Cardiomyopathy UK
the heart muscle charity

# What is Cardiomyopathy?

An introduction to the disease of the heart muscle

- Cardiomyopathy is a disease of the heart muscle.
- It affects around 1 in 250 people in the UK.
- Although a diagnosis of cardiomyopathy can be life-changing, with the right treatment and support most people can live full and active lives.

## What is cardiomyopathy?

Cardiomyopathy is a group of conditions that affect the structure of the heart muscle and reduce its ability to pump blood around the body. It is not a single condition but rather a disease of the heart muscle. The word "cardio" means heart, "myo" means muscle and "pathy" means disease.

## Who gets cardiomyopathy?

Cardiomyopathy is a rare disease that affects around 270,000 people in the UK, which is around 1 in 500 people. The incidence of cardiomyopathy varies depending on the type of cardiomyopathy. Dilated cardiomyopathy (DCM) is the most common type of cardiomyopathy and affects around 1 in 250 people. Hypertrophic cardiomyopathy (HCM) affects around 1 in 500 people. Restrictive cardiomyopathy (RCM) is rare and affects around 1 in 10,000 people.

## How cardiomyopathy affects the heart

Cardiomyopathy is a condition that affects the muscle of the heart. It can cause changes in the shape, size and thickness of the heart muscle walls, which can impair the normal functioning of the heart. There are different types of cardiomyopathy, and each one has a different impact on the heart.

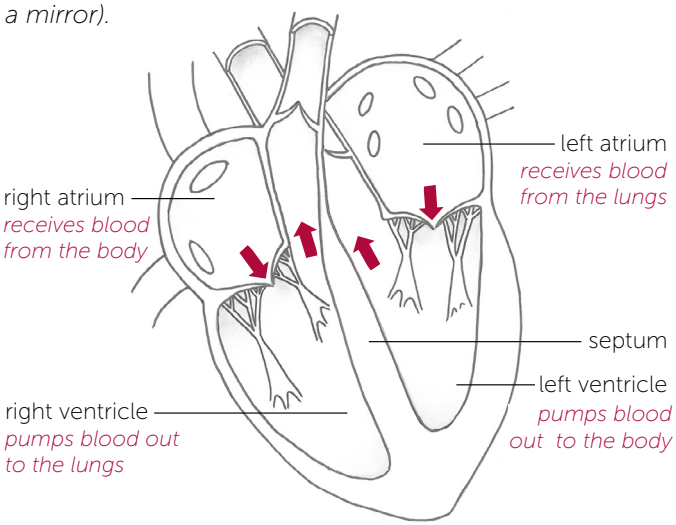
## What does the heart do and how does it work?

The heart is a vital organ that ensures the delivery of oxygen and nutrients to all parts of the body. It works as a powerful pump that contracts and relaxes in a rhythmic cycle. The heart has four separate chambers that each perform a specific function in the circulation of blood. The right atrium receives blood from the veins and sends it to the right ventricle. The right ventricle pumps blood to the lungs, where it gets oxygenated.

The left atrium receives blood from the lungs and sends it to the left ventricle. The left ventricle pumps blood to the arteries, which carry it to the rest of the body. The heart muscle cells are specialised to maintain this constant activity without fatigue or rest. The heart is also protected by a layer of connective tissue called the pericardium, which prevents friction and infection.

*For more information see our information sheet 'About the heart'*

*The structure of the heart (as if you were looking in a mirror).*




## Types of cardiomyopathy

**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. Sometimes DCM develops during or after pregnancy, especially in the last month or within five months of delivery. This is called peripartum cardiomyopathy.

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**Hypertrophic cardiomyopathy (HCM)**
This is a genetic condition that causes the heart muscle to thicken abnormally. This can affect the size and function of the heart chambers, and sometimes block the blood flow out of the heart. The thickening of the heart muscle can also make it harder for the heart to relax and fill with blood.

**Arrhythmogenic cardiomyopathy (ACM or ARVC)**
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.

**Restrictive cardiomyopathy (RCM)**
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 syndrome**
This usually happens during a time of extreme physical or emotional stress. The left ventricle becomes enlarged and weakened. In many people it is a fully treatable condition, however, it can take time for the symptoms to fully resolve.

## What causes cardiomyopathy?

There are many possible causes of cardiomyopathy. Some types are genetic: caused by a mutation in the person's DNA (genetic material) which affects how their heart develops. Genetic conditions may be inherited (passed from parent to child) so cardiomyopathy sometimes runs in families. Often if one person is diagnosed with cardiomyopathy it is recommended that their close family members such as parents, siblings and children (known as first-degree relatives) are tested for the condition too. Other causes include viral infections, autoimmune diseases (which affect the immune system), and some medications (such as some used to treat cancer).

What are the symptoms of cardiomyopathy? The symptoms of cardiomyopathy can vary depending on the type of cardiomyopathy and the severity of the condition. However, some common symptoms include:

- Shortness of breath
- Fatigue
- Swelling in the legs, ankles and feet
- Dizziness or lightheadedness
- Fainting during physical activity

It is important to note that some people with cardiomyopathy may not experience any symptoms at all. If you are experiencing any of these symptoms or have concerns about your heart health, it is important to speak to a healthcare professional.

## How is cardiomyopathy diagnosed?

To find out if a person has cardiomyopathy, a healthcare professional may use different tests to check the heart's function and structure. Some of these tests are:

- **Family history:** The clinician may ask about any relatives who have had heart problems or sudden death, as some types of cardiomyopathy can be inherited.
- **Physical exam:** The clinician may listen to the heart and lungs, measure blood pressure and pulse, and look for signs of fluid buildup in the body.
- **ECG:** This test records the electrical activity of the heart and shows how fast and regular the heartbeat is. It can also detect any abnormal rhythms or damage to the heart muscle.
- **Exercise ECG:** This test is similar to an ECG, but it is done while the person is exercising on a treadmill or bike. It can show how well the heart responds to stress and if there is any reduced blood flow to the heart.
- **Echo:** This test uses sound waves to create a picture of the heart and its chambers. It can measure the size, shape, and thickness of the heart muscle, as well as how well it contracts and relaxes. It can also show if there is any valve problems or fluid around the heart.
- **MRI:** This test uses a strong magnetic field and radio waves to create detailed images of the heart and its tissues. It can show more information about the structure and function of the heart than an echo, and can also detect any scar tissue or inflammation in the heart muscle.

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## How is cardiomyopathy treated?

Although it can't yet be cured, treatment options aim to reduce and control the symptoms. They include medication, cardiac devices and surgery.

## What next?

You may be reading this information sheet because you, or someone you know, have been told that you may have cardiomyopathy. Or perhaps you have been recently diagnosed. It can be a difficult time and you may feel overwhelmed. You may have read information about the condition that has really worried you. It is natural to have lots of questions, and you may want to talk to someone who understands. Although the possibility of a diagnosis of cardiomyopathy may feel devastating, with the right information and support most people can live full and active lives.

## We're here for you

At Cardiomyopathy UK we offer help and support for you and your family. We have information about each type of cardiomyopathy as well as diagnosis, treatment and lifestyle issues. Look on our website or call us for more information. Call our helpline to talk to our cardiomyopathy support nurses. We can put you in contact with other people affected by cardiomyopathy through our support groups, peer support volunteers and social media. Contact us for more about our services, or look online.

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