Season 2 | Episode 31

An Unplanned Journey

Joshua Fast

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Crystal Keating:

I'm Crystal Keating and this is the Johnny and Friends Ministry Podcast. Each week, we're bringing you real conversations about disability and finding hope through hardship and sharing practical ways that you can welcome and include people living with disability in your community. Be sure to subscribe wherever you listen to podcasts, so you don't miss any of our encouraging conversations. You can also find all of the helpful resources that we've talked about at johnnyandfriends.org/podcast. Well, it's great to have our new Canadian friend on the podcast today. I'm happy to be speaking with the founder of Priceless Youth Ministry. Joshua Fast, welcome to the podcast, Josh.

Joshua Fast:

Thanks. Glad to be here.

Crystal Keating:

I'm glad you're here too. As you know, I love starting each conversation with personal stories. As we begin, could you share about Priceless Youth Ministry and talk about how your family's unique journey led you to create this organization? What was your goal in starting this ministry?

Joshua Fast:

Well, over six years ago now, my son Malakai was born, but before Malakai was born, we were very excited to be pregnant. We'd actually taken about two years to get pregnant. It was a bit of a challenge in that. Everything was going along normally pregnancy wise, my wife was maturing a little larger than normal, and we were looking into why that was happening. It turns out she was carrying a bit of extra fluid. They started doing the regular tests for that kind of thing. Because it's not super uncommon. Actually, the evening of Saturday, we were over at my brother's place and my wife's water broke. Now this was early, this is 35 and five days I believe early. We were like, "Okay, what's going on?" This is our first kid. We've never experienced any of this kind of stuff before, let alone a premature child.

We got to the hospital and everything like that. Everything's like, "Oh yeah, your water broke. Pretty normal. It'll be a ... The child will be a preemie, not a big deal. We've dealt with this before. He might have some troubles breathing with his lungs being maybe slightly underdeveloped, but not a big deal. You know, you'll be in NICU for a bit and then you'll be out in home and happy, and everything will be fine." Needless to say, things did not go normal, or fine, when it came to Malakai's birth. We knew that my wife would have to have a C-section because we knew Malakai was breech. Upside down in the womb. We started to get all that prepped in and go into the room. So yeah, they got my wife on the table and everything's going according to plan, they're doing C-section. Hearing weird noises and try not to look over the curtain because I really don't want to see what's really going on and everything's going normal.

Then my son is born and comes out and you know how almost like a movie, you always listen for that baby's cry right away. Right?

Crystal Keating:

Absolutely.

Joshua Fast:

You want to hear that sound of life? Right? We didn't hear that. We didn't hear that sound that entire day, or for many days after. My son was born with myotonic dystrophy, which is a genetic disorder, which my wife has, which we had absolutely no idea. We were completely blindsided in the moment. He has lower muscle tone, and it was weaker muscles. Because of that, he wasn't drinking the amniotic fluid like he should have. When he was born, well, the world outside of a nice big fish tank of a womb is much harder on muscles for sure. He wasn't breathing for half an hour. I'm trying to keep my wife calm as she's being sewn up.

So, she doesn't panic or have an issue. I'm saying, "Any minute now, we're going to hear that sound. Any minute now we're going to hear that." As I'm watching them do compressions on my son and you know, using the begging and there's a nurse there who doing chest compressions on him, his little body. After they finally got him somewhat stable and brushed him out of the room, my wife was like, "I just want to see him and what's going on?" And the doctor's like, "Sweetie, he's really sick. And you just let us work and we'll get it. We'll get things sorted out." They sewed her up and we'll throw her out of the room and her and I are sitting in the recovery room, and she looks at me and says, "What do we do? How, like what, what do we do?"

I said to her, "God doesn't give us anything we can't handle without him."

Crystal Keating:

Amen.

Joshua Fast:

Obviously, we go through crazy difficult times like this, and everyone has stories. I'm sure that are similar to ours, especially in the disability community. We're going to go through these tough times, but God is there for us. She looked at me and said, "Okay, if God's got us, we got this." We struggled for a while to, "Are we going to have a son or are we not going to have a son? Or are we going to have to bury him right away, or is he going to live on? And then what's this all going to look like?" Over the next four and a half months of him being an incubator and being three pounds, 14 ounces when he was born, so preemie. Very small. Hand towels looked like a full blanket to him in his little incubator.

We walked through this time together and it drew us closer to God throughout all of it and leaning on him. Because we were completely out of our element and completely sideswiped by the whole situation. This journey has definitely inspired me and my wife in helping others who have been through similar circumstances. My wife also helps with the NICU fundraisers and things like that and connects with other parents who've been through similar circumstances to us. I one time was a meeting at a church with Apologetics Canada. They're the organization in BC. I met with them about their project, called The Human Project, talking about dehumanization. I met with Steve Kim and recommended to me this book called Disability in the Gospel. When I told them my story about my son, after reading that book, I was like, "This is awesome. This lays out how a disability ministry should work and should look."

I'm not seeing disability ministry anywhere in my area.

Crystal Keating:

Really?

Joshua Fast:

There was one church channel of, in Abbotsford, pretty much all the churches on the Island here. I haven't heard of a single disability ministry. Some churches have some rough idea or might have someone on staff that has a rough idea of what a disability ministry looks like, but there's nothing in the churches. We saw other families when we were at church come and go because there was no support within the church. That really inspired with my experiences and with reading this book that was recommended to me to start a disability ministry. Obviously through church and stuff, Johnny's name would come up and the Johnny and Friends Ministry has had come up and I looked into what you guys were doing. And I'm like, "Wow, I got 40 years of experience. Why would I reinvent the wheel?"

Crystal Keating:

I think your story, and even the experiences that you and your wife had just in those first few moments of your child's birth ring true for so many families when they're not sure if their child is going to live and if they live, what will life be like? Your eyes start opening and you have so many questions. I'm so glad that God brought a couple of key people into your life. Even just using that book Disability in the Gospel, which is written by Mike Beates, who is on the board of Johnny and Friends, and how God just allowed you to connect with our ministry. I just love your heart for Western Canada and for encouraging churches to really think about what did the scripture say about God's heart for all people. I'm curious to know more about how God has equipped you to lead the ministry that you have right now?

Joshua Fast:

It's really funny looking back at my life and growing up as a teenager and as a kid in the church and how many people have come across my path that have disability or even my mom was actually a TA and worked with severe behavior kids. I actually grew up with a lovely young ladies twins. One has cerebral palsy. Is quadriplegic, extremely intelligent. They're both very intelligent people. The other has just very mild cerebral palsy. And there was that dynamic there that was challenging. Being a twin, but we hung out. We swam. For people who have low muscle tone or cerebral palsy and stuff like that. Water is so freeing and suddenly you're an equal, right? You can swim and splash around with and keep up with in a lot of ways, everyone else your age. Their parents had a backyard pool, and we'd often go and hang out with them.

All of these experiences kind of informed and helped my worldview grow in understanding what disability is and understanding how people are affected by it, how people live. Then obviously my own experiences with my son as well has equipped me. It's funny. We would run into someone who ... Like we were on the ferry one time, and somebody heard my son's suction machine go off. Cause it's quite loud and noisy. Sometimes younger kids get freaked out and go, "Mommy, what's that?" But another family went, "Oh, we know that sound, that's a suction equipment." They came and approached us. And they had a daughter who was 16, who was on a sidelier. Which is kind of like a portable wheelchair across with a bed kind of system. She had a trake and we were able to talk with her a little bit through her mic and talk with her mom and share some of our experiences. Having a child with disability has this, we have this in as an automatic connection with people who have similar experiences, right?

That's really helped in talking with churches as well as talking with other families and things like that. Right? Because you instantly relate with the struggles. With the medical system, with equipment, with everything that you go through on a daily basis. Yeah, it's just really neat that you get those connections.

Crystal Keating:

You do. I think that is so important. We often talk about how beyond disability, the hardships that families face really are a symptom of isolation and not feeling like anybody understands or has limited understanding, which I think your ministry and ministries like Johnny and Friends are trying to do. We're really trying to change the culture and change the understanding of people so that we can all say suffering is a part of life. The Bible has a lot to say about it, but there is something so unique about another family who says, "Wow, I even know what a suction machine is." The last time we were talking on the phone, I heard him in the background. I remember thinking, he sounds like such a happy kid. What are some of the ways myotonic dystrophy impacts his body and communication? How does he eat? What's his suction machine for? Maybe you can tell us more about your son.

Joshua Fast:

Yeah, for sure. Myotonic dystrophy is a genetic disorder. It has to do with the DNA code. Inside our body, obviously the DNA helps. It's like a blueprint, right? That blueprint helps write all of our muscles and all of our ... Different parts of our body as we grow well in Malakai and my wife to a lesser extent, the genetic code that has to do with specifically with muscles is skipping like a record player. Like think of a scratched CD back when we played CDs or a record, it's like the track skips when you get to that point. Malakai has 1,000 to 3,000 skips in his genetic code and my wife has a hundred to 300 skips. You don't really notice a whole lot. She's fatigued more often. She has weakness in her hands and can't really lift Malakai at almost 50 pounds now as a six-year-old.

Malakai can't even sit up. He has troubles holding up his head, moves his arms and hands and has a really good strong grip with his fingers and hands on toys or on your hand. But he doesn't have that core strength or ability to stand. The interesting thing is it can affect or change over time. As Malakai gets stronger and able to do more things, he actually will improve as he gets into his 20s and kind of the prime of his life. Then as he gets older, those struggles will become worse. Again, like he was when he was born, and then other issues start popping up like cataracts and heart problems and things like that. He has MD1, so myotonic dystrophy type I, and there's a type II as well. MD I is considered to be more severe than MD II, but there are just different parts of the genetic code that have that skip in them.

Then that caused the cerebral palsy. Like I mentioned with him, not breathing for half an hour. Cerebral palsy obviously is some sort of brain damage usually caused by lack of oxygen to the brain. It's very hard for him to do any kind of ... His muscles are kind of off and on, which is very similar, very common with cerebral palsy and has very little fine motor skills. This also affected his speech. Malakai is non-verbal and some people, when you hear non-verbal, they get all scared and like, "Oh my kid's never going to talk. I'm not going to be able to communicate with them." Non-verbal does not mean non-communicative.

Crystal Keating:

Yes.

Joshua Fast:

That's a huge distinction that we've definitely found with other families, as well as ours. Malakai is very communicative. As you heard.

Crystal Keating:

I did hear it.

Joshua Fast:

Yeah. He loves to ... Yeah.

Crystal Keating:

I said, "What does that sound mean?" My ears are not attuned to him like a parent's would be, right?

Joshua Fast:

Yeah, and he's very happy and giggly, I was tickling this morning, or I come up to him and say, "Hey buddy, how's it going?" He kind of scrunches his face and scrunches his nose up and smiles at me. And so, he's very emotive and very communicative in his own way. When we put them in the pool and he just laughs and giggles and splashes, and just absolutely loves the freedom that comes with that. Our day to day is a bit of a challenge because we have the suction unit, like I mentioned, and what that does is he has a lot of secretions in the back of his throat. Because if you think about it, almost everything in our body as a muscle. Our heart, our whole digestive system is a muscle, everything is driven by muscles in our body. He creates a lot of secretions that he's not able to quite get them all the way up and out of his throat and he can kind of get them up.

Then we can go in with the suction unit and get those out. If we don't do that, what happens is he can aspirate, so that secretions, or it can cause him to throw up. That goes into his lungs and was obviously very dangerous. We had a bit of a fight to try and get the suction unit originally because we were saying, "Listen, this is a major problem. I'm trying to use syringes or whatever I can to get that stuff out of there. Can we please get a suction unit?" The medical community was like, "No, no. You don't need a suction unit. They're very dangerous." He did end up actually aspirating and we had to take him into the emergency. Within a week after that we had a suction unit, like before we left the hospital, we had a suction unit.

Crystal Keating:

My goodness.

Joshua Fast:

It was yeah, very dangerous. He was not happy. He was coughing up a little bit of blood and things like that. It was a scary time. He's always kind of like ... A lot of parents have to worry about their kid getting into mischief or whatever. We just have to worry about our kid breathing. That's a totally different way to look at raising a child for sure. Right? We don't have to worry about him running around or getting into something. We do have to worry about him being able to breathe on a regular basis. He was in the hospital and about a year ago and he had a massive hip surgery and its complications after that. Something that came out of all of that was nursing support. We now have nurses are able to come into the home and take care of him at night sometimes as well as during the day during his school hours, which obviously right now with what's all going on, he's not going to school, but normally he would be going to school and being able to participate.

He definitely loves that interaction with other kids, loves hearing their voices. It was interesting too, that the kids at first were kind of scared of him, but the teachers used a dodgeball activity, and he was the doctor. Dr. Dodgeball. Anytime they got hit, they had to go and touch Malakai's hand to actually-

Crystal Keating:

To be healed?

Joshua Fast:

Yeah, exactly. To be healed or resed. It was awesome. As a parent, tears came to my eyes when they told me about this and all the kids after weren't afraid of Malakai anymore. That's what a lot of what I'm trying to do is break down those barriers, break down those walls within community and social groups, because people with disability aren't scary, they're amazing, and have these amazing personalities and amazing characteristics. If you can just get to know them and who they are as a person.

It's amazing. He has a suction unit. He has a button, which is basically a permanent port to his stomach. His actually has two ports on it. It goes from out from his stomach and also longer into his upper intestines, his de junim. That's where we feed him through that. We also drain off his stomach bile. Because obviously if we're at a risk for aspirating and things like that, we don't want to have the stomach acid being drawn up at all and going into his lungs. We try and reduce that as much as we possibly can through that system. He has that. He has an oxygen tank with him at all times. He has a wheelchair set up where we can kind of recline him or sit him up more for things. He loves music and instruments and things like that. Playing with drums or tambourines or the nurses like to read books to him as well and show them the pictures. He really enjoys that.

Crystal Keating:

Yeah. A smile and the laugh can go a long way to communicate exactly how he's feeling. Well, Josh, I'm wondering about you. How has being a father to Malakai impacted your spiritual life? I mean, how has the Lord used a relationship with your son to teach you more about himself as God the father?

Joshua Fast:

Yeah. It's impacted and taught me a lot of different things. I think the biggest one is a lot of people question why there's evil in the world. I find that as my favorite question answer, it's so opposite of, or counter-intuitive to what you would think, but is seeing disability and seeing suffering in a sense upfront and up close has taught me so much about how God communicates with us and how in suffering, and in those tough times, we often call out to him and are drawn closer to him because how many times have we been in situations where everything's going great and everything's going peachy and we're not ... How many times did we call on God in those times? We don't. We often forget about, and, and it goes to our back of our mind, but you know, as C.S. Lewis put it, "Suffering is like a megaphone that God uses to rouse a deaf world."

I've seen that firsthand so many times. Even in everything we're going through with COVID, I've seen that, that this world is being aroused by his megaphone because of the suffering and the things that we're going through. He's definitely drawn me closer in those times and learned too that even those times when things are going well, to be able to rely and trust in him when things aren't going the way we think they should be going, right?

Crystal Keating:

Right.

Joshua Fast:

To still rely and trust on him and build that relationship in the tough times so that when the good times, we don't forget about him.

Crystal Keating:

That is right. In the good times we give thanks and praise. In the hard times we can look to him and trust him. We can trust him at all times. Well, tell me more about your lovely wife, Nicole.

Joshua Fast:

We actually met through youth group. I had graduated high school and was going into college. I went directly into college. I didn't take a break. My wife was in high school at the time. We did long distance for about five months and talked just about every night. Then we got together kind of once a month. Then her dad offered me a job doing construction here in Victoria and found a place to live and moved over when I was 19.

Crystal Keating:

Well, you've been married 12 years now. How has marriage changed since having Malakai?

Joshua Fast:

It's definitely been an up and down. It's a struggle too emotionally. A lot of times, depression is a very easily and slippery slope to, to fall into. My wife struggles with that because it's hard to go to a park or go anywhere and see other kids that are running around or doing normal things. That I really struggled. I think she really struggled too with that at first, and then realizing actually they have a program in the medical system where they literally compare your child to the average child. For our first little bit, we went in every month or so. They basically say, "Okay, well how's Malakai doing on this graph? On this, like where are his abilities compared to the average child?" At some point my wife said to them, "Listen, this is not helpful. This is hurtful. I hate these appointments. Malakai is an individual. Malika is Malakai. He is not the average kid. Let's stop comparing them the average kid. And let's just knock this off. Like, this is, this is silly."

They said, "Okay, fine." They actually ended up stopping doing that. In one of those appointments, we mentioned to them that we'd love to have other kids, but obviously this is a genetic disorder. 50, 60% chance the next child would have the same disorder. One of the doctors said, "Oh, it's fine. Get pregnant normally like you normally would, we'll just do the genetic testing. If the child has myotonic dystrophy just abort them."

Crystal Keating:

You're kidding me.

Joshua Fast:

No, I looked at him and was like, "So you're saying my child's sitting right beside me in this appointment has no value because he has myotonic dystrophy?" It blew me away that that was the advice that we were being given and it broke my heart. I've actually been able to help other families who have had similar circumstances as well. Been able to talk with pastors who have people in their congregation who are struggling with those same feelings and getting the same kind of advice from the medical system. I've hopefully, hopefully been able to help in those situations.

Crystal Keating:

That is so hard for families who longed to have other children and who feel the pressure, not only from maybe their own community, but the medical community, who doesn't seem to understand, to have compassion to value life, especially for us as Christians and to see life as precious. That can add to the depression, even that sense of grief. Actually, you gave this insightful glimpse into your story.

When you wrote, "Grief is often a normal response to disability. You grieve the loss of mobility or the normalcy of activities you once loved to do, but this grief is profound and difficult to put yourself out, at times. It's like someone has broken into your house and robbed you. You feel helpless and violated and miss the use of those positions. But unlike getting robbed, you can't simply go out and buy new things to replace the old ones. You have to learn how to live without those things and adapt to a new world. Fear can often be a big part of the sudden or gradual onset of a disability. Fear of being taken advantage of, and also fear of social isolation." With what you shared, can you tell us how you and your wife, Nicole, have processed that grief and overcome your fears when Malakai received the initial diagnosis, but also prognosis for what life might entail these last six years? I'm sure you've had to do that on a regular basis.

Joshua Fast:

Yeah, for sure. Something someone told me early on in our struggle when Malakai was still in the NICU was you have to take some time and more in the loss of the child and the life you thought you were going to have. I found that to be very helpful and very insightful piece of advice and something that I would definitely encourage people who are going through similar struggles. You have to realize and warn that there is a loss there. There's something that you have dreamed or wanted or expected to have happened, and it hasn't happened. It's super important to acknowledge that and to work through those feelings, not bury them. That's something that we did is work through and do that. I think that was helped even more by seeing Malakai's amazing personality and who he was as an individual. Early on, when he was in the incubator at one point, he was having a bit of trouble with jaundice as most preemies or most little ones have.

They turned on the sunlamp to help with jaundice. In the incubator, he put his arms above his head, behind his head, his hands behind his head as if he was suntanning on a beach somewhere.

Crystal Keating:

He was relaxing.

Joshua Fast:

Yeah. We asked the nurses, "Did you guys put his arms like that?" They're like, "No, he did that all on his own." That's just kind of the fun personality that Malakai has. He oftentimes will hold his hands one over the other kind of close to under his chin in this super cute angelic pose and look at you and smile and you just can't help. But your heart melts. He often will fall asleep like that too. It's just amazing. His own personality and who he is and how much our life has changed. I mean, when we were talking back, when we first met, about having multiple kids, we wanted two, three, potentially even four kids. That obviously is a reality that we can't have in a natural way. We definitely have considered adoption. Even potentially adopting a child with disabilities.

I mean, our house is already outfitted for that. Why not? We already have some experience, why not? That also really changed my heart when it came to this idea of children having to be genetically yours and really broke my heart for that and said, "Listen. Kids don't have to be genetically yours to be yours, right? Like they don't. In heaven, genetics don't matter. In heaven, they're your kids. It doesn't matter. The life experiences, the relationships you've had and have with them are eternal." I think our society oftentimes put so much emphasis on that. On that they have to be your genetic kids. It's like, "Really? That's not how God sees things, at least from what I understand."

Crystal Keating:

Amen.

Joshua Fast:

Then working with youth and working with kids and seeing that, "Wait a minute, these are kind of in a way, my kids too, and why not?" These families that I can help. There, in a way, those relationships and those are the things that we build with them are so much more important than having genetic offspring.

Crystal Keating:

Just as you know, having a child that's not of your body, doesn't make it any less your child. I think similarly for parents who are largely absent, there are mothers and fathers who have raised children that are not genetically linked, and it doesn't make them less of a mother and father. In fact, even more so, because those positions are not by blood, but they're by action. Being a father is a role and responsibility. Like a mother is as well. I pray that God guides you and your wife, as you seek to enlarge your family, whatever that looks like. That God would give you guys wisdom. Well, I'm so curious to know about COVID-19 restrictions in your neck of the woods in Canada. What's it been like for your community and your family and how are you guys warding off isolation that so many of us are experiencing, especially families impacted by disability?

Joshua Fast:

It's been a definitely a difficult time. I think in some respects, the entire world is getting a little glimpse of what it's like to have disabilities. Because the whole world at this point, especially here in Canada, where we are really locking things down is getting a little glimpse of what it's like to have a disability and not be able to go out or do things in the normal way we would do things, right? Shopping has become just extremely stressful as I'm constantly when I go shopping wearing a mask and either ... Sometimes I'll work gloves going into a grocery store or I'll just wash my hands, but I'm always super cognitive of like, "What am I touching? And have I touched my face? Have I not touched my face?" Right? Like trying to super conscious of, "Okay, who am I in contact with?"

It's not living in fear. I really try to make sure that I'm not living in fear because ultimately God has it, but still using what He's given me to help prevent as much as possible Malakai getting this disease. The other thing too, is that if let's say I got it, where do I isolate? I'm one of Malakai's main caregivers. I can't isolate at home. That would potentially impact him. Like there's all of these things. Even having nurses.

Crystal Keating:

They're real questions that families are asking themselves.

Joshua Fast:

Yeah. For sure. Even like nurses in the home. Okay. How much do you trust the nurses coming into your home? If you trust that they've been good when they're out and about, or have they got it and not know that they have it now, then obviously the burden that they have, all of the families that they're in contact with. That they're making sure that they don't put our little ones at risk either. I know a lot of families have actually canceled their support and a lot of people who have profound disabilities and quadriplegia or whatever they need, that support, have canceled their support because the fear or the risk of getting COVID is worse than not being able to get out of bed or not being able to brush your hair or do the normal things. Right? That's been definitely a challenge.

We've tried hard with Priceless Youth Ministry to reach out to these families and kind of find a way to be able to still connect or have them connect. We started doing, at one point we were doing monthly meetings through Zoom and offered a pay for Zoom subscription and offered families more than 45 minutes to be able to connect and chat and discuss things like, how do we cope? It was really neat and to be able to connect. One family said to me, "This is a highlight of my week, is that we're able to do these meetings and connect." We're also able to do a young man who has, I believe it was spinal issues and has trouble walking. The family reached out to him and said, "Hey, we'd love to a birthday party for our kid, but we can't get out and do that."

I was able to host a birthday party over Zoom for him and just said, "Here's the codes. Here's the logging information. I'll step away from the computer. Just here you go. And here's how to do the doodling stuff in Zooms. The kids can all draw and doodle together." They had a blast, and it was really great for them to be able to connect and still have a somewhat normal birthday party, but not put themselves at risk. Right? As numbers are starting to spike, like how do we manage those things and how do I continue to reach out and work with people as much as we possibly can, right? Without putting those families who have loved ones who are high risk at risk.

Crystal Keating:

That's right. Well, I love the creativity that you are employing through this strange time that we're living in. We love what you're doing with Priceless Youth Ministry. Josh, I'd love to have you back on the podcast again, to talk more about your ministry. If you're up for that.

Joshua Fast:

Yeah. I would love to come back and share more of what we're doing.

Crystal Keating:

Thank you for listening today. To get our next conversation automatically, please subscribe wherever you listen to podcasts. If you enjoy today's episode, leave us a five-star review. I'm Crystal Keating and thank you for listening to the Johnny and Friends Ministry Podcast.

Episode link: An Unplanned Journey | Joni & Friends (joniandfriends.org)