

Peripartum (pregnancy-associated) Cardiomyopathy (PPCM)

A guide for women with PPCM, their families, and carers in Australia and New Zealand.

Peripartum cardiomyopathy (PPCM) is a condition where the heart muscle weakens and changes shape during the last month of pregnancy or within five months after giving birth. This makes it difficult for the heart to pump blood efficiently.

PPCM can affect women who have never had heart problems before. Most women recover well with early diagnosis and treatment, though some continue to have reduced heart function afterwards.

This information is for people affected by PPCM and their families living in Australia or New Zealand. It is general information only and should not replace advice from your doctor or healthcare team.

What is Peripartum Cardiomyopathy?

In PPCM, the heart muscle becomes weakened and stretched, meaning it cannot pump blood effectively. This can cause fluid to build up in the lungs and body, leading to shortness of breath, swelling, and fatigue.

The exact cause of PPCM is not known, but some possible causes have been suggested. These include dietary factors, autoimmune conditions, infections, hormones and the stress that a person's body experiences during pregnancy and childbirth. It has also been found that up to 20% of women with PPCM have a genetic change that is also seen in other types of cardiomyopathy.

How common is PPCM?

PPCM can occur in any person late in pregnancy or shortly after delivery. It is relatively uncommon - estimated to affect about 1 in every 1,000 to 2,000 pregnancies worldwide, though the exact number in Australia and New Zealand is uncertain. Some women may be at higher risk of developing PPCM, including those over 30 years old; multiple pregnancies (for example twins or triplets); people experiencing pre-eclampsia, high blood pressure, or gestational diabetes; or with a family history of heart failure or cardiomyopathy. People from certain ancestral groups are also at higher risk of PPCM, including those of African, Pacific, or Indigenous descent.

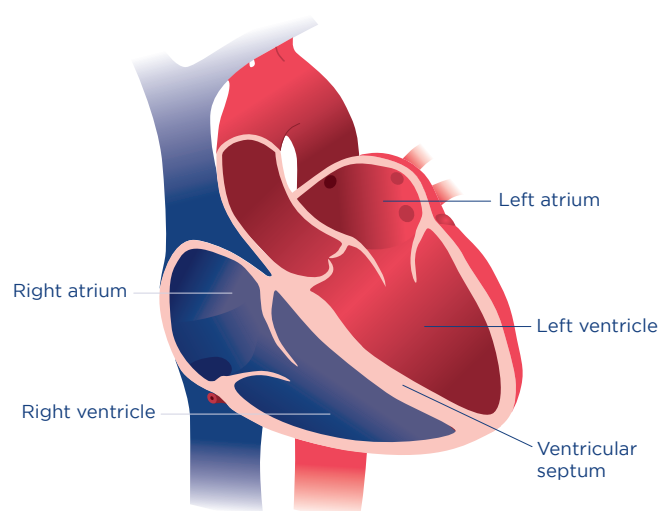
What are the symptoms of PPCM?

The symptoms of PPCM can be difficult to distinguish from normal changes that occur during the late stages of pregnancy. They usually appear in the last month of pregnancy or within the first few months after birth.

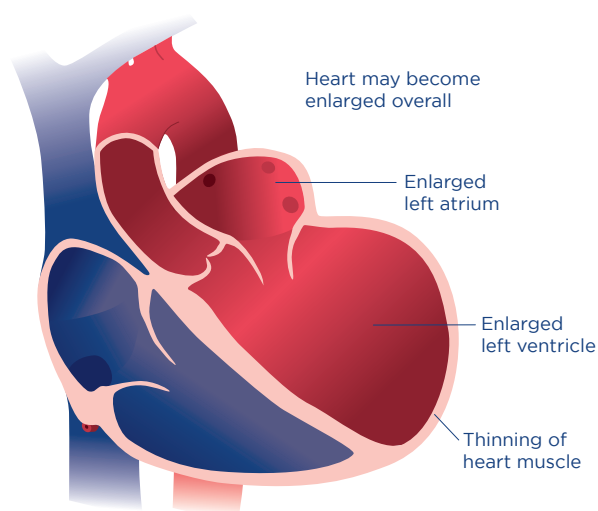
Symptoms may include:

- Shortness of breath at rest and on exertion
- Dizziness or fainting (syncope)

Heart without Peripartum Cardiomyopathy



Heart with Peripartum Cardiomyopathy



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- Chest discomfort, including pain described as dull, sharp, radiating or non-radiating
- Unexplained fatigue, tiredness, or reduced exercise tolerance
- Palpitations or fluttering sensations in the chest
- Swelling in the belly, legs, or ankles
- Cough, often worse while lying down

If symptoms worsen quickly or if you have severe shortness of breath, chest pain, or fainting it is important to seek medical help immediately.

How is PPCM diagnosed?

To find out if someone has PPCM, doctors use a range of tests. 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 the walls of the heart are thinned, and 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 measure cardiac markers and check kidney, liver, and thyroid function.
- **Genetic testing:** may be considered if there is a family history of cardiomyopathy.

How is PPCM treated or managed?

Treatment for PPCM focuses on supporting heart recovery, relieving symptoms, and preventing complications. Treatments can differ depending on whether the PPCM is being experienced by someone who is still pregnant, or who has given birth already, because some medicines can increase the risk of complications for the baby. Treatments for PPCM include:

- **Angiotensin-converting enzyme (ACE) inhibitors and angiotensin II receptor blockers (ARBs):** reduce blood pressure and help the heart pump more easily. They are key treatments in PPCM **after pregnancy**, but cannot be used during pregnancy, and most cannot be taken while breastfeeding.

- **Beta-blockers:** help reduce blood pressure and strain on the heart. Some beta-blockers can be used during pregnancy or breastfeeding, while others should be avoided.
- **Anti-arrhythmic medicines:** used to correct abnormal heart rhythms. The choice of medicine depends on pregnancy and breastfeeding status.
- **Diuretics (also known as fluid tablets):** help the body get rid of excess fluid, which can ease swelling and breathlessness. Some diuretics are safe in pregnancy but require monitoring.
- **Mineralocorticoid receptor antagonists (MRA – e.g. spironolactone):** reduce fluid retention and improve heart function **after pregnancy**. They must not be used during pregnancy and are usually avoided during breastfeeding.
- **Anticoagulants (also known as blood thinners):** lower the risk of blood clots, which is an increased risk for people with PPCM. Some anticoagulants are unsafe in pregnancy, so alternatives may be used.

Some people recover completely within months, while others may continue to have mild or moderate heart weakness long-term. If the heart muscle does not recover from PPCM, surgery may be considered to place a pacemaker or implantable cardioverter-defibrillator (ICD) or in severe cases, a heart transplant may be considered.

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

- **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.
- **Limit alcohol and avoid recreational drugs:** these can raise your heart rate and blood pressure. Limiting alcohol and avoiding recreational drugs completely 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.
- **Reduce salt and monitor fluids:** lowering salt can help reduce fluid retention, and in some cases your doctor may also advise that you limit your fluid consumption.
- **Staying up to date with vaccinations:** Infections like the flu and COVID-19 can cause strain on the heart and worsen PPCM 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.
- **Keeping a diary and staying in touch with your doctor:** monitoring your weight, fluid intake, and ability to exercise can help to highlight any

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changes in your heart health early. Keeping a diary that records this (and any other symptoms you experience) is very helpful for your doctor.

- **Pregnancy planning:** it is crucial to speak with your doctor to confirm when it is safe to become pregnant again. PPCM can recur, especially if heart function has not fully recovered. Your doctor can advise on safe contraception and future pregnancy planning.
- **Genetic testing and family screening:** if genetic testing identifies a change in a gene (a gene variant), first-degree relatives (parents, siblings and children) may be encouraged to be screened for the variant and early signs of cardiomyopathy. A genetic counsellor can explain test results and help your family decide if testing is appropriate.

Where to get support

Support is available for people affected by PPCM in both Australia and New Zealand.

Your GP, cardiologist, and obstetric team are the main contacts for discussing symptoms, treatment 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.

Australia:

- Visit the Australian Heart Foundation
www.heartfoundation.org.au
- Emotional and mental-health support — for example, from PANDA (Perinatal Anxiety & Depression Australia)
www.panda.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
- Emotional and mental health support is available from PADA (Perinatal Anxiety and Depression Aotearoa)
www.pada.nz

Scan here to visit the CMANZ website



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