

For Broadcast: 12th May 2019

SPECIAL PARENTING - *The ups and downs of Aspergers*

Interview

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This is Messages of Hope and I’m Celia Fielke. It’s hard enough to parent when everything is running smoothly but add into the mix children with special needs and unpredictable behaviour and you can find yourself feeling like you’re never good enough. Recently Andy Voigt interviewed Kirra about some of the challenges she has faced raising her son Asher who has Aspergers.

Andrew: Kirra what have you found that’s been really helpful for you in the journey with Asher?

Kirra: For us the diagnosis and understanding that was pivotal. So we had wondered what was going on and once we received that diagnosis we just went right, that’s what it is and now we’ve got something to work with. Because I think up until then you’re just kind of clutching at straws and go why is this kid not behaving like my first born and why is he not behaving like his peers? What have we done wrong as parents? And there was a real degree I felt of judgment from peers or the onlookers at the supermarket. Oh my goodness! Going shopping was always difficult. You put a child in a shopping centre where they’re sensory overloaded, so for our son light, colour, sound, textures things like that. He had a real trouble processing and filtering into the appropriate categories. And so for him an experience to walk into a shopping center was just to put him into overdrive trying to work out what all these things were and to filter them. And so if we hadn’t pre warned him enough to say “we’re not going straight home after swimming, we’re actually going to the supermarket” guarantee he would have a meltdown because he hadn’t had the capacity in him to really process and navigate it himself — i’ve got to prepare myself for supermarket. And so a grandma or you know a plain citizen looking on at this, seeing me trying to negotiate with the child about how we can’t actually take that, your Rice Bubbles aren’t here, and he’s melting down, will look and think “what a spoilt little brat, just give him another packet of rice bubbles.”

Andrew: So how do you feel when you sensing that judgment? What’s happening? What challenges are you facing just personally?

Kirra: Turmoil, absolute turmoil because often I would have a baby and a pre-schooler at the same time and more than once I just abandoned the shopping cart and walked out of the store because I just didn’t have the ability to cope with it. When you’re a parent with a child with special needs you feel, well I felt like a bit of a failure as a parent because I’ve got all these issues going on and I can’t seem to do everything that everybody else does. And many

situations that you walk into you just don't know, it's like you're carrying a little volcano with you. It's like you just don't know when it's going to erupt. And so that adds a lot of stress on you as a parent and adds a lot of stress on the family as a whole and it impacts the siblings as well.

Andrew: So where have you found support to cope with that stress?

Kirra: Well one of the best things that a family member, when I actually finally sit down with our family and told them of Asher's diagnosis, a sister in law was the first to speak up and said "What can we do to support you? I think that was the most vital thing for anyone to say. She didn't sit there and say "Are you sure or how did you get around that diagnosis or have you tried this or have you taken anger and garlic out of his diet? Gluten free works you know." All these other options but instead they said what can we do to help you and support you? And that was probably the best thing.

Andrew: What about support outside of the family?

Kirra: The respite worker coming in or my mother in law blessed for a period of time there and paid for a housecleaner to come in. Two hours a week a woman came and cleaned my house for a period of about 10 months when we were in very intensive therapy and that was amazing! I've never had that kind of experience. So that kind of practical stuff is really invaluable.

Andrew: Is that something you tend not to ask for?

Kirra: No you'd never ask because that again is a reflection of I'm failing as a housewife. You know as a housewife and a mother, y'know I can't seem to be able to do this therapy with this one, take this older one to kinder, feed the baby, get a full night's sleep, communicate to my husband, have meals on the table every day! How do you do all that? I don't know. Some super people probably could but it's not something you would ask for but when it was offered it was an incredible gift.

Have you ever doubted yourself as a parent and had to face feelings of guilt and regret at not being good enough? What would you say to encourage your younger self? Why not start the conversation on our Facebook page – Messages of Hope. Your encouragement could make a real difference for another parent.

Andrew: Parenting is never easy but it is easy for parents to focus on their mistakes and shortcomings especially when something happens in a public space like the supermarket. When that gets out of perspective it can lead to deep feelings of guilt and regret and even a sense of shame. How do you come to terms with feelings like this?

Kirra: Someone said to me once that I wasn't given Asher as a mistake. That I am the best mother for Asher. And I will always be my own worst judge in all that I do and I will always and have always at my own fault compared my kids to other kids and early on when....

Andrew: We all do that!

Kirra: I know. Early on when he was very obviously different to other peers at a young age, with other mothers I would feel quite judged by them, wrongly or rightly so. When your kid's different standing out in the crowd you can't help but think that everybody is looking at them and then looking at you thinking "can't you control them." And I think at the end of the day I don't know what helped that judgment. Probably faith in just trusting and believing that God is

giving me all that I need, all the resources I need to parent him. And at the end of the day, most days I'd fall on my knees and ask God "what now, what next?" I don't know how many times I've prayed for wisdom or grace or forgiveness. Our family asked for forgiveness of each other a lot. Parents to children and children to parents because you know I messed up a lot in the way that I parented in those younger years and probably still today. But just in making decisions out of frustration and tiredness. Yeah I lost self-control. Here I am trying to control your self control but look at me and I'm the adult! So yeah without faith and I think also our faith in God has also brought with it a faith community and without the faith community we couldn't have done this either. So you know on one hand I'm leaning on God but the other hand we're leaning on community.

Andrew: Are you able to put into words what is this faith in God that you have and what does that mean for you?

Kirra: It's a knowing that I am loved unconditionally. It's knowing that God is there to be called on in the highs and the lows. Just really having a presence, having something there to speak to, yell at, cry with. "God I don't actually know how I'm doing this and I don't think I have the capacity to do this." You know if you had told me at 20 I was going to get married and have a child with autism I think I would have said, "well I'm not going to get married or I'm not gonna have children." But God doesn't make mistakes in giving life to people. And so Asher's not a mistake and neither is my being, his parent.

Andrew: It's several years since your son Asher was diagnosed with Aspergers. Where are things at now?

Kirra: He is a very different boy today to when he was diagnosed before he was four. How can I explain him? He's just colour and light. He adds so much life to our family. He is an expert of many things. At the age of eight he had read Lord Of The Rings, The Hobbit. He is incredibly self aware of who he is. Even just recently at the start of the school year we were going shoe shopping and we were sitting there waiting to be served for school shoes and I just reflected with him and I said "Ash do you remember starting prep and do you remember how much you hated putting on shoes? You used to tell us that when you put on socks and shoes your feet would scream". And I said "Do you remember at your early intervention that you threw your shoes at the occupational therapist? Do you remember her teaching you how to put on socks and shoes and stay calm?" I said "Gosh you've changed so much." I said "isn't it amazing that that's gone away." And he looked at me like I'm a bit of an idiot and he goes "Mum it doesn't go away," he goes, "you just learn how to control it." So yeah I can't, I'll be honest there were times in the early days that I wished him out of our family. I just wondered what on earth have you been given to me for because this is just too hard. But these days I couldn't imagine our family without him. He brings such a depth into our family of understanding and understanding people that we never would have had without him.

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