



**James talks about his experience of Kawasaki Disease, how the consequences of delayed diagnosis have affected his adult life and how he's been able to overcome the challenges of heart damage.**



Back in 1985, being just a few months old, I was taken into hospital with an unexplained fever, a patchy red rash and peeling of my skin. According to what I've been told by my parents, the doctors were perplexed. About six months later, I was formally diagnosed with Kawasaki Disease.

As a child I remember spending hours in the cardiac outpatient department of Alder Hey hospital and the process of getting an ECG, an echo and then seeing the Doctor. Occasionally, as I got older I would also have an exercise tolerance test and on two occasions I had a coronary angiogram. I was 8 years old when I had my first angiogram and 12 when I had my second.

As I got a bit older and I began to take more of an interest in the disease and my well-being, I learned that the disease had left me with quite a large aneurysm in my main coronary artery – this was a permanent aneurysm. I was told that we would know by the time I turned 21 (fully grown) whether or not I would need a procedure to fix the problem that the giant aneurysm was causing – likely a stent or worst case scenario, a bypass graft.

When I graduated from University I became a Cardiac Physiologist – an Echocardiographer and Pacemaker Technician basically! This was completely coincidental to me having the heart problem, believe it or not. I didn't aim to have a job that would link to my own personal life so intimately. Honestly, I didn't!

Towards the end of 2010, at the age of 26, my Consultant decided it would be a good idea to get an updated angiogram. At this point I had no symptoms – playing sport twice a week and staying pretty healthy. However, as soon as the doctors had finished the angiogram they explained that the artery had become blocked.

Eventually a date was set and in June 2011 I was booked to have a coronary artery bypass graft (CABG) in Manchester

Royal Infirmary. It was a weird time for me. I had a two month old daughter, I was busy in work and with study, and I was also caring for my mum who was ill at the time. I suppose this put the thoughts of my own health at the back of the pile.

At no point in the lead up to the surgery did it enter my mind that something could go wrong, or that I wouldn't make it out. My wife finds it hard to believe that I didn't think about the worst, but I didn't. I can't explain why but there you go. I suppose I just knew it wasn't my time, and I'm usually a pessimist!

Anyway the procedure was performed and in fact I had two grafts during the operation, both taken from the internal mammary arteries, so no veins/arteries were taken from my legs or arms as is sometimes the case, and the procedure was a complete success. I then spent a fairly uneventful five days recovering in hospital before going home.

After just under 3 months off work, I returned and soon got back into the swing of things. My life returned to normal (albeit with the new baby!) and we were happy to announce that we would be having a second child in the following May.

I now play sports regularly including football and I cycle as much as my busy schedule allows, aiming for 2-3 hours of vigorous exercise a week. I even manage a girls football team. Today, I watch my diet, monitor my exercise – I wear a fitbit and aim to walk 15000 steps a day, which I more often than not manage. These are lifestyle things I choose to do rather than specific advice I've been given – but looking after myself is important for myself and my family

So, after 12 years since surgery I remain on 4 cardiac medications (Amlodopine, Aspirin, Losartan and Simvastatin) and have regular follow ups with my Cardiologist. That's my particular regime! I'm relatively fit and healthy and enjoy a completely normal life. Kawasaki Disease has been part of my life but I think it's fair to say, it's never been a main part!

I hope sharing my experience has given some insight into what it's possible to achieve – which is actually a pretty normal life from my perspective – as well as the sorts of challenges which can be faced when living with the consequences of Kawasaki Disease.

To listen to James' *podcast on Soundcloud*, [click here](#).

