

# My Marvellous Guide to PPCM (Peripartum Cardiomyopathy)

*A Mum's Story*



**Authored by patients like you**



HELPING PEOPLE LIVE BETTER WITH HEART FAILURE

# WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



This guide has been created by women who have all been diagnosed with Peripartum Cardiomyopathy (PPCM). The Foundation wishes to express a huge vote of thanks to Emma, Tracy, Aleena, Sarah-Jayne, Paula, Janey and Claire, who came together to share their emotions around their own experience of being diagnosed with this condition, many a tissue was required as the women discussed the impact on them and their families. Thank you for your courage and willingness to share your understanding of PPCM. This "Marvellous Guide" therefore reflects on their journeys, from diagnosis to a life living with PPCM, and their belief that there is HOPE and a positive future ahead for you and your family.

If you have recently been diagnosed with PPCM, then you will have many questions that you wish to have answers for, we HOPE the following is helpful. If your question is not here, then do ask your Clinician. You or your loved one may not be able to take in all this information at once, the guide is there for you to return to whenever you wish, indeed you may find the information is something you wish to refer to time and again as your understanding of your condition grows.

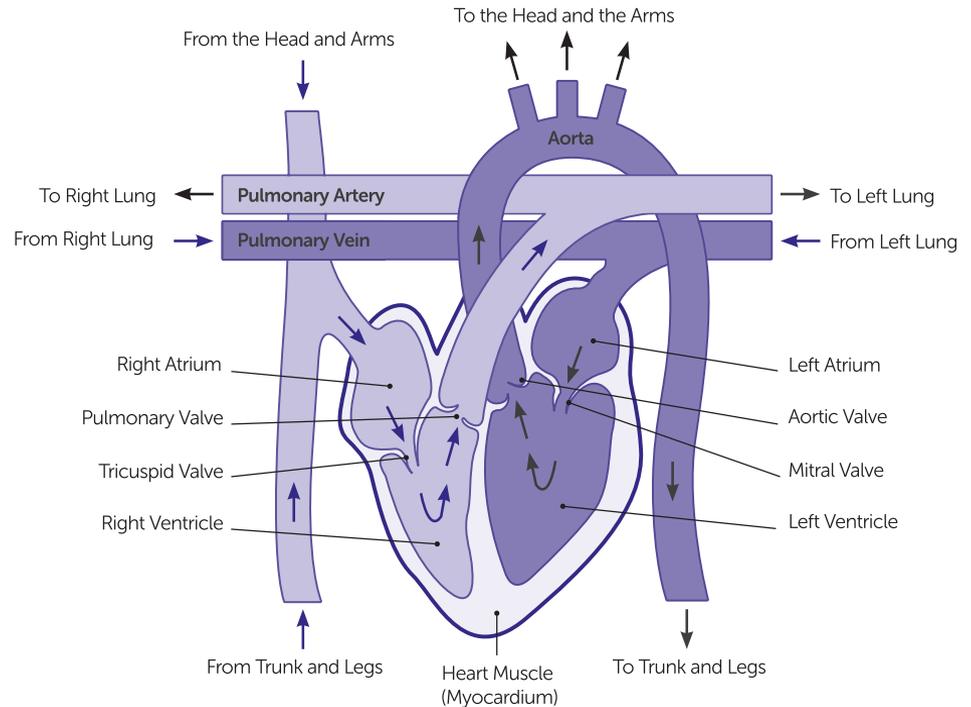
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**Please note:** this booklet should not replace and/or substitute the interactions with and advice you are given from your Healthcare Professional. If you have any concerns about your condition then do discuss them with your Healthcare Professional at the earliest opportunity.

# How does the heart work and what has happened?

The heart is a muscle that pumps blood around the body. The blood contains oxygen and nutrients that your body requires in order to function effectively. Indeed, in pregnancy the heart has to greatly increase its workload to supply the blood the growing baby requires. With PPCM the heart is unable to pump efficiently and is thus termed to be failing to do its job, as a consequence you may have been told you have heart failure or PPCM. We are not completely sure what actually causes PPCM, although a number of theories exist. These theories include alterations in the immune system, genetic links, inflammation and infection – but we really don't know. Research continues into the exact cause of PPCM.



# So what does PPCM actually mean?

Let's break it down. Peripartum means occurring in the last month of pregnancy or the first few months after delivery. Cardio relates to the heart and myopathy means any abnormality of a muscle. Therefore, a weakness has occurred in the muscle of the heart around the time of a woman giving birth.

## Why me? Was it something that I did or did not do?

It was NOT your fault. PPCM can occur to anyone having a baby at any age. It is a rare condition and few valid statistics exist as to how many women develop PPCM in the UK. We do know that the body goes through many changes with pregnancy and many symptoms of PPCM are at first put down to the normal symptoms of pregnancy. Many Clinicians are unaware of PPCM and it is when there is difficulty or a delay in diagnosing the condition that serious problems may occur and the mother's life may even be at risk.

## How has it been found out that I have PPCM?

In order to diagnose PPCM, a scan of the heart is undertaken, this is called an echocardiogram or echo. A tracing of the rhythm of the heart will be undertaken and various blood tests, however it is the echo that will provide a picture of the heart to assess its size, shape and to measure how effectively the heart is pumping blood out of that important part of the heart; the left ventricle chamber. We call this the ejection fraction. A normal heart will pump out approximately 60% to 65% of the blood in the chamber; however in PPCM that figure can drop alarmingly.

## What will happen to me now and in the future?

Even if it is found that your heart is pumping very poorly and you may have been very ill requiring a high degree of medical input, the heart can recover and how poorly your heart was failing to function does not appear to have a bearing on your recovery. For some, with appropriate treatment, the heart will completely recover. Some women may be left with a poorer heart function than normal but manage day to day life successfully. For a small number of women who have this rare disorder, their condition will further deteriorate and a Left Ventricular Assist Device or heart transplant may have to be considered. PPCM is a rare condition, and unfortunately can lead to maternal death.

## Will my baby be alright?

Your baby should not be affected by this condition. However, if you are diagnosed pre-delivery then your heart may not be working well enough for both you and your baby. The timing of delivery and the method of delivery (natural or caesarean section) will be determined by how well you are.

# What are the symptoms of PPCM?

Due to the heart not functioning effectively as a pump, fluid can accumulate in places it shouldn't. This will show in your feet, ankles and legs becoming extremely swollen, extending to the top of the thighs. You may have noticed that as a result of the swelling your weight will have risen rapidly as much as 2 to 3kg (4 to 5lbs) in 3 to 4 days. You will get breathless on minimal exertion and when lying flat, particularly at night when you may find you have to sit up to get your breath and are gasping for air. This may be accompanied by a cough as a result of a build-up of fluid within the lungs. You may have palpitations; a feeling that your heart is racing, skipping beats, long pauses between beats or fluttering and a feeling of heaviness or pain within your chest. Many of these symptoms you may experience in a pregnancy, but it is the extreme severity of these symptoms which will be leading to concern.

## Will I be able to have other babies?

This is a question that you may feel is the last thing on your mind. Most women with PPCM are advised not to consider another pregnancy because the condition can be worse if it occurs again. Some women who have completely recovered have successfully had babies after PPCM. It is something you will need to discuss with your Doctor. It will be dependent on how well you have recovered from PPCM. If the heart completely recovers its function, then a further pregnancy is possible; however, you will have to be very carefully monitored before and during your pregnancy, as it will recur in about a third of women. The baby will not be at risk, it is the mother's condition that will be of concern. If the heart has not recovered then it may be that further pregnancies should be avoided. It is highly recommended that you discuss any future plans for pregnancies with your Healthcare Professional and your partner. For your partner, the experience of having their loved one develop PPCM will doubtlessly have had a psychological impact.



# How will I be treated?

You may find yourself extremely poorly when you are first diagnosed and you may require intensive medical intervention to stabilise your condition. When you are stable then your team of Clinicians will commence medical treatment to support your heart which is failing to pump effectively. On the next page is a list of the key tablets you are likely to be prescribed. NOTE many types of the medication you will need will be started at low dosages and then they are increased on a gradual basis, in order for your body to become adjusted to the dosages. This is called uptitration and gets you on the optimum medication.

First some general tips on taking medication:

- Be in charge of your own medication. Know exactly what you're taking and how often, and understand why you are taking it.
- Medication can sometimes make you feel worse before it makes you feel better, so don't give up or suddenly stop taking your medication without first discussing it with your Healthcare Professional.
- It can be a slow process to get to the dose of a medication that works best for you. Sometimes some tablets have to be started at low doses and gradually increased, so don't get discouraged – you will get there in the end.
- You may need to take a lot of tablets – they've all got a role to play.
- Try not to miss taking your medication and make sure you take each one on time and as recommended. A daily tablet organiser could help.
- Remember, this is a partnership between you and your Healthcare Professional, so discuss how your medications are making you feel with them and if you have any questions or need any help, just ask.



# Medications

These are some of the medicines you may be advised to take for your condition.

Medications	What they do	Potential side effects
<p><b>Beta Blockers</b></p> <p>The names of these medicines will often end in '-olol' e.g. BISOPROLOL, CARVEDILOL.</p>	<p>Make your heart beat slower but stronger.</p>	<p>Tiredness.</p> <p>Dizziness.</p> <p>These tablets are started at low doses and slowly increased because they may lower your heart rate too much.</p>
<p><b>ACE (Angiotensin Converting Enzyme) Inhibitors</b></p> <p>The names of these tablets will often end in '-pril' e.g. RAMIPRIL, LISINAPRIL.</p>	<p>Ease the workload of the heart by relaxing the blood vessels around the body, which reduces the strain on the heart.</p>	<p>You can take ACE Inhibitors when you are breastfeeding, although this advice might be different if your baby is very premature.</p> <p>Lower your blood pressure and upset your kidneys.</p> <p>Expect to be monitored with blood pressure checks and blood tests.</p> <p>Occasionally you may experience a dry, irritable cough which often settles. However, if this proves troublesome, your Healthcare Professional may use an alternative medication, which is an ARB (see below).</p>
<p><b>ARB (Angiotensin Receptor Blockers)</b></p> <p>For patients who cannot tolerate ACE Inhibitors, these make it easier for your heart to pump by widening your blood vessels. The names of these medications often end in '-sartan' e.g. CANDESARTAN, LOSARTAN.</p>	<p>These work in a similar way to ACE Inhibitors (see above).</p>	<p><b>There is no data to say whether these are safe, or not, when breastfeeding. If these drugs are suggested then discuss breastfeeding with your doctor.</b></p> <p>Lower your blood pressure and upset your kidneys.</p> <p>Expect to be monitored with blood pressure checks and tests.</p>
<p><b>Diuretics - or "water pills"</b> (e.g. FUROSEMIDE, BUMETANIDE, SPIRONOLACTONE, EPLERENONE).</p> <p>You may be on more than one type of water tablet because they work in different ways on the kidneys.</p>	<p>Help your body get rid of extra fluid, so there is less fluid for your heart to pump.</p>	<p>You may find it inconvenient as you may need to visit the toilet more frequently than normal.</p> <p>You may need to plan your day around your water tablets - for example, staying at home for a while after you have taken them.</p> <p>You will require regular blood tests to ensure your kidneys are not affected by the number of water tablets you are taking.</p>
<p><b>Ivabradine</b></p>	<p>Slows the heart rate down to allow it to pump more effectively (similar to Beta Blockers).</p>	<p><b>NOTE YOU MAY NOT BE ABLE TO TAKE THIS IF YOU ARE BREASTFEEDING.</b></p> <p>Your heart rate may become too slow.</p> <p>Dizziness.</p> <p>Phosphenes are a visual symptom of enhanced brightness - these are not serious and usually resolve.</p>

# Devices/Pacemakers Diagrams

For some women who have PPCM, and as a result heart failure, additional support may be required to support their heart.



## Cardiac Resynchronisation Therapy (CRT)/Biventricular Device

A CRT/Biventricular Device may be suitable for some people with heart failure. These devices send tiny electrical signals to the heart to help it beat in a more synchronised way and ultimately help the heart to pump more efficiently. However, these devices only work in specific situations and not for everyone – this is something you may wish to discuss with your Clinician.



## Implantable Cardiac Defibrillator (ICD)

Not only does the heart have a beat, but also a rhythm. Sometimes there is a problem with the rhythm which may have serious consequences. In these cases an ICD may be recommended. This requires the implantation of a small box under the skin in the top of the chest – wires are attached to the muscle of the heart on one end and the box at the other end. This provides a means of dealing with any would-be-fatal heart rhythm problems.

Occasionally a CRT and an ICD may be combined together into one device.

If you would like to learn more about cardiac devices then head to [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org) > **Academies** > **Patient Academy** > **Heart Failure Toolkit** and click here to find all our resources.

# How will I know that I am getting better?

You will know by how well your symptoms are improving, and that you are able to undertake more of your daily activities. Clinicians find the New York Heart Association classification a good tool to gauge how you are doing and you may find it helpful too.

## So where are you in New York?

A strange question perhaps, but patients and Healthcare Professionals often find the New York Heart Association (NYHA) classification scale useful in assessing the severity of this condition based on the symptoms you are experiencing. You may find that you move up and down on the scale as a result of your condition and treatments.

<b>NYHA Class</b>	<b>Symptoms</b>
<b>NYHA Class 1</b>	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations or shortness of breath.
<b>NYHA Class 2</b>	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations or shortness of breath.
<b>NYHA Class 3</b>	Comfortable at rest, but less than ordinary activity causes tiredness, palpitations or shortness of breath.
<b>NYHA Class 4</b>	Unable to carry out any physical activity without discomfort and tired and short of breath even at rest. If any physical activity is undertaken, discomfort is increased.

Women with this condition often find they have a certain amount of energy – like a battery – to get them through each day. How much energy is in your battery generally depends on how your condition is assessed on the NYHA scale. Just as you would think about how to get the most out of a battery it's good to think about the amount of energy you have and to try and plan out how you will use it throughout the day to prioritise the activities that are most important to you.

# What are the things I need to be careful of to manage my condition?

Self-management can be a very powerful tool, it helps you to make and respond to changes and reduce your chances of any further difficulties arising with your condition. Below are a few things that will help you in this process.

Keep an eye on...	Tips	Call your Healthcare Professional if...
<b>Sudden weight increase.</b> Sudden weight gain may mean that fluid is building up in your body because your heart failure is getting worse.	Weigh yourself every day at the same time.  Watch how much fluid you are taking in. Don't exceed the amount suggested by your Healthcare Professional.	You gain about 4-5lbs in the space of 2-3 days.
<b>Swelling.</b> When the body retains fluid, you may notice swelling in your lower legs, abdomen or feet.	Keep your legs elevated on a stool.  Have frequent rests during the day. An afternoon catnap in your bed may be helpful.	Any swelling becomes significantly worse.
<b>Breathing.</b> On occasion, fluid may gather in your lungs which may affect your breathing.	Your fatigue worsens and begins to affect your day-to-day activities.	Your breathing or coughing is getting significantly worse.
<b>Fatigue.</b> Many people with this condition will feel very lethargic.	Remember your energy levels, be kind to yourself and rest when you need to.	
<b>Dizziness/lightheadedness.</b> Due to your condition and the medication you may be taking, you could experience dizziness and/or lightheadedness.	Don't rush around!  Try not to stand up or turn around too quickly.  Take your time to get out of bed and steady yourself before you begin to walk.	

# Emotions

Having a baby should be one of the most enjoyable experiences of a woman's life. For some who have had a diagnosis of PPCM that experience was not what they imagined, as the condition seriously impacted on their ability to have the kind of delivery that they expected. Women talk of the loss, anger, grief and a feeling of being cheated of something precious that they had anticipated, indeed for a small number of women the actual delivery was something that they are only vaguely able to recall. Most women will feel emotional post-delivery. The joy and responsibility of having a baby can feel overwhelming and combined with a surge of hormones, being diagnosed with a cardiac condition and possibly separated from their baby whilst their own condition is stabilised, can bring additional feelings of fear, anxiety about the baby, of being alone, feelings which are no doubt being felt by partners, families and friends.

The mums with PPCM in the Pumping Marvellous family all expressed similar emotions, so firstly these feelings will be normal considering the circumstances. So here is what they say helped them:

- Talk to your partner, family, friends about the emotions you are feeling.
- Do not hesitate to contact your healthcare team, GP, Midwife, Health Visitor, Heart Failure Specialist Nurse and discuss your feelings, particularly if you feel that they are overwhelming you.
- If you cannot recall events due to your being so unwell at the time, and you wish to know, then ask your family what actually occurred at the time, mums felt that they wanted to be able to fill in the gaps.
- If you have questions then write them down and ask the relevant member of your healthcare team for answers.
- You could ask your Obstetrician for a 'debrief' when things have settled. This is a chance to talk about what happened and ask any questions you have.

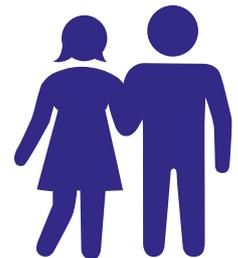
## Separation from baby

Due to your condition it could be that you have been separated from your baby, and you are concerned about the bonding process with your infant, which is so important to both mother and baby. Your healthcare team, it is hoped, will ensure that you have as much contact with your baby, that you are kept informed and involved in your baby's care, and that you and your family are kept together as much as possible. If you feel that is not taking place then raise the issue with your healthcare team as soon as possible.

# Your Partner

The impact of being diagnosed with PPCM can be equally as devastating to your partner. They too will have looked forward to the wonderful experience of becoming a new parent, and feel those same emotions of extreme concern, fear and loss, coupled with the heartache of seeing their loved one extremely ill. It is often the partner who is left to tell other family members of what is happening and continue to manage the care of other children in the family. So the next section is for them.

- Don't be afraid to ask Healthcare Professionals what and why things are happening, ensure that you are informed of the treatment that is being given to your partner.
- Events may be occurring that are far from how you and your partner anticipated the arrival of your child, you are entitled to feel the loss, anxiety and even anger that you may be experiencing. Share and talk things through with family and friends. Continue to talk with your partner, listen and share your experiences.
- Attend as many appointments as you can with your partner so that you have an understanding of what is happening and you can ask your questions.
- Inform your employer of the complications as they may be able to provide you with additional support in caring for her.
- Obtain a copy of the "Marvellous Guide to Caring for Heart Failure Patients". In there you will find additional information and resources to support you physically and emotionally in the role of supporting your partner. Visit the Pumping Marvellous website for further information.
- Engage with the wider family and don't be afraid to ask for hands-on support in caring for your partner and your family.
- Keep talking and sharing, that's the overwhelming message from the mums with PPCM, remain a couple, don't let the diagnosis define your relationship, continue to have time for each other.



# Other Children in the Family

Having a new addition to a family can be a bewildering experience for any child, the implications of Mum being diagnosed with PPCM can be a trauma. You, no doubt, will have prepared other children for the addition of a new sibling and your diagnosis again may have altered the planned joyful occasion that you may have all looked forward to.

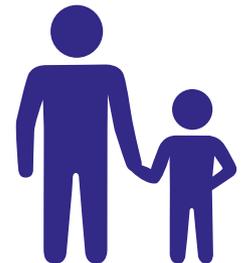
Think carefully about what you are going to say to children in the family. Give realistic assurance and simple honest answers, and try not to overburden them with additional information. Stress how this does not affect the love that you feel for them. Keep children informed and remain open to further questions as they may wish to return to the subject on a frequent basis.

Try and keep some time together, and involve them with tasks to help both you and the baby. The most important thing is to stress that this is not the new baby's fault. This also applies as your baby grows and becomes a child and if you continue to have heart failure, they may need the reassurance that this was not due to you having them.

Stay in touch with school, inform your child's teacher of what has happened so that they can watch for any unusual behaviour as a result of anxiety they may be feeling. If you have concerns do discuss them with your GP or Health Visitor.

## Don't forget your own parents

Your parents, no doubt, will also be highly anxious and concerned regarding your health, keep them informed and ask for their hands-on support, helping with the baby, other children and household tasks. Show them this booklet or email them a copy of this guide from the Pumping Marvellous website. Give them realistic reassurance, they will no doubt be keen to support you and your family as you continue to progress.



# Candlelight and Romance

Resuming a sexual relationship after the birth of a child is something that is approached with anticipation and apprehension. The complications of PPCM may generate some concern for both you and your partner.

There is both an emotional and physical aspect to a sexual relationship, talk openly together of your expectations. It's good to find different ways to show affection, especially until you feel comfortable and confident on re-establishing the physical aspect of your relationship. Practically you should refrain from sexual activity if you are unwell, listen to your body's energy levels, and choose a comfortable position, in a warm and familiar setting. Take your time and reassure each other that what is happening is right for you both.

Make sure you have sorted out contraception because getting pregnant without planning could be very serious. There are many different options now so ask and find out which is best for you and your partner.

You can obtain initial advice by visiting the following website:

<http://www.nhs.uk/conditions/contraception-guide/pages/contraception.aspx>

There is a wide variety of contraception available from the NHS, the website will direct you to where you can obtain them and how to decide which is best for you.

## Additional Services

If you are finding it difficult to cope with the physical implications of your PPCM or it has impacted on your ability to return to work, then the following website may be of help.

It is difficult to keep up-to-date with the various services that are offered, as these change on a frequent basis. For England and Wales the following website, however, will point you towards the services offered in your area by entering the relevant postcode.

<https://www.gov.uk/apply-needs-assessment-social-services>

# Financial Support

The impact of your condition may have a bearing on your financial income, this could be as a result of your or your partner's inability to work.

The UK system, again, is subject to change, and financial support and benefits will be subject to current legislation, and your personal circumstances. The following website will provide you with the various benefits that may be open to you:

<https://www.gov.uk/browse/benefits>

The Citizens Advice Bureau may also be able to help you to steer through the maze of the benefit system, their website will point you to your local organisation:

<http://www.citizensadvice.org.uk>

Your local Town Hall will also be able to direct you to any local Welfare Rights Team that will be available within your locality.

If you do not have access to the internet, ask a member of the family who may be able to do this for you. If that is not possible then contact your local Town Hall who will be able to direct you to your local Social Services Department.

You may wish to discuss this with your GP, Health Visitor or Heart Failure Specialist Nurse who will be able to make any necessary referrals. Your Health Visitor particularly will be able to provide information that may be of assistance in supporting you in relation to any childcare issues.

# Future Developments

As with all medical conditions, research is ongoing into PPCM. The European Society of Cardiology has instigated a registry of patients who have developed PPCM. It recruits those diagnosed within a 6 month period, in order to understand PPCM better, and allows Clinicians to manage and treat it as well as they can. This is something you could raise with your Clinician or contact the UK's lead Cardiologist Professor Mark Petrie, email [mark.petrie@glasgow.ac.uk](mailto:mark.petrie@glasgow.ac.uk) who will signpost you to your nearest regional centre for addition to the registry.

# Quotes

**You can't throw things off the same any more.**

**Some days you can talk, others you can't.**

**It is not the end.**

**I don't mind taking the tablets, if I am here for my kids.**

**I put it out of my mind and got on with my life.**

**You may not be able to climb mountains but can walk little steps.**

**Failure is fatal, it's the courage to continue that counts.**

**Birth is a celebration, so don't forget that.**

# Top tips from the PPCM Team

- Know your limitations and conserve your energy.
- Don't be afraid to ask for help and support.
- Don't be afraid to ask Clinicians questions.
- Don't let this define who you are or dominate your future.
- Know your red flags and have an emergency plan in place.
- Have a team, e.g. family, friends and HCP.
- Ask about Cardiac Rehabilitation.
- Get a Heart Failure Specialist Nurse.
- Take this guide with you to any appointments, not all Clinicians are aware of what PPCM is.

Our final recommendation is the PMF Facebook group. On there you will find a number of women who have all experienced the same thoughts, emotions, reactions - the ups and downs of PPCM, they will be your best buddies, they get it!

If you feel the Foundation can be of any further assistance please visit our website.

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

or call **0800 9788133**

You can also access all of our online patient and carer resource by following this link to [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org) then go to **Academies > Patient Academy > Heart Failure Toolkit**.

## Visit our patient Facebook communities online

On Facebook, search for 'Heart Failure Aware' and click on the Heart Failure Aware link.

On Facebook, search for 'Help for Hearts' and click on the Pumping Marvellous Help for Hearts Closed Group.



If you have any concerns then take this booklet to your  
**GP, Midwife, Health Visitor or Obstetrician.**



*Another Mini Toolkit by The Pumping Marvellous Foundation  
Crowdsourced information from REAL patients.*

### *Acknowledgements*

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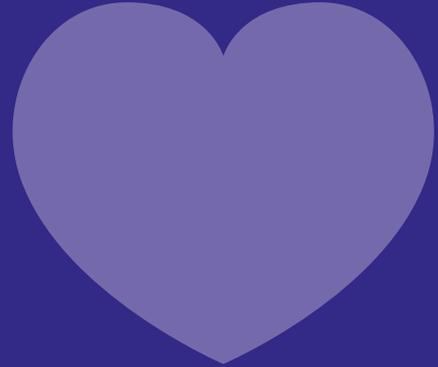
@pumpinghearts



heart failure aware



help for hearts (closed support group)



## Can you help us by donating or fundraising?

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