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.

**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 short-lived 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.