

My name is Manda and I'd like to tell you about my daughter Emily, when she was diagnosed with Kawasaki Disease when she was three.

We were playing when I was getting her ready for bed. I was giving her tickles. I got just around the neck and that little sweet spot around her neck and she started crying. I got really upset because I thought I'd hurt her and then I thought actually, she's probably just tired.

The next morning when she woke up, she couldn't get out of bed. She was screaming, she was saying her neck was stiff and she was hysterical when I tried to get her out of bed. I tried to pick her up and she was like a board. She was absolutely hysterical and I thought something's not right here. So I said, listen, I think we need to go and see the doctor.

When I saw her, she said, "I don't like the look of this. She's got a temperature, she's got this red lump on her neck, we're not happy."

All kinds of things got mentioned on that day. They were talking about toxic shock syndrome. They talked about meningitis. They talked about leukaemia.

They came and took blood, they gave antibiotics intravenously, there was a never ending supply of people around a bed for about 10 hours and then ultimately they said "we think it's viral."



When I got home that night, I put her to bed and I couldn't sleep because my brain was just racing. So I picked up the discharge notes that we'd been given and I started reading through them.

Kawasaki Disease came up as a diagnosis on Google. And I read it and I thought no, it's not that she hasn't got any of those symptoms.

I noticed that she had a really angry red rash all over her body in the groin area and all around her back. And the first thing [I thought] when I saw the rash was meningitis.

And then somewhere in the back of my mind, I thought I read something last night that had a red rash. But anyway, I phoned the hospital explained about the rash. I think their thinking was either again, sort of septicaemia or meningitis, and they asked me to bring the straight back in.

I looked at her in the bed, and I noticed that she had got red eyes, really, really bright red eyes. Then I noticed that her tongue had got like a white thick, pasty layer on it. I thought I've read these symptoms somewhere before. So I went back through again and there it is, again, it's Kawasaki Disease. I sat and watched her over the next six hours, literally develop every symptom, line by line.

We waited two or three days at home, and I got a call off Alder Hey, asking me to bring Emily in.

We were in Alder Hey for 20 minutes. I'll always remember her name - her name was Dr. Claire Payne - and she came to me and she said it's refractory Kawasaki Disease. We've literally just had somebody leave last week with Kawasaki Disease. We've seen it, we've treated it, we know what it is. You're in the right place.

The second set of relief was much bigger than the first. Within 20 minutes, they had her in a bed, we had her on IV steroids and they said to me, listen, don't worry if she doesn't respond to this. We've got other weapons in the locker. There are other treatments available. You are not at the end of the journey by any stretch of the imagination. We will keep going until we find something that works for her.

It was just a completely different situation. Within 24 hours, she was a completely different child.



The difference in her was incredible. She was sitting up in bed. We saw our first genuine smile in over two and a half weeks at that point. And she was, she was a totally different kid.

Fortunately for Emily, she didn't have any long term effects. We were seen for two years outside of that and that was it. So we were two and a half years, I think, in our journey before we were officially discharged.

She's now 15, that was in 2011. She's now 15 She's happy, she's healthy and I thank my lucky stars every day that my GP spotted something and sent us to the hospital. And that Alder Hey we're able to basically help her and get us that treatment.

I'm just so pleased that she's come out of this, the well-rounded teenage miracle that she is. I just wish she'd wash the dishes more!

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