

It started when my daughter, Millie, got a very sudden high temperature of 39.6 out of the blue one night.

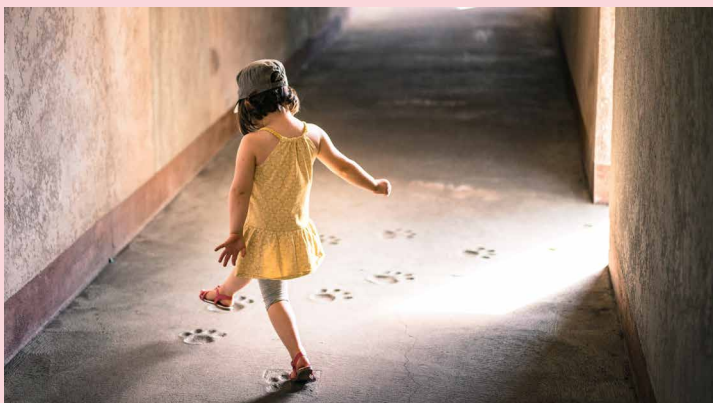
We gave calpol and put her to bed but 90 minutes after going to sleep she woke screaming her neck was hurting and she seemed unable to move it. This is where our journey of discovering Kawasaki Disease started.

From that moment we had paramedics out, 2 trips to A&E, a call to the GP (who wouldn't see her as we had been to hospital) a negative covid test and a diagnosis of viral, followed by a diagnosis of swollen lymph nodes. By this point her neck was very very swollen and we got sent away with anti biotics.

After 48 hours on these, she was no better at all and still had a raging temperature we just couldn't control. I knew then that there was something very very wrong.

My daughter was admitted to hospital on our 3rd trip to A&E on the 28 February 2021. Luckily it was the same doctor we had seen on the 2nd visit and she remembered us. I am certain had that not been the case, then we would have been sent home again and things could have been very different.

Almost as soon as we were admitted an array of other strange symptoms kept popping up, a rash, red swollen feet and hands, cracked lips and red eyes. We were trapped in a side room for 6 days, just me and her with no one else allowed in apart from medical staff. My husband would have been allowed in if I left,



but I would have had to stay away for 24 hours and my daughter wanted me to stay with her. She was only 3 and she was extremely irritable, so it was a very tough time dealing with her and trying to remember and take in everything all the different doctors and nurses were telling me so I could relay it back to family. I experienced my first ever panic attack whilst there and it wasn't nice at all.

She had 2 rounds of IVIG and she seemed to change instantly once she was on it, more like her usual self. Her heart scans were luckily all clear which we are very thankful for.

Once we were back home my daughter bounced back quite quickly and seemed better in her home environment. The irritability seemed to last for quite a few months but whether that was just her age at the time we don't know. She went back to nursery full time after having a week at home from being discharged.

It was just all so scary. We didn't know anything about Kawasaki Disease. Being apart from my husband and my eldest daughter was just awful. It was just the worst time.

Thankfully my daughter isn't affected daily by Kawasaki Disease. She will occasionally ask to see the photos of her time in hospital and remembers things about that time. We feel strongly her personality and behaviour has altered greatly since the diagnosis.

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