



Kris tells how Kawasaki Disease has impacted him throughout his adulthood. He talks about some of the health challenges he has faced and the struggles he has met with being a younger person with heart damage.



Hi I'm Kris, I'm 34 and I live in a small village in the Cotswolds with my wife, my three children and cat. I grew up in a small village in Gloucestershire in the countryside. Me and my brother loved to get outdoors whenever we could. I loved to play football, rugby, tennis and any other sports that we could keep us outside more.

I first fell ill with Kawasaki Disease when I was 10. The first signs of any illness was when I got mouth ulcers, a red rash all over my body, headaches, severe back pain and sickness, as when I got Kawasaki Disease I also had Campylobacter at the same time. That makes you feel very sick, have dizziness, fevers, and diarrhoea. So, this also made it very hard for the doctors to determine what I had. For the first three to four days they were treating it like I had meningitis.

After having Kawasaki Disease, my parents were told that my heart had been damaged and something like surgery may occur later on in life.

At the beginning of my illness, I felt very alone at school as I couldn't join in with any sport activities and couldn't stay at school all day. My mum said I was very down for a long time during those first two to three years after the illness.

During the years between the ages of 10-18, I had to keep going for regular treadmill and ECG tests. However, as I was doing a lot of sports at school during this time. I was very fit and athletic and in fact, I was the captain of football, rugby, and basketball team. I didn't really suffer any problems when I did go for the tests, and they were happy with the results.

As I stopped doing more sports and was working more in my early twenties, I started to develop loss of breath and quite

frequent chest pains. From the age of 17 – 26, I had three angiograms to check how my arteries were functioning and they said that they could see the effects of Kawasaki Disease but there was no need for surgery at this time because they weren't concerned.

Back in 2011 I was diagnosed frontal lobe epilepsy. From 2011 - 2019 the epilepsy was controlled but I had a lot of problems with sickness which was down to the fact that during my Campylobacter I had stomach ulcers that went untreated for a long time.

During 2020 I started getting chest pains and doctors investigated the pains with scans and ECG's. On my return from my scan in December 2020, I had an epileptic seizure whilst driving home and had to be airlifted to Gloucester hospital. I suffered fluid on my right side of my brain and crystals in my ear. I couldn't walk due to my loss of balance, and I temporarily lost hearing in my right ear and lost 16 months of my memory. (I don't remember anything about Covid).

I was in hospital for just under a month. During this time, I found out that my wife and I were going to have another baby in 12 weeks. The next 5-6 months were very difficult health wise, and financially, and put a lot of stress on myself and my wife. When I was in hospital, I had been complaining of chest pains. They sent me for ECG's and other scans and everything came back "normal for me".

In June 2021, I had another angiogram just to rule anything out. The doctors were shocked at what they saw and told me to wait for a call from the specialist. The next morning at 9:00am, I received a call to say come into hospital within the hour. They told me that I needed a double bypass surgery within three weeks. It actually took them a long time to do as there were a lot of covid staffing issues and I had the surgery in October 2021. The operation went OK but during the operation my lungs collapsed, and I need a triple bypass not a double bypass.

I continued to recover at home and after 3 months went back to the surgeon who was shocked to hear I was still in a lot of pain and still being sick etc. I then had another

angiogram in 2022 and two out of the three bypasses had collapsed. In October 2022 I had to undergo a 5-hour stent procedure and had to have 5 specially made stents as they were very very enlarged due to my previous Kawasaki Disease. They said that was the reason I had been experiencing the chronic pain and I was still very inflamed around the heart and sternum was because of the Kawasaki Disease.

In January 2023 I had a severe angina attack and was hospitalised for 5 days. Following on from that they said I needed to have another angiogram and was promised within 1 week – it took another 3 months to have the procedure and they had to enlarge the stents again. I now am waiting to talk to the doctors again as there hasn't been much improvement.

One of the biggest battles with the doctors is that my age is an issue. Most of the patients with heart problems tend to be older and when I complain about chest pains or loss of breath, they are quick to dismiss the fact that it could be anything too serious. If I hadn't had the first angiogram in 2021 and they had just looked at the information from all the scans and tests that came back "normal" I may not be here now.

If any cardiology doctors are listening – it is hard when you go to the doctors and you get brushed aside because of what you are – you're young, you're fit, there aren't any drug or drink related issues. So just bear it in mind that we need to definitely investigate, regardless of their situation, how they look or how young they are – they just need to be tested.

One major positive that has arisen because of Kawasaki Disease is that I feel I have more of a resilience in life. Especially at school – the more people told me not to do something, the more I did it – and excelled at whatever I was doing! I feel like what I have been through the last few years, there isn't anything I can't handle.

For any families with children or teenagers growing up with Kawasaki Disease, I would say to keep healthy and trust your body. If something doesn't feel right, get it checked out. Keep having regular check-ups and keep laughing together. I know it's cheesy, but it is true).

The biggest help to me in terms of living with the effects of Kawasaki Disease is having the support of my wonderful wife, friends, and family – and always laughing!!!!

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

