

MY HYPERTROPHIC CARDIOMYOPATHY STORY

Hypertrophic Cardiomyopathy, otherwise known as HCM is a relatively common heart condition, which affects 500,000 people in the UK. It is genetic. Each child of an affected parent has a 50% chance of inheriting the condition. The heart muscle of an affected individual is thicker than it should be. Symptoms vary greatly. Some people have no symptoms. Symptoms can include fatigue, exercise intolerance, breathlessness, chest pain, heart failure and arrhythmias.

HCM is the most common cause of sudden death in young people and athletes. Unfortunately many people who have died suddenly from HCM didn't even know they had the condition, because people often have little or no symptoms. Sudden cardiac death can be prevented. Each person with HCM must be individually assessed by an arrhythmia specialist to evaluate whether they are at risk of sudden death. If they are at risk they need to be given the appropriate treatment to prevent a lethal arrhythmia from occurring.

I inherited HCM from my mother. Unfortunately she suffered from severe heart failure, and passed away 2 years ago, 1 year after having a heart transplant. I have three children. My nine year old son has HCM, and my other 2 children are genetically positive. They will likely develop the condition sometime during their teenage growth spurt.

I was diagnosed with HCM at the age of five. For most of my life since then I had very mild symptoms. It wasn't until my last pregnancy that I started having serious problems. I became very breathless. I couldn't breathe especially when I would lie down. I started having more arrhythmias; most significantly, I started having runs of ventricular tachycardia. When I was 20 weeks along, I was told by one consultant that I had a 50% chance of living through the pregnancy. I spent a month in hospital before I gave birth, but in the end everything went well.

After the pregnancy, I was still having significant symptoms. So a year ago in March, I had open heart surgery, a procedure called a myomectomy, where a portion of my thickened muscle which was causing obstruction to my mitral valve was removed. It took me months to recover, but the surgery was successful, and I feel better than I can ever remember feeling.

Although the surgery was successful, I was still having non-sustained ventricular tachycardia, which is a risk factor for sudden cardiac death. I was taking amiodarone to prevent a life threatening arrhythmia. However, in September, my routine blood test revealed that I had become thyrotoxic from taking amiodarone. I became restless, hyper and started to lose weight. Unfortunately, being thyrotoxic can cause dangerous arrhythmias, so I had to stop taking amiodarone.

The discussions on whether or not to have an ICD began. I realise now that I had already sub-consciously made the decision to go ahead. However, it took me several months to consciously come to terms with my decision. I knew from my work with the CMA that the decision whether or not to have an ICD is very complex. Apart from the physical side of having the implant, there are all kinds of psychological issues that can come up. How would it look? Would it stick out? What if it 'fires'? Will it hurt?

After much deliberation I gave the go ahead. I no longer wanted to live with the fear that I could drop dead at any moment. I think the moment that I concretely decided was when I was lying in bed with my baby daughter, who had fallen asleep on top of me. My bedroom door was locked. My husband knocked on the door. I didn't answer because I didn't want to wake up my baby. He called out to me, but again, I didn't answer because I didn't want to wake my baby. She had just had her immunisations, and was very unsettled. It had taken a while to get her to sleep. I

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then heard some strange noises outside my window. I managed to gently move my baby onto the bed. I looked outside my window. My husband had got a ladder out of the garage and was about to climb it in order to get into my room through the window. He feared the worst. It wasn't just my fear. My family had to live with it as well.

The day came to have the procedure done. I arrived at the hospital very early. I met with my electrophysiologist, who explained the procedure to me and answered my questions. After having a little time to relax, I put my gown on and walked into the catheter laboratory, where the procedure was to be done. I had requested a general anesthetic. The procedure is usually done while the patient is awake and sedated, but my memories of the myectomy were too fresh in my mind. A mask was placed over my face. I suddenly became very afraid. Although I knew I was doing the right thing, I was scared. The anesthetist said some soothing words to try and reassure me. Then everything faded away. In what only seemed like seconds, someone was calling my name and trying to wake me. I was still in the catheter laboratory. It was over. My head hurt, and my body felt numbingly cold. I was brought back into my room, where I drifted in and out of sleep for several hours. My chest and shoulder were sore. It hurt to move, but the pain was definitely manageable. I looked down at the implant sight; a bandage was over the incision. I gently felt it. My skin was numb, and I could feel a slight lump.

I felt tired and sore for about three days. Each day after that I felt better. Within a week I was out and about. I couldn't drive for a month, and had to be careful not to lift my arms all the way above my head for a few weeks. But all in all it wasn't too bad.

While my physical recovery was going on, something amazing happened to me psychologically. It started only hours after I had the procedure done. I was lying in my bed, and I had an arrhythmia. I tensed up, like I always did, hoping that it would stop hoping that it wouldn't degenerate into a cardiac arrest. Then I suddenly realised, I don't have to worry anymore because the worst thing that could happen is that I could get a life-saving shock from my ICD.

I didn't realise how scared I was until that fear was gone. Now that that fear is gone I have a future. Fear is very powerful.

When I think about the time leading up to my ICD, I realise what a mess I was. I didn't think about dying all of the time, but it was always in my subconscious. I withdrew from my family. I didn't want to be too close to my children, because I was afraid they would lose me. And I was afraid of what I would lose by not being there for them. I couldn't look forward to the future. I couldn't make plans. I couldn't relate very well to my friends, because everything else seemed so small to me. I felt cheated. I looked normal. I felt pretty normal, but at any moment I could die.

My future is looking bright now. My family and friends have me back. I am looking into the future. In fact, I'm going training to be a midwife in September. I hope to eventually be involved with the care of pregnant women with heart conditions.

My main concern now is for my nine year old son who is also considered to be at risk of sudden death. He recently started taking amiodarone, but will likely need an ICD in the near future.

Having an ICD has changed my life. I am no longer afraid of dying. I feel extremely lucky to have this life saving device. I consider it to be my man-made guardian angel.