



Season 4 | Episode 9

## **Complex Regional Pain Syndrome: Finding God's Gifts Amid Suffering**

### **Darci Steiner**

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Crystal Keating:

I'm Crystal Keating and you're listening to the Joni and Friends Ministry Podcast. Each week we're bringing you encouraging conversations about finding hope through hardship... and sharing practical ways that you can include people with disability in your church and community.

In 2000, Darci Steiner nearly lost her life after a debilitating fall down the stairs left her bedbound for almost four years. Although her life was spared, Darci now faces complex regional pain syndrome or CRPS. She's joining us today to encourage anyone with chronic pain or disability and share a message of hope - that God gives us powerful gifts: perseverance, courage, and direction when we feel we can't go on. Welcome, Darci.

Darci Steiner:

Oh, thank you so much, Crystal. Thank you for having me.

Crystal Keating:

Oh, I am so glad that you're joining us on the podcast today. I'm so glad to have this conversation. We've heard from many who struggle with pain, especially CRPS (complex regional pain syndrome). So, I know that your story and your words of hope through Christ are gonna minister to many. So, Darci, as we begin, would you take us back to that day that changed your life in 2000? What was running through your mind when you had that terrible fall and suffered such a tremendous injury?

Darci Steiner:

Yeah, well, I was a young mom. So, I was running up the stairs to get some music for my little girls and I, they were five and two and a half at the time. And so, I ran up the stairs, which was fine, but then I slipped on one of their drawings that was on the stair, and I went tumbling down, but the baby gate was up at the bottom of the steps and the mind does weird things when you're falling.

I don't know. For some reason I was like, I've got to hurdle that gate. And so, I did. I, I hurdled over it.

Crystal Keating:

Oh, my goodness.



Darci Steiner:

And, uh, I twisted my ankle and I crashed into the wall and then faceplanted onto the ground. So, my little girls, my two-and-a-half-year-old came and plopped down beside me.

And my five-year-old was above me and she was like, Mommy, are you okay? Of course, you don't say you're hurt to your little girls that don't know what's going on. So, I laid there for a while, but it wasn't like I was bedridden immediately. So, I functioned for a little while with driving. Driving hurt. It hurt to get in the car. I actually played a volleyball game and went up for a spike and came back down and I was like, oh, that was kind of the final straw that broke Darci's back, so to speak. And, um that's when I started spending more time in bed. So, what was running through my mind was fear.

I became increasingly more fearful because I was like this is getting worse. This isn't getting better like things are supposed to get better, right, right as time goes on. But it wasn't. And so, I was fearful for my girls because I was like, wow, I need to, we need to get some childcare.

And fearful for my husband because he just had a new job, and he was having to spend more time taking care of the girls. And so, I was afraid of a lot of things. Yeah.

Crystal Keating:

Well, and maybe you're thinking too like I just fell and hurt my ankle. Like, why am I bed-bound? I mean, what is it like to live with complex regional pain syndrome? Is that what you were experiencing at the time? Was your body in shock? What was happening?

Darci Steiner:

You know, it's weird. CRPS develops as a result of an injury, usually to a limb.

Crystal Keating:

Okay.

Darci Steiner:

Um, and it was my back that was injured, but I did twist my ankle when I fell.

So first I wanna say, I really appreciate this question and I think it's an important question to ask people who have chronic pain. What is it like to live with that? I really had to think through it because it's so involved, but the CRPS, I don't know exactly when it crept in.

I just know that I was increasingly more incapacitated. It's a nerve pain disorder that sends nerve signals to your brain. It overfires them. And so, you feel this horrendous, constant pain and the other name for this is it's called the suicide disease. And that's hard to say because I don't wish to take my life, but I have wanted to die.

It gets that bad where you just, you beg God to take you because it's so hard to live with that pain day after day after day, year after year after year, you know? So, what it's like is it's debilitating,



it's disappointing, and it creates dependence. So debilitating pain dictates what I can and can't do every day.

It's my pulse, pain is my pulse. When part of my body atrophies, it results in bone loss. Other parts of my body can't function, you know? So, it's like a domino effect. So, it affected one part of my body. Then that part overcompensates. So, then something else happened. So, it's this overcompensation.

So, I got to the point where I couldn't use either of my feet. So, I used my hands to try to help transfer my body to a chair or some other place. And then, you know, so my hands get disabled and it just it's like this domino effect, different parts of the body get affected and that becomes debilitating.

So that is one thing and probably the feeling that I feel the most is disappointment. And to feel that multiple times a day, day after day, and I feel it every day. It's, it's disappointing because you know, you can't make progress. It's, it's this mysterious disease where you can't just get better. You have to deal with it for the rest of your life. It goes into rare remission, but there is no cure for it. And so, it's not like you can make progress. And I try, I try to walk more steps each day. But some days I can and some days I can't, you know, two months ago I walked the farthest I could ever walk. I could walk to the end of the block.

But I can't do that today. And so, you'd think, well, she walked to the end of the block two months ago. She should be able to walk around the block.

Crystal Keating:

Right. Like you want to keep progressing to more and more ability, not more and then less again. I would imagine that it's confusing too, cuz we wanna figure out what was the key that led me to the progression. And now why am I declining? What happened?

Darci Steiner:

Right, which is why you're disappointed because it makes no sense. Yes. Yes, you can't make sense of it. And so, what I've learned to do is just live with it, day to day, rather than over a period of time. Like, I can't look at it like, okay, I have this goal for the week.

Uh, no, you can't do that, or you get so disappointed. So, my goal is to get through today and not compare it with another day because you can't make sense of it.

Crystal Keating:

That is good advice. You know, when we were talking to Dr. Andy, Laurie, who lives with a disease that simply was bewildering to him, he had to change his definition of success.

What are the little wins that I can celebrate today? And I mean, I think what you said is it's like a fullness of that where you don't even compare your wins with yesterday's wins. They are, they are wins in themselves today that you can praise God for. So Darci after your fall, you not only lived with pain and the inability to walk but as you said, it's called the suicide disease and you



sank into a depression. And we hear from so many people here at the ministry who live with chronic illness, chronic pain, who fight depression on a regular basis. So, I'm wondering if you could share how your relationships were impacted by your disabling condition, and not only that, how did God meet you through the people who loved you through this dark time?

Darci Steiner:

Mm-hmm, another great question. You know, I had relationships that were impacted in a bad way and in a good way. Hmm. So, I was young. I was thirty-five when I fell and my church, I, I'm careful to use this example, but I do believe every church should be educated on what to do when someone becomes unable to serve in at a certain capacity because I was a leader in the church, and I felt like I no longer had a role.

I was no longer important. I lost my best friends who were also leaders in the church who didn't know how to deal with it. You know, what do you do with a leader who becomes incapacitated? And so, my, my encouragement is - find a place, find a place for us. We are in a different place, but what I felt like was I had more to give.

I felt like I had more to give and yet there was no one to give it to because no one was asking me.

Crystal Keating:

Mm-hmm, what do you mean you had more to give?

Darci Steiner:

I felt like God was showing me different things that I had never seen when I was able-bodied. Yes, he was giving me deeper wisdom. He was giving me insights into scripture that I never understood before.

It was exciting. I was like, that's what that means. And I was writing things down, insights in my journal and it was like, it was between me and God. And yet I, I craved, I longed to share these things, but I didn't have people who wanted to listen. And Mark, my husband tried. He wrote a paper about it and gave it to the elders of the church, and they didn't even read it. And you know, that was an isolated incident, but I do think that we have a place in the church, and we need to have multi-ability ministries.

Crystal Keating:

I love that term. That's right.

Darci Steiner:

Yeah, I kind of just coined that but multi-ability ministries. Yes, we need to have every ability, multi-generational I think is healthy. I think it's just; we need to include people like me who can't get out much, but you know, I am willing to mentor people and that's why I'm podcasting. You know, that's why I wrote my book. It's like, I don't wanna keep these secrets to myself anymore.

God showed me some things. He's shown me a lot of things and how dreadful if I just keep it to myself, right, when others can benefit.

Crystal Keating:

That's right. And I can't tell you how many people write to us. I talked about how many people write to us with chronic pain, but how many people write to us with a disabling condition or they're wrestling with an unresolved illness, and they would like a counselor who understands. They want someone who's been there and has seen God and experienced his power and hope and like you said, has received that. I mean, what's the holy spirit, the holy spirit reveals things in the scriptures that maybe we understood before, but now we really grasp it in our own lives.

I, I just think that you have such a voice and such a place for that, for many people who you haven't met yet who desperately need to hear the encouragement that the Lord gave you through your dark times. Isn't there a scripture that talks about the treasures of the Lord are found in some of the darkest of places?

Darci Steiner:

That's a good one.

Crystal Keating:

Well, you mentioned that you had your first accident, and it was devastating, but then you had a process of recovery, and you were re-injured again. You became more able, you're able to walk. You were able to kind of resume life, similarly to what it was before, but then you were re-injured, and you could not walk. What happened?

Darci Steiner:

Yeah. So, this is like a boxing ring and I'm in round two. But I, I completely healed. God miraculously healed me the first time because people don't get better from CRPS.

But what happened was I found this protein drink in a book that I read, and I, I actually earned my master's degree while I was recovering, and I was my case study for my program.

Crystal Keating:

How often does that happen? That's interesting.

Darci Steiner:

I know. So, I was my case study and as I was studying, I was implementing things that I was learning, and it was working like it was working. God used natural foods to help me get better. For nine years I was healed and I was hiking mountains. I had no pain. Wow. No pain at all. And opened my private practice of nutrition counseling. I taught sports nutrition at the local high school. It, it was...

Crystal Keating:

Life was full.



Darci Steiner:

It was full. And then, my daughter got married, which was also great. And we saw her and her husband off at the wedding. And then during cleanup, a chair that was leaned against the wall, it was a heavy wooden chair, it slid down as I walked by, and it hit my ankle, my ankle, the same exact place where the CRPS had settled and was most prominent before.

And I felt like my ankle was broken. It, it was just such severe pain. And I knew, I knew immediately, I'm in a battle again for a long time. You know, a chair hitting your ankle should just be a sprained ankle, right? Yes, and it was for a while. But then again, the CRPS crept back in, and I became increasingly more disabled.

I wasn't bedridden so to speak this time. Um, I was kind of, because my husband brought up a mattress from the basement. So, I was laying in the bed in the living room, but I wasn't alone in the bedroom. Again, I was trying to walk and get better, and I knew you have to try to stay on your feet.

You have to try to keep walking and live with the pain so that CRPS doesn't come back. Hmm. I was trying that, but then my other foot became disabled. And then again, I was using my hands to move my body from place to place and ended up in the ER, and I couldn't use my hands or my feet. I felt like I had spikes pierced through them.

And the ER doctor began crying and she had to leave the room. She couldn't finish my intake report and I saw her in the nurse's station, just crying. Oh, and I couldn't go console her. But they didn't know what to do with me. Oh, and so night after night after night, I begged Mark to take me back to the ER and he's like, honey, they will just send you home.

So, the worst night of my life, the most painful night of my life, I was begging Mark to take me to the ER. He said, no, honey, let's figure out what we can do. And I was like, you know what, you need a night off. I'm gonna just wrestle with this alone, with the Lord.

And so, I laid back in the recliner and I was looking at the picture that I have of Jesus in our bedroom. And Jesus is in the Garden of Gethsemane, and I felt these spikes in my hands and my feet. And I'm like, my God, my God, why have you forsaken me?

And I prayed. And the interesting thing that happened was I would pray. And then I would say Bible verses that came to mind. It was like, God answering me. And they were verses that I had memorized before but didn't know that I remembered.

And I felt like God was meeting me in my darkest night. And he was giving me answers from his word that I was not alone. Amen. And it was the worst night of my life. But it was the best night of my life because I have never experienced the father as close as that night. And he has met me in this darkness over and over and over and over again to the point of where I wonder if I get better, will I be as close to him?



You know, being disabled, having pain makes me so dependent on him that I, I love it. I love it. And that that's an honest answer. It's kind of upside-down.

Crystal Keating:

It's upside down and that's exactly the beauty of living a life completely in step with his spirit, where every moment you're looking to him for your next minute and for the hope that you have and you're experiencing it. What does he say that his power is perfected in our weakness?

Mm-hmm. So, for someone who hasn't experienced pain or the ongoing deep disappointment, maybe that wouldn't resonate, but I can imagine some of our listeners saying yes, I understand what you mean.

Darci Steiner:

Hmm. I would think so. I would think so. You know, and Paul, like the more Paul lost, the more he gained. Think about Paul's life.

He wrote, what 13, 14 books in the New Testament, more books than anyone. And yet he had a thorn in his flesh. God used this man who was suffering, and he wrote four of those books while he was in prison. Right. And so, God has a purpose for our pain. It is not wasted. And I look to Paul because Paul had a thorn. I have a thorn. God is gonna use this pain somehow, however he determines. And all I have to do is just hold on for the ride, cuz I can't direct it.

Crystal Keating:

Right, right. Oh, my goodness. When you really surrender to enjoying God and to knowing him, that is eternal life, right? It's to know God, not just know about him, but to fully understand who he is and experience almost like a unity in his sufferings.

Doesn't the Bible talk about that, that we are united in his sufferings, but we're also united in that grace as well. Mm, well, Darci, can you tell us a little bit about some of the insights you share in your book, *Beauty Beyond the Thorns*? I love that title, discovering gifts in suffering you're touching on it, but maybe especially the ways God deepened your understanding of who he is and how he's empowered you to go on when you felt like giving up when you were hopeless.

Darci Steiner:

Yes. So, the book, *Beauty Beyond the Thorns*, I didn't know I was writing a book at first. I was just writing because writing is cathartic. So, I was just writing, and I was like, you know, maybe I can start a blog. And so, I started a blog. And then I was like, you know, I'm seeing a theme here. I'm seeing all these gifts that God has given me in suffering, gifts like direction, defining my purpose. My purpose hasn't been compromised by my disability. It's been defined by my disability. So that was a gift, then hope and courage and perseverance and gratitude.

You know, when you are hurting, no matter what kind of hurt - it doesn't have to be physical. You can be going through a divorce or something, but you become grateful. So, we have this trail behind our house, and I see people walking on it and it's a trail that I used to walk on. And I think, I wonder if those guys even know to be grateful for their ability to walk.

Crystal Keating:  
Right. The things that we take for granted.

Darci Steiner:  
Yeah. And then I look to the yard and I'm like, God, would you someday allow me to pick up the dog doo? Like, I would be so grateful to pick up the dog doo and how your perspective changes. Yes. You know? You become grateful for the smallest of things and for the yuckiest of things. Um, you're willing to do anything if you could just do it, you know?

And so, it's like the lepers who, who were healed. Ten of them were healed and only one came back. But gratitude needs to be forefront. We need to be grateful even when we're hurting for the things around us that are good. There's so much good.

Pain can make you so selfish, but we have to look outward. And the antidote is to give, to give instead of just lament in our pain. And the thing that helps me the most in my pain, when I forget about my pain is when I'm giving to someone else.

Crystal Keating:  
Yeah. Oh, and it's so good. How can listeners get a copy of your book *Beauty Beyond the Thorns*?

Darci Steiner:  
Well, I just released my audiobook, which was fun. I bet. Yeah. I recorded it in our bedroom closet and, um my husband wrote a chapter on caregiving.

And so, he was able to record his own chapter, which was fun too. But it's available on Amazon. It's on dot coms.

Crystal Keating:  
Okay, good. You know, so the audiobook and the physical book.

Darci Steiner:  
Yeah. And there's an eBook too. Okay. So different, different formats.

Crystal Keating:  
Good. Well, let's talk about your husband because, in your book, you express such a loving respect for Mark. And as you said, you're just so grateful for the ways he tenderly cared for you through the ups and downs of pain and disability. And you really have a heart for others who are in the role of caregivers. What were some of the most helpful ways your husband supported you and what are some words of wisdom you'd like to share both for the caregiver and for those being cared for?

Darci Steiner:  
You know, the way Mark is and what he says, he says, honey, this is our journey. This isn't your journey affecting mine. This is our journey. And God has placed me in this position for a similar





reason he placed you in your position. And so, God has things to teach me as well as you. And he's always considered this, our journey that it's not something that's you know he's angry about.

Yeah, he has his moments. He does, you know. He wouldn't be a human being if he, if he didn't, you know, have to deal with the anger and the impatience and things like that sometimes. But for the most part, he's an exemplary caregiver, and I've encouraged him to do some podcasts. He's been speaking into that role because he has a heart for it as well.

But the caregiver suffers in their way. And it's not an easy role to be a caregiver, but Mark has created some really unique dates. He's been very creative. We went camping in our living room and he, he got awesome. He put the tent up and he, he bought sounds of like crickets and he put, put plants around.

And one of those things called where you got stars that are, are lighting up on the ceiling for a child's bedroom.

Crystal Keating:  
Oh yeah.

Darci Steiner:  
He did that like we were camping and, and he bought a child's bow and arrow thing. And so, we went hunting. It was just so creative, love that. And so loving. It took him like an hour to set it up so we're just like, we went on a camping date, and it was just so thoughtful.

That's the kind of thing that he does so that I can still do things. So yes, we went camping because of Mark. But I think, you know, speaking into caregivers is know that you aren't God. It's a terrible weight to carry the burden that only God can bear. Amen. So, you aren't God and it's okay to ask for help.

And to those who are being cared for, I'd encourage you to read the story of Hagar. Hagar gives God a new name, El Roi, which is the God who sees and your caregiver and people around you are not gonna understand. They can't understand what you're going through. But El Roi does. Amen. He sees.

And when you're alone in your bed at night and you feel lonely, you are not alone. You are with El Roi, and he sees you and he is caring for you. So, know that.

Crystal Keating:  
What a comfort that is. Well Darci I'm so thankful for our time on the podcast. Are there any final words of encouragement or hope that you'd like to share with our listeners today?

Darci Steiner:



You know, I think about the story of Job a lot and it's a long story in the Bible and it's kind of complicated, but really simplified. I heard a, a sermon from Tim Keller and he said, you know, God gave Satan only enough rope as to hang himself. It was a great point. And I'm like, okay. So yeah, God allows Satan some room in this world because it's not heaven, but only enough to hang himself. So, Job ended up proving Satan wrong in the end, right? And so, we need to remember that we don't need to know the why. Job never knew the why. Yeah. And we don't need to know the why.

We just need to understand that God knows the why and that's enough because he is God.

Crystal Keating:

Amen. And he loves us so much. Darci, thanks again for coming on. Her book, *Beauty Beyond the Thorns: Discovering Gifts in Suffering* is available on Amazon and other booksellers online.

What encouragement you gave us today. And for all who are listening, who are struggling with chronic illness and chronic pain, you know, my prayer, and I know Darci's too, is just that God would show himself as you lean into him, and you search the scriptures and pray. And as a community of believers come alongside of you and he would show you who he is through your hardship.

Darci, thanks so much for being on the podcast today.

Darci Steiner:

Oh, thank you, Crystal. Thank you so much.

Crystal Keating:

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