

### Hi, my name is Alister my daughter was diagnosed with Kawasaki Disease at 12 weeks old.

Up until 12 weeks she was a happy, healthy baby. At 12 weeks, she started to be ill with sickness and a rash.

We then ended up in hospital. We were on holiday in Exeter at the time and ended up in hospital where they ran a variety of tests. Never mentioned Kawasaki Disease. We didn't know what it was. It was thought to be meningitis, viral/bacterial, they kept going backwards and forwards.

And it was only after about two weeks when one doctor had said there was a really rare condition called Kawasaki Disease. But it won't be that.

They then did an echocardiogram, which again we'd never heard of. And now we know it back to front. And they found really obvious signs of progressed Kawasaki Disease.

It was very serious. At that stage, we were rushed from Exeter to Bristol. And we were told that she might not be coming out the next day, that might be it.

So, we're in intensive care which I wouldn't wish on anybody. It's a place that's amazing in terms of the technology, but just an awful place to be with your with your child.

We then met the most amazing doctor who we feel saved her life, made her stable, and started the care



to halt the Kawasaki Disease or stop the progress in layman's terms, even though the damage was done by that stage.

And then the next stage of her care started, or it felt like it started. The first bit where everything seemed to go wrong and then the next bit under the consultant at Bristol where it felt like he was completely in control.

After two weeks in Bristol, we were then discharged home with a lifelong care programme, including a variety of drugs and regular check-ups. We then visited back to Bristol initially, and then under the care of the Evelina London.

So the emotions that you go through on those days are hard to describe. But you come out and you always feel liberated after those meetings of 'great, nothing's worse, we can carry on as normal.' And then as you go through this period of adjusting to everything, nobody there initially can tell you everything will be alright. But it often is, if you've got then the right care and you're treated properly. And you get used to this new normal that as a parent of a child with Kawasaki Disease that you go through. And then you start enjoying life again and everything does feel a bit more under control.

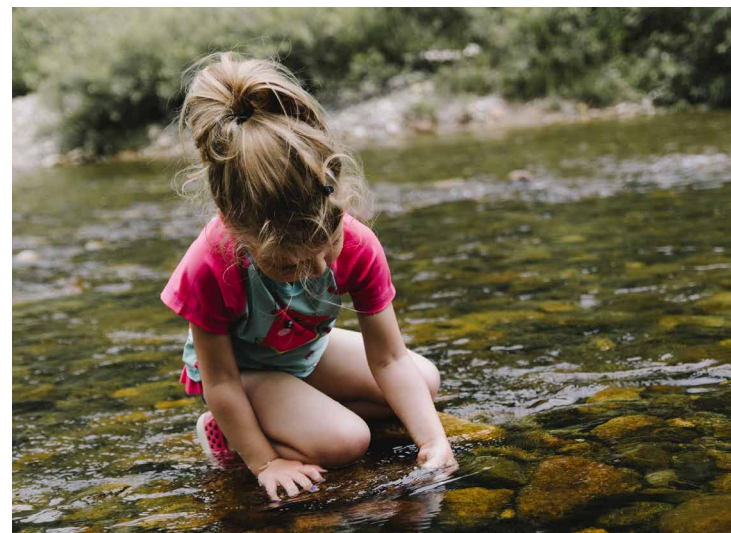
I guess the main thing for us and part of the reason that Societi was really interesting and really helpful is that there's other people going through it. And there's other people that have probably been through what you have.



We always used to find it quite nice to see the older children at the Kawasaki clinics because you like, 'Oh, they're all the [Kawasaki Disease] children and our baby, will get to that.'

The positives have come after with the care and the management through the amazing professionals within the NHS. And we've been very lucky that we had an amazing consultant at Bristol, who then had an amazing network of doctors that he knew. And we've been under the care of another amazing doctor at our local hospital, who's known our daughter since she was 14/15 weeks old. So we feel very lucky in terms of the people that we've met.

I think it's hard to be positive prior to the diagnosis. I mean, if anyone could do that they're doing well. But it's the bit after. I think if people are reading this, and they're at that stage where it feels like the world is ending, it still does feel like that - but it doesn't - and the life after that is the positive bit.



It's been an interesting process for my daughter go through. She's only known this. I think the way she approaches life - she literally bounces through life. I wish she'd bounce less and just keep her feet on the ground. I thought she would be a quiet child and be affected by her condition but she has limitless energy, she wants to be involved in everything. She's just joined Rainbows.

The way that she approaches life and how she lives it she lives it to the max every day. I think that's the bit that makes me most proud. There's no point almost wallowing in self pity because she doesn't. And you've got to be there to make her life as amazing as possible because she's doing that for us. So that's what she makes me proud every day.

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