Will I be left with a scar?

Will you be able to see the pacemaker?

Preparing for your stay...



...time to get packing

Don't forget!

♥ Pyjamas

Try to pack pyjamas or shorts and vests that are comfortable and easy to take on and off. After surgery you might feel sore, making it difficult to move around, especially for the first few days.

♥ Clothes

If you are not planning to stay in PJs (like we did) be sure to pack clothes that are comfortable to move around in.

♥ Meds

Remember to bring your current medication with you. The ward team will need to know what medication you are on in case they need to take over or change your prescription.

♥ Wash stuff

Bring your toothbrush, toothpaste, comb or hairbrush, face wash, moisturiser and lip balm (we found our lips were extremely dry!). If moving around hurts you may want to bring some baby wipes, just to freshen up.

♥ Personal items

You want to feel as comfortable as you can during your stay, sometimes that means bringing items with you that you cherish most. Don't feel embarrassed to bring them with you! This could be anything from a cuddly toy to one of your favourite pictures. You are never too old for a cuddly toy!

♥ Get organised

There may be many things you need to think about before having your procedure, for example getting organised with school/college/work and thinking about whether you need to tell people that you are coming into hospital. You may also want to plan telling friends and family and to give them the ward number or your own phone number to contact you.

Top Tips for boredom

There can be a lot of waiting around when you come in to have your procedure so we wanted to share with you our top tips for beating boredom.

- ♥ A book
- ♥ The latest 'Trashy' magazine
- ♥ Phone/iPod/iPad (Don't forget your chargers!!)
- ♥ Puzzle books (word search & crosswords)
- ♥ Films
- ♥ Spending time with friends and family



The procedure

Before being admitted to the ward, you will have a pre-op assessment to make sure you are fit and healthy for your operation. Now is a good time to ask any questions.

"You are Calm
Brave and Strong"

On average a procedure can take between one and three hours, however this will always depend on the individual.

With pacemaker surgery, you will usually be given a general anaesthetic, however, if you would feel more comfortable with a local anaesthetic, please discuss this with your consultant. For new procedures you will need to stay in for an x-ray and pacemaker check the day after your operation. For a replacement, you may go home the same day. Replacements are usually needed every six to nine years.



While you were sleeping...

charging

When you wake up you
will be fully charged!

You may feel slightly worried and a bit fragile
but trust us when we say it's normal!



Moving on...

Once doctors are happy with your progress, you will be able to continue to recover at home. Be confident in going home and take this time to rest. Everyone's recovery process is different but you will know when it's time to get back into your everyday routine.



A photograph of three young women with dark hair, smiling and holding colorful drinks with straws. They are in a casual indoor setting. The photo is used as a background for the text overlay.

Back at home

Allow time to recover

Don't rush it or feel pressure to return to school, college, university or work. Do things at your own pace.

Look after yourself

As you get back into your daily routine, be mindful of the area where you have had your operation. Be careful not to overdo it, no monkey movements!

Food and drink

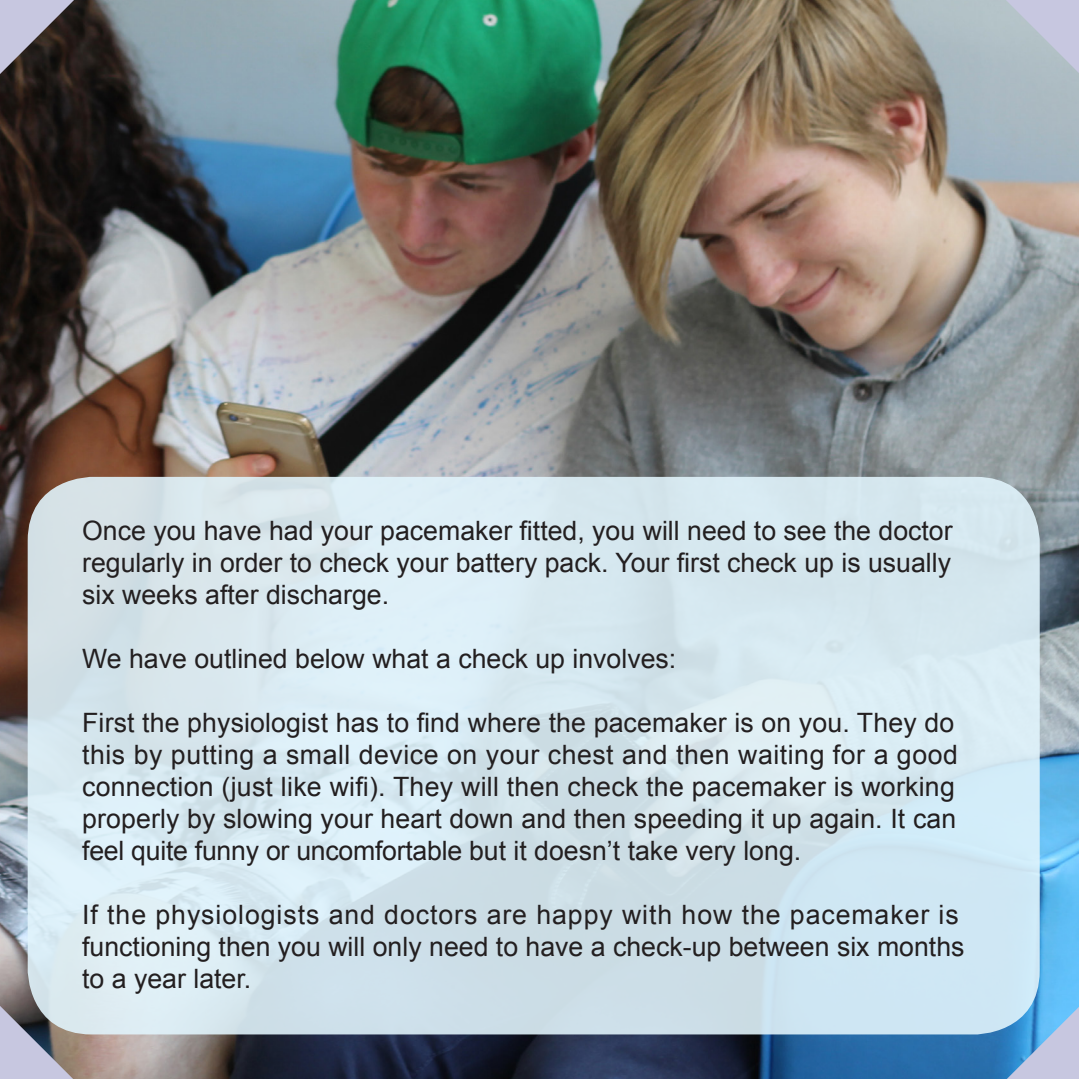
It's important to keep hydrated so drink plenty, whether this be water, juice or tea. As well as drinking, eat well in order to give your body the nutrients it needs to strengthen.

Body care

Before leaving the hospital, you will be advised on how long to keep your dressing on for. When showering, be careful of your dressing, keeping it as dry as possible.

Don't worry

People around you will be getting on with their daily routines, don't let this get to you or make you feel left out. You will be joining them again soon!

A photograph of two young men sitting on a blue couch. The man on the left is wearing a green baseball cap and a white t-shirt with blue paint splatters. He is holding a gold smartphone. The man on the right has blonde hair and is wearing a grey button-down shirt. They are both looking down at the phone with interest. A semi-transparent light blue box with rounded corners is overlaid on the bottom half of the image, containing text.

Once you have had your pacemaker fitted, you will need to see the doctor regularly in order to check your battery pack. Your first check up is usually six weeks after discharge.

We have outlined below what a check up involves:

First the physiologist has to find where the pacemaker is on you. They do this by putting a small device on your chest and then waiting for a good connection (just like wifi). They will then check the pacemaker is working properly by slowing your heart down and then speeding it up again. It can feel quite funny or uncomfortable but it doesn't take very long.

If the physiologists and doctors are happy with how the pacemaker is functioning then you will only need to have a check-up between six months to a year later.

Important things to know

As weird as it sounds, your pacemaker is an electronic device which means that there are certain things that can interfere with how your pacemaker works.

Below are some items to be aware of. If in doubt, consult your doctor or look out for this pacemaker sign...

- ♥ Magnets
- ♥ MRI machines
- ♥ Mobile phones
- ♥ Metal detectors
- ♥ Airport security
- ♥ Body fat scanners



We are not saying you can't use your phone or favourite 'gadgets' but just be careful! It is advised that you keep them at least 15cm away from your pacemaker and answer the phone on the opposite side to your implant.

The hospital will provide you with a patient identification card. We advise that you keep this on you at all times in case you need to let people know you have a pacemaker.

We
still
do
the
things
we
love



Keep in touch!

Dear battery packer,

You did it! You are now an official member of the pacemaker community, you've achieved something amazing!

The hardest part is over but this journey is only just beginning. It might take a little while to notice, but our lives changed a lot once we started living with our 'battery packs'. We are excited at the opportunity this new device may be able to bring you.

Sometimes we feel a little out of place and not many people are lucky enough to have a pacemaker (before the age of 80). Let us reassure you, that only the best people have them. We want to wish you a speedy recovery!

**“May your heart beat stronger
than ever before”**

Hannah & Katie



Glossary



Arrhythmia

An arrhythmia is an abnormal heart rhythm, which means that your heart beats too slowly, too fast or has an irregular beat.

Sick sinus syndrome (SSS)

Sick sinus syndrome (SSS) is a general term for a group of disorders caused by a malfunctioning sinus node. The sinus node acts as a pacemaker inside the heart. Sinus rhythm (the normal beating of the heart) is controlled by electrical impulses from the sinus node. Without the correct impulses, the heart cannot beat properly.

Heart block

In people with heart block the electrical pulses that control the heart rate are disrupted, causing the heart to beat more slowly. There are three levels of heart block and usually only the most serious type causes symptoms. This type of heart block is known as a complete, or third-degree, heart block.

Syncope

Syncope, commonly known as fainting, refers to a sudden loss of consciousness, followed by a rapid and complete recovery. A number of disturbances in the rate or rhythm of the heart can cause syncope.

Heart failure

Heart failure is a condition caused by the heart failing to pump enough blood around the body at the right pressure. It usually occurs because the heart muscle has become too weak or stiff to work properly. If you have heart failure, it does not mean your heart is about to stop working. It means your heart needs some support to do its job, usually in the form of medicines or a pacemaker.

Pacemaker

A pacemaker is a small device that's placed in the chest or abdomen to help control abnormal heart rhythms. The picture on page 15 shows the size of the pacemaker. This device uses electrical pulses to prompt the heart to beat at a normal rate.

Notes:

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Appointments:

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**Written & created by
Hannah Phillips & Katie Miller**

‘Our aim was to show that information doesn’t have to be clinical and boring. We hope it will answer any questions that you or other young people have as well as guide and support others on their journey.’

This booklet was written for young people by young people, with support from the engagement team at Evelina London Children’s Hospital, part of Guy’s and St Thomas’ NHS Foundation Trust.

**Graphic Design & Photography
by Jeannie Ford**