



Rosie was unknowingly affected by Kawasaki Disease in her late teens which went undiagnosed. She talks here about the health issues and the challenges she has been faced with throughout her adult life because of this.



I'm 36, married and happy! I have a great life, I love going on holiday with my husband, I go skiing with my family and our friends, I love seeing my friends – the majority of which I met at school, apart from Mikey who is marrying his fiancé Mark next year which I am very excited about as I love any chance to get involved with doing flowers and general party planning! I'm from Portsmouth originally but due to getting my online dating filters wrong and accidentally setting my catchment area to large, I met my husband – a country boy! I now live in a small village in Wiltshire with him and my wonderful dog Marmite who I love walking with everyday. I now love living in the countryside and the peace that it brings but I do miss the sea and so I go down to visit Portsmouth as often as I can. Also – I miss being able to get a domino's pizza delivered!!

I recently did the Yorkshire 3 peaks with a lovely friend of mine, Vicky (she's in the RAF so it was a breeze for her!). We walked across the 3 mountains (the equivalent of higher than Ben Nevis) and the length is just under a marathon by a kilometer or so. It was a really tough challenge but I have to say I loved it (apart from the second peak which was very tough!) and I am so proud that I did it. I managed to raise just under £2,500 for Societi as well which felt really great. A very worth wise cause.

I joke that I have 6 parents, my Mum, my Step Mum, my Dad, my Step Dad and my lovely in-laws. I'm also one of four so there is always someone to be catching up with and I wouldn't have it any other way. I'm the only one that has emigrated though, even if it is only an hour up the A34!

I work in the medical industry. I was previously working in clinical nutrition and dysphagia (which is when patients do not swallow very well) but after my own heart surgery journey, I wanted to be in that environment as I can offer a unique perspective to the healthcare professionals as a previous beneficiary. In my new role I am working in cath labs partnering with various healthcare professionals from cath lab technicians to cardiologists to junior surgeons to show them how to use my companies equipment.

When I was in my second year of uni I had gone home for the Christmas break. I had been at my friends house on the 27th of December (yes, I remember the date!) and I drank too much. I remember being at my parents house the next day and feeling like I had the worst hangover of my life – I am sure those Southern Comfort and lemonades played their part ...but then I just didn't get better.

I continued feeling incredibly ill and developed a fever that just wouldn't shift. I remember having awful fever dreams which were intensely emotive and my PJs and bedsheets being wet with sweat. I also had incredible back, neck and shoulder pain which was incredibly unpleasant and actually a bit scary. I also had swollen glands in my neck but I didn't think anything of that because they would always get bigger when I was generally unwell.

Eventually the fever wore off – I think it must have been a week or so but then I just felt wiped out. I felt the most tired I had ever been in my life for weeks and weeks afterwards. I was too tired to eat, I barely had the energy to get out of bed and I had lost a lot of weight.

I remember one day when I was having a better day my mum insisted that we left the house and she took me to Primark to get some clothes as the ones I owned were so loose. I remember being in the disabled changing room and her physically helping me to put on the clothes because I just didn't have the energy.

Another day she thought it would nice for me to have a facial (how tiring could that be?!) and I fell in to an incredibly deep sleep on the table. The therapist couldn't wake me up and she came and got my mum because she thought I had passed out.

Somehow in my 19 year old wisdom I was determined to go back to my uni in Birmingham for the Spring term as I was starting to feel a bit better. I was a VERY swotty student and I have always adored biology so I really didn't want to miss any lectures. However, I had seen the GP in Portsmouth, Dr Dinapala, and he wanted me to come home straight away after getting the results of my blood test.

I remember getting a call from my uni doctor asking me to come in immediately for more blood work, the surgery was closed but they ushered me in.



I remember them asking me loads of questions about fevers, sore joints, swollen glands, weird bruising, weight loss and at

the time me thinking “All of these questions are the signs of Leukaemia, what’s going on?” – like I said, I was a swot. They also said to me “Don’t go on Google and look these symptoms up” and think “Yeh, cos you think I have cancer” but of course, I didn’t say anything as an unsure 19 year old. The results came back and the doctor wanted to see me straight away and she asked if my mum could come to the appointment.

In the appointment the doctor pretty much said that there was something seriously wrong as my white blood cells were all over the place and my platelet level was sky high, I think it was something like 1300.

She was worried it was cancer and also that I was so anaemic that she was worried I was internally bleeding. That turned out to be wrong – I was still very anaemic but not blood transfusion worthy, there was error in the test.

I had more tests with her and I sent my mum home (I can’t believe she went but she was just in shock and did as I asked) and went to my biotechnology lecture. I was in complete denial.

The next day when I was in the lab I rang her and she came and picked me up straight away but not before I sat down with my professor and explained what was happening. He was as good as gold and the uni made every accommodation for me. I missed a lot of work but I still got a first for the year which is still one of my proudest moments.

Anyway, long story short, lots of blood tests and a few hospital appointments later, I had an appointment with a haematologist and he believed I had had the flu. The proper flu – not the kind when people have a cold and tell everyone they have the flu.

My family and I accepted that and by about Easter-ish, I was pretty much back to normal. My anaemia had improved, my energy was back and I could eat a full meal.



I think about the lead up to the diagnosis a lot. I started going to the doctor saying “Ow my chest hurts”. When I was 31 about Easter time in 2019, 3 years before I had my surgery. I was completely fobbed off, was it muscular? Was I asthmatic? Nope it was classic angina but because of my age and gender it was just never even considered even though I had the classic symptoms.

During this time there were two things that were said that to

me by GPs that will always stay with me “Well, you can walk your dog, you can walk 10km, you’re fine” and “Rosie, we may never know the source of your chest pain, you’re going to need to live with it”.

In 2020 Covid hit and I stopped going to the doctor to say “Ow it hurts” and I did my daily exercise. I had stopped running by this point because the angina was getting worse and it didn’t feel worth it.

I would go on long walks with my husband and he would say “Oh your just unfit, you need to get fitter” as I was gasping for breath and my chest was hurting, and by this point, the pain was radiating down my arm but I totally agreed with him!

I thought I was an unfit hypochondriac. It was simple. I needed to man up and get on. Then in 2021, I had a sore shoulder and started seeing a physiotherapist. I told her about my chest pain and she said “Are you sure it’s not your heart?” and I said “Oh no, they have done an ECG, it’s fine!”...then I saw another one and he said “Are you sure it’s not your heart?”...it was when the third physiotherapist said the same thing that I thought maybe they had a point but didn’t do anything because they turned me away before.

My husband was getting a bit bored of “Ow it hurts!” and said “Just book a GP appointment and tell them you have private health insurance”. I did, I saw the same GP and he was really flippant about getting me referred, “but who should I refer you to? It could be anything!” Eventually I saw a rheumatologist privately and he said “Oh, I think it might be your heart, lets get you a CT scan”. Now, I need to mention that this was the week before my wedding. I had the scan 3 days before it. While I was on my honeymoon I got a phone call saying when could I come in and see the cardiologist? Again, denial, “oh yeh, they said maybe my heart but, unlikely right?”

We got back from our honeymoon to a pile of letters saying that I had extensive heart disease and well, you know the rest, I’m now part of the zipper club. It was a weird time. Something I really remember was having a conversation in the back of a taxi with my husband that if I die on the operating table that he should move on and find someone else because I just want him to be happy. We have had the conversation again since, at the end of the day, I do still have extensive heart disease.

As my Kawasaki Disease went undiagnosed it did catastrophic

damage to several vessels, called extracardiac vessel damage, in my brain and pelvis, but most notably my coronary arteries. I have giant aneurysms in my left anterior descending (LAD) with stenosis – so I have balloon shapes followed by tight narrowings giving my LAD the appearance of a string of sausages.

My right coronary artery, although its aneurysm free, is completely blocked. These two coronary arteries being blocked has meant that I have needed and received a double bypass which I had aged 34, 18 months ago.



Kawasaki Disease totally affected me emotionally, but it's funny, when I was in the depth of dealing with the prospect of heart surgery I thought that I was fine. When people asked me "How are you doing?" I would genuinely say "Oh fine, not a lot I can do so I am just prepping what I can but I will be OK".

What I didn't link together then was the fact that I was not sleeping through the night and would lay awake for hours at a time. I remember asking my doctor for sleeping pills a couple of times and him refusing to give them to me. And me "prepping" was classic crisis management but I didn't see that at the time.

Before my operation, I made a load of meals for the freezer (even though my husband is a chef), I did gardening in January in the rain and the dark because I knew I wanted a "sorted" garden. I washed everything I could, organised for a cleaner to come twice a week, I organised friends and my mum to be at the house after the operation to help out – everything in my power to get organised.

Before the operation as well I needed to write a will as with bypass surgery the risk of dying on the table is real thing...aged 34, writing my will, I couldn't quite get my head round it but I just did it, almost on auto.



I have seen so many specialists since my surgery trying to get to the bottom of why I needed a two coronary artery bypass grafts and also a couple of scary diagnoses as well.

When I first met my cardiologist he had never seen anything like it and he consulted with a retired paediatric cardiologist who mentioned Kawasaki Disease. However, because I said I had never been ill as a kid it was quickly dismissed as a reason

as to what had caused the damage.

When I then met my surgeon he seemed to think it was linked to when I was ill at 19 and it was likely to be some burnt out vasculitis but it was always just hinted at with no real distinct answer.

During my surgery they took a piece of left internal mammary artery and it was sent to histology but the results were confusing and led to them being misinterpreted. So, I was told I had arteriosclerosis which would have meant that the disease potentially would have come back if not controlled properly and so would effect my treatment plan.

What the report actually said was "intimal thickening" which is actually very common and isn't an indicator of arteriosclerosis. I lived with the fear of having this disease for quite a while and being upset/nervous about eating the wrong foods...or worse, that I had eaten the wrong foods previously and getting really upset and blaming myself for the condition.

Our plan was to get married, go on our honeymoon and start trying for children the following year. But with the surgery we knew it would need to wait for at least a year and I was put in touch with a wonderful cardiologist in Bristol, Steph, who started talking me through it a bit more, just 4 months after the operation.

However, 6 months post op I had a little bit of angina (running on a VERY hot day) and then I had a cardiac stress MRI which showed that 6% of my heart wasn't getting the blood it needed. It wasn't the worst result but it led Steph to be concerned that I would have an INCREDIBLY high risk pregnancy, potentially have an MI (heart attack) whilst pregnant or having such chronic and unmanageable angina that I would need a termination or the baby being born very premature. This made me take a step back and think as you can imagine.

About 4 months after that, I met Prof. Tom Johnson who diagnosed it as very likely Kawasaki Disease from the "classic" calcified aneurysms and said that my aneurysms shouldn't cause a problem but that he would let Steph chat re: planning pregnancy. After Steph had talked to Prof Tom Johnson she felt better about things and was much more optimistic about me becoming pregnant.

However, part of her feeling more confident was for me to

have a full brain to pelvis cardiac MRI to image my blood vessels to rule out Fibromuscular Dysplasia, a disease which can be fatal (so that was fun, processing that). However, although they ruled out FD they found that I do have extracardiac vessel damage as a result of Kawasaki Disease from my brain to my pelvis. Again, a worrying thing to hear. This led to me being seen by a lovely Consultant Rheumatologist who's job was to rule out anything else on going. It also led to my images being seen by a vascular surgeon who wasn't happy with what he saw and was worried about me being pregnant.

I'm actually going for another Cardiac/vessel MRI scan tomorrow to see what my vessels look like 6 months from my previous scan. They think that if they haven't changed then I am "back on" for being pregnant but I will remain very much a "bit of an unknown quantity". There is a huge internal thought process for me about becoming pregnant. Is it safe? Will I be hurt? Would the baby be OK if Steph's original concerns are correct? Do I want to put myself through it? I had angina a year ago under physical stress...will it happen again and have disastrous consequences? Do I want a baby so much that I am willing to put my physical and actually, mental health at risk? At the moment I'm at "No" but, you never know how you will feel in a years time or so.



I believe that the initial diagnosis was overlooked when I was 19 years old. Looking back, I displayed all the classic signs of Kawasaki Disease in adulthood, including a high fever lasting over 5 days, swollen neck glands, joint pain, and an extremely high platelet count. While I didn't exhibit the typical "mucosa" symptoms such as rash, tongue, or eye issues, I understand that these are less common in adults with Kawasaki Disease.

Had the disease been detected at that time, it's highly likely that I would not have experienced the catastrophic damage I am facing now. Early intervention and treatment could have prevented or minimised the long-term effects of Kawasaki Disease on my health.

I hope that moving forward, medical professionals will become more aware of Kawasaki Disease occurrence in adults and consider it as a possibility when presented with the relevant symptoms. By raising awareness and recognising the signs early on, we can avoid such severe consequences for others who

may be suffering from this condition.

I appreciate my first cardiologist's dedication and expertise as he is a wonderful doctor. Having known him from a non-patient perspective and having spent time with his team in the cath lab, I can confidently say that he is highly regarded. However, there was a lack of awareness regarding Kawasaki Disease in adulthood, which led to the dismissal of its possibility due to my age at the time of illness.

If there had been more awareness of the symptoms and the fact that Kawasaki Disease can occur at the age of 19, I believe I could have received an accurate diagnosis much faster. This would have spared me a lot of heartache and stress post-op, as I would have known from the beginning what I was dealing with.

I believe it is crucial for adult cardiologists to be familiar with and recognise the signs of "classic calcified aneurysms" in adults caused by Kawasaki Disease. Early recognition could prevent misunderstandings about the disease, which can be caused by lifestyle factors or genetic conditions and can potentially be fatal.

Moreover, it would be beneficial to educate cardiologists about the extracardiac damage that Kawasaki Disease can cause. This way, if a diagnosis of Kawasaki Disease is given, a comprehensive cardiac brain to pelvis MRI could be automatically performed to check for any further damage, rather than it being an afterthought.

Overall, enhancing awareness and education among cardiologists about Kawasaki Disease in adulthood will undoubtedly lead to better and faster diagnoses, preventing unnecessary stress and uncertainties for patients like me.

The only reason I was further investigated to determine the cause of my heart damage was because I was contemplating starting a family, and it is disheartening that such a significant concern prompted the investigation rather than a proactive protocol in place for identifying Kawasaki Disease in adults.



For any families with children or teenagers growing up with the effects of Kawasaki Disease, I would say keeping an electronic document to track all appointments, scans, results, and discussions related to treatment, as well as outlining the plan

for ongoing treatments, is crucial.

It can be easy to lose track of everything happening during such challenging times, and having a centralised record can help you stay organised and well-informed about your or your loved one's medical journey.

In addition, don't hesitate to seek help and support from your loved ones. People often offer assistance with a generic "If you need anything, let us know," but it's essential to be specific about the help you require. Whether it's asking for help with household chores that have been neglected due to hospital visits, requesting meals for the freezer to ease the burden of cooking, or seeking assistance with pet care, don't be afraid to reach out. These practical tasks are often overlooked in the midst of a crisis and can lead to additional stress for families.

By openly communicating your needs and accepting help when offered, you can create a support network that lightens the load and allows you to focus on the well-being and recovery of yourself or your loved one. Remember that seeking help is not a sign of weakness; it's a strength to recognise when you need assistance and allow others to provide it during difficult times.



I asked my husband if he felt there were any positives in our lives that only occurred because I had been affected by Kawasaki Disease and he just flatly said "No". I actually disagree with him though.

Experiencing and being aware of one's mortality through a health crisis truly puts things into perspective. Recently, my partner and I invested a considerable amount of money into plans for an attic extension. However, after waiting for over a year and realising that it would result in a substantial cost for not much extra space, I couldn't help but reflect on the situation. I found myself saying, "Yes, it was a significant expense, but compared to what I've been through, it's manageable. No one has died because of this."

Similarly, on challenging days at work, I often remind myself, "At least I can work." This new-found appreciation comes from knowing what it's like to face greater difficulties and endure pain.

Now that I can exercise pain-free, I recognise that it's a positive

outcome despite the prolonged pain I endured. When I exercise and feel out of breath, I can simply tell myself, "I'm just out of breath, and that's okay; I can push through it."

The experience has also strengthened my love for my family and friends. Going through a health crisis revealed who truly values and cares for me, and it has been an eye-opening process. It separated those who genuinely care from those who may not have been as supportive. Ultimately, this ordeal has helped me appreciate the important people in my life even more and has shown me the depth of their love and care.

In the end, facing mortality has given me a fresh perspective on life, making me cherish every moment, embrace the positives, and find strength in the face of challenges.

I couldn't have done this without the support of my loved ones. You know the expression "It takes a village to raise a child"? Well I think it takes a village to help you get through an event like mine. My therapist has been amazing, a real source of comfort - I would recommend talking therapy to anyone, at anytime.

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

