My condition doesn't define me—my journey with HOCM

*In our monthly feature, Patient Stories, the people on the receiving end of the care you deliver share their experiences, challenges and lessons of diagnosis, treatment, care and life with various cardiac conditions. This month, 22-year-old **Steffi Moore** reflects on her journey with hypertrophic obstructive cardiomyopathy, and how she arrived at the full, albeit challenging, life she lives today.*

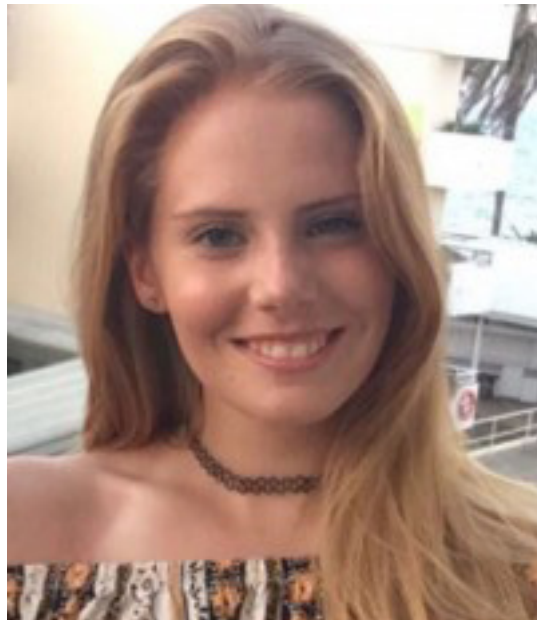
My heart journey started when I was very young—the doctors discovered a heart murmur during a check-up when I was a baby and decided it would close on its own, so no action would be taken. I spent the rest of my life as a child swimming nearly every day, taking part in sports competitions and doing physical education at school; never once did I think that my lack of stamina and slight breathlessness was down to an underlying heart condition.

During my teenage years, I started getting tired all the time which meant lying in bed, not being able to wake up in the morning and skipping activities because I didn't have the energy. This led to shortness of breath and chest pain which I started to experience even while sitting down. I felt like I couldn't breathe and that my heart was going to explode out of my chest, as it was so tight. I knew this wasn't right and I had to see my doctor, which for an 18-year-old is a difficult thing to do.

Originally, I was given an asthma pump and lung capacity kit to help with my symptoms but I didn't feel any relief from the pain. My GP sent me for a chest x-ray which came back with abnormal results; my heart appeared oversized compared to my body and although the hospital said this may be because I was stood at an angle, they wanted to get it checked.

I went back for an ECG which led to an appointment for an echocardiogram 2 days later because I was in such pain when I couldn't breathe. Once it was done, the nurse told me to go and wait in the coffee shop while the results were being processed and then I could go home. I was sent to the family room near the cardiologist wing in the hospital and told to wait there. By this time, I was hysterical and couldn't stop crying (AQ: were you alone?). I had no information and didn't know what was going on. Then a nurse popped her head around the door and said, 'Are you allergic to anything?' to which I screamed out 'No!' and she told me my bed is nearly ready.

I started to feel sick and worried as I wasn't planning on staying... I only thought it was asthma! I kicked up such a fuss that they decided to give me my own room to process all this new information as I was a young 18-year-old in an adult ward.



22-year-old Steffi Moore is finding a new normal

Hypertrophic obstructive cardiomyopathy

The cardiologist explained that the reason I was getting symptoms such as breathlessness, chest pain, dizziness and fatigue was because I have a condition called hypertrophic obstructive cardiomyopathy (HOCM), meaning the muscle around my heart is thickened and my heart was unable to pump blood effectively around my body. At 18 years, old I thought it was impossible for my heart to be failing!

Ongoing bad news...

The bad news didn't stop there—my heart was struggling so badly I was told I needed an ICD fitted as soon as possible because without it, my heart could go into cardiac arrest and I could die. I was told that the ICD was a pacemaker and defibrillator, which meant it could detect unhealthy rhythms and correct them through a shock or a pace. With so much bad news, my positive outlook on life was stunted—I was told if something wasn't done, I will die. All I kept thinking was that it wasn't fair at 18 years old to be diagnosed with a serious heart condition.

I was in hospital for a total of 5 days, being monitored and waiting for my ICD to be fitted. At one point, I was even abruptly woken up in the middle of the night with a group of nurses putting my bed into the CPR position and checking that I was awake and breathing. During this time, I had visits from many nurses who specialised in arrhythmia and heart failure—another group of words I never wanted to hear. This was too much too quickly but it was happening whether I liked it or not.

Regaining control and a different normal

I decided to take back as much control as I could while in hospital. I learned as much as I could about cardiomyopathy as I could and tried to understand my condition and what impact it would have on my life; this helped me to get through my time in hospital.

This feeling was shortlived however as once I came out from my operation, I was in unbearable pain, feeling self-conscious and mentally drained. I had a scar, no feeling in my arm and a box in my chest that would keep me alive in a life-threatening situation, but felt horrible.

I was also worried that the ICD would give me a shock or that something else bad was going to happen. I wrote these off as some of the worst weeks of my whole life—I had to start all over again and learn to live a different normal.

Second chance at life

After a lengthy 6 weeks of feeling sorry for myself and processing the emotional and physical impact of what I had been through and was going still going through, I decided not to live my life in fear and instead, to look at it as a second chance at life. The diagnosis was horrendous but I was still here and I was going to live my life to the full!

Seeking out support

I started by going to a Cardiomyopathy UK support group at my local hospital where I met other people with the same condition but at different stages in their life; this gave me hope for the future but there was still no one my age. Cardiomyopathy UK approached me and told me they were considering setting up a youth panel and I was on board right from the start. Their aims were to get more young people talking about cardiomyopathy, creating resources and making a difference for young people so that together, we can cope with our condition.

Taking it in my stride

The confidence I gained from attending the youth panel led by Ali Thompson allowed me to continue my life in my own normal way; I travelled, worked and partied just as a normal young adult would and made the most of my life every day. I still face challenges on a day-to-day basis with symptoms and new information, but I have learned to take it in my stride.

The future looks bright in terms of my opportunities and although I am constantly being assessed for a new heart at Harefield Hospital, I know that my nurses, Cardiomyopathy UK and my family will be there the whole way! I now work full time, I travel widely and volunteer for the nation's only cardiomyopathy specialist charity, Cardiomyopathy UK. I share my story as proof that everyone has their own normal and my condition doesn't need to define me. BJCN