

Season 3 | Episode 3

Can't Steal My Joy: Facing Unexpected Heartbreak

Bekah Bowman

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Crystal Keating:

I'm Crystal Keating and this is the Joni 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 include people living with disability in your church and community. Be sure to subscribe wherever you listen to podcasts and find all the resources mentioned at joniandfriends.org/podcast.

In a time when so many things in our lives seem simply out of our control, how do we stay rooted in the Lord and grounded in joy? Bekah Bowman is joining us on the podcast today to have a conversation about experiencing deep, God-given joy, that survives through devastating grief and unthinkable circumstances. I'd love for you to introduce yourself to our listeners.

Bekah Bowman:

Yeah, let's see. I'm a mom of two little guys, and we'll talk about them here soon, both with disabilities. I'm a coach's wife, we're in our 16th season here, so I feel pretty seasoned in that. And I've gotten an opportunity to do all kinds of things. I've been able to be a children's pastor. I've gotten to teach kindergarten. That was fun. I work for a nonprofit now in the child welfare system, helping volunteers learn how to advocate for kids in foster care, so that's been really a fun ride. And of course, I get to write all the things that God puts on my heart and I just love whatever the next season brings. I look forward to it.

Crystal Keating:

I wish we had time to talk about your work with the nonprofit. That sounds fascinating. And you are indeed a writer. You actually wrote a book called, *Can't Steal My Joy*. And I think this is such an important topic, especially because so many people have been facing varying degrees of unexpected challenges because of the pandemic and its ripple effects. Can you relate? It's just been so difficult. So you wrote a book called, *Can't Steal My Joy*, and it's specifically centered around you and your son, Titus. You have two sons, as you mentioned, Titus and Ely. And Bekah, I'd love for you to share with us what your family has experienced over the past few years.

Bekah Bowman:

Wow. Yeah, we have experienced, if I summed it up in a couple of words, it would be an unexpected plot twist, which when hit this pandemic and this very unexpected plot twist hit us, I almost felt a little bit like I've been training for this for a while. And I'll take you back a few



years. My husband and I, we had our first little guy, back in 2010, Titus and then Ely in 2013, three years later. And our family was just... picturesque would maybe be a word I would use for that. We both had great jobs. We were financially stable. We had a wonderful community that we were a part of, faith community and lived in a great neighborhood. We had two boys that just kept me on my toes. Titus was the kind of kid who would go a hundred miles an hour, or zero. He's either completely asleep or he is on fire. So, that was our life. And we had great friends. It was going as I had expected it to go.

It wasn't without challenges. I look back and I think, "Oh, we actually went through a lot during that time," but it just is so minimized compared to what we were about to go through, that we didn't know about. We were doing well. And Ely was, I want to say he was about six, or seven months old and Titus suddenly had a seizure at preschool and we got a phone call that he was rushed to the hospital and we got there and there was really no explanation for why he'd had this out of the blue seizure. No fever, nothing to explain it. And so we were sent home, "Just check in with neurology when they can get you in." And that was like how specialists go. It was four months down the road kind of a thing.

And so we just went home, baffled and shocked, scared, like what in the world happened? Then the next day he'd had another seizure and then he had another one that day, and we got into the pediatrician and were just trying to be a little bit more urgent about this issue. And what followed was just a whole lot more seizures. We finally got in. They were able to get us in on somebody else's cancellation. And we saw the neurologist and he was diagnosed with epilepsy and put on some medications and we went home thinking, "Okay, this is just a new normal that we're going to do and we'll keep going." But what followed in the year after that, that whole year was just a lot of really alarming things that nobody could explain.

So Titus, he had more kinds of seizures, the seizures lengthened, they were just taking over his entire day. We were noticing that he wasn't walking as well. He was completely independent. He was like a typical preschooler with a little speech delay. That was all we were dealing with at the time, and he started having issues walking and he had issues saying words that he used to be able to say very well. We noticed behavioral problems that we had never seen before, were so impulsive, and he was immediately just remorseful. It was like he had no control over them, just heartbreaking. We went into the doctor said, "What do we do?" We were just so alarmed and terrified.

And I remember, his seizure was in February of 2014, and so a year later, March of 2015, I remember emailing, or Facebooking, or something to a bunch of my mom friends, just how terrified I was, because Titus had lost six pounds that month. He was refusing to eat. He was choking on his food. He was falling all the time and hitting his head, and it was just very scary. I could not let him out of my sight. It was terrifying. And so we've wound up getting admitted into the hospital. They still had no answers. And we tried a lot of tests and things to find answers and everything came back normal. And so the 'Hail Mary' was this genetic panel that tested all of these different diseases that cause epilepsy. And so in April of 2015, we finally found out that we were actually fighting against a rare, fatal genetic disease called Batten, and specifically their type is CLN2.

And wow, genetic was just mind blowing for us, because when we thought about genetics, we thought about who's going to get my husband's speed, or my soccer skills, or who's going to get whose nose, or whose colored eye. We didn't think about broken, mutated genes. And to find out that both my husband and I carried this mutated gene, the same one, and passed this onto Titus, that was a lot to process. And at that time, we were told there was nothing that they could do. And this disease is 100% fatal. There's no treatment. And, basically they could help us with some



palliative and hospice care and comfort, and to just fully enjoy our days with Titus. So, we went from this place of a three and a half year old who suddenly has a seizure, but is otherwise pretty typical, and this life that we have before us looks very clear and we thought we had a whole lot more control than we really do.

But about 14 months later to find out that his days are numbered so much more than we ever would have imagined.

Crystal Keating:
It's devastating.

Bekah Bowman:

Yeah, we were so broken and obviously it's still tender, but when we found out it was genetic, we thought, "Oh, we have to get Ely tested. We have to know." At the time, he was not even two yet. And so obviously not showing any kind of signs. So there was no way to say, "Oh he's got it," or, "he doesn't have it." And we had to get him tested. And so we did, and we found out about two months later that he also had Batten disease.

I don't even know how to explain exactly, but just in this place of complete surrender, because we could not save our boys from this. We were on vacation when we received Ely's diagnosis, and I just remember gathering our family together. And it just felt like déjà vu. We'd just told everybody, it felt like, about Titus, and now we were going around telling everybody again, the news about Ely. And I remember God just meeting me that night at like 1:30 in the morning. We were staying at my mother-in-law's house. I was in the bathroom, just trying to find a place to just get away. And I had my journal and I remember God just saying, "Just do this moment right now." I was like, "How do we do this? Just this whole thing. I can't. I don't have strength for this."

And he just reminded me that, "You don't have to have strength for an hour from now. Not even a few minutes from now. You just have to do right now, just do this moment, be in this moment." And that was such a gift for me. And it really did set me on a perspective and a path as we navigated this rare disease world with our boys. We were thrown into the deep end. We had no idea this was going to be part of our story. He was just so good to give me that perspective at the beginning.

Crystal Keating:

God met you right there in the darkest of times for you and your husband. How did you and your husband come together through this time as mom and dad to Titus and Ely, both who now were carrying this disease?

Bekah Bowman:

Yeah. We're very different. We always talk about, everything you could think of we're pretty much opposite on, with the exception of our faith. And we have a very strong faith and also supportive of each other. So we've understood from being married long enough that he is going to deal with this differently than I do. And so we need to give each other space to grieve and to process the way that we each individually need to. And so I'm thankful that we were able to do that. It was hard. It was still so hard. There were things that would make both of us just so angry and you peel it back and realize that's grief talking. And we had to go back and ask for forgiveness.



Crystal Keating:

Disability can really impact a marriage, as we've heard it over and over again, but especially when there is deep grief.

Bekah Bowman:

Yes, absolutely. For me, when I would be so angry where I'd think, "Why are we even trying to do this?" I would think to myself, "He's the only one that understands what I'm going through, besides God. He's the only one. He's my children's father, and I need him and he needs me and we've got to do this together." And it has been incredible. Really. Our marriage has been strengthened through these trials.

Crystal Keating:

Going back to that place in the bathroom where you're saying, "God, I can't do this," and him replying, "Yeah, you can't do tomorrow, but I'm going to give you grace for this moment." How did you live on that for the next day and week and month? Take us through that period in 2015.

Bekah Bowman:

So the next day, as I already shared, we were on vacation visiting my mother-in-law and she had a little kiddie pool out in her backyard. And I just remember the whole family sitting around that kiddie pool, the boys were in the water, Ely was grabbing a cup and scooping water up in it and just tossing it up in the air. And most of the time it just landed right in his face. Every time he just laughed over and over, he thought it was hilarious that he was chucking water right into his face. But I could tell you the colors and the temperature outside and what everybody's faces were doing. And we all had our phones out. We were taking pictures and video and just really capturing these beautiful moments, that maybe if I hadn't had this diagnosis right in front of me, I might've sent Grandma and Grandpa to go play in the pool and maybe I would have gone to do something else. Just having that awareness that right now is a gift and to look around and enjoy.

And after we had both the boys' diagnoses, I remember just at home, every little thing. I would cry over the happy things. I'd cry over the sad things, because I just I was so aware that these wouldn't last forever. And in a way that could very well have stolen from my moments, that fear of what was coming. But I just found myself digging in, like I want to hear that laugh. I want to see that smile. And I want to hold and dance with my boys, and I want to remember how they smell.

Crystal Keating:

You wanted to take it all in, each moment.

Bekah Bowman:

Yeah. And that's where the gifts were found. I found joy in these places, because I realized that I'm a dreamer and I'm a big thinker. And I like to anticipate the things that God's going to do, and be part of those things. And I tend to forget that God is in my everyday moments. And he is right here in front of me working. And he has these beautiful gifts of wonder to gift me and joy. And being more present in that moment with my boys, I was able to grasp those. And they became lifelines for me, as we were dealing with this fatal disease. Titus's body was quickly deteriorating. It was so fast. When I lost him, we say he ran to Jesus, just a year and a half after we got his diagnosis. So it was like whiplash, really, to go through all of that with him. I'm just



astounded at the way God centered me and my heart on him and on his everyday gifts and how empowering and strengthening that was.

Crystal Keating:

All of God's promises are true. But I think over and over again, we've heard from men and women like you who've experienced God's presence in the midst of grief. And that he says, "I am near to the broken hearted." And we do experience God's nearness at different points in our life. That's what I'm hearing from you, that God was incredibly near. It doesn't make the grief go away. It doesn't make the pain of losing your precious son alleviated, but there is a joy there that none of us on the outside looking in could understand.

Bekah Bowman:

Absolutely.

Crystal Keating:

Well, and Bekah, right now I've been astounded actually this year, as we're hearing from friends writing into the Response department, who are struggling in the heaviness of life to just find peace. And in fact, just this month, we've received over 50 emails from people around the United States, asking for prayer for the weariness with depression. And that blew us away. We know that whenever we talk about depression, we definitely get a large response and it really saddens me. But when I think about you and your life and what you've written in your book and your blog, you write about having to put your hope in someone and something greater than your ever-changing circumstances. So if we could just talk about how you found such lasting hope and joy as a grieving mother, how did you find that lifeline? God was ministering to you.

Bekah Bowman:

Yeah.

Crystal Keating:

Were there also steps that you were taking? Or what was that like?

Bekah Bowman:

Yeah, I think that our culture, and I believe that I was living in this false truth, unintentionally, but I think our culture feeds us this message that we need to just think positively. We need to pull ourselves up by our bootstraps. We have what it takes. We have the grit to get through this, and I've always just loved Jesus. But I think I lived that way where I pulled from my strength and really had this perceived control about a lot of things. And then when this unexpected plot twist comes along and these circumstances are not controllable, I'm suddenly facing death for my kids. And I cannot fix that. And I got to this place where I had to recognize my limitations, my brokenness, I literally had nothing if I didn't have him. And so I think I really found my hope and my joy when I was willing to recognize my brokenness.

Bekah Bowman:

I think we run from brokenness so much. We are so afraid of pain. We're so afraid of letting ourselves go there. But I found that when I asked Jesus to go there with me, I still feel it. I've



already been emotional in this conversation. I'm obviously not over losing my son and having to battle this with my other son, but there's this partnership in it. And to put it quite bluntly, I always feel weird when I say this, but we're all going to die.

Crystal Keating:

Yes, it is true.

Bekah Bowman:

And this is so temporary. And I think I was holding onto my boys' lives. Like, "No, no, you cannot take this from them." And then I'm like, "Take what? It's all going to be taken. It's all going to be redeemed someday." And we get to live in that promise and we get to live in it right now. And then we get to live in it when it comes.

Crystal Keating:

That's so powerful.

Bekah Bowman:

Yeah. We think about the people, Hebrews 11, it talks about all these incredible people who are part of God's big story. And they pass away and have never received the promises that God had given them, but they saw it from a distance and they welcomed it. And that's what I keep going back to. We have these promises that we can hold onto. And so practically speaking, I did things like I just asked God to be part of my everyday moments in life. And so I was just very aware that he was present and he was there. And I'd have conversations, "God, I don't know what to do for Titus. He's crying and I don't know what to do. I need wisdom, give me something. I'm broken." Just crying, "Be with me, hold me."

The Psalms were just so good for my heart, because those emotions that the Psalmist wrote about, I could feel. And it wasn't a quick fix, like, "Oh, okay, let's get over those emotions and move on." It was like, "Let's sit in these emotions and let God know how we feel about him and let him be here, present with us." I did start naming things that I was thankful for and writing them down. And then also we rented in Orange County and we had this dining room that had a huge mirror in it. And so I couldn't hang anything on there, but I could sure write in dry erase all over it, so that was fun. So I grabbed my dry erase markers and I would just write God's promises that he has given us up on that mirror, so that as I'm doing medications and getting food ready and caring for my boys, that I can see it. And it's at the forefront of my mind.

And it just helped me battle the deception and the lies that Satan wanted me to believe about, maybe God had abandoned me, or, "I don't deserve this. This isn't fair." Some of those things that would come to mind, it just gave me a resilience and kept me focused on truth, that I could lean on him no matter what was happening.

Crystal Keating:

Yeah. Especially when you pass by that mirror and you look at yourself. And when life is out of our control, we can get caught up in our own thoughts and our own fears and to stop and see God's promises is such a perspective shifter. I love that. And Bekah, I just feel like we've just scratched the surface. As we close our time together, I would love if you could just share a few words to encourage others who may be going through seasons where they feel like their life is out of control, and maybe feel like that ground floor of peace and joy that they would like to



stand on is really hard to find. How would you encourage our listeners to feed their joy in the Lord?

Bekah Bowman:

I just finished reading *Life Without Lack* by Dallas Willard.

Crystal Keating:

Love him.

Bekah Bowman:

Isn't it? It was such a good book. I actually picked it up in October and I just did not have the brain space to process the depth that he was writing at, but I picked it back up a few weeks ago and just tore through it.

And I loved what he left us with at the end of the book. And he was talking about scheduling a day to be with Jesus. And he said, "Not a day where you clear your schedule and you find quiet space and you just pray all day. But a day that you go about your normal routine, you're doing all of your things and you asked Jesus to come be a part of it with you." And he said, "And just be aware that he's there and have a conversation with him throughout your day. And if you are struggling with something and you're going to do something, I love how practical he was, "You're going to do something that he may not really like, and you're not ready to change that. Let him know that you're not ready to change that. You're about to do something he probably won't like, and you're just going to need his help with some things."

Crystal Keating:

Don't break the intimacy, just keep open with the Lord.

Bekah Bowman:

Yes.

Crystal Keating:

Yep.

Bekah Bowman:

The idea is that perfection is not required. Just invite him in. And I think that spoke so much to me, because even as we've gone through this and I've learned these things over and over, I so often think, "I've got to get over this. I've got to get through this. What is wrong with me? Why am I depressed?" And you get to a certain level and then invite Jesus in, but invite Jesus in, in those broken deep dark pits right now. He can be there. He's gone there. He's gone there for us when he died on the cross. And so he knows exactly what it's like down there.

And I think there's just so much power to not feeling like you've got to get better before you invite him in, just invite him in right now.



Crystal Keating:

That's right. that's right. He loves us. He made us and he knows what we're going through. Bekah, thank you for opening your heart with us. I know this is tender to you and thank you for sharing this with us. I'd love to continue this conversation, even in what you were saying about still living with the grief. Do you get over it? How do you move forward? So I would love if you could join us again in a conversation next week...

Bekah Bowman:

That would be awesome.

Crystal Keating:

... where we talk about that, Bekah, bless you and may God comfort your heart even today. Thank you for what you've shared.

Bekah Bowman:

Thank you, Crystal. It was wonderful to be part of this conversation.

Crystal Keating:

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