Restrictive Cardiomyopathy (RCM)

CARDIOMYOPATHY
Australia New Zealand
The Big-Hearted Community

A guide for people with restrictive cardiomyopathy, families, and carers in Australia and New Zealand.

Restrictive cardiomyopathy (RCM) is a rare form of cardiomyopathy. It happens when the heart muscle becomes stiff and less able to stretch, making it harder for the lower chambers (ventricles) to fill with blood. This can lead to symptoms such as breathlessness and swelling.

This general information is for people living in Australia and New Zealand who are affected by RCM and should not replace advice from your doctor or healthcare team.

What is Restrictive Cardiomyopathy?

Restrictive cardiomyopathy (RCM) is a condition where scar tissue or abnormal amounts of proteins build up in the heart tissue. This makes the walls of the ventricles (the lower chambers of the heart) stiff and less able to move freely.

During RCM, the heart is usually still able to contract to pump blood out to the body. However, when the heart relaxes, less blood is able to enter the ventricles because the stiff heart muscle doesn't relax fully. This means the heart receives less blood than normal, reducing blood flow to the body. RCM can also cause blood to back up in the circulation, leading to a build-up of pressure in the veins and lungs. Over time, this increased pressure can cause the atria (the upper chambers of the heart) to enlarge. It can also lead to heart rhythm disturbances and heart failure.

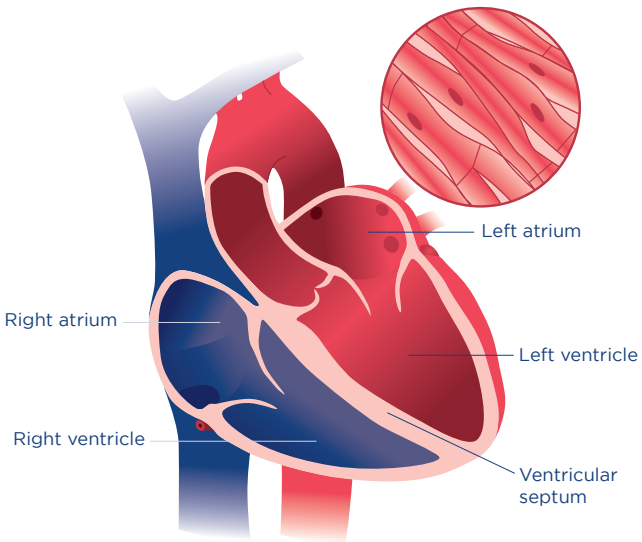
What causes Restrictive Cardiomyopathy?

RCM can occur on its own or as part of another condition that affects the heart muscle (called secondary or acquired RCM). This includes other types of cardiomyopathy. It can also be idiopathic, which means that the cause is not known. Some conditions that can cause RCM are:

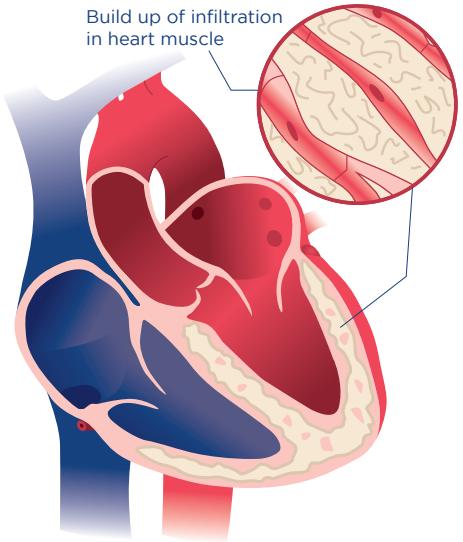
- **Infiltrative diseases** – where substances build up, or infiltrate, the heart tissue. This includes a build-up of abnormal proteins (amyloidosis), cells from your immune system (sarcoidosis), or iron (haemochromatosis).
- **Genetics** – where gene variations cause changes to heart tissue.
- **Cancer and cancer treatments** – particularly some kinds of chemotherapy and radiotherapy.
- **Scarring or fibrosis** which can happen after other heart conditions.

RCM can affect both adults and children, but it is most common in adults over 40 years of age. Cases in children or adolescents are most often inherited, from genetic causes. These genetic variants are typically inherited in an autosomal dominant pattern, meaning there is a 50% (1 in 2) chance of a parent passing the variant to each child.

Heart without Restrictive Cardiomyopathy



Heart with Restrictive Cardiomyopathy



However, not everyone with a variant will develop symptoms and severity can vary within the same family.

In Australia and New Zealand, the most common cause is secondary RCM from conditions like cardiac amyloidosis.

What are the symptoms of Restrictive Cardiomyopathy?

The symptoms of RCM happen because the stiff heart muscle cannot fill properly, causing pressure in the lungs and blood vessels. Symptoms may develop gradually or progress over time.

Common symptoms include:

- Shortness of breath (especially while lying flat or during activity)
- Swelling in the legs, ankles, or belly
- Fatigue or feeling unusually tired
- Irregular heartbeat or heart flutters (palpitations)
- Feeling dizzy or light-headed
- Fainting (syncope) in advanced cases
- Difficulty exercising or performing usual activities

How is Restrictive Cardiomyopathy diagnosed?

To find out if someone has RCM doctors use a range of tests. No single test can confirm the condition on its own, but each helps build a clearer picture. Some of the tests used are:

- **Electrocardiogram (ECG):** measures heart rhythm and can show if the electrical signals controlling the rhythm are normal. An ECG can be measured in a doctor's office, or in some cases a portable ECG will be worn for 24–48 hours (sometimes called a Holter monitor).
- **Echocardiogram (an ultrasound of the heart):** shows if the heart is an unusual shape or size, particularly if it is filling up and emptying blood normally.
- **Chest x-ray:** can also show if the heart is an unusual shape or size, as well as if any fluid is building up where it shouldn't be.
- **Cardiac magnetic resonance imaging (MRI):** provides detailed images of the heart muscle that can show changes in shape and size, as well as how well the heart is pumping blood.
- **Exercise testing:** monitors how well your heart is working and its rhythm while you are doing physical activity.
- **Blood tests:** to detect changes that may identify possible causes (e.g. thyroid conditions or viruses).
- **Genetic testing:** looks for changes in the genes that can lead to RCM.
- **Family screening:** close relatives of people diagnosed with genetic RCM are encouraged to receive genetic counselling and testing.
- **Heart biopsy:** occasionally performed to confirm a diagnosis such as amyloidosis or sarcoidosis.

How is it treated or managed?

There is currently no cure for RCM. It is managed by treating symptoms and reducing the risk of complications. This can involve changing your lifestyle, taking medicines, or sometimes having an operation.

Treatments that aim to ease symptoms and stop the progression of the condition include:

- **Angiotensin-converting enzyme (ACE) inhibitors and angiotensin II receptor blockers (ARBs):** reduce blood pressure and make it easier for the heart to work. ARBs are often used if someone can't have ACE inhibitors.
- **Beta-blockers and anti-arrhythmic medicines:** used to correct abnormal heart rhythms.
- **Anticoagulants (also known as blood thinners):** lower the risk of blood clots and stroke.
- **Diuretics and mineralocorticoid receptor antagonists (e.g. spironolactone):** also known as fluid or water tablets, help the body get rid of extra fluid, which can ease swelling and breathlessness. These are widely used and available in both Australia and New Zealand.
- **Pacemakers or implantable cardioverter-defibrillators (ICD):** are small devices that are implanted under your skin to monitor your heartbeat. If it changes (going too fast, slow or becoming irregular) these devices send an electrical signal that helps the heart to keep a normal heart rhythm.
- **Cardiac resynchronisation therapy (CRT):** uses a pacemaker to help coordinate the different chambers of the heart to beat as efficiently as possible.
- **Heart transplant:** in people where symptoms are severe and do not respond to other treatments, a heart transplant may be considered. A heart transplant for RCM is quite rare and only considered in people who meet strict eligibility criteria.

Lifestyle changes that can help maintain general health and manage symptoms include:

- **Staying active:** physical activity is good for your heart and general health. The amount of exercise that is appropriate will be different for every person, so it is important to discuss this with your doctor.
- **Limiting alcohol and avoiding recreational drugs:** alcohol and recreational drugs can raise your heart rate and increase blood pressure. Limiting alcohol intake and avoiding recreational drugs is good for your heart.

- **Eating a heart-healthy diet and maintaining a healthy weight:** a balanced diet can help to keep a healthy weight, which will reduce the impact on the heart as well as helping with general health.
- **Reducing salt intake:** as well as monitoring how much fluid you are consuming, can help regulate the volume of blood which makes it easier for your heart to pump effectively.
- **Staying up to date with vaccinations:** infections like the flu and COVID-19 can cause strain on the heart and worsen RCM symptoms. Vaccinations are recommended by clinicians as they can reduce severity or sometimes prevent infections. Talk to your healthcare professional about which vaccinations are right for you.
- **Having regular health checks and keeping a diary:** regular checks with your doctor to monitor your blood pressure, weight, fluid intake, and ability to exercise can help to highlight any changes in your heart health early. Keeping a diary that records this (and any other symptoms you experience) is very helpful for your doctor.

Where to get support

Support is available for people affected by RCM in both Australia and New Zealand. Your GP and cardiologist are the main contacts for discussing symptoms, treatment choices, and ongoing care.

You can also get information and connect with others by visiting **Cardiomyopathy Australia New Zealand**, joining our private Facebook group, and following our social media channels.

Additional information and supports:

Australia:

- Visit the Australian Heart Foundation **www.heartfoundation.org.au**
- For young people, visit **www.heartkids.org.au**

New Zealand:

- Ask your cardiologist about a Heart Failure Nurse Specialist in your area
- Visit the New Zealand Heart Foundation **www.heartfoundation.org.nz**
- For young people, visit **www.heartkids.org.nz**

Scan here to visit the CMANZ website

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Created in partnership with Heart Foundation

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