

My name is Laura and my daughter Josie was diagnosed with Kawasaki Disease on 1st March, 2018.

She had been a little unwell in the week, leading up to the weekend. The Thursday, Friday, she'd complained of a stiff neck, a little bit of a sore throat.

She got worse as the day went on. And her teacher called to say she was really having trouble turning her head because her neck had become quite swollen. So I went and collected her and brought her home but in true Josie style, she still was convinced that she was going to Beavers that night, and she wasn't going to miss out.

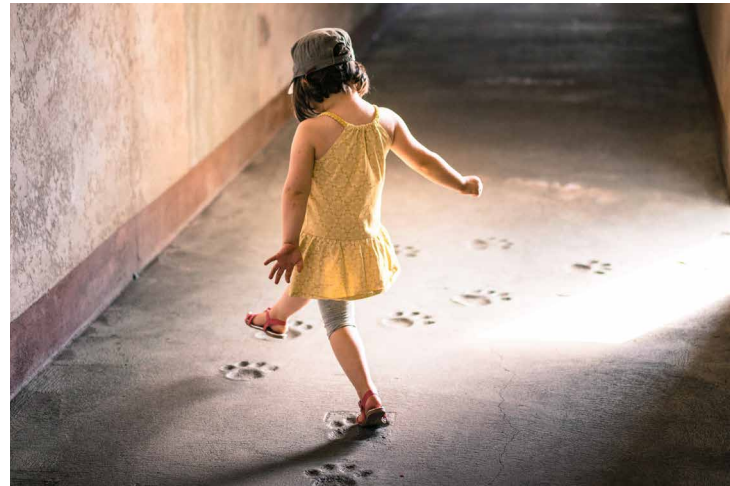
About 20 minutes, half an hour in, she called to say that Josie was in tears and she was really, really in a lot of pain with her neck.

Her throat was very sore. Ice cream was all she wanted and ice lollies. There was a lot of that over the next 24 hours, she didn't really keep much down - she was being quite sick. The temperature just didn't seem to shift for longer than a couple of hours.

So we dialled 111 and spoke to someone there who said that the on call doctor would give us a call back. About an hour later they called to say that unfortunately because there were so busy, what they would recommend was for us to take her to her local A&E.

So we went on up and about 20 minutes after we arrived, the triage nurse saw us and I gave her a bit of a back story to Josie's history in the hope that it helped her take us seriously. And she quite quickly decided that it wasn't anything serious and actually, we should just go and see the on-call out of hours GP.

She gave Josie a fairly thorough examination. And at that point, she said that she felt there probably was something that needed investigating and sent us on



up to the children's ward at the local hospital - to the paediatric assessment unit.

When we got up there, I quite quickly recognised a paediatrician as a doctor that had dealt with Josie before. And he quite quickly put me at ease that they would do their best to get to the bottom of it quickly.

We started IV antibiotics and IV fluid that evening. So it was the Sunday night. And I stayed over in hospital with her that night, we had our own separate room in case she had anything contagious.

She had a bit of a rash that morning that seemed to spread, so we marked it up with a pen and we took some photos and left it at that. They ran the bloods and the CRP levels were climbing higher. So we could quickly rule out that the antibiotics weren't really doing much, but we tried a different combination, I guess that was what the doctor suggested.

Then we got to the day the "beast from the east" hit. And it's funny that that's the bit that I remember because it was such a pivotal moment for the hospital I think, but it was a pivotal day for us as a family.

The doctors had been through in the morning and there seemed to be a lot of head scratching going on with what was going on with her.

At that point, a doctor turned up – a paediatrician that I had seen a couple of nights previously. But Josie hadn't really been awake when she'd come in. And she said she'd come back because they were reviewing Josie's case. And she said I just have a few questions and wanted to see Josie. She looked Josie over and she kind of said, the bloodshot eyes she's got, how long have they been there? And it was something I kind of noticed but figured you know, we were in hospital, the heat was really dry. Then she asked about the cracked lips and the strawberry looking tongue. And we kind of just offered the answers, you know how long we thought she'd had those.

She then asked about the rash that we'd spotted on Monday and had we taken photographs – and we had. So we showed her those. And at that point, her manner changed. And she said that they needed to act quite quickly now because she was certain that Josie had something called Kawasaki Disease, which was something we had absolutely no idea about.

The doctor explained that she actually specialises in cardiology, so she had seen a couple of cases of this before, but not many. She said at that point, she wanted to do an ECG and an echo [echocardiogram] as quickly as possible to have a look. She obviously explained to us at that point that it affects the blood vessels. The heart being the place that could be most affected.

The doctor that diagnosed her had done the ECG and the echo. She said she felt there was probably something on there showing some kind of dilation of the arteries. But the scan needed to be sent off to a more specialist hospital, closest to us, for them to take a look at and they would do that the following morning.

The next day, about six o'clock in the morning, we'd finished a fair bulk of it, [IVIG infusion] but there's still some more to go. But she'd slept all night and she was as bright as a button.

And the doctor that she had loved seeing all week popped his head in to say I can't believe we've got to the bottom of what's been wrong with her.



He said to her is that anything you would like at this point? And she said I'd love some cheesy wotsits and a diet coke. And at that point, we were a bit like oh it's half past six in the morning you can't have that.

And he was like No no, no. This is the first food she has asked us for all week. I am going to get her the cheesy wotsits and the can of diet coke. So we've got a great image of her just sat in bed looking completely dishevelled. But she's happy as Larry with her cheesy wotsits and her diet coke.

At that point, he sat us down and said that he felt there was probably fairly significant damage. Both her arteries were definitely dilated and that he wanted to have a CT [scan] done in order to see more of the damage.

We came back home on the basis of they'd be in touch about an appointment. I didn't expect the call to come as quick as the following day, saying can you come back again for us to do the scans now. So we went back, Josie sat through the scans, not a problem. She was more than happy to see familiar faces and the doctors and the consultant.

Straight after the scan, we had expected to go and someone to call us in a few days time. But the person performing the scan said actually can you go straight back up to the cardiac unit, the consultant will want to see you today.

At that point, he sat us down and explained that actually, Josie's, his heart was significantly damaged and that he needed to start anti coagulants straight away.

The consultant was very honest with us and said that, given the level of damage, in his opinion, it wouldn't resolve. At that point, I think we were fairly heartbroken but there was still that piece of hope in us that actually, we'd caught it what we thought was fairly early, she'd had steroids, she'd had the IVIG. Maybe this would get better. It's just cases he'd seen before that hadn't and she would be unique, she would be different.

We've been on that journey for almost five years now and nothing has changed. I think at the two year mark, the last little bit of hope left us.

But in that five years, there is a little girl that's very determined to be exactly like everyone else. She has turned up to consultants appointments every six months to see the same doctor.

He likes to remind her of the time that she turned up with a list in her pocket of questions of things she wanted to know if she could do. She wanted to know if it was still okay to ride her bike. Could she join the cricket club? Could she still go on all the rides at Legoland?

To which he simply said to her, you can do everything a normal child can do Josie but you know yourself when something isn't right. And you need to just tell us when something doesn't feel right. Because that's the quickest way we're going to find out that something might not be as it is.

Since that day, we've decided that sharing our story and raising awareness of Kawasaki Disease was really important. Because actually, if we can help other people that end up in our situation or help other people not be in our situation, then it's really, really important to us that we can do that.

I know that in my local area, the hospital that diagnosed us have definitely considered Kawasaki Disease earlier than a lot of childhood illnesses that friends have told me about where doctors and nurses have quickly asked the question, could this



be Kawasaki Disease. And we feel some amount of pride in that because Josie has shared her story.

One piece of advice I'd give to families or parents going through this is to find the information on the Societi website and the family portal specifically as quickly as possible. It provides you with an insight into how things are and it actually helps prepare you before things may happen.

And I remember Josie's consultant at the time when I started asking questions - him being surprised at my level of knowledge. He said to me, have you had experience of this? And I remember having to tell them no, but I'd seen it on a website. And to which he said well, its obviously a good one.

We went on holiday the year Josie was diagnosed, to France and actually we went back to somewhere that my husband and I had met for our 10th wedding anniversary. It was nice to do that and have Josie there and I remember thinking that day I want to create all these special memories with Josie. I want her to have all of the things in life that she would have had, had this not happened. It was at that point I think for us - and it was only a few months after she was diagnosed - that we pulled ourselves back on track and thought this is it. We've got one life now let's absolutely live it and make all these special memories together.

If you'd like to listen to Laura's family story podcast you can do so [here](#).