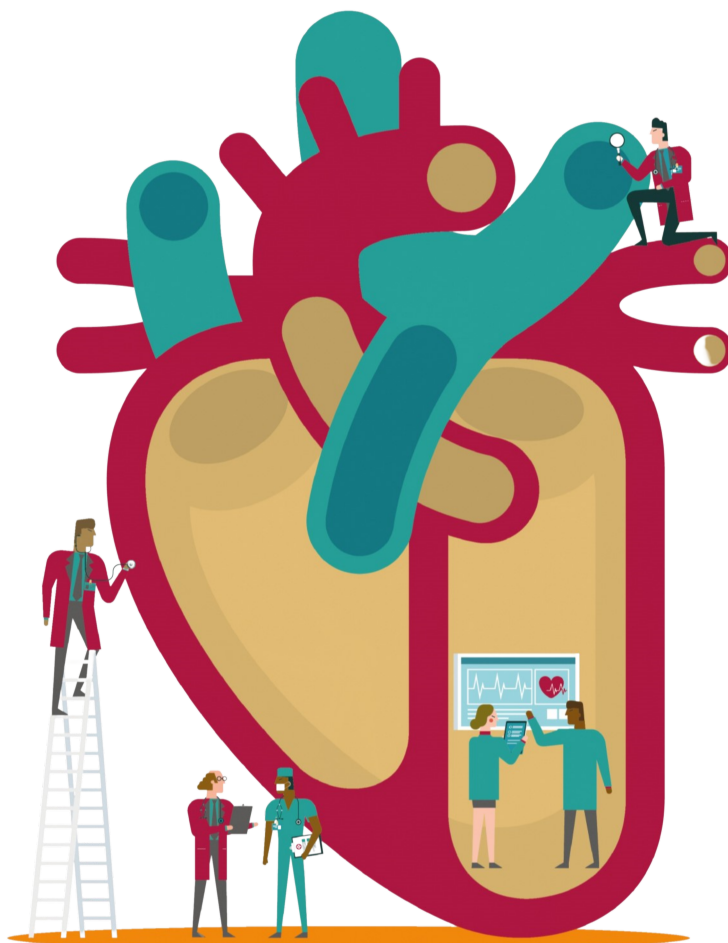


My Cardiomyopathy and Me

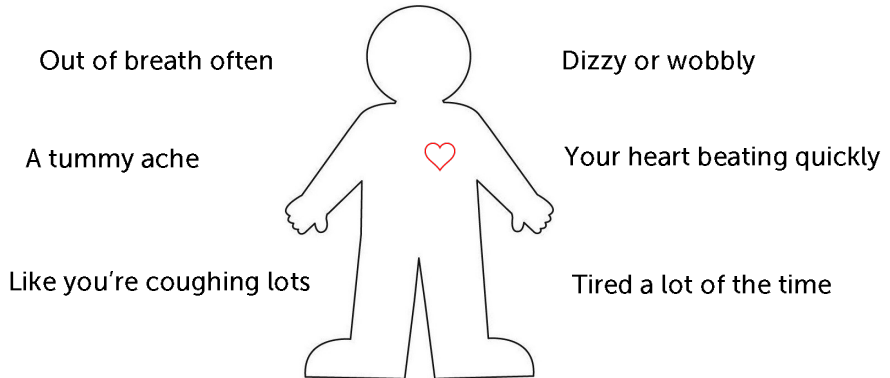


Name: _____

My Body

Inside your chest is a muscle called your heart. Your heart works hard to pump blood around your body to deliver the nutrients it needs to work. Put your hand on your chest. Can you feel your heart beating? This is your heart squeezing and pumping the blood around your body.

When you have cardiomyopathy, your heart can't pump the blood around your body as it should do. A lot of the time, you might not notice this at all. If your heart needs some help, you might feel:



You could call these your heart feelings. **Draw a circle around any of these heart feelings which you can feel in your body.**

Do you have any other feelings? Draw or write them here.

My Helpful People

When you feel poorly or have some of your heart feelings, there are lots of people who can help you by:

- Giving you healthy food and drink, and any medicine you need
- Comforting you if you feel unwell, sad or worried
- Listening to you and talking to you about how you are feeling
- Helping you to understand more about your heart and heart feelings
- Answering your questions about your heart, body or feelings
- Spending time with you and having fun with you

These people could be:

Family

Doctors

Nurses

Teachers

Friends

Social Workers

Childminders

Pets can also be very good listeners and help you to feel better if you're worried or feeling unwell



Who are your helpful people or pets? Draw or write their names here.

These people make up your cardiomyopathy family.

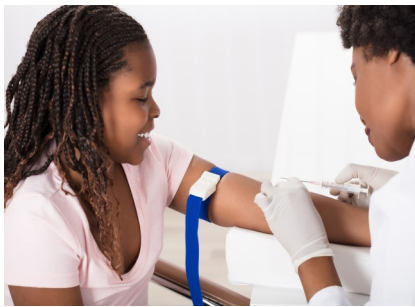
My Hospital Visits

A heart with cardiomyopathy can be helped to feel better with medicine and treatments. Having cardiomyopathy, or someone in your family having it, means you will need to have your heart checked at the hospital or clinic. At your appointment you will see a doctor or nurse who will ask you how you're feeling. You can ask them any questions or talk to them about any worries. There can be a lot of waiting around in hospital, so you might want to bring along something to do while you wait.

Parents/carers: Our Activity Pack for children can be downloaded from our website: www.cardiomyopathy.org.

Blood Pressure and Oxygen

A nurse will take your blood pressure with a cuff that wraps around your arm and puffs up. They may put a little clip on your finger for a minute to check the oxygen levels in your blood.



Blood Tests

You might also have to have a blood test. The doctor or nurse will use a special cream or spray on your arm to make it numb, then you will need to keep very still for a few minutes whilst they take a sample of your blood.

Echocardiogram (Echo)

You may need to have an Echo. The Echo can show you a picture of what your heart looks like. You will lie on a bed and a special gel will be put on your chest. The doctor or nurse will then use a probe which they will move around your chest to get a good look at your heart.



Electrocardiogram (ECG)

An ECG tests the activity of your heart. If you have an ECG in hospital, you will sit or lie down and stickers are put onto your arms, legs and chest. These are connected by wires to an ECG machine which creates a pattern showing your heart rhythm. You need to stay very still so that the machine can work properly.



Your doctor might need you to take an ECG monitor home with you and wear it for a day or two. This is called a **Holter** monitor. You can carry on doing the things you normally do but you will have stickers and wires under your clothes and carry a small monitor around (it normally clips onto your trousers or you can wear it like a bag).

An ECG machine will draw out the rhythm of your heart. Ask your doctor or nurse to show you the pattern that your heart makes!



Cardiac MRI (CMR)

The doctor may need to take photos of your heart using a Cardiovascular Magnetic Resonance Image machine (Cardiac MRI or CMR). It looks like a huge doughnut! A doctor or nurse will ask you to breathe in and out and they can play you some music to listen to whilst you lie still inside the machine and it takes photos of your heart (a bit like an x-ray).



My Healthy Body and Mind

Its important for everyone to look after themselves. This means doing the best you can to keep your body and mind healthy. Your helpful people can help you to do this, and might include things like:



Choosing healthy food and drink



Keeping active in a safe way



Having fun with people you love



Getting enough rest and sleep



Taking any medicines you need



What things do you do to keep yourself healthy? Draw or write them here.

My Life

Your heart is one of a kind. Your doctor or nurse will talk to you about your special heart and how to look after it. They can help you to:

- Make sure the sports and hobbies you like are still safe for you to do
- Make choices about what you eat and drink to stay healthy
- Make some changes to your routine if you need to
- Make a plan with your school so they understand your cardiomyopathy and how they can help

What things do you enjoy doing? Draw or write them here. Talk to your doctor or nurse about how you can enjoy these things safely.

Now you've finished your booklet you can show it off! Why not share what you've been drawing and writing with your parent, carer, doctor or nurse? Keep it safe – it's yours to keep.

Parent or carer? We have a range of information and services to help you to support your child and family. Visit our website, join our closed Facebook group or connect with us on social media (details overleaf).

Cardiomyopathy^{UK}
the heart muscle charity

Supported by






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w: cardiomyopathy.org

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