

Bethany's Story – A Journey of Hope and Trust

Interview with Jo and Luke

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Tania: Hi, this is Messages of hope, and I'm Tania Nelson. Today we'll be hearing from Jo and Luke about their daughter Bethany, who experienced heart issues right from when she was born. Jo and Luke share with us what got them through such a difficult time and where they found hope.

Jo: Our second daughter was diagnosed with a heart condition, and so we knew while I was pregnant that we had this diagnosis and that at birth, we would be flying to Melbourne for heart surgery. And so, we were prepared for that. But then when she was born, the diagnosis was a little bit more severe than what they originally had anticipated. And so, it was a challenging time because even the doctors didn't know what her outcome was going to be. They had not seen this before and they actually consulted with a number of specialists around the world. So, she was a bit of a special and unique child right from birth.

Luke: As soon as she was born, it was a bit of a roller coaster ride, and things happened pretty fast with what the doctors here in Adelaide wanted to do. We were sort of just left in a world where we weren't sure what the outcome was and it was not a good place at the time.

Jo: The doctors really didn't know what to do, and they ended up coming back to us and they said, 'look, to be honest with you we may not be able to fix her, and it might be too risky for surgery.' And so, they had to give us that option to say that we may have to just choose to let her live out her life naturally, which would have been another four weeks of life. This was already while we were in Melbourne waiting for the doctors to operate. We burst into tears. Like, imagine a computer crashing and just your whole world just crumples. That was probably that turning point for me where, okay, we've hit rock bottom, but where do we go from here?

With this great belief that our doctors have these amazing skills but still didn't know how to fix her, we knew that that wasn't going to be our source of hope. And so, for us, it was, 'where else can we go for some sense of light in this? Because at the moment we're pretty rock bottom.'

And so, Luke and I did the only thing we knew to do, and that was to pray.

Luke: We just had to hand it over to our God to deal with.

Jo: We hold onto this hope and belief that somebody else is in control. And even at that moment, as we prayed together, it was talking to our God who we know

loves us and cares about us. We knew that he didn't put us in this situation for us to fall down. And so, for us, the prayer was: 'Lord, this child was yours to begin with.' And it was that handing over of Bethany to our Lord who created her in the first place to say, 'if you allow her to live, let her live, loving Father.' We couldn't do anything. I remember at the time that was actually very comforting and when she went into surgery, we actually felt quite calm.

Luke: Walking back to the hospital, I had this expectation that things would work out.

Jo: Before surgery, we had a chaplain come in and see us. Part of that experience was a clear sign from God that he was there with us. I think we hold onto this trust in a God who has greater power than us. And I think even just that knowledge that God was with us.

Luke: And a lot of people back home and around Australia were actually praying for us as well. The community was sort of coming around you and carrying you.

Jo: We had people pray for us around the country, some people didn't know us and some people knew us very intimately. Even a mass being held in Perth, groups of people around dining room tables. But to have that sense of community where people were rallying around us was quite significant.

Luke: Yeah, it's a much bigger picture out there than we know about.

Jo: It was interesting that on the day of the surgery, when we actually did let go and let God, we were able to walk out of that hospital with confidence.

Luke: I knew that the doctors were gonna try their utmost best to do what they were skilled to do. And I had full confidence that they were going to give it their best shot. I can't say that I necessarily was gonna expect to come back to the hospital and they say that she'd passed away, I just had this expectation that she's going to pull through.

Jo: I didn't know what to expect. And so, for me, it wasn't so much that confidence that everything was going to be okay, but the confidence that God had it under control. Just that freedom of not having to make a decision or knowing that it's out of my control. It sounds terrible that it was out of my control, but that's something that was actually a good thing I could hold onto – that I had done all that I could.

So, I guess for me, having God in control means a great deal of trust, a great deal of hope, and a great deal of confidence in knowing that whatever the outcome, God will pull us through.

Tania: Our culture often makes us try and be independent, and think we need to do everything on our own. But Jo and Luke found a sense of freedom in realising they couldn't change anything. They had to put their hope in something bigger than themselves.

And Bethany's surgery was successful. Hear Jo and Luke explain what that moment was like:

Jo: We were sitting there in the waiting room at 1:30 in the morning and I swear the surgeon had a spring in his step. He had this great big grin on his face and he walks in and he says 'we've done it!' Normal heart babies take about six to eight hours in surgery. Bethany took 15 hours. And so, we knew it was pretty big. But to have the look on the face of the surgeon to say, 'we've done it' was enough confirmation for me to know the next step is going to be a lot easier.

You hear quite often of babies being born with a hole in the heart. And for her, that was actually the saving grace for her because she only had one artery, and it was on the wrong side, so it needed to be put on the other side. The actual hole in the heart was the space where the blood could flow. When she was operated on, even with all these little intricate things of the four main arteries, the replacement of the valve, the hole in the heart, we're talking about operating on a heart the size of a grape. So, the extent of the surgery was pretty big. And the thing that actually got me was the surgeon, in the lift on the way up, he said, 'we have been blessed with a donation from another baby.' And so, I can't think about that too hard, but what I can say is by the grace of God, our child was able to live.

Tania: And Luke, how did you feel in that moment?

Luke: It was a sense of relief. But I mean, there was still things we still had to keep an eye on.

Jo: She does need further surgery. In fact, she had another lot of surgery when she was 11 and she'll need another lot of surgery when she's an adult, because these parts do wear out.

After the surgery, they did warn us that because she'd been on bypass for some hours there could have been a delay in development. And so, throughout the next few years, they were gauging that and giving us an idea that she might just have her milestones a little bit later.

She only really started walking at 22 months, which is nearly two years, which, in their eyes was quite acceptable and okay, but what we noticed is, as she was heading towards the age of primary school, she really didn't have a grasp on a lot of things that children her age had a grasp on. And so, we knew there was something not quite there. And the way they have described it to us is that her developmental stages have all come in different gradients of development. Her emotional development and her intellectual development are quite significantly low, but then she still acts like a teenager in other aspects, which is actually quite challenging.

Luke: You've got two dynamics, two extremes to deal with.

Jo: The adventurous spirit, but not having the capacity to understand safety or boundaries.

Luke: And then developing her and our other children as well. And it's hard when she sees her other siblings moving forward. Not that she can probably verbalise it, but it's been a challenge for her in dealing with it. The funny thing is with the rest of our children, Beth is the most resilient probably. She's quite a tough young lady.

Jo: She experiences pain, like the rest of us, but she doesn't understand how severe it is because she's had it all her life.

One of the challenges we found in a number of situations is sometimes they just think these children are naughty; they're misbehaving, they're acting up. But for Bethany, for the most part, she can't verbalise it. So, she has to express herself in another way. And so that's been quite challenging for teachers to be able to navigate. But as soon as you inform the teachers that no, actually this is her response to say, 'I don't understand,' then the teachers start to discern that actually, no, she's not a naughty child, she just isn't processing the information. But even us as parents in our own home, to be able to provide proper instructions for her, quite often, we have to rephrase a question several times.

Luke: It's been a learning curve for sure for us as parents.

Jo: And discovering how unique each of our children are is something that I think has been helpful.

Tania: Can you give me an example of that with Bethany?

Luke: Bethany actually likes to do things together and that's something that I've learned. She doesn't like to be told to go off and do something by herself. If you actually take her alongside with you, she's in her element. So, the dishes, for example - she quite often now comes up and helps me do the dishes, and I'll wash up and she'll rinse off and put it in the dish rack.

Jo: Something we've learnt to have to open up with was she's a very tactile person. We call that 'sensory seeking', and it means that she will go to the supermarket and she'll have to touch everything. It is challenging. Like I was brought up on board games, card games and the like, but having a child with a disability means you do have to structure games that are inclusive. So, it's often, we'll team up with Bethany and Bethany can be our partner and she is included in that way. We do have to think creatively about what kinds of things we offer for the children.

Luke: You adapt. You learn to adapt to your children so you can meet them where they're at.

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