

Cardiomyopathy<sup>UK</sup>  
the heart muscle charity

# Cardiomyopathy

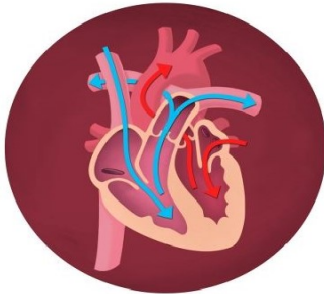


## and Me

# What does cardiomyopathy mean for my body?

Cardiomyopathy is when your heart muscle isn't working how it should be, because of its size, shape or thickness. This can affect the way it pumps blood around your body. There are different types of cardiomyopathy which each have a different effect on the heart muscle. Here are the most common types:

Adapted from [Doctorsaustralia.com.au](http://Doctorsaustralia.com.au)



A healthy heart



Dilated cardiomyopathy (DCM)



Hypertrophic cardiomyopathy (HCM)



Restrictive cardiomyopathy (RCM)



Arrhythmogenic cardiomyopathy (ACM)

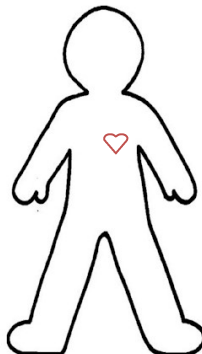
There are at least 160,000 people in the UK with cardiomyopathy. Every heart is different and everyone with cardiomyopathy will have different symptoms, which may include feeling no different at all! Without the condition being managed, some of the things people could experience are:

Feeling out of breath

Uncomfortable chest

Feeling tired

Feeling not quite right



Feeling dizzy or faint

Heart beating quickly

Feeling bloated or full

Puffy legs, ankles and feet

Talk to a parent, carer, doctor or nurse about any symptoms you have.

## Why me?

You may have already been diagnosed with cardiomyopathy, or perhaps you haven't been diagnosed but it's a possibility due to symptoms you're having or your family history.

### Causes

There are many possible causes of cardiomyopathy, though often the specific cause for each person is unknown.

- Some types are genetic, caused by a change in the person's DNA which affects how their heart develops.
- Other causes can include viral infections, autoimmune diseases and some medications.

In many families cardiomyopathy is an inherited condition, which means it can be passed on from a parent to their children. If someone in your family has been diagnosed with cardiomyopathy, a change in their DNA might be identified. This change can then be looked for in other close family members. People with close family members with a diagnosis of cardiomyopathy may be offered regular screening at the hospital to check their heart for signs of cardiomyopathy.

### Do other young people have cardiomyopathy?

Yes! Being diagnosed with cardiomyopathy, or having regular testing for it, is likely to bring about strong feelings. These feelings are normal and it's likely that you're not the only person feeling this way. It may help to talk to other young people who have cardiomyopathy or who are in a similar situation to you. Cardiomyopathy UK have a Youth Panel made up of young people affected by cardiomyopathy who are here to listen and to support you. You can:

- Join our closed Facebook group **14-25 Cardiomyopathy UK**
- Connect with us on social media
- Live Chat on our website
- Call us on 0800 018 1024

**Aged 16-17?** Once you turn 18 you will be seen by an adult cardiology team. You can talk to other young people who've recently been through this transition by getting in touch in any of the ways above.

w: [cardiomyopathy.org](http://cardiomyopathy.org)  
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## What's going to happen next?

Cardiomyopathy isn't curable, but there are loads of things that can be done to help you feel better and get on with your life. Your treatment plan will depend on the type of cardiomyopathy you have and will be unique to you, but here are some of the things which you may expect:

### Regular check ups

Approximately once every 6 months - 2 years, you'll go along to the hospital or clinic for a check up. A nurse will take your blood pressure and talk to you about how you're feeling and any symptoms you've been having. You might also have a blood test. You'll see a doctor and talk to them about how you're managing your condition and discuss any further tests or changes to your treatment plan.

### Genetic testing

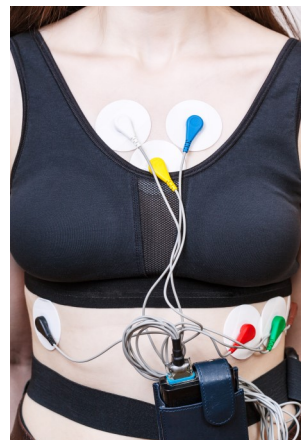
You may be advised to have genetic testing. This involves a consultant or genetic counsellor looking at your family tree in addition to taking a blood test and/or a mouth swab to have a look at your genes, located in your DNA, for specific changes related to cardiomyopathy.

### Clinical screening

Clinical screening is when you have tests to look for or monitor signs of cardiomyopathy, perhaps because of symptoms you're having or because a family member has been diagnosed. This may include:

### **Electrocardiogram (ECG)**

The ECG looks at the rhythm and activity of your heart. 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. A **Holter** or **24-hour ECG** is a similar test but records your heartbeat over 24-48 hours. You will wear a monitor under your normal clothes and go about your normal daily life, keeping a diary of your activities. You will then return the monitor to the hospital for them to analyse.





### Echocardiogram (Echo)

An Echo creates an image of what your heart looks like. A gel will be put on your chest then the doctor or nurse will use a small probe which they will move around your chest to get a good look at your heart.

### Cardiovascular Magnetic Resonance Image (Cardiac MRI)

The Cardiac MRI, or CMR, captures detailed images of your heart. You need to lie very still while the machine does its work. It is quite noisy so you can ask the technician to play some music.



### Exercise Tolerance Test (ETT)

An ETT assesses your heart when it's pumping at a faster rate e.g. whilst you use an exercise bike or treadmill. The rhythm and function of your heart, as well as your blood pressure and breathing, are monitored during this test.

### Treatments

There are many treatment options for cardiomyopathy, depending on the type of cardiomyopathy and symptoms. These could include:

#### Healthy lifestyle

Eating and drinking healthily, exercising safely (informed by your doctor's recommendations) and getting enough rest and self-care are very important in managing all cardiomyopathies, as well as refraining from smoking, vaping, drug taking and heavy alcohol use.





## Medication

Your doctor may prescribe you medication to take every day to help manage your condition. Some people find that an app on their phone helps to remind them to take their medication on time.

## Surgery and medical devices

Your doctor may recommend surgery or implantable medical devices to improve or manage your condition. Your doctor will tell you more about these, but they could include:

### *Implantable cardioverter-defibrillators (ICDs or S-ICDs):*

These are small electrical devices implanted in the chest. The purpose of an ICD or S-ICD may be to pace your heart to a normal rhythm and/or to automatically defibrillate (shock) your heart if it develops a dangerous rhythm.



### *Septal myectomy:*

This involves removing part of the thickened wall of the heart to improve blood flow from the heart.

### *Heart transplant:*

If other treatments are not appropriate, a donor heart may be needed.



## Healthy mind

Looking after your mind is just as important as looking after your body. Coming to terms with a medical condition can feel like a loss and it's important to have help and support. If you develop feelings of low mood, depression or anxiety, or are getting involved in risky behaviours, it's important to talk to someone who can help. This may include: feeling hopeless, not being able to concentrate, not enjoying things you did before, using drugs, alcohol or sex to take your mind off things, and having thoughts about harming yourself. Visit [www.nhs.uk/mental-health](http://www.nhs.uk/mental-health) for info.

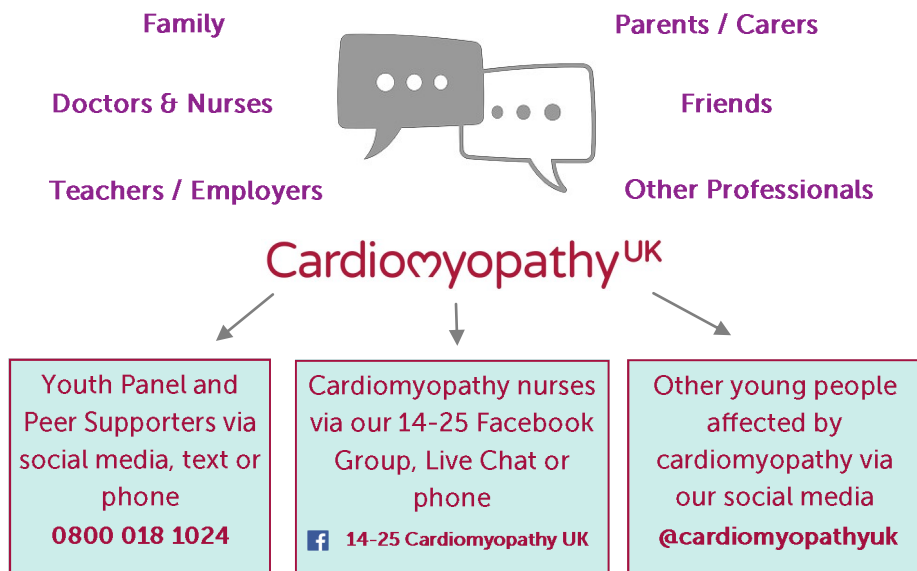
## What does cardiomyopathy mean for my life?

Cardiomyopathy doesn't automatically stop you from doing the things you enjoy. **Most young people with cardiomyopathy can continue to have normal hobbies, relationships and experiences.** Life may look a little different than you expected, but it can open up new opportunities you'd never even thought about—just ask our Youth Panel!

It can be hard to find a balance. **Many young people feel like their parents or carers are too overprotective and many parents or carers feel their child's actions are too risky or unsafe.** Remember that your parents or carers may be acting in a certain way because they are worried about you. Talk to them about how you feel and the things you want to do, then discuss these with your cardiologist, doctor or nurse together as part of your treatment plan.

## Who can I talk to?

It's up to you who you talk to about your cardiomyopathy but it's important to talk to someone. All of the people you choose to have around you on this journey make up your cardiomyopathy family.



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