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PARENTING – Coping with unexpected challenges

Interview with Katrina

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Celia: Katrina faced her biggest fear at the birth of her second child when she was 21. How could she cope with challenges she didn't understand? I'm Celia Fielke and this is messages of hope. How do you cope with unexpected challenges? How would that change if you realised your challenge would be lifelong? Katrina confronted that very thought at the birth of her second child Joshua.

Katrina: I realized on the first day in hospital there's something deeply wrong. I knew that infants gaze at their mother. They're little stare bears, they can't help it. They stare and because we'd already had one child I knew this eye contact thing. So, I'd put myself in his line of vision and he would not give me eye contact, he'd look away! So, they took him to the special care unit and I just cried and cried because the child that I had received was not the child I'd been expecting.

Celia: I know when you were younger that you'd had fears about having a child with disabilities.

Katrina: I was age 15 and for some reason was contemplating what if I was given child with a disability and I've always been someone that does like a backdoor option when things get too hard in my life. This is true.

Celia: What do you mean a backdoor option?

Katrina: A backdoor option. I never finished my year 12 because I just got so scared about the exams that I made myself sick for a few months. I never finished my first university degree because I got scared when it came time to do the practicals. I Just had this knee jerk reaction to run away from trouble, not push through and learn to grow through troubles.

Celia: But what made you think about having a disabled child at 15?

Katrina: Perhaps it was the fear that I had every time I saw a person in a wheelchair or someone whose body looked really different and unusual. Through my mind would go these thoughts of "I don't know how to react to that human. I don't know how to interact. Do they need something from me? I want to run away." So then thinking I'm obviously the wrong person to have that kind of someone!

Celia: You're Shaking your head Katrina!

Katrina: I'm shaking my head because this is an instance where I didn't get to choose. There was no backdoor. So, you don't have the option. You raise this child, they're your child. If I'd known then the life I'm living now, wow, I would have been so overwhelmed. I would have thought I can't do that because, that me, couldn't do that!

Celia: Joshua was eventually diagnosed with severe intellectual disability and autism. Even though he is now 20 years old, he operates at the level of an 18 month old child. One of the outcomes of that is he can't speak. Katrina, what does that mean for you as a parent?

Katrina: That was one issue that I had a fair bit of guilt with. I should be working harder to get him communicating. I actually had a recurring dream that I had left Joshua, my son, underwater. When he was retrieved he was fine but I thought I had delayed his development further. It had been my fault. I really had to come to terms with realizing that was a fear I had, that I was holding him back. I actually needed a change of mind there to realize actually I'm one of the people helping him move forwards!

We've tried a range of things. We've tried signing and he does have a couple of signs. We've tried using the picture cards for him to exchange with us. We've tried using an iPad with a voice to speak for him when he presses things. But you know what? He would just prefer to use intuitive communication like walking to the fridge when he's hungry or pointing to the car when he wants to go somewhere. So, in the end we figured out to let him have the lead with communication. And if speech isn't there for Joshua, that's okay.

Celia: So, you've learnt to live with Joshua at his pace?

Katrina: That's right, you learn along the way.

Celia: Did you ever have those moments where you wanted to run and find the back door?

Katrina: I can definitely remember thinking "I can't do this." We got to a point late last year where Joshua's usual winter blues weren't coming to an end. He was starting to make dangerous choices like maybe pull a fish tank down on himself. Even just physically undressing just to show that he was so upset. And he doesn't know what's wrong and he's so upset that all he can do is bash his head against the window, be whacking me as much as he can reach.

So, every 30 seconds you have to turn around and see what he's doing. And there's nothing I can do to calm him down. I can try and be funny. I can yell at him and get angry. He will not change. And so then you're stuck without options and then you think I'm going to live through this again this afternoon and then I've got it the next morning and got it the next afternoon and that's not a very pleasant life. So, you think, "I'm not in a good place here. This is dark." At that moment you really have to stop thinking about day by day and just pull it back to hour by hour and then pull it back to minute by minute.

Celia: Where do you find the strength to do that next minute or that next hour or that next day?

Katrina: I will first turn to God and say "Why the heck did you do this to me?" Like he needs to know I'm not coping and he would rather I come to him and tell him that, than walk away from him. And I'll say "If you've got me into this, you've got to help me now, like I mean now!" and then just wait, take a few deep breaths or also perhaps at times have maybe a special Bible verse, you'll see that I have them in my home up on the walls.

Celia: What's one that would come straight to your mind in those moments?

Katrina: I can do all things through Christ who gives me strength. That's not about I could be a famous actor or Olympic champion through Christ who gives me strength. No! That's, I can do shopping with Joshua when everyone in the shop wants me out of there! When you even just say the words, there's a strengthening and a peace that I've experienced. It doesn't necessarily change the circumstance. It changes your perspective. Through a dark night there's always the dawn and by God's grace he's helped us to see something needs to change. Let's not change the family unit. Let's change something else and then you make adjustments and you can carry on.

Celia: Over the last 20 years Katrina has seen how Josh's disabilities have created beautiful moments, both in their own family and the wider community. Katrina, what's something that you absolutely adore about Joshua?

Katrina: He has a really cheeky sense of humour and that's one of the things that has developed while a lot of his other development has stayed subdued. If there's a room full of people laughing, he will belly laugh along with everyone, he just picks up on the vibe and he joins in.

Celia: He has that sense of joy.

Katrina: There's a joy and he likes to share your joy. Occasionally if I'm a bit down he'll maybe try and cheer me up. I get migraines and once I was laying on the lounge just trying to rest and he brought a blanket and layed it over me. Now he never shows care like that for people, it doesn't enter his thinking. But on that one occasion he reached out and just volunteered to do a thing for me, his mum. That was really, really beautiful

Celia: Yeah, it just seems to me that in the busy-ness of our lives we forget to stop and appreciate those moments of gold.

Katrina: Yeah

Celia: You've had another gold moment recently, surprisingly in a hospital waiting room.

Katrina: Yeah. The little waiting area, once you've been called in, is very tiny and to my surprise there were two big burly security guards and a gentleman, probably in his early twenties, in a blue like pajama suit, manacled to a wheelchair. I just put two together and thought this is someone from prison. Anyway, Josh was fascinated because he has a wheelchair and he's never seen anyone wearing pajamas out in public! Never seen anything that would look like handcuffs and he particularly does like men. So, he thought it would be fun to sit right next to that man and we were all just sitting quietly as you do, very polite. Then Josh thought "Hmm, no one's speaking so now I'll reach out my hand and grab his wheelchair and hold the wheel and make a connection with this man I'm next to." So, he did that. Everyone's noticing this is kind of awkward. Finally, the gentleman in the wheelchair just noticed that Josh had a handmade top with some birds on it. He just said "Does he like birds?" Well, that opened up things and then I was able to converse with him and we talked a bit about Josh. So, Josh's vulnerability helped that gentleman to feel like he could open a conversation even though normally he might feel like the lowest pecking order person in a room. Joshua made the way for him to take a lead there. Believe it or not, by the end of our appointment and session we were all kind of smiling and waving goodbye to each other, guards included!

Celia: What a lesson!

Katrina: Yeah, Joshua doesn't judge by outward appearance. He just sees another human being and knows what to do - you connect with them.

Celia: Yeah. Looking back over the last 20 years of raising Josh, would you change anything?

Katrina: If you'd asked me that five years out I would have wanted to change things. 10 years out I would be able to say "Well I am thankful" but then maybe I'd still want to change things. But now I would just miss Joshua terribly. If I had never had someone with such needs in my life I certainly wouldn't be as empathetic or soft or have a heart that just wants to embrace vulnerable people. Now when I when I enter a room, I'll seek out the person that no one else would want to talk to because I'm just interested in them and their life. I want them to know they're loved.

Celia: Totally opposite to the 15 year old you!

Katrina: Yeah! Now I look forward to the future with great hope because I look back and see the mountains that we've climbed and the valleys we've been through. There's nothing ahead that God's not going to see us through.

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