

# Frequently asked questions by patients diagnosed with peripartum cardiomyopathy (PPCM) and suggested answers

Breaking news about a new medical diagnosis to a patient is a crucial and sensitive task that requires empathy, clear communication, and a supportive approach. As medical terminology may be confusing to the patient, the managing physician should explain the diagnosis using plain and understandable language. The clinician should encourage the patient to ask questions and express their concerns.

In the following section, we provide a summary of commonly asked questions from patients who have recently been diagnosed with PPCM, with simple answers.

## Diagnosis of PPCM

### What is wrong with me?

PPCM is a specific type of heart failure that can occur in women during or shortly after pregnancy.

### What is heart failure?

Heart failure is a condition where the heart can't pump blood effectively, which means it doesn't supply the body with enough oxygen and nutrients. This might explain why you are experiencing symptoms such as shortness of breath, fatigue, or swelling in the legs or ankles, and a persistent cough.

### What causes PPCM? Why did I develop this disease?

While the exact cause of PPCM is not fully understood, ongoing research indicates that certain individuals are more prone to developing the condition. In these individuals, something sets off an imbalance in hormones associated with pregnancy. Prolactin, the hormone linked to breastfeeding, is believed to have a role in the development of PPCM.

Is it something I did wrong?

No, it is important to understand that this is not your fault that you developed this disease.

Who is at risk of developing PPCM?

Women with African heritage, young or older mothers, those with multiple pregnancies or twins, and women with high blood pressure during pregnancy are at higher risk.

Could PPCM run in my family and affect my sisters, daughters, or nieces?

Research shows that women with PPCM are more likely to have close relatives with heart failure. This suggests a genetic predisposition. However, this does not mean that your sisters, daughters, or nieces will definitely develop the disease.

## Management of PPCM

What investigations will I need to undergo?

To understand the severity of your condition, several tests will be done:

- An ECG will be done to record the electrical activity of the heart.
- An echocardiogram uses ultrasound to look at your heart's size and how well it pumps. It can also detect other abnormalities in the heart, such as valvular lesions.
- A chest X-ray will be done to help visualize the heart and lungs, providing information about your heart's size and any lung congestion.
- Blood tests can determine the seriousness of heart failure and check your kidney function. They can also detect anaemia and assess your iron levels.

Can PPCM be cured?

While PPCM cannot always be cured, it is a treatable condition. As such, there are effective treatments available to manage and improve the heart's function.

## What is the treatment for PPCM?

The treatment of PPCM typically involves a combination of heart failure medications, such as beta-blockers, ACE inhibitors, MRAs, and SGLT2 inhibitors. Diuretics are used to manage congestion. Additionally, for a short period after diagnosis, it is advised to take medication to stop breastfeeding.

## Will I need to take medications for PPCM for the rest of my life?

It is not advisable to discontinue heart failure medication. However, this decision may be reconsidered for some of the medication once your heart's pumping capacity returns to normal.

## What about contraception?

As it is not advised for you to fall pregnant again whilst your heart's function is decreased, contraception is strongly recommended. As such, intra-uterine devices or injectable contraception is preferred over the pill.

## Is it safe to have another baby?

New research has shown that subsequent pregnancy is safe in patients, in whom the heart's function has recovered. However, in patients with impaired cardiac function, subsequent pregnancy is discouraged.

## Maternal outcomes of PPCM

### How serious is this condition?

While some patients experience mild symptoms only, others can become severely ill. Nevertheless, in all cases, it is crucial to take the diagnosis seriously to ensure a positive outcome.

Am I at risk of dying due to this condition?

Roughly one in ten patients with PPCM sadly pass away within the first year of their diagnosis. This risk is mitigated when taking your medication.

Is there a likelihood that my heart will recover?

Approximately half of patients diagnosed with this condition will regain normal cardiac function. Your chances of recovery are better if you are adherent to medical therapy.

### Neonatal outcomes of PPCM

Will my baby be fine?

Patients with PPCM are at risk of having babies with lower birth weight. Worldwide, neonatal mortality is 5%. However, there is significant global variation in neonatal outcomes.

Can I breastfeed?

Patients with severely impaired pump function are advised to take medication that will stop breastfeeding. This is because the hormone linked to breastfeeding is also thought to be involved in the development of the disease. The discontinuation of breastfeeding means that you would need to use formula feed.