

Season 3 | Episode 4

Carrying Grief

Bekah Bowman

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Crystal Keating:

I'm Crystal Keating, and this is 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.

Bekah Bowman is joining us on the podcast again to encourage our hearts with a message for finding a hope in Jesus that doesn't disappoint. A love in him that anchors us, a joy from the spirit that remains through unexpected loss, and a perspective shift that goes beyond our circumstances.

Welcome back to the podcast, Bekah. It's so great to have you again.

Bekah Bowman:

Thank you. It is so good to be back.

Crystal Keating:

At the end of our last conversation, you were talking about coming to a point in your life where you felt like, "Man, I realize there have been times where I've been pulling myself up by my own bootstraps." You realize, I've been putting on a brave face to go through two sons who have a terminal illness, Batten disease, the loss of one son, but you came to a point where you felt like you couldn't do that anymore.

Bekah Bowman:

Well, and as I shared in the last episode, it was this realization that what we were up against, I truly could not do anything about, and it was so far out of my control. Before we got the diagnosis, I just kept saying, "There's an answer. There's an answer. We're going to get to the bottom of this and then we're going to move on and be back to normal, whatever this normal is." And then the realization that no, we are not going to get back to that place.

We are on a different path, a very broken one. And I remember it was October, so this was 2015. I was journaling and I just process so much through my words. Before this day in October, I had been writing a lot and sharing it on my blog, and when I was getting ready to start my blog, it was just right before the boys' diagnosis. I remember thinking, "What am I going to call this thing?" And it just came to me that Satan has been trying so hard to steal my joy and he can't steal my joy because my Jesus is more powerful, and his joy is everlasting.

And so I thought, that's like my work high, can't steal my joy. And so I created this blog and I shared my writings on there and it was therapeutic for me, but it was also, I was finding other people reading and saying, "You are saying the words that I feel, but I didn't know how to express, so thank you." And so I just kept sharing those things. And so writing became very important to me, both from a therapeutic side, but also from seeing how God was using our story in a bigger way.

So, as I was writing in October, continually learning how to let go, and I realized the definition of brave in the kingdom of God is learning how to let go, and it is a whole different definition in our world. And so I was learning to let go and I was just writing out this prayer to him and he gave me this incredible image of a flower with these deep, strong roots and this stem. And if you look up the flower, you see the stem is actually so broken. It's hanging by a thread and on the end of this broken stem and the leaves are eaten by bugs, they have holes in them, at the end of the stem is this beautiful blooming flower. That doesn't make sense. It should not be blooming.

It's like, "Bekah, this is you. You are blooming in the midst of this broken place because your roots are so firmly deep in my truth." This is a promise that He gave me. Like, "I will continue to hold onto you." And it just, over and over, it brings me back to Ephesians 3 when it talks about, "Your roots growing down into God's love and keeping you strong. So you have the power to understand, as all God's people should, how wide and how high and how long and how deep his love is." And it's so sustaining.

So, this picture stuck with me. I couldn't get over the dynamics of the story that it told and the fact that it was my story, and it was also a promise that God gave me that no matter how ugly these stems and these leaves are going to be, he will redeem. He will be good. He will do good. He will provide hope. He will provide joy. And so I journaled all that down and I actually did not share it on my blog. I felt like, "I think this is just for me right now. I'm going to let this just be for me."

Well, then we go through the next a year and Titus passes away and we go through a whole thing with Ely, we might get into later, a whole other chapter with him. And it's November of 2016, at this point, Titus has been gone for about two months and my husband's out on the back patio and he is cleaning everything up. And I guess I should back up.

A couple of days before that, he'd been out chopping wood and we had this beautiful yellow flower that was blooming in a pot out there. And when he was chopping wood, a splinter flew off to the side and just cut the bloom off of that flower. And we were so sad because yellow was Titus' favorite color and we didn't know this flower would be yellow and it had bloomed yellow and it was just kind of like a little piece of Titus out there and this bloom was cut off and we were just so sad.

And then a couple of days later, he's out cleaning the back patio and I hear this knock on the door and I go over, and my brother-in-law, who's helping him, in his hand was this pot with a flower and it is literally blooming yellow on this broken stem hanging by a thread. But I had drawn in my journal in October of 2015, this flower at the exact same angle. I looked at that and I go, "That's my flower." And Edward goes, "Yeah." And it was just this reminder in this moment of loss, like raw loss.

It had only been two months and still fighting for Ely and just this reminder, "Hey, remember my promise to you. I am here, stay rooted in me, continue to let go of all you feel like you need to cling to. I've got this and there will be beauty and redemption that come out of it, no matter how broken it feels right now."

And so that has just been a continual promise, and of course it was so special that when I went to write *Can't Steal My Joy*, the book, I just knew that flower had to be on the cover. And so it is, it's on the cover and the subtitle is The Journey to a Different Kind of Brave. Because for me, it was that journey of learning how to let go and how to cling tight in my roots to God's truth to make it through.

Crystal Keating:

And we need those touches from God that only we can know that is from the Lord and nobody else. That he would give you that picture beforehand to say, "I'm with you. I haven't forgotten you. I see you and I love you." What a gift.

I think about history and the women in the past who've lost children. Bekah, to be honest, I've heard some who just don't recover. The depression overtakes them, Christian women. In our last conversation, we did talk about how many people struggle with depression, and then off record you and I were talking a little bit about counseling. But I'd love to ask you, was counseling a part of how God strengthened you? Were you talking to someone? Was that important to you? What did that look like for you? How did you gain strength through that?

Bekah Bowman:

Well, during those really difficult months and year and a half with Titus, I would say that I didn't have time to go to counseling. My life was 24/7 care for him and managing nurses and the people coming through our doors and all of that, and it was exactly where I needed to be. But what I did have in that time, that I would encourage people to walk out of your comfort zone and go find this, was just a couple of mentors who were down the road in life.

I mean, these people were in their 60s and 70s and were prayer warriors. Either these couples would come over for dinner and just encourage Danny and I, and they would just feed our souls. They would pray with us and they would just validate how hard it was of what we were going through. Neither of them had ever gone through anything like this. And the validation in itself was so healing because it was like I didn't have to hide my pain.

I didn't have to feel like I needed to rationalize it. It was hard and they said it was, and then we could pray and just bring it to Jesus, and when I couldn't do that, they did it for me. That was so healing for us in that grief journey. Because we were living in grief far before we lost Titus, that anticipatory grief is, man, it rocks your world because you just don't know when you're going to lose the next thing, and so they were rocks for us.

One of them was our pastor and his wife, and then the other was a man who my husband met at a men's retreat and he and his wife had led that retreat and we just connected with them and we would invite them over. And anytime we had to make a big decision, we had to meet the hospice team and really talk about like, "It's very clear that Titus has moved into the end-of-life stage. What is this going to look like for him?" And we invited them to be at the table with us, along with my parents, and it was just very important for us to have their input because we trusted them and they were praying for us all the way through.

Crystal Keating:

Those are decisions that no parent ever wants to have to make.

Bekah Bowman:

No. You never begin your parenting journey ever thinking you're going to have to make those. It's just not on your radar at all. So we had just an amazing amount of wisdom around the table that day when we had to hold that meeting. And really the whole time we were journeying through that, these people were just so incredible for us. And then after we lost Titus, I noticed in myself, grief takes on so many different things.

I'm not naturally an angry person. I'm pretty go with the flow, pretty optimistic. But I was getting very angry. On a dime, I could just flare up and I thought, "What is my problem?" Like, "Why am I doing this?" And so I just thought, "Maybe I need to go get some tools to understand how to handle this grief." And that was huge for me.

So, I wound up finding a counselor, a Christian counselor, who I could talk to, with my faith as I wanted it to be a part of my counseling. And it was so healing for me to one, know that I'm not the only one that reacts that way when I'm in grief. So I'm not alone in that, and I don't have to stay in that place.

I could have the tools and the awareness to notice that when it's coming and then be able to choose a different way to respond. And so I'm not perfect. I still get angry, but I have, through counseling, been able to recognize, oh, I can call that grief. And then I can actually say those words to my husband or to whoever, "I'm sorry, this is just painful for me because of," whatever it might be.

Yeah. I feel like that has been huge. I see myself going back again in the future to continue to work on this because it's a continual journey of grief that we live right now.

Crystal Keating:

Yeah. And I think that's something to recognize for those listeners who have lost a loved one or are dealing with losses and dealing with grief. I like what you said before that, that question of, "When am I going to get over this?" And the truth is we don't get over it. We go through it and God meets us and He gives us his self and community to help us through. I think there's a freedom when we recognize, okay, this is normal and there's no expectation to get over it. That's an unrealistic expectation.

Bekah Bowman:

Exactly. It's like my roommate, I call grief my roommate now, just moved in and it's going to be here.

Crystal Keating:

Yeah. Not a roommate you ever would choose, but God is also there. Well, let's talk a little bit more about your community. I love that you had seasoned Christians to be there for you and your husband that you could process through. You could say probably anything, to be around you when you were with the hospice team.

Because I think when people are in crisis or just trying to maintain daily sanity, it's really hard to articulate what we need. And for some of us, it's just hard to acknowledge our dependence upon others. I remember Vaneetha saying that, Vaneetha Risner, when she was suffering many losses, to say, "I used to be the helper. I used to be the minister, and now I need help. I need people ministering to me."

So talk about more ways God used your community to bless you and minister to you and your husband, even when you may not have been able to organize support or get help for yourself. What was that like for you?

Bekah Bowman:

Oh my goodness. I could go on for hours about this. I'm trying to think of where to even start.

Crystal Keating:

Good. That's awesome.

Bekah Bowman:

I know, it's incredible. I get that so much because Danny was a pastor's kid. He was raised in the church. I was also raised in the church, but as a layperson's kid. It was service, we served, and then we both went into ministry and we were pastors on staff with children and youth. So from that perspective, we always were helping others and we had our own lives were together and we were doing okay.

One of the most potent memories maybe in my mind of when someone did something for us when I didn't even really realize that we needed it, and then how that felt after. I remember it was track season, so I was basically single parenting a lot and I had Titus, who was having seizures, and actually at that time, Ely, started having these really terrifying episodes. Where he'd spit up and then all of his airways would clog, and he couldn't breathe and I'd have to suction him out to get him to breathe again and he was becoming failure to thrive because he wasn't able to keep anything down.

And it was just, it was a lot to deal with. And I remember having both my boys down for a nap one day and I could barely keep my eyes open. We'd been up through the night, several nights. And so I laid down on the couch to sleep. And at that time, I was a full-time children's pastor and really should have started working at that point when they went to lay down for their nap.

But I fell asleep and I remember waking up briefly and hearing what sounded like a lawn mower outside and I just kind of opened my eyes and saw this head full of white hair bobbing along under my window on our side yard. And I was like, that's Jack, that's my boss, our pastor. And then I fell back asleep. I could not keep my eyes open.

Bekah Bowman:

And when I got up from my nap, I was like, "Wait a second. Was that really, was that real?" And I look outside, and I joke because our lawn is grass, but it was basically dandelions, and our dandelions were all mowed and-

Crystal Keating:

Oh, like, "Did I dream that?"

Bekah Bowman:

Yeah. And so, it's all mowed, and I'm like, Jack came and just did it. He just came and mowed the lawn and he didn't even-

Crystal Keating:

And you didn't ask him.

Bekah Bowman:

He didn't call ahead. He didn't ask permission. He just came and mowed the lawn. And we have had those kinds of things happen so many times and I am so thankful for that because in the moments when people ask me, "Let me know if you need anything," or, "if there's anything I can do, please tell me." I did not have the capacity to even manage that. I couldn't have the capacity to say, "Oh, I need this. Oh, so-and-so could probably do this. I'll call them."

I just did not have the capacity and so for people to just see the need and step in and do it, I know that sometimes we think, "Oh, we don't want to overstep." And there's things, I didn't want anybody coming over and doing my laundry, that was weird. And people offered it and I was like, "No, that's okay. I got it."

But there's so much that we could do that is okay. Make a meal and just drop a meal off. Don't ask if they want it. They'll probably say no. They do, they want it. I promise. I always did. So just take a meal and make it a freezer meal. They could throw in if they already have plans.

I had a friend whose sister-in-law owned a salon there in Orange County, and goodness, Orange County, it costs a lot of money to do your hair down there.

Crystal Keating:

Yes, my goodness.

Bekah Bowman:

And coming from a little farm town in Chicago to Orange County, I was sticker shocked, and so I trimmed my hair and didn't do a whole lot. And I just was in the mood for something different and new and so I asked her about her sister-in-law's salon, and she wrote me back. She said, "I talked to her and they want you just to come in, it's on them and they want to just gift you this haircut."

Crystal Keating:

Oh, yeah.

Bekah Bowman:

And I was like, "Seriously? That's incredible." And so I went in and she did this great haircut, color, all the things, and then she goes, "I'll call you in six weeks and when it's time for you to come in again and it's on me."

Crystal Keating:

Oh, my goodness.

Bekah Bowman:

And she did my hair for two years for free.

Crystal Keating:

Wow. And that's time for you that you get taken care of.

Bekah Bowman:

Yes. Yeah. It was huge, and she knew that. And so I'd go eight weeks and I wouldn't have reached out and she'd text me, "Hey, it's time for you to come in." So she was on it and just used her skills and what she had to offer to bless other people.

Oh goodness, we have so many stories. So, Titus got to the point where he could not be in the car. It was not safe to put him in his car seat and drive around and so we were basically home bound and our pastor, of course, because he and his wife were so much a part of our lives. They knew that this was going on and we were just like, "We'll never get there. We'll never be able to afford that." And at the time we had a minivan and so we were looking at maybe getting that adapted, but everything was just so expensive.

Well, our pastor and the elders of our church, they said, "Well, we really want to help with that." And I'll be honest. My first thought was, "Well, that's sweet. Whatever couple thousand dollars they raise, we'll put away and we'll just hope that we can save up enough over time to get this someday."

Crystal Keating:

Yeah. Like, do they realize how expensive these things are?

Bekah Bowman:

Yes. Exactly.

Crystal Keating:

For sure.

Bekah Bowman:

So they reached out again. They said, "No, we're serious. We really want to help with this, and we put together this little committee to raise money for the Bowman van." And I'm not kidding, in a weekend, they raised enough money for us to take in ... We sold our minivan, took the money from that, and they raised enough for us to go get a brand-new Toyota Sienna with all the trimmings, with everything we needed, with cash.

Crystal Keating:

Oh, my goodness. Praise the Lord.

Bekah Bowman:

Yeah. It was just-

Crystal Keating:

And I bet every person who gave was so happy to do it.

Bekah Bowman:

Yeah. It just energized our faith community and people who were watching, who weren't part of our faith community or weren't part of that project were in awe. Like, "People do that for each other still? Wow, that's amazing." You just don't hear those stories very much and God is just at work in his generosity in those ways. And I realized that at some point, I don't remember exactly when, but I realized at some point during this journey and people were just pouring into us in many, many different ways, that this is really the epitome of our relationship with God.

We try so hard to be independent and to look like we've got it together and not ask for help and not accept help when it is given, and how often do we do that about our relationship with him? When obviously, we could never do enough to get to him and he sent his son to die for us and to bridge that gap and to say, "You need to learn to receive because that's all you have to do, is receive." And it was just this reminder for me over and over, like, "I am flexing this spiritual muscle of receiving, and that is at the heart of the Gospel." That's what He asks us to do.

Crystal Keating:

That's right.

Bekah Bowman:

So that for me was just really powerful.

Crystal Keating:

It is. And I just love how even people who weren't part of your faith community could look and be sort of astounded that such love existed, and didn't Jesus say that? I always say this on the podcast, I'm a broken record about it. But Jesus said, "People will know that you're my disciples. Why? Because you're such a good person? No, because of your love for one another."

Bekah Bowman:

Absolutely.

Crystal Keating:

And so when we have opportunities to open our churches to welcome and embrace everyone in the love of Christ, with the Gospel, with the opportunity to be discipled, to use our spiritual gifts, if the world has an opportunity to see that it confounds them and how much you are to say this is the Gospel. Like you said, all you have to do is receive it, and in receiving, transformation happens. Oh, I love that. God bless your church.

Well, this has been such a great conversation. As we close our time today, we'd love for you to give us an update on your son, Ely. How is he doing? And how can we be praying for you?

Bekah Bowman:

Oh, thank you for asking that. So, Ely is just incredible. To give you a little glimpse of the rest of our story up to this point. If you've listened to the last episode that when we got the diagnosis, there was no treatment, no cure, nothing that could be done for this disease. And for the duration of the rest of Titus' life, that was true.

And the week that we were saying, we knew Titus would go at any day, we received an email from a hospital in Columbus, Ohio, a doctor who was doing a clinical trial for enzyme

replacement therapy for this particular disease. And it said, "Ely qualifies and we would like for him to come out and go through the process of formally being qualified and entered into this clinical trial."

And I'm literally, it was on a Tuesday, and I remember calling Danny home just before I got that email because I was counting Titus' breaths and they were slowing and I just thought he could go and I need Danny home. And so he had come home from work and we're sitting there all gathered around Titus and my phone bleeps and I get this email that Ely is getting this shot at a clinical trial. And I just didn't even know what to do. It was like pain and joy clashing together right there.

And so, of course, I emailed back, like, "Absolutely, we want to come out. Here's our situation, let us know what we need to do next." And Titus didn't pass that day. He wound up passing on September 17th, which was a Saturday. And literally 10 days later, we climbed on an airplane and we flew out to Columbus, Ohio for Ely to be formally assessed and all of those things and he went in for surgery two days later for brain surgery to get a port placed and-

Crystal Keating:

Oh, my gosh.

Bekah Bowman:

There's like a whole story about this with our community. We actually had a man who rode his bike from Irvine, California, up to Montana, 1300 miles, and bicycle, not motorcycle. And he raised money. He called it the Ride for Ely Campaign.

Crystal Keating:

What?

Bekah Bowman:

And he left before Titus passed away.

Crystal Keating:

I heard about that.

Bekah Bowman:

Did you?

Crystal Keating:

I did not know that was your son.

Bekah Bowman:

Oh, my goodness. That was Ely. So he left before Titus passed, and so Titus passed while he was on the road and he got the news and he just kept riding and money just kept coming in for this. Because the clinical trial's covered, but the travel to get out there, and we had to go out every other week, was not covered nor was housing or anything like that. We actually got Ely into his,

where they take him in for surgery. We say goodbye, we go to the waiting room, and we get a picture from Rocky that he has arrived at his destination as Ely is going in for surgery.

How amazing. Rocky has completed his journey. Ely's in for surgery to get this treatment. We've been through so much over the last 12 days at that point. Just this continual understanding that God is weaving good through all of this.

So anyway, Ely comes out of surgery and we start treatment with him, and initially the only site in the US was in Columbus, Ohio. And so we had to travel from Orange County to Columbus, and that was three times zones every other week. It was a killer, but we end up-

Crystal Keating:

It's overwhelming on so many levels and-

Bekah Bowman:

Oh, my goodness, we just lived in exhaustion all the time. But it was hope, we got this treatment. There was a lady out in Columbus who had a beautiful town home. She had space and she was a mutual friend, but we'd never met her, but she had a mutual friend of ours and she opened her home to us and we stayed there every time we went out. She's part of the family. Her name is Bonnie, but we call her Bon-Bon. And so we did that for six months. We went every other week for six months.

And in the meantime, our doctor and our team in Orange County were working on opening a site under clinical trial at Children's Hospital of Orange County. They got that open. We were able to go back home full time. And Ely has been getting treatment since 2016. He's seven, he's going to be eight this year.

Crystal Keating:

Praise God.

Bekah Bowman:

Which blows me away. Titus passed away when he was six, and we just, every day with Ely, we are so aware of our gift and he's just thriving.

Crystal Keating:

Awesome.

Bekah Bowman:

This treatment, it doesn't cure the disease and it doesn't stop it, but it has really slowed it down. And so Ely has lost his vision. He's completely blind. He's probably what most would consider non-verbal, but he's got lots and lots of sounds and he's actually gaining some words, which is really incredible. Still walking independently, he's very independent in all ways, and he's just a joy. He loves to make people laugh. He's a clown.

We like to update. If anybody ever wants to see Titus and Ely on Facebook, it's Team 4 (the number 4) Titus & Ely, and we spell it weird. We spell it Ely, E-L-Y, poor thing is called Ellie all the time. But we post a lot on there just about what Ely's doing and he's just incredible. So it's a gift. We are so thankful for him. And when we moved to Idaho, we were able to open a site here

as well, and so he receives treatment here at our local hospital and he just had his 112th infusion yesterday.

Crystal Keating:

Oh, my goodness. Praise the Lord. Praise God that he continues to provide that physical strength, that stamina. Tell us again how people can follow you on Facebook to lend support and to pray and to see Ely's smiling face? He's a cutie.

Bekah Bowman:

Yeah, he is. You can find us on Facebook. Our page is Team 4 Titus & Ely, or you can go to my website, bekahbowman.com, and it will link you to our social media. And there's also a newsletter that you can sign up for that I send out monthly just to encourage people who are going through really hard places. Yeah, that's how you can find us.

Crystal Keating:

And we're going to put all of those in the show notes as well. So you can come to joniandfriends.org/podcast to get a link for each of those.

Bekah, it's so uplifting to talk to you. Thank you for just pointing us to the Lord and that eternal joy that we have in Him, no matter our circumstances. God bless you and we will be praying for you and Ely and your husband. May God continue to cover you.

Bekah Bowman:

Thank you so much, Crystal. I really appreciate it.

Crystal Keating:

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