What can I do about Cardiomyopathy

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‘a diagnosis of cardiomyopathy may feel devastating, but with the right information and support most people can live full and active lives’

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What is cardiomyopathy?

Cardiomyopathy is a disease of the heart muscle.

('Cardio' means heart, 'myo' means muscle and 'pathy'means disease.) It isn't a single condition, but a group of conditions that affect the structure of the heart and reduce its ability to pump blood around the body.

Who gets cardiomyopathy?

Cardiomyopathy can affect anyone, at any age. It is thought to affect around 160,000 people in the UK, which is around 1 in 500 people.

Cardiomyopathy affects the muscle of the heart. It can affect the shape of the heart, or the size and thickness of the muscle walls. This then affects how the heart works. The way the heart is affected depends on the type of cardiomyopathy the person has.

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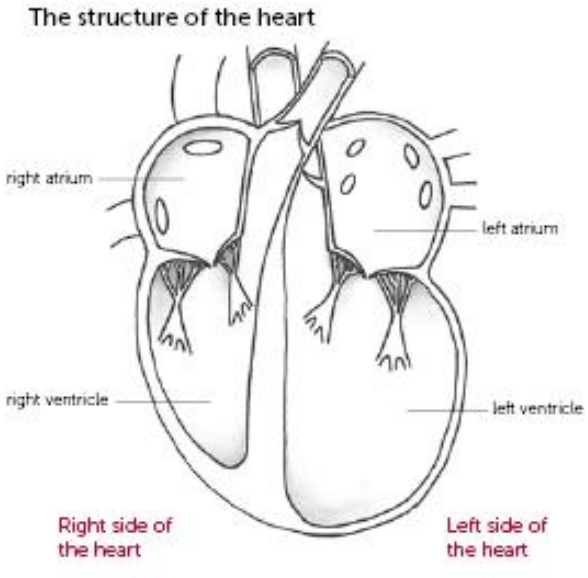
Types of cardiomyopathy

There are different types of cardiomyopathy, which vary depending on how they affect the heart muscle.

Dilated cardiomyopathy (DCM)

This is when the muscle of the left ventricle becomes enlarged (dilated) and stretched. This makes the wall of the ventricle bigger but thinner, and so the muscle is weaker and less able to pump blood out of the heart. Although DCM can affect anyone, it can develop when a woman is pregnant, when it may be referred to as peripartum cardiomyopathy.



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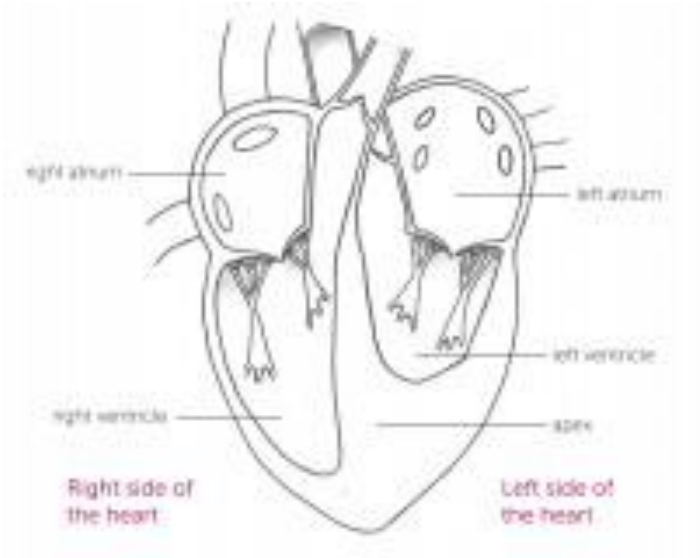
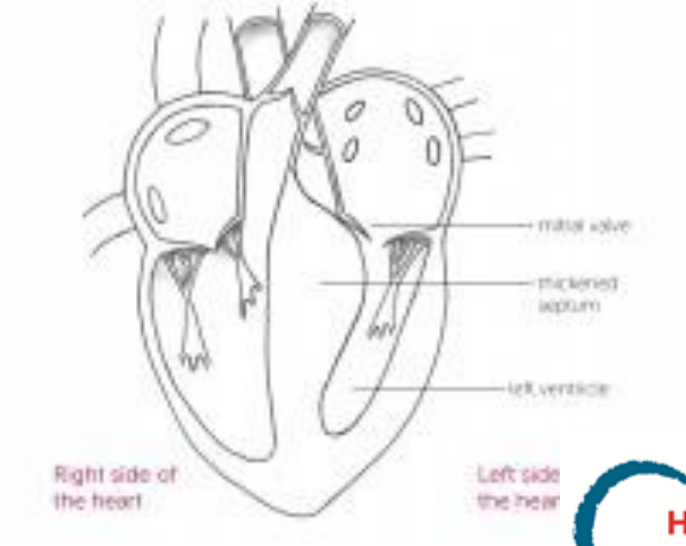
Hypertrophic cardiomyopathy (HCM)

This is when the muscle of the ventricle thickens (called ‘hypertrophy’) and makes the ventricle smaller. The thickening means that the heart has to work harder to fill with blood, and pump blood around the body. It can also block the blood flow out of the heart.





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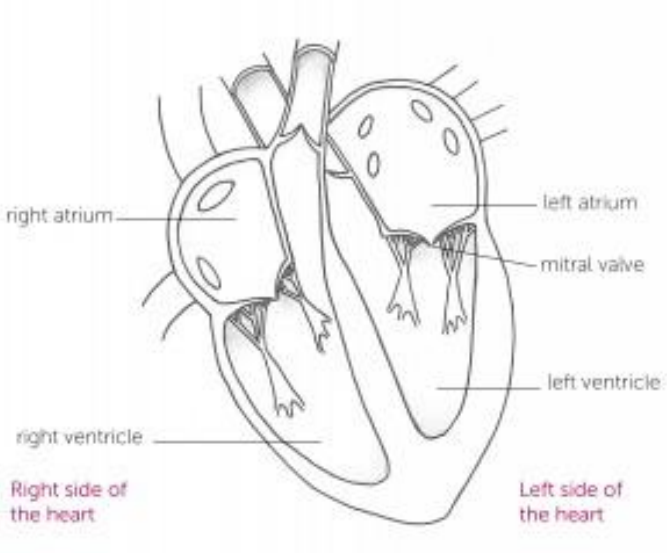
Arrhythmogenic right ventricular cardiomyopathy

ARVC also called arrhythmic cardiomyopathy This is when heart muscle cells are not joined together properly, and so they die and get replaced by scar tissue or fat. This makes the heart muscle stretched, thinner and weaker, making it less able to pump blood out of the heart as well as it should.



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Restrictive, LVNC, & Takotsubo

Restrictive cardiomyopathy

This is when the heart muscle becomes stiff and cannot relax properly, which makes it harder for the top chambers to fill with blood. The chambers then become enlarged and blood cannot flow properly.

Left ventricular non-compaction (LVNC)

This is when there is a problem with how the heart muscle develops in an unborn baby. The muscle cells do not compact (tightly pack) together as normal, which causes small indentations in the muscle and it appears spongy. This affects how the heart works.

Takotsubo or 'broken heart' syndrome

This usually happens during a time of extreme stress (which gives it the name 'broken heart'). The left ventricle becomes enlarged and weakened. It is often only temporary, and usually gets better with time.

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Symptoms

Although some people have cardiomyopathy without having any symptoms, other people might experience symptoms such as:

- tiredness (due to low oxygen levels);
- breathlessness (due to fluid on the lungs);
- swelling in the abdomen and ankles;
- palpitations (feeling your heartbeat);
- pain in the chest; and
- dizziness or fainting

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How is cardiomyopathy diagnosed?

To diagnose cardiomyopathy, there are various tests that a cardiologist (heart specialist) might suggest. These include taking a family history, a physical exam, an ECG (electrocardiogram) during exercise to look at the electrical activity of the heart, and an echo (echocardiogram) or MRI (magnetic resonance imaging) scan to look at the structure of the heart. Genetic testing, family screening

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How is cardiomyopathy treated?

Although it can't be cured, the following treatment options aim to reduce and control the symptoms.

- Some people take medication to control their heart rate (beta-blockers), to reduce the chance of blood clots forming (anti-coagulants), or to reduce the build-up of the fluid in the body that causes swelling (diuretics or 'water tablets').
- Some people have a device implanted (put into their body during surgery) to control the rhythm of their heart (called 'pacemakers'), or to control the rhythm and shock the heart if it goes out of normal rhythm (called implantable cardioverter defibrillators or ICDs).
- Some people have surgery to remove areas of heart muscle if it affects blood flow from the heart.
- A very small number of people may need a heart transplant (a heart from a donor).

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Family screening

As cardiomyopathy is often inherited

Positive genetics

First-degree relatives should be offered clinical screening with an ECG and echocardiogram, and physical examination

Potential benefits of screening in childhood include reduction of uncertainty and anxiety, psychological adjustment, the opportunity to make realistic life plans, and targeted clinical surveillance

From around the age of 10 years and then 6-12 monthly during growth spurts

On maturity, may recommend 5 yearly screening

Letter from cardiologist to proband who can then distribute to the family.

Clinical or genetic testing at a younger age may be appropriate in families with early-onset disorders

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Genetic testing in cardiomyopathy

If you have a definite diagnosis of cardiomyopathy you may be offered genetic testing. Testing also includes mapping a person's family tree, to see if genetic traits occur in other members of their family. A gene is found in 25–60% of people who have genetic testing for cardiomyopathy. In this case, the test can be used to identify whether the person's first-degree relatives also have the same gene.

Genetic testing can identify whether an individual's relatives have, or are at risk of having, the same condition. This may help in treatment.

What is pre-implantation genetic diagnosis?

Pre-implantation genetic diagnosis (PGD) is a type of IVF (in vitro fertilisation) that tests the fertilised eggs for certain medical conditions before they are implanted into the mother's womb.

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Lifestyle management

Minimise alcohol – alcohol can raise your heart rate and increase blood pressure. Keep within recommended guidelines

Healthy eating – a balanced diet, a healthy weight, which will reduce the impact on the heart as well as helping with general health.

Minimising salt –help to reduce water retention (which can cause swelling in the ankles and tummy) and blood pressure. Your specialist can give you guidance on your salt intake.

Stopping smoking is important to help your overall health as well as your heart and lung function (as it can reduce oxygen levels in the blood as well as narrowing blood vessels).

Minimise caffeine – some people are more sensitive to the effects of caffeine, and it can cause palpitations in some people.

Exercise is often recommended for people with a heart condition. Moderate exercise can be important for people with cardiomyopathy, depending on what type and symptoms they have. It is important to talk to your doctors about what exercise is suitable for you.

You might also like to ask whether you can have cardiac rehabilitatio which offers practical advice about exercise.

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What will help??

"Share a tip"

- Be proactive and be your own advocate, believe in yourself.
- Ask for referral to specialist hospital.
- Keep a health / appointment diary – to review.
- Keep all your info – appointments, results in a folder to refer back to.
- Be prepared to wait for answers.
- Book 'rest days' to avoid fatigue.
- Join a support group!

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Day to day living with cardiomyopathy

Dealing with a diagnosis of cardiomyopathy can have a huge impact on every aspect of day to day life, from relationships to work, travel, driving and even benefits.

Find out about your condition

Cardiomyopathy UK

Find a specialist near you

2014 ESC Guidelines on diagnosis and management of hypertrophic cardiomyopathy

NICE Heart failure guidance 2018

The Equality Act 2010 is a law that protects people with certain ‘protected characteristics’ from being discriminated against or treated unfairly due to these characteristics.

Know your rights

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Information booklets, podcasts, website, information days. Meet other people who have cardiomyopathy, normal lives.

Find out who can help you when you need it eg nurse specialists, CMA helpline, friends, local GP

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