



Season 3 | Episode 35

## Finding New Purpose After My Ehlers-Danlos Syndrome Diagnosis

Cady Bell

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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 or find us at [joniandfriends.org/podcast](https://joniandfriends.org/podcast).

We're joined by Cady Bell, a young woman whose life was dramatically changed after receiving a diagnosis of Ehlers-Danlos syndrome, a connective tissue disorder that affected Cady's mobility and strength. Listen in, as she talks about the ups and downs of this invisible disability and how God is using Cady's hardship to show others who he is.

Thank you for being with us on the podcast today, Cady.

Cady Bell:

Thank you so much, Crystal. I'm so excited to join you.

Crystal Keating:

You were an EMT, you were on the path to start medical school, pursuing a call to be a physician. But all of that shifted when you started experiencing some changes in your health. I would just love if you could take us back to that time in your life when you started to notice something was going on in your body, something was changing.

Cady Bell:

Absolutely. So when I was younger, we did notice some early signs. I did have pain ever since I was two, I'd complain about joint pain, things like that. And then I also always had stomach issues, but you never know. We just thought it was something that was pretty typical.

And then in high school, I got a lot worse. I started developing a type of seizure, as well as struggling just with fatigue and severe pain, as well as stomach issues. But we still had no answers. We had gone to the doctor; blood work didn't show anything. So you just go about life.

And I had goals of becoming a physician and had just gotten my EMT certification, was going to college. I felt like, "I have gone where God wanted me to go. This is it. I've made it in a sense."

And then all of a sudden I progressively got worse. My seizures became out of control. My joint pain was severe. At the time, I didn't know I was dislocating joints, which is part of EDS, but I was dislocating joints. And so, the pain and the fatigue, and it also causes heart issues. So I started passing out. Just between all of that, I ended up having to drop out of college. I had to



stop working and we knew that there was definitely something going on, but we just could not figure it out.

And so, we searched for over six years before I actually ran across a YouTube video. I had no idea that the girl had EDS, but she was explaining some of the things she had. And then these light bulbs started going off and I was like, "Oh, wow. That sounds like what I've had." And so I found a doctor a couple hours away that knew about this disorder and sure enough, that's what I had, was this rare genetic disorder.

After I got diagnosed, it was honestly kind of a sense of relief because it's like we knew what was going on, when for so long blood work came up negative with anything and doctors couldn't find anything. And I just kind of felt like, "What is going on, God?"

Crystal Keating:

Oh, yeah. It's so hard when there's a mysterious illness. How old were you when you got your diagnosis?

Cady Bell:

23, I believe.

Crystal Keating:

So after you received the diagnosis, what did you learn about this syndrome and how many others are affected by this disorder?

Cady Bell:

One thing that was really interesting is it's rare and it's genetic. You can't just see it. So it was hard when things came up negative on blood work and then doctors were like, "You look fine." And so to finally have answers, it was great. It started putting all the pieces together of like, "Oh, my joints hurt because I'm dislocating them all the time."

So EDS is a mutation of your connective tissue. So your soft tissue, which is in every organ, your ligaments, tendons, everything. So all of a sudden, it made sense why I was having stomach issues as well and trouble with some of my organs. And it also affected my brain with these very specific kind of seizures, as well as heart issues. Now, a lot of these are something called comorbidities, which means, think of a domino effect of EDS. And that causes me to have all these other disorders. So I technically have like seven or 12, or I don't even know, kind of lost count of how many disorders I have. But you have disorders with your stomach, with your heart, with your brain. And so, I finally understood why I was passing out or seizing or couldn't eat full meals.

Crystal Keating:

Right, because one was affecting the other, especially if you think about connective tissues being throughout your whole body.

Cady Bell:

Well, and the other thing about it is it is rare. So it's a rare genetic disorder and people are taught, doctors especially are taught to look for horses, not zebras. Meaning, it's probably not the rare thing you think it is. And because of that, many doctors, they've heard of EDS, but they



don't know much about it. They don't know what to look for. And so, that's why me and many, many others that have this rare genetic disorder go years without being diagnosed.

Crystal Keating:

So when a diagnosis comes, I'm curious about treatment... Are there treatment protocols? Do you treat the symptom? Do you treat the whole body? What have you encountered in the medical community?

Cady Bell:

I think that was what was a little bit hard to swallow when I got diagnosed, was finally I had answers for what was going on, but I was hoping with those answers came significant treatment options that would just basically fix it. And that wasn't the case. Basically, what they could offer was physical therapy and medications to try to help with my symptoms. But other than that, I've progressed worse. Many people do, and there's just really no good treatment or cure for it.

Crystal Keating:

And one of the things that you mentioned is that this syndrome is largely invisible, and I'm even curious about that. It's invisible to just the human eye, but is it possible for doctors to see dislocated joints?

Cady Bell:

It is just invisible. If you were to look at me right now, if I'm not in my wheelchair, I didn't have my port access, all of that. You would have no idea that I was disabled at all. That's I think partly why it was hard for people to understand that something was wrong and even hard for doctors. Because when you're young, they assume you're just perfectly healthy.

And a lot of times when I would dislocate joints, I actually, from a young age, just kind of learned how to naturally just pop them back in. So I would relocate my joints all the time just because I'm like, "Oh, that hurt. Well, that made that better." You just kind of figure it out.

Crystal Keating:

Kind of intuitive.

Cady Bell:

Yeah, exactly. It's intuitive. And so, a lot of times they didn't know, and lot of times they could check and go, "Oh wow, you're really loose. You're not stiff. Or it's not getting caught." And so, they were looking for something that, "Oh, I feel this grinding or I feel it getting caught." Whereas they're like, "Oh, wow, you're great. You're actually super loose." And when actually nothing was holding and that's what the problem was. And so, it took a specialist who did this whole criteria and checked my mobility, asked me different questions about, "Do you have this issue or this issue? Or have you noticed this problem?" And took a very specific diagnostic test to assign that. Doctors just wouldn't stumble across it without looking for it.

Crystal Keating:



When we think about disability, it's really important we understand that diagnosis goes way beyond the physical challenges experienced. And especially when the disability is largely invisible. I'm so glad you found doctors who could pinpoint it.

Let's talk about the emotional life of what's happening. I'd love if you could share some of the emotional and relational challenges you faced through the ups and downs of EDS.

Cady Bell:

Honestly, of course the pain and the physical part is very difficult and was hard to swallow. But honestly, one of the harder parts of a disability, especially an invisible disability, is that it's very confusing for people. And it can feel very lonely to the person that has the invisible disability. So when it's invisible, people can't see it. They might see me in a wheelchair one day and then they might see me walk to the bathroom next, because I have some use of my legs. And maybe if my joints are holding on that day, I'm able to walk to the bathroom. Or if my stomach's cooperating, I might eat a meal. Whereas, most of my meals come from feeding tube formula. And so, it's very confusing for myself included to go, "Why today am I doing better and then the next day I'm not?"

So for someone looking from the outside, it can be very confusing. It looks like you're fine one day and bad the next, and then you're fine again. And so, people tend to assume, or are afraid to ask questions. They feel like they'll be rude. And so, instead, they just don't ask and just assume things about it. And I've actually had people apologize for not believing my disability or not understanding or taking the time to learn about it and ask those questions, even if it's awkward.

And so, I really appreciated that friend, but it was one of those things that is very hard. But honestly, it did become easier when I started having to use my wheelchair all the time, because it was something people could see. It's something, they went, "Oh, she's not going to be able to do that." When I couldn't lift that, even when I was out of my wheelchair, all of a sudden it was a visible reminder or that there was things that I couldn't do or weren't safe for me to do when other times, maybe the day before, if I wasn't in a wheelchair, they would ask, because they forget and that's natural. People aren't always going to remember.

But the other thing about it that is hard is sometimes because people don't want to ask or they feel awkward, you kind of feel like a polar magnet sometimes. It feels like they don't know what to do with the situation or how to ask. So it feels like they kind of go around you. They kind of avoid you and I don't think it's-

Crystal Keating:

That's painful.

Cady Bell:

Yeah. And it's not purposeful. It's just, they feel awkward when they don't understand. And so, they just kind of avoid it. But as the person with it, that can feel really lonely because you feel like there's something wrong with you or something awkward or it can just be hard to be able to see people being awkward around you. And that can feel really lonely.

Crystal Keating:



Oh, absolutely. That must be awful. I mean, if it was me, I would take it personally and I would feel like, "Wow, just ask me." I'm curious, for the friends who have asked you the hard questions, what did they ask you?

Cady Bell:

I think when friends have asked the hard questions, it's a lot of times in the way they ask them. And I think that goes for a lot of people with disabilities, not even just invisible, is most people do not mind you asking about their disability if it's coming from a place of truly wanting to understand, caring about their heart, wanting to understand them more versus someone kind of random going, "What's wrong with you?" That doesn't feel very good to anyone.

If someone asked me with a heart of caring and understanding, I love to share it with those people. It's funny, I've had so many different questions, but people go, "Can you explain it to me? I don't understand why you were using a wheelchair if your legs can move." Or people will ask, "Oh, why do you have to use feeding tube formula?" Or people will ask, "Are you used to your wheelchair? Does it feel natural now?" Just interesting questions. But some of my favorite, especially are when friends and family ask and it's about my heart, not just my disability. When they care about my heart, and that's why they want to know. You feel really loved when they ask.

Crystal Keating:

Well, and I know you have some wonderfully supportive people in your life. You have a great husband, and a good family, a church, a group of friends that have really come alongside of you on this journey. And you're even part of an online Bible study support group with your bestie, Renee Dollenmayer, who was on our podcast not too long ago. Along the same lines, what are some of the most helpful ways you've experienced encouragement from those around you through this time?

Cady Bell:

I love that question. A lot of people would ask, "If you could just be healed, would you want to be healed?" Or, "If you could just not go through this or could be able-bodied, would you do it?" And honestly, I wouldn't change a thing if it meant that my life would look different, that my relationship with God would look different, that it meant I didn't meet the people I did in my life. Because of the encouragement, because of what God's taught me through them and through this, it's hard to encapsulate kind of the deep encouragement that I've gotten from my husband and friends and family and church members, because it's this unconditional love and support that is so deep. It's not just, "Oh, here's a meal." Or, "You're doing great," which is very encouraging, don't get me wrong. There's nothing wrong with that.

But my husband for instance, I started showing signs when we got married and were together, but I progressed further after we were married. And through each change, he has worked to help me, to support me. He helps me with daily care and honestly, disability has strengthened our marriage to really look at what's important and really look at one another and value those things in one another, the little things in life are much more precious. And he has such a selfless love for me and... Sorry, it can make me a little emotional, but he has-

Crystal Keating:



Love should do that. Great love should do that. Sacrificial love, right? Because we know the source of sacrificial love. And I mean, we are called the bride of Christ as the church. And to be a bride, to be so loved in all of our troubles. So healing.

Cady Bell:

Exactly. It is so healing. And it doesn't mean that every day is easy. Marriage is hard, because you're an imperfect person and you realize you have flaws when you get married. But the selfless love that he shows me is so encouraging.

But also, my family members that before I was married were at every doctor's appointment with me and were there with me when I didn't want to step foot in a hospital again. Or my dad who went out and built a ramp the same day that I needed it because he wanted me to be able to get in and out of their house. And my in-laws-

Crystal Keating:

Go dad. That's awesome.

Cady Bell:

Yeah, I know. All of a sudden he's like, "Oh, by the way, I built you a ramp." It's the way my dad is encouraging. He just does it.

And my in-laws have never doubted my abilities. They're like, "We're going to the lake, you want to come?" I'm like, "Yeah." And friends like Renee Dollenmayer, who you said you had on earlier. She's one of those friends that I wouldn't give up disability because it'd mean I wouldn't have met her. And she is one of those friends that she calls me throughout the week, all the time, to pray, to encourage me in Christ, to lift me up, to rejoice in the wins, to cry together about the losses, about the hard days, to cry together when disability can be really hard and to be able to feel that together. And that's a unique and wonderful friendship.

Crystal Keating:

We are blessed women if we have close, loving relationships through the hardships in our life, especially a good church. Let's talk about that a little bit. Have you encountered any barriers in your church? And if so, what do you wish the church knew about people who live with invisible disabilities? I know you can't speak for everybody, but how can we better love and compassionately come alongside of those who have invisible disabilities?

Cady Bell:

This is coming, like you said, from my own personal experience. But I think there's been a lot of times when a lot of this comes out of love from people at the church and just maybe more of a lack of understanding. But a lot of times people assume that the main thing you want healed is your physical body. When honestly, sometimes for me, I'm like, "My heart really needs prayer. I really need God to meet me in this situation." And I am not even thinking about my physical disability at all. I have more things to me or more things I'm going through than my physical disability.

And I think too, there can be a lack of support sometimes, especially for those with invisible disabilities. Or sometimes the church thinks, "Great. You will be great in disability ministry or



you will do great heading of that, or you'll be great insight for helping with disabled children." When in reality, people with disabilities are meant for all aspects of the church.

Crystal Keating:

Amen.

Cady Bell:

We have things to offer in every office, every place, everywhere in the church. People with disabilities have good insight.

Crystal Keating:

That's really insightful that you would share that. And that is part of being a body. I mean, when we think about church ministry, much of it takes place on Sunday mornings. So it can be hard to find community during the week between services. So we often need a reminder that being the body of Christ means meeting real needs, building community with others. And like you said, removing isolation that people with visible and invisible disabilities so often experience. So if any listeners are looking for how to do this or learn some practical ways to reach out and build community, we have a great Joni and Friends minibook called [Doing Life Together](#), that we'll link in the show notes.

So Cady, for you, how is God using EDS to reveal himself to you and through you to others?

Cady Bell:

God has done some amazing things through EDS. And I have grown so close to God through this time. Even if it's through so much hardship, I've learned just so much through EDS. So to be honest, when it first all happened, and got my diagnosis and I progressively got worse, I honestly was just upset and mad. And I was in the car and just crying out to God, going, "God, why would you waste me? Why would waste my ability to do things for you? Why would you not allow me to do things for you?" And I told him, "I would've gone to villages in Africa. I wanted to be a doctor that went on Mercy Ships abroad and show them you through these great things I could do." And he told me, it was one of those kind of just smack you in the face kind of moments. God goes, "This is your village in Africa. I have called you to disability. And I'm going to use this to show people my strength, even through your weakness." And I went, "Wow, that's amazing. And I don't want to do that."

But thank goodness, God has a much better plan than I do.

Crystal Keating:

Well, I love the reality of that. I know you're not alone in some of those same reactions and the same questions for God.

Cady Bell:

Yes. And through that, I slowly just started to press into God, to cry out to him in the middle of the night, to cry out to him when I was in pain or when I was struggling. And then to try to look outside myself and go, "Okay, God, if this is my Africa, you're going to use me through disability,



then what do you want me to do?" And so I started helping with our youth group where there happened to be two girls in wheelchairs, several other students that had the same diagnoses of certain things like seizures and other heart conditions that were similar to mine. And all of a sudden, I was able to reach them in a way I never would've been able to without disability.

And then I was able to find Renee in her Bible study, that's now becoming a ministry. And through that, been able to reach other women that might feel purposeless or hopeless and be able to just share that joy that God brings through disability and that purpose he brings through disability.

And I've also seen, it's just been an opportunity to share. I didn't realize it would be. A lot of times people will pity you. Go, "Oh, I'm so sorry you have EDS." Or, "I'm so sorry you're disabled." And I'll tell them, "Oh, I appreciate you saying that. But actually, God has done so much through it." I say, "Actually, I have a lot more joy." All of a sudden, I've had all these times to be able to share Christ and something God showed me a long time ago was... I really struggled with people staring at me when I go into the grocery store when I was in my wheelchair and it was just new and it was a little bit hard. So I was like, "Well, they're going to stare. Let's show them Jesus. Well, let's show them what you got God." It's really just changed my perspective on being disabled, that God has used it in so many amazing ways that I would have never been able to even think of. And I just love that he wastes nothing, even disability.

Crystal Keating:

That is right. And Cady, you're willing and you asked God those real questions and you are being used of him right where you're at, right within who you are. You are a lovely soul, my friend.

Cady Bell:

Thank you, Crystal.

Crystal Keating:

Yeah. Well, as we close our time together, Cady, would you like to share some words of encouragement to others who may be facing an unexpected and unwanted and life-changing diagnosis and maybe wondering about God's purpose in their own life?

Cady Bell:

Yes. I think that's one of the hardest things when you first become disabled or first get your diagnosis, is you can feel like you've lost your sense of purpose, that you've lost who you are.

And I would just encourage those people that one, it's okay to be upset. It's okay to grieve. Because I felt like I just needed to be okay with it. God can take your grief. God can take your frustration and sadness and he's not going anywhere. But when you're ready, he's got an amazing plan for you. He's got a purpose for you exactly where you are. It might be a different village in Africa than you thought, but God doesn't mess up anything. God doesn't waste anything. And he's going to use this as part of his plan to show people his glory and how much he loves you.

And I just encourage you to press into him and ask him, "What is my purpose, Lord?" And you might not know all at once, but it is one of the most beautiful seasons, seeing all these things come to be that God has planned for you, that you would've never imagined.



Crystal Keating:

Well, those are some very encouraging words, Cady. Thank you again, for joining us on the podcast today. And may God continue to bless you and use you and shine through you, my friend.

Cady Bell:

Thanks so much Crystal. And thank you everyone who listened and took the time to learn more about invisible disability.

Crystal Keating:

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