Connected and Loving: Raising a Son with Special Needs

Interview with Bart Bruehler

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The Bruehler family at a beach in Adelaide

Bart and Anne's life was turned upside down when their son Pascal received a diagnosis of a rare genetic disorder at eight months old. Today on Messages of hope, Bart shares what they've learned from Pascal's journey and where he finds hope in the face of constant uncertainty.

Introduction to Bart and his family

Emma: Welcome Bart.

Bart: Yeah, it's great to be here. Nice to talk to you.

Emma: Would you like to share a little bit about what you maybe do day-to-day, Bart, and a little bit about your family?

Bart: Sure. Yeah. As your listeners might pick up pretty quick, I'm American. You could pick up my Yankee drawl, if you will, pretty quickly. So, we moved here to Australia about three years ago, and I work at the Uniting College in Adelaide, and I'm their director of Biblical Studies. So I teach a variety of classes at the college around the Bible, and do a number of things with the Uniting Church in South Australia.

I'm married to my wife Anne, coming up on close to being married 30 years. We have three children and our oldest son, Soren, is still back in America. Our middle son, Pascal, who's 20 that we'll talk a little bit more about is here with us in Australia. And then we have a daughter who's 16. Her name's Eleanor.

Emma: What are some things that you love about your family?

Bart: Oh wow. Everybody in our family is very different is just absolutely the case. My wife and I were just chatting the other day of our oldest son is just absolutely the sort of adventurer enthusiast, try every new thing, he wakes up in the morning with a list of 72 things that he's gonna do that day, and probably 36 of them will get crossed off 'cause there's 20 new things that will occur to him by 10:00 AM that he's gonna do. Whereas our daughter is much more of the reserved type, she's a little bit of a homebody. She likes her space and her stuff and she's really organised and, new things? No, not really her thing so much necessarily. She likes the familiar and the stable. And so my wife and I joke that I fail to see the trees because of the forest, and she fails to see the forest because of the trees. I'm very big picture patterns and huge vistas type of person, and she's a very detail oriented, focused on specifics kind of person. And so we're always figuring out interesting ways to try to navigate all of those differences and get along and compromise and yeah, we've just made a habit of that.

We all know that we're all different from each other and we just, we live with that and keep finding ways to have fun together.

Understanding special needs

Emma: One of your sons, Pascal, has throughout his life encountered a number of special needs. Could you tell us about that?

Bart: I might start to say, there's a lot of discussion about the language around disability. Is it handicapped? Is it disability is even a notion, or differently abled? I kind of do like the language of special needs. We all have needs. Some people happen to have needs that are both, or either more unusual than some people or more intense.

And yeah, Pascal, he's capable of doing a lot of things, but then he does have needs that are unusual. You'll tell him to go down the street and turn left and he'll turn right. So that's kind of unusual. We've gotta be present for those kinds of things. And he has needs that are intense; specialised medications, specialist doctor's visits, things that just you don't run into on a daily basis.

But again, it's, not like muscular dystrophy or spina bifida or something like that, where some of the key challenges are really just purely physical challenges – Are you breathing adequately? Are you able to take in food and process it adequately? For Pascal, more of his challenges have been developmental in nature, and sometimes behaviourial.

Pascal's story

Emma: So, tell us about Pascal's early life and finding out that he had these special needs.

Bart: He was born with a rare genetic disorder called Tuberous Sclerosis Complex; there's one little pair of genes in a particular lineup in his DNA that don't match quite right. And it happens to be a set of genes that is designed to manage and control cell growth in your body. And so what happens with Pascal is he develops a kind of tumour, they're technically called tubers, they're not cancerous, they're not malignant, they're not aggressive, but they're growing too much in places where they shouldn't be is the dilemma. And there's a variety of manifestations with his disorder.

There are a couple of life-threatening aspects to it, especially for young children. They don't know why this is, but those tubers can grow in the heart. Of course, if they're in the wrong place in your heart, it can be very dangerous, heart surgery has prevented a lot of deaths for young children. They tend to then fade away and disappear by age five. Which we wish all of them did that, but they don't. There's also some kidney complications that can be life threatening, but most people have a relatively normal lifespan with that disorder. And again, it affects people all across a really broad spectrum.

We didn't know, that Pascal had this when he was born. When he was eight or nine months of age, he started to have what we now know were a rare type of seizure. Hard to describe, he's kinda having this funny sort of jerking motion and he seems upset, but we don't really know what it is and it's exceedingly rare.
So, it took us a while to figure out that's what was going on. And it was about that time too that we started to notice some issues with his development. He wasn't standing up, wasn't making quite the sounds that you would expect a child of eight or nine months of age to be making.

And so, yeah, that's kind of where we started on this journey with him. His health wasn't seriously threatened, but we had to try to manage the seizures, and then do some extra things at that point to help encourage his development and give him some supports where he needed them.

He is now 20, that was 20 years ago. We've been through lots of ups and downs.

He was on some medication that controlled that early seizure pretty well for a few years. But it is a medication that tends to sunset in its effectiveness over time.
So, we found that with him. And then he started to develop another kind of seizure a little bit before he was two. They were mild, just what they call partial seizures. So he would just tilt his head grimace and you could tell he was not quite fully aware of what was going on. But he would have clusters of them ranging up to 70 times a day.

We were blessed to be connected to a clinic that specialised in his disorder that was a few hours away from where we lived, but close enough to be accessible. They recommended some additional testing for him and discovered that those seizures were all originating in a particular part of the left side of his brain, which makes him a good candidate for brain surgery.

So just a little bit after his second birthday, he had brain surgery.
And so, we noticed a really significant improvement in his seizures after that. You know, they describe those seizures as, imagine if you were watching a television show and every 30 seconds it was interrupted by a commercial. You'd lose track. They said it would just interrupt any kind of memory or learning, or your sleep functions and all these kind of things.

So once we got those seizures taken care of, we really did see a big bounce up in his development. It's like he could suddenly get traction in the world. And he did really pretty well for a few years. We noticed, at that point though, that he became susceptible to having very infrequent but now very severe seizures. They would come up if he was stressed or a lot of times if he was sick or something like that. They required major medical intervention. He went on a diet, special diet, high fat, high protein, low carbohydrate diet. And that was really helpful for him, kept those seizures at bay for a few four years.

We came out on the other side of that. And he was seven or eight by that time, and we had an older brother at that point. And the no doubt that was hard on Soren. Pascal took a lot of care. He took a lot of attention. And, you know, wasn't a normal little brother to play with necessarily. He could be a lot more difficult, even though brothers can be difficult period. But he could be a lot more difficult and, it had effect on him. We debated about having a third child. We eventually decided to do that. And that was good, been good in a number of ways. Partially when Eleanor was coming into her toddler development, about two-ish when a lot of those developmental things really start to pick up and they start talking and colouring and puzzle, you know, all those things, Pascal was six about then, and he too was on a developmental, downhill slope at that point. So they hit this groove together, the two of them, even though he's four or five years older than she was. So that was really good to have a built in playmate for both of them. And they jived pretty well with each other for a number of years.

He was diagnosed as being on the autism spectrum. He doesn't have classic autism, if you will, but some of the features of autism, some communication difficulties, a little bit of eye contact trouble, a little bit of what they call perseverating or focus on a particular topic, he'll do some of that as well. And the autism diagnosis gets you access to a bunch of treatments and supports and all kinds of things like that.

So now, he's been on a specialised medication for goodness, 10, 11 years, something like that, that actually targets the disorder that he has pretty well. It's insanely expensive. It's covered by most insurance, fortunately, but it is a challenge just because it's a really expensive medication. It's also used as cancer treatment, is how I understand why it's so expensive.

I describe him now as being a really healthy, robust 20-year-old man. He is six foot four, loves to play basketball, a healthy, robust guy, in all of those ways. To just look at him, you wouldn't know that he has a disability necessarily. But, socially, emotionally, he's probably kind of 12 or 13, gravitates to that age of folks, acts like a teenager at home sometimes. But cognitively he's probably five or six. He can do some very basic reading, some very basic math. But yeah, it's probably kind of plateaued for some of those things. So it's an ever evolving kind of process of what his health is doing, how he is.

The emotions of parenting a son with special needs

Emma: And so, what were some of the feelings that you experienced as parents when Pascal initially had this early diagnosis followed by brain surgery and other complications?

Bart: It's quite an emotional soup, it is what I would say, around his initial diagnosis. So just having a diagnosis was a bit of a relief as far as that goes.

There's a lot of fear and uncertainty. People with his disorder range all across the spectrum from extremely mild manifestations to pretty severe. So just all of a sudden all the maps that you get as a parent of here's all your developmental milestones, you just chuck those. ‘Cause who knows at this point? You just don't know.

And there's a fair amount of grief involved. You know, there's no guarantees, but, will he ever learn to drive a car? Will he ever graduate from high school? Will he ever get married? I mean, all of these things go into question and start to feel unattainable. So, things that you want for your child now are lost. So yeah, there's a lot of grief in that, as well.

I would say now, we're kind of navigating the transition to adulthood with him. And so that's not easy for anybody but especially for him. And I think now my wife and I, we probably experience a fair amount of anxiety: Is he gonna be okay? Is this the right thing to do? Is this gonna be too much or too little? How is he doing? Can we move to Australia? Can we not move to Australia? Yeah. So there's just a sort of another layer of potential risk involved with anything and everything that we do in our lives because of his particular needs. And so, yeah, it sort of hovers around you as you go on with life. It gets worse on occasion to be sure, but it just kind of hovers in the background of an additional kind of layer of concern or fear.

Finding support

Emma: So what would you say are some of the things you've leaned on in these many times of uncertainty and anxiety?

Bart: Yeah, that's a good question. There's times at which that settles into some routine, and we're grateful for those, and they do all right. There are other times when that's a real burden, either because of the uncertainty that's hovering around it or just the weight. And even though I don't know that it's super helpful, I do end up asking God, why? Why is this happening to us? Why is this thing happening right now in those kinds of ways? So that's a real question, I don't avoid it necessarily. I don't know that I expect big answers to it, at the same time.

I think we are really blessed. We have seen a number of families torn apart by these kinds of needs. It's just too much for the family structure in relationships to bear. So, we really leaned on each other as family members. We try to give each other extra grace quite frequently. We all can know when Pascal is demanding a lot of us for one reason or another, and acknowledge that and be supportive, in that.

Church has been a mixed bag, if I'm honest. Churches like most other institutions in the world are based on a relatively narrow band of normalcy, and if you don't operate in those kinds of ways, it's not that we don't want you here, it's just that it's like we don't know how you be here, necessarily.

So we run into that situation in a lot of churches, where again, Pascal doesn't fit all the normal patterns necessarily, and so it's just awkward to be there and difficult to be involved in certain things. At the same time, it's often been relationships in churches where we've found our best friends and best support. People who make the effort to understand or make the space for us to be included, those are really important for us.

As I mentioned, I work at the Uniting Church College here and, so, yeah, trying to grasp and probe a little bit deeper, 'how do I understand God and God's ways in the world through particular experience with Pascal?' It's a meaningful part of it for me as well.

What Bart has learned

Emma: What are some of the biggest things you've learned then?

Bart: Disabilities is no respect of persons. It strikes people who are relatively fortunate in other parts of their lives and people who are relatively unfortunate in other parts of their lives. And so, yeah, it just comes along to everybody in some form or fashion.

Pascal's situation where it was random mutation of gene, there's no blame to be found anywhere. There's no cause. And so that's challenging just to feel like it's just the nature of the world that we live in, where things go wrong for no apparent discernible reason at all. People acquire disabilities through accidents that also don't make any sense. There's no understandable cause for them in some cases. So that's definitely a struggle to ask, **how do we understand the presence of God in a world that can seem random and randomly evil, in those kinds of ways?** That's definitely a hard one.

I think probably one of the things that it opened my eyes to on the other side is, particularly in Western culture, we have a definite preoccupation with capacity and productivity when we think of ourselves and our lives in terms of our strengths and the things that we can get done and what we can accomplish. And Pascal throws a wrench into that kind of way of thinking about the world in a good way, because it makes us pull back and say, 'okay, his life definitely isn't characterised primarily about by what he can accomplish. It isn't defined primarily by his capacities or capabilities or strengths or skills. Again, not that he's lacking any of those, but there's just significant ways in which that's not gonna define who he is, which then makes us think, 'okay, well who are we in the image of God then? Yeah, we have strengths and skills, capacities - God granted us the ability to co-create in a world that God has made. And so we do those co-creating kinds of things. But that's not it. It might be part of who we are, but it's not *all* of who we are. And sometimes we focus on that just a little bit too much.
Maybe we value the relational things a little bit more.

We're not as concerned about necessarily being effective and efficient as we're concerned about being connected and loving. And that those are probably more at the core of who we are in the image of God than the effectiveness things are in the long run.

Emma: So that almost sounds like a blessing.

Bart: Yeah, it opens your eyes up, to things that you didn't see before. That's absolutely the case.

For us, it's made us better at trying to process and talk through those things and to figure out, okay, this is something that we can do together. And it works this way and this is how we're gonna compromise or cooperate in order to get that.

So I think it's made us better at communicating with each other. I think it's made us appreciate more just the time spent together and to value that rather than accomplishing a bunch of things along the way. I mean, we like to do stuff too. But, yeah, I think appreciating that together.

What we can learn from Jesus about special needs

Emma: What have you found in the Bible that speaks into this space?

Bart: Looking at a variety of different kinds of challenges that people face who are either in some kind of other special need, poverty, imprisonment, something like that, or intense kinds of needs, Jesus identifies those people as his sisters and brothers, as this kind of special relationship that Jesus has with them and connection to them that isn't true of “normal people” in the same kind of way. Our Christian walk is then, I don't wanna say it's defined by, but our treatment of those who are weaker or more vulnerable shines a magnifying kind of lens on where our relationship is with God.

It's really has made me think more about weakness (if we can put that label on it broadly); weakness both sensitises us to our need for God and our need for other people as well, which I think is sort of the ground level of loving God and loving others.

And that way weakness can be a gift. We may not ask for it for Christmas, but it's a gift that opens up some of those dimensions of connection and love, that if we believed ourselves to be strong, we might never open ourselves up to in any way.

Advice for parents

Emma: What advice would you give to someone who is starting out on the journey of parenting a child with a disability?

Bart: Get ready for deluges of emotions. They come along. It's not unlike the journeys that I, and I think other people have experienced with grief.
When you have a loss, usually don't feel the loss a hundred percent of the time, all day long. Normal life of making breakfast and tying our shoes, it just occupies our attention. And then that loss kind of crashes into your consciousness in some kind

of way. That's okay. That's just how that's going to be and it will be challenging at times to just cope with the onslaught of it.

Again, disabilities range across a whole scope of things. So figure out what kind of supports you need for the particular kinds of things that are gonna be associated with the challenges that your child or loved one is gonna face, and make the most of those.

May God send you a few people who can bear that load with you. They're worth their weight in gold. Keep them, hold onto them. They're really important.

And, become your loved one's own best advocate or find someone who can. Pascal and I have been joined at the hip for a long time. I am his advocate. I know when his breathing is funny. I've learned a lot about his disorder, and I've learned a lot about neurology and I've learned a lot about all kinds of things that I never thought I would need to know anything about.

Find the great doctors and then stick with them. 'Cause they're really helpful and can do a lot for you along the way.

Finding hope for the future

Emma: So you've mentioned a lot of the challenges over the years and struggles, and this grief process and things, and then also you just mentioned this interesting stage you're at now with Pascal being a fully grown adult and asking 'what's next?' And there's not a lot of pre-planned structure for that, no clear path forward. Where do you go for hope when you have all this uncertainty?

Bart: I think there's a couple things. Just again, as with any other children or loved ones in your family, Pascal accomplishes things or finds joy in life around things and that's great. He loves to play basketball, and he will get up early on a Saturday morning, earlier than I want to get up on a Saturday morning, to go play basketball 'cause that's what he loves to do. And so, anything like that to just throw fuel on that fire, that's great. So yeah, find some joy in those kinds of things.

A little bit of understanding that God does see us through the ups and downs, that there's sometimes really tough periods of time. We had a few years there where it just seemed like all the pistons were firing. And then there's long plateau times. And so yeah, we just trust that God is providing what we need in each one of those phases. 'Cause they come and go, sometimes a little bit unpredictably. You can't necessarily tell when one is coming or going, very clearly. So yeah, we just trust that God can provide what we need in those phases when they do come to us.

Advice for communities

Emma: Do you have any advice for a community who would like to welcome people with different needs?

Bart: Yeah, this is a hard one. There's a saying, I think it's a saying in the disability community that goes, if you've met a person with a disability, you've met *a person* with a disability. People are all different, disabilities are all different. And so that means there's no stock set answer for how to approach anyone.

It can be awkward to bring it up and sometimes. Some families are not through the grief process of owning the challenges that they're facing or owning the severity of them, or some mix of those. So some people don't want to talk about it. Some people wanna talk about it a lot.

Letting people be isolated isn't good, but you can engage too much too fast. So just allowing people to sort of be there and just do what's going on with maybe not of a lot of attention is a kind of good way to melt some of that ice, to begin to lower some of the defences, to begin to make some connections.

Most people have a pile full of stories to tell you that will help you understand about their past and present and what they think about their future. So yeah, once you've gotten a little bit over the hump of some connection, just to understand where people are and if they want to engage and to what degree they want to engage.

Asking questions, is a good thing. Usually asking questions of caretakers first is a helpful way to go. Again, some people with certain disabilities are actually gregarious and social, and that might just be their personality in some respects. And some people with certain disabilities are gonna have real difficult times socially, and they're going to have anxiety around, it's gonna be overwhelming. So often talking to a loved one is a good way to start with that. And then asking some questions is really helpful.

And then being aware of that very often unconscious bias that just normal expectations can create real barriers for families who have people with disabilities in them. Again, things that we think you might not think twice about that are just tough for that family to do. And again, asking questions at that point is helpful. But just being observant, I think goes a long way, of somebody to say, 'is there a way Pascal can be involved in this if we do X, Y, or Z?' It really means a lot, I think, to most people.