Peripartum Cardiomyopathy: Claire’s story

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By Claire Sheppard

There are significant dates in everyone's life that suddenly change their path forever. For me, the day my dreams came true and I had my son, Flynn, was one of them. My pregnancy was everything I had dreamt it to be, until the very last month. At the height of summer, with my bump twice the size it should have been, I started having symptoms of, what I would later learn, was Peripartum Cardiomyopathy.

My waters broke naturally, three days before Flynn’s due date. When I hadn’t dilated past 2cm naturally, I was put on a hormone drip. After over 48 hours in labour, as our heart rates were both dropping, I was whisked into theatre for an emergency C section. Nine minutes later, my Flynn was born, loudly announcing his arrival to everyone as he was pulled from my tummy.

As is common for new mothers, I felt emotionally and physically drained after the birth. However, a week later, I noticed a crackling on my chest as I lay in bed at night, followed by an almost desperate need to sit upright and cough as I felt like someone was sitting on my chest and I was drowning. This continued every evening, and the only way I could sleep was by sitting upright after an hour or more of severe coughing.

Knowing something was terribly wrong, and with Flynn tucked up in his pram, I waited to be seen at my local surgery. Eight emergency appointments later, after seeing five different doctors, being given an incorrect diagnoses of a blood clot on my lung and gastric asthma, I was told I was just a hormonal, overanxious new mother. This was despite me mentioning that I thought that my symptoms sounded heart-related and could be Peripartum Cardiomyopathy.

My symptoms persisted, worsening until one evening my husband was so concerned he rushed me into A&E. I was gasping for air and felt extremely dizzy. Finally I was taken seriously and a blood test and echocardiogram were carried out. Within minutes, the Echocardiographer turned to me and told me I had Peripartum Cardiomyopathy. My Left Ventricular Ejection Fraction, a measure of heart function, was less than 18%. An angiogram was carried out which confirmed for sure his diagnosis was correct.

I was put in my own private room and started on a high dose of diuretics to help reduce the amount of fluid around my lungs which had been causing my breathing problems. I was also treated with a beta blocker and ace inhibitor to help my heart muscle. Flynn was not allowed to stay with me as I was too ill to look after him. Being away from him almost broke me, although fortunately my husband brought him to visit me every day. Then, on top of all this, I was told I would not be able to have any more children as future pregnancies could kill me.

Over the years my heart function has improved to 48-50%, and despite being medication-dependent, I can live an almost normal life. The health care I have had where I live in Wales has been neglectful. My cardiologist, after 6 years of treating me, decided there was nothing more he could do and signed me back to the care of my GP. I felt so lost and alone, scared for what the future would hold as I got older living with Cardiomyopathy.

Thankfully with the help of Cardiomyopathy UK, I am now under a new consultant at Bristol Heart Institute. I am being very well looked after, recently undergoing genetic testing that showed I have a faulty gene, which, along with my stressful labour, caused my condition. I am seen regularly and am having testing which should have been carried out when I was first diagnosed. Flynn is now nine years old and, despite being healthy, is awaiting tests on his heart, which I now know should have been instigated much earlier. Our journeys through life may not be what we plan. I am just so grateful to be here to watch my son grow.

Author Bio: Claire Sheppard born in Hong Kong but now living in South Wales, with her husband Stephen, 9 year old son Flynn and their two cats. Since being diagnosed with PPCM in 2014, she shared her experiences of living with Pregnancy induced Cardiomyopathy to help others understand their diagnosis better.