



When Kawasaki Disease hits your family, without warning, and you're suddenly surrounded by doctors and nurses - in and out of hospital, faced with many questions and many hard decisions - and through it all, standing by your child as they battle a serious illness, it can take its toll on your mental health. But there's often not much time to think about this - perhaps until later. Here's one parent's perspective and reflections

.....When my son was in hospital I heard the words "You've got to be strong", "You are being so strong" "Keep being strong..." But was I really strong? Or was I forced in to a situation where I had no choice and no control? A situation where I had never heard of Kawasaki Disease and had no knowledge of the road that we were about to go down, I certainly did not want to be in this situation. However there was an expectation that I had to be "strong" so I could be the best advocate for my child to keep him strong. Where does being strong end? After all we are not all born with the same level of strength are we?

I wonder what being strong actually means - and how you know if you are "strong"..... When I looked up what "strong" means everything that came up was to do with physical strength. Yet what I needed - and what I drew on when my son was seriously unwell was my emotional and psychological strength. These were "hidden" within me though and at times, really not that strong! And it was difficult, really difficult to keep being "strong" on the outside when I wasn't always coping on the inside.

And just because I didn't ever cry in front of people it didn't mean I didn't cry tears inside.... did that make me strong? Because I didn't ask for help - did that make me "strong"?

No. It didn't.

So I guess my learning is that being asked to be "strong" might be - and almost certainly always is - well intentioned, but it's not a helpful thing. Because "strong" does not mean you are not allowed to cry,

it does not mean you have to cope on your own. It does not mean you shouldn't reach out for help. It doesn't mean you're assumed as having all the coping strategies and skills!

It means cry as much as you need to but be willing to carry on after that. It means lean on whoever you need to, they will be there to help. It means ask for help when you need to - it will make the next step a little more bearable. Being strong doesn't mean you avoid the truth instead you accept it, learn about it and then deal with it - together. Being strong does not mean you need to accept being emotionally shredded - support is there; it's OK to reach for it. Being strong means you are getting there every day, little by little. That is real strength.

Being strong is walking through a journey like many of us have been through and genuinely accepting that it is OK not to be OK and to ask for help when you really need it.

Resources

We've shared a link below on emotional first aid - a TED Talk which is about 15 minutes long. It's not specific to parenting or to having been through the experience of having an unwell child - but just talks about the importance of all of our emotional wellbeing, and offers some really great tips on improving that. We love TED Talks, and if you've a little time to watch this one, it's a TED Talk we'd really recommend!

