



PRESS RELEASE

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75% of people mistake symptoms of heart conditions as 'normal' during and after pregnancy

Cardiomyopathy UK urges the public and healthcare professionals to recognise cardiac symptoms in women and take action to cut maternal deaths

- 70% of people are unaware of serious heart conditions that can develop during and after pregnancy
- 75% of people think common cardiac symptoms are 'normal' to experience during and after pregnancy
- 55% would be more cautious about seeking medical help as a result of concerns over Covid-19
- Cardiomyopathy UK launches *Beating for Two* to raise awareness of serious heart conditions, like peripartum cardiomyopathy, that develop during and after pregnancy

Cardiomyopathy UK has launched its new campaign, Beating for Two, to raise awareness of the rare, but potentially life-threatening heart muscle disease, peripartum cardiomyopathy (PPCM), which can develop during the last part of, or in the first few months after, pregnancy.

New research commissioned by the charity shows the majority of people (70%) are unaware that serious heart conditions such as PPCM can develop during and after pregnancy. And in a small survey of patients and the family of those who have been diagnosed with PPCM, prior to diagnosis, 98% were unaware that serious heart conditions can occur during and after pregnancy.

While people are better at spotting more obvious cardiac symptoms such as chest pain and heart palpitations, three quarters (75%) of those surveyed think common cardiac symptoms are 'normal' during and after pregnancy, and 66% wouldn't seek medical help if they were to experience them.

Some of the less obvious cardiac symptoms, which often get overlooked but could signal a serious heart problem, such as PPCM, include:

- tiredness completing everyday tasks
- shortness of breath when at rest or lying down
- sudden swelling of the ankles
- excessive and rapid weight gain

Top reasons people gave for not seeking medical help if they or a loved one were experiencing PPCM symptoms include 'assuming the symptoms are 'normal' during pregnancy' (58%),

'assuming symptoms will go away on their own' (32%), 'fear of being viewed as overreacting or fussy' (29%) – something which is higher in women than men (32% to 26%) – and 'feeling guilty for using the NHS's time' (24%).

The findings also show the pandemic has had an impact on people's behaviour, with 55% saying that because pregnant women are in a higher risk category, they would be more cautious about seeking medical help as a result of concerns over Covid-19.

Cardiovascular disease is the most common cause of maternal death in the UK, with PPCM accounting for one-third of cardiovascular maternal deaths. However, because awareness of the condition is low, opportunities to detect and treat the condition early are being missed, and as a result, women's lives are being put at risk.

When showing concern over symptoms, 45% of those in the Patient Survey who have been diagnosed with PPCM, were told symptoms were 'normal' during and after pregnancy.

Through its Beating for Two campaign, Cardiomyopathy UK wants to make it easier for women and their families to spot the signs of PPCM, and to feel confident seeking medical help sooner.

Survey respondents indicated that, if they knew more about which symptoms were 'normal' and 'not normal' during and after pregnancy, 66% would feel more confident raising concerns with a healthcare professional.

The charity also wants healthcare professionals to 'think heart' when considering symptoms, and to ask about history of medical problems that run in the family to ensure PPCM symptoms are not being mistaken as 'normal'.

Joel Rose, Chief Executive of Cardiomyopathy UK, says:

"During pregnancy, an expectant mother's heart is put under additional pressure as it adapts to keeping two humans alive. This incredible organ is beating for two, but we don't always give it the recognition and attention it deserves. While PPCM is thankfully rare, its effects can be devastating if left undetected.

"However, the condition is completely manageable if caught early and most women who are diagnosed live healthy and fulfilling lives.

"We know women often put their needs to the bottom of the priorities list, but we urge people to trust their instincts and to watch for signs that their heart might be struggling to cope, during pregnancy and after birth.

"If you feel that something isn't right speak to your GP, midwife or health visitor."

Cardiomyopathy UK is working hard to ensure better recognition of the symptoms so that every woman with PPCM is diagnosed in time to manage the condition safely.

Sascha Wells-Munroe OBE, Deputy Chief Midwifery Officer for England, says:

"It is vital that any woman with any cause for concern about her or her baby's health speak to their midwife or maternity team without delay. It can be easy to think that symptoms like tiredness or shortness of breath are 'normal' but, no matter how big or small a symptom might be, please seek advice – the NHS is here for you.

"Alongside our NHS 'Help Us Help You' maternity resources, campaigns like Cardiomyopathy UK's 'Beating for Two' provide critical reminders that it's just as important as ever to seek help

from maternity services and it's so crucial that women and healthcare professionals alike 'think heart' to make sure no opportunities to keep women and babies safe and healthy are missed."

For more advice and information about the signs and symptoms to look for, and what is 'normal' and what is not during and after pregnancy, visit: <https://bit.ly/2XQ6UfL>

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Notes to editors

For further information, please contact:

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Case studies

Available on request.

About the polling:

General public survey

Censuswide polled 2,041 people, between 25.11.2020 – 27.11.2020

Patient survey

Cardiomyopathy UK polled a further 40 people who have experience of PPCM, between 14.12.2020 – 13.01.2021

Patient survey key findings:

- 85% had never heard of peripartum cardiomyopathy (PPCM) before diagnosis
- 98% were unaware that serious heart conditions such as PPCM can occur during and after pregnancy
- 45% were told their symptoms were 'normal' during and after pregnancy
- 43% said healthcare professionals did not initially recognise the symptoms as being PPCM
- 30% were initially misdiagnosed
- 57% thought shortness of breath on minimal exertion i.e. when lying or sitting down was 'normal'
- 80% thought tiredness carrying out everyday tasks was 'normal'
- 97% think there needs to be better awareness of PPCM and the symptoms to cut maternal deaths

About Cardiomyopathy UK

Cardiomyopathy UK is the national charity for people affected by the heart muscle diseases cardiomyopathy and myocarditis. We provide support and information services, work to raise awareness of the condition, campaign for better access to quality treatment and promote research.

What is peripartum cardiomyopathy?

Peripartum cardiomyopathy (or PPCM) happens during pregnancy, usually starting between the final month of pregnancy and the first five months after giving birth. In PPCM the woman's heart becomes enlarged and its pumping action weakened.

PPCM is similar to dilated cardiomyopathy, in that it affects the left ventricle of the heart. This is the main pumping chamber of the heart: pumping blood out of the heart and to the rest of the

body. Normally the left ventricle pumps blood out of the heart efficiently, with enough pressure to reach all areas of the body. In PPCM, the left ventricle chamber becomes enlarged. As the ventricle becomes bigger than normal, the muscular wall becomes stretched and thinner. This makes the muscle weaker which, in turn, means that it works less well.

For more information visit: <https://www.cardiomyopathy.org/peripartum-cardiomyopathy/intro>