Royal Brompton \& Harefield N/HS
NHS Foundation Trust
A lifetime of specialist care

For children and young people

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This leaflet is about your visit to the cardiomyopathy clinic at Royal Brompton Hospital. The leaflet tells you what will happen at the clinic. You can read the leaflet with your parents or carers before you come in to hospital. If you have any questions, you can ask your parents or carers. You can also ask the doctors and nurses at the clinic.

## Visiting the clinic

You are coming to see doctors and nurses in the cardiomyopathy clinic. The doctors and nurses want to find out more about your heart, to see how well it is working.

Your parents or carers can stay with you all day.

## In the clinic

In the clinic you will meet some doctors and nurses. You will also meet a play specialist. Play specialists use play to help children with their tests.

There is also a psychologist in the clinic. A psychologist is someone who can talk to you about how you are feeling, and any worries you may have. They might also meet with members of your family. If you would like to speak to a psychologist, let your parents or the doctors or nurses know. It is your choice about whether you meet with a psychologist or not.

When you get to the clinic, you will wait to see the doctors and nurses in the waiting area. The waiting area has toys, colouring pencils and a TV.

You can also bring your favourite toy, electronics or game, so you don't get bored while you are waiting. You can connect to the hospital's wifi too (if your parents agree).
Finding out about your heart

To find out more about your heart, the doctors and nurses will do some tests.

A nurse and a play specialist will tell you more about the heart tests. You can ask them if you have any questions. You can also write any questions down in the space at the back of this leaflet.

The following pages tell you about all the tests. You might not have the tests in the same order as this leaflet says.

General tests
A doctor or nurse will check how fast your heart beats, and how your heart pumps blood through your body.

A nurse will measure how tall you are and how much you weigh.

## Blood test

Your blood can tell the doctor more about your heart.

The nurse uses a needle to get some blood, a bit like an injection. The needle can hurt a bit, but not for very long.

The nurse has 'magic cream' and spray. The cream or spray goes
 on your hand or arm and makes it numb, so it shouldn't hurt.

## Electrocardiogram (ECG)

Your heart beats using a sort of electricity. The doctors and nurses can learn more about your heart by watching the electricity, and the patterns it makes.


To see the electricity, the nurse will put some stickers on your chest. The stickers attach to wires that are connected to a monitor. You have to lie still, but this test doesn't hurt.

The monitor shows the electricity patterns. The pattern prints onto graph paper. If you want to see the patterns, ask your nurse.

## Echocardiogram (echo) <br> Doctors can see your heart beating by using a scan. They will put some squidgy jelly onto your chest and use a special probe to see a video of the inside of your heart beating.

You need to lie as still as you can. Although it can tickle, this test doesn't hurt.

The doctor will use the picture to measure parts of your heart.


Magnetic resonance imaging (MRI)scan
An MRI scan shows photos of the inside of your body. It shows doctors how your heart is working.

Your parents or carers can sometimes stay with you for the scan.

Before the scan you will change into a hospital gown.

You may need a 'cannula'. A cannula is a tube (like a bendy straw) that is put into a vein in your arm or hand. A needle is used to put the cannula into the vein. You will be given magic cream or spray so it doesn't hurt.

Not everyone needs a cannula. Ask your doctor or nurse on the day if you will need one.

If you do need a cannula, we can use it to take the blood test as well, so you won't need to have two needles.

For the scan, you lie on a bed, and the bed goes inside the scanner.

The scanner is noisy, but you will wear headphones to make it quieter. You can still hear the people around you though. The scanner has a microphone, so you can talk to everyone. There is a screen so that we can see you and know that you are OK. You will also have a special button to hold. If you are not OK, you can press the button to tell everyone.

The scan can take an hour. You need to lie very still when the pictures are being taken. It doesn't hurt and you can listen to music if you want.
The doctors will ask you to hold your breath occasionally during the scan, so try to practise doing this at home.

Sometimes children fall asleep during the scan. It is fine to fall asleep.

## After your tests

When the tests are finished, you can leave the clinic for a while to get some lunch. You will need to come back in the afternoon to see the doctors.

The doctors will ask you some questions. They will also examine you by feeling your hands, feet and tummy. They will also listen to your heart.

The doctors will tell you what they found out from your tests, and what happens next.

## Finding out more

If you or your parents or carers want to know more about your visit to the clinic, you/they can phone the paediatric clinical nurse specialists on 0207352 8121, extension 2205 (Monday to Friday, $9 a m-5 p m$ ).

If you need to change your appointment, your parents or carers can call the paediatric cardiomyopathy clinic scheduler on 0207352 8121, extension 2919 (Monday to Friday, 9am-5pm).

## My questions

If you have any questions, you can write them down here:

## For parents/ carers

If you are unhappy with the service you have received in hospital, you can call the Patient Advice and Liaison Service (PALS) Royal Brompton Hospital on: 02073497715 . You can also email: pals@rbht.nhs.uk. PALS is a confidential service that provides support and advice to patients, families and carers.

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