

# Peripartum Cardiomyopathy

## Pregnancy-related cardiomyopathy

- Peripartum cardiomyopathy is a rare type of heart muscle disease which occurs during the last part of pregnancy, or in the first few months after pregnancy.
- Peripartum cardiomyopathy affects the function of the left ventricle of the heart.
- Peripartum cardiomyopathy is a serious condition, which can be life-threatening but around 70% of women recover by 1-year following diagnosis.

## What is peripartum cardiomyopathy (PPCM)?

Peripartum cardiomyopathy (or PPCM) is a type of cardiomyopathy that only occurs during or following pregnancy. It is usually diagnosed either during the last trimester of pregnancy or the first five months after giving birth.

PPCM affects the left ventricle of the heart - it's main pumping chamber, which pumps blood out of the heart and to the rest of the body. In the normal heart the left ventricle pumps blood out of the heart efficiently, with enough pressure to reach all areas of the body. However, in a heart affected by PPCM the muscle walls of the left ventricle can become stretched and weakened and so it becomes less efficient at pumping blood out of the heart and around the body (as in dilated cardiomyopathy - DCM).

This is often referred to as a reduced ejection fraction and causes symptoms of heart failure, such as breathlessness, coughing and extreme fatigue (because the heart is failing to meet the body's normal oxygen requirements).

*See our infosheets on how the heart works and DCM.*

The ejection fraction is a measure of the amount of blood that is pumped out (ejected) from the heart each time the left ventricle contracts. It is usually measured as a percentage of the amount of blood within the ventricle. A normal ejection fraction is 55-60%. Ejection fractions lower than this can mean that the heart is working less well. In PPCM the ejection fraction is generally less than 45%.

## What causes PPCM and how common is it?

PPCM is rare and can only happen during or following pregnancy. The incidence of PPCM varies globally from around 1 in 100 pregnancies in African countries to 1 in 10,000 pregnancies in Denmark. It is not currently known what the incidence of PPCM is in the UK.

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The reasons why PPCM develops are still not fully understood and more research is needed. PPCM can develop in women with no previous history of heart conditions, however it is more common in women who have a history of high blood pressure or who develop pre-eclampsia during pregnancy. Other risk factors include Black African ethnicity, family history, being pregnant at an older age (over 30-years), obesity, having a multiple pregnancy (such as carrying twins) as well as lifestyle factors (such as smoking and malnutrition). Pregnancy is a natural stress test for the body and this may trigger PPCM, particularly where these other factors also exist.

## What happens to the heart during pregnancy?

During pregnancy, the body goes through lots of changes. Changes to the cardiovascular system occur from the early weeks of pregnancy and continue as the pregnancy progresses, including further changes to cope with labour, and again as the body returns to normal after the baby is born. Changes during pregnancy include:




- 40% increase in total blood volume
- increased heart rate
- increased cardiac output (a measure of the volume of blood that is pumped by the heart during one minute) which can increase by 40 -50% by the first six weeks of pregnancy
- blood also becomes more susceptible to clotting

Everything has usually returned to normal again by 6-weeks after the baby is born.

## What are the symptoms of PPCM?

Symptoms of PPCM include:

- feeling breathless
- having a fast heart rate and/or palpitations
- a persistent cough, mainly at night, which feels like 'gasping for air'
- being unable to lie flat in bed (needing to be

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- propped up with pillows or to sit up)
- noticing sudden and severe swelling of feet, ankles and hands (due to fluid retention)
- sudden and significant weight gain (due to fluid retention)
- excess fatigue
- feeling or looking 'not quite right'

PPCM causes heart failure as the heart isn't working as well as it should and fails to pump enough blood (at the right pressure) to meet the body's needs. The symptoms of PPCM are symptoms of heart failure. However, in pregnancy these symptoms can often be dismissed or considered to be normal as they overlap with common symptoms of pregnancy. It is really important to be aware if these symptoms occur, particularly if they are severe and affect your day-to-day activities. If you have symptoms, please talk to your midwife, GP or obstetrician immediately. Describe your symptoms clearly - it is helpful if you can explain how these symptoms are affecting you by giving examples, and let them know that you are worried. As PPCM is relatively rare, you may want to ask them directly to consider whether your symptoms could be caused by PPCM. Ask "Could it be PPCM?"

## How is it diagnosed?

If any symptoms of heart failure develop, several investigations will be undertaken to check how well the heart is working and to determine whether these symptoms are due to the pregnancy, other non-cardiac conditions, or if they are due to a problem with the heart. Once other causes for these symptoms are ruled out and cardiac disease is suspected, the woman should be referred to a cardiologist for specialist review. There is no specific test to confirm PPCM, so it can only be diagnosed when all other causes for the symptoms of heart failure are ruled out. Examinations may include:

- A medical history** – the clinician will ask questions about your past as well as present health and enquire whether anyone in your family has (or had) heart disease, or if there have been any unexplained deaths in your family. They will also ask you to describe your symptoms in detail, including when they first started, when and how often you notice them and how much they affect your everyday life.
- An echocardiogram** – similar to an ultrasound scan to look at the structure and function of the heart muscle and valves, and check for any blood clots within the heart chambers.
- A physical exam** – this might include listening to your heart and lungs, checking your blood pressure and pulse, measuring your oxygen saturations (with a probe on your finger) and

- looking for any significant swelling.
- Blood tests** – to check how the kidney, liver and thyroid are working, to check for hormones which may indicate the heart is under stress and to check for other causes of the symptoms such as anaemia or an infection.
- An ECG (electrocardiogram)** – to look at how electrical impulses are conducted in the heart, and check for arrhythmias (abnormal heart rhythms).
- A 24-hour ECG (Holter)** – this checks for any episodes of heart rhythm disturbances.
- A chest X-ray** – to look at the shape of the heart.

In some cases the following tests might also be done to help with reaching a diagnosis:

- Cardiac MRI (type of scan)** – to look at the structure and function of the heart. This might be used if the results from the Echo are not clear, and to look for blood clots. It can also be used to rule-out other conditions that can affect the heart (such as infections or inflammation).
- Coronary angiogram** – this looks at the blood supply to the heart (through the coronary arteries which supply the heart muscle with blood). It is used to check that the arteries are not narrowed or blocked due to coronary artery disease.

In summary, PPCM may be diagnosed when:

- symptoms of heart failure are experienced
- the heart's ejection fraction is 45% or lower
- the heart may be enlarged (although not always)
- no other cause of the symptoms can be found.

## How is it treated?

Treatment focuses on managing the symptoms of heart failure and will be personalised to the individual, considering whether or not they are still pregnant or if they are breastfeeding. There are specific guidelines for the treatment of heart failure and these include the use of medications such as:

- diuretics (water tablets)** – to reduce the build-up of any fluid on the lungs or the ankles by encouraging the kidneys to get rid of water as urine;
- beta-blockers** – to reduce the rate and force of the heart's contraction, by reducing stimulation of adrenalin (which would normally make the heart beat faster); and
- ACE inhibitors (angiotensin-converting enzyme inhibitors)** – to relax the smooth muscle around the blood vessels to reduce the workload on the heart and reduce the volume of the blood, making it easier for the heart to work.
- Anticoagulants (blood thinners)** – to prevent dangerous blood clots from forming.



Although it is very rare, PPCM can be life-threatening and needs to be treated promptly. The earlier PPCM is diagnosed and treatment is started, the better the woman's chances of making a good recovery. Recognising symptoms and telling your midwife, GP or obstetrician about these is important to start the process of getting a diagnosis and the right treatment.

### Which healthcare professionals will be involved?

Because pregnancy is a time of changes within the body, a variety of specialist healthcare professionals will work together to ensure the woman receives the best care. This is known as a multi-disciplinary team (MDT) approach. The MDT may include: cardiologists, obstetricians, obstetric physicians, midwives and specialist nurses (amongst others).

Each member of the team will discuss the options available and work collaboratively to help the individual to be involved in making choices about their care.

### Does PPCM affect pregnancy and delivery?

PPCM is often not diagnosed until after delivery, however signs and symptoms may have been present during the pregnancy. It is important that symptoms are recognised as early as possible and a diagnosis made, so that appropriate treatment can start at an early stage to prevent the condition from worsening. If PPCM is diagnosed during pregnancy, the MDT will decide on the most appropriate plan for delivery according to individual circumstances. The mother's wishes are a key consideration and will always be respected. It is usually possible to plan for a vaginal birth with PPCM, however there may be instances in which a Caesarean is recommended. If the woman's condition deteriorates during pregnancy, it may be necessary to deliver the baby early, before the expected date of delivery. If the baby needs to be delivered preterm, a paediatrician (baby doctor) will explain how the baby needs to be looked after once it's born. This may involve the baby being admitted to the neonatal intensive care unit for a while.

The mother may need to be transferred to a cardiology ward after the baby is born, where the team will closely monitor her heart. Being separated from your baby is not easy but it may be possible for you to visit your baby in the neonatal intensive care unit (NICU) or for your baby to visit you on the cardiac ward. The midwives will visit you and make sure you are recovering well from the birth and they

can help you to spend time with your baby. We know that having PPCM can be a traumatic experience and can affect your mental health as well as your physical health. It is important if you are feeling stressed or low in mood to tell someone about this. The midwives or doctors will not judge you and can help you to find the right support for your mental health if you tell them how you are feeling. Don't bottle up your feelings or feel embarrassed about them, they are important and so are you. Cardiomyopathy UK has peer support services and can put you in touch with others who have had PPCM so that you don't feel so alone.

### If someone has PPCM during pregnancy, will they always have it?

Although PPCM is a serious condition, it is worth remembering that many women will make a good recovery. Over half of women with PPCM will have normal heart function again by six months after giving birth. For a small number of women, recovery can take much longer due to the severity of their symptoms and the ability of their heart to recover. If the mother does not recover well, she may need ongoing treatment and will continue to be under the care of a cardiologist. The drug therapies for PPCM can be very effective, but other treatment options may be considered according to individual needs.

For example, a small number of women affected may require a mechanical support device such as LVAD (Left Ventricular Assist Device) and possibly eventually be considered for a heart transplant.

### If someone develops PPCM, will it happen with future pregnancies?

If a woman has had PPCM during pregnancy, research suggests that she has an increased chance of getting it again in future pregnancies. Pregnancy following PPCM therefore needs to be carefully planned and prevented until the heart has recovered well enough to be able to cope with another pregnancy. A discussion about appropriate contraception will be part of the maternity postnatal care, so that women with a history of PPCM can be advised how to protect themselves from the potential risks of an unplanned pregnancy.

Becoming pregnant again before the heart has properly recovered can worsen the mother's health and can be potentially life-threatening. Very occasionally, in severe cases, where an unplanned pregnancy threatens the health of the mother early in pregnancy, the medical team may advise a termination of pregnancy in order to protect the mother. For



this reason it is strongly advised to use appropriate contraception to prevent pregnancy occurring before the heart is fully recovered.

Women who are considering another pregnancy should be referred for pre-pregnancy counselling with a specialist cardiologist and/or obstetric physician/obstetrician with a background in cardiac disease in pregnancy. This will help to ensure that all aspects of care can be considered in advance and future pregnancies are carefully planned and managed to keep the mother and baby safe and well.

*This information sheet is specifically about peripartum cardiomyopathy - a condition that develops during and because of pregnancy. Some women have cardiomyopathy that is not due to pregnancy, but may need particular treatment and management of their condition during pregnancy. We have information on other types of cardiomyopathy on our website.*

## We are here for you

At Cardiomyopathy UK we offer help and support for you and your family. You can call our helpline to talk to our support nurses on 0800 018 1024. We can put you in contact with other people through our support groups, support volunteers and social media. Contact us for more about our services, or look online -

[www.cardiomyopathy.org](http://www.cardiomyopathy.org).

Send your feedback to [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)

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