



Season 3 | Episode 13

## **Growing Up with a Neurodegenerative Disease: Friedrich's Ataxia**

### **Stephanie Magness**

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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](http://joniandfriends.org/podcast).

We have a special guest on the podcast today as we're joined by Stephanie Magness, who at the age of 22 was diagnosed with Friedrich's ataxia, or FA, which is a rare, debilitating, neuromuscular disorder. Although Stephanie's transition to life with a degenerative disease has not been easy, she has learned to lean on her supportive community, and has found her strength in trusting the Lord, that he is good and sovereign. Welcome, Stephanie. It is an honor to have you on the show today.

Stephanie Magness:

Thank you so much.

Crystal Keating:

Thank you. I'm so glad to talk to you and I'm really looking forward to our conversation. I wanted to just start with your childhood. I'd love to hear, what was life like growing up? Was disability ever on your radar? Was it something you thought about?

Stephanie Magness:

No, not really. There were signs, but it was not until I was diagnosed that you actually would look back, and say "Oh, okay. That's what that was." But it wasn't ever a thought... I don't think that for most people you go through life and think, "Huh, I think I'm going to end up in a wheelchair."

Crystal Keating:

So when you had symptoms as a young girl, and things that you were exploring, you weren't thinking, "I wonder what life's going to be like at 20 or 30 or 40."

Stephanie Magness:

So before the diagnosis, I was just a really clumsy kid. I mean, that wasn't anything that made me like, "Oh, a disease." I was just clumsy.



Crystal Keating:

Right.

Stephanie Magness:

I was pretty normal. I did dance and I'm sure I wasn't the star ballerina or anything.

Crystal Keating:

But a typical childhood in that you were active and involved.

Stephanie Magness:

Yeah, until about 12 everything seemed to be okay, and then when I was 12 is when I got scoliosis diagnosis, and everything was like dominoes from that.

Crystal Keating:

So it sounds like you went through maybe some years of misdiagnosis after the discovery of scoliosis in seventh grade. How was your life changing at that time, especially as a teenager?

Stephanie Magness:

For every teenager, right?

Crystal Keating:

Yes.

Stephanie Magness:

You go through a really weird time. So obviously a lot of change. I think for me the hardest thing was, I just didn't want to deal with it. I wanted to be like everyone else. Being a kid, and have fun, and go to high school, and be cool.

Crystal Keating:

Right, make friends, do well in school.

Stephanie Magness:

Yeah.

Crystal Keating:

Figure out what you want to do in life.

Stephanie Magness:

Yeah. I think I was doing fine, but I always felt like I had something to hide. Looking back, I always think, I really wish that maybe I had not felt like that. Maybe it would have been a little bit easier for me, so I wasn't worrying about what everyone else was going to think.

But again, I'm sure that being a teenager is like that anyway. Right? You're always worrying about what everyone else is going to think.

Crystal Keating:

That was my experience. Yeah, right. That's something that as teenagers, at least, I wrestled with. Whether it's how we dress, or what we look like, or who likes us, or if we're good at something and...

Stephanie Magness:

Right.

Crystal Keating:

There's a freedom that's found when you can let that go.

Stephanie Magness:

Yeah. So I really wish I had let that go a long time ago, but maybe that helped me be who I am now.

Crystal Keating:

That's true. Especially, I know that you are a strong, faith-filled Christian. How do you live in that freedom of not being worried about what people think at this point in your life?

Stephanie Magness:

Well, that's obviously still a struggle... for everyone. I don't think anyone's totally secure, but I know for me, I think it really helps to know that I am only the vessel and God uses me.

Crystal Keating:

You're a vessel.

Stephanie Magness:

Even though I'm broken, I can still be used.

Crystal Keating:

That's right. Even though you feel broken, God uses the things that are weak to demonstrate his strength.

Stephanie Magness:

Right.

Crystal Keating:

The things that the world would not look upon, but he uses. Joni always says that her broken body is used to demonstrate the power and healing presence of God.

Stephanie Magness:

Thank goodness for that.

Crystal Keating:

Yes. Thank goodness for that. That's hope.

Stephanie Magness:

Yeah.

Crystal Keating:

That's hope. We talked about you as a teenager, and then 10 years later genetic testing confirmed Friedrich's ataxia at 22 years old, which is a progressive disease. And because Friedrich's ataxia is degenerative, you've also had to make some of those transitions even as a young woman. Are you using a wheelchair right now?

Stephanie Magness:

I am. Yeah.

Crystal Keating:

How did you make the transition from walking to needing a walker and a wheelchair?

Stephanie Magness:

Looking back, again, maybe I wish I had done things a little bit differently, but maybe not, because it made me who I am. So it was really hard and I'm very stubborn. When you're in your early twenties, it's like, "A wheelchair, really?" I thought, "Oh my gosh, that will be it. My life will be over, forever." I was really stubborn about it and I stumbled around a lot. I tried to use a walker a couple times only because I was kind of made to, and I didn't really like it. Not only was it embarrassing, but I felt like I was probably at the point where I was past that and I actually needed a wheelchair. It was really obvious...

I think I always tried to downplay it or hide my symptoms... You know, how I walked, and I'm sure I was not hiding it. I'm sure it was very obvious. So, yeah, one of my friends bought me a wheelchair, and I think she probably knew I was not going to make that choice. I needed someone else to do it for me.

Crystal Keating:

So even though you may not have felt ready to go there, your friend anticipated that you might need it. And it sounds like your friends are the ones that helped you to make that transition.

Stephanie Magness:

Yeah, definitely, and that meant so much because that was such a hard choice to make. Obviously it was inevitable. I had to make it, but now it's turned a story that I would not have liked into something better. A gift that I did not want, but I needed.

Crystal Keating:

Yeah. The wheelchair can be described as a prison or the thing that sets you free, that keeps you moving and able to connect. So many life principles could be taken from that very thing. You know, I just think about how important community is in someone anticipating your needs. And



especially having Christian friends who can come alongside and point us to Christ in our hardships. Loving support you had from friends reminds me of how Joni's friends came around her following her accident.

Stephanie, what advice would you give to someone who is making a similar transition?

Stephanie Magness:

Number one, be kind to yourself because it's really difficult, but it's not the worst thing. Because like you said, it's actually freeing, and I did feel that. It's something that you resist for so long and then you accept it and it's like, I should have been okay with this a while ago and it would have been easier.

So I think I would say be kind to yourself and that it's totally okay, and that it will probably enhance your life in ways that you wouldn't think.

Crystal Keating:

That's good advice. Be kind to yourself and to learn to accept the helps and supports that are available for you because it could enhance your life. That's great advice.

Stephanie, you've shared that as Friedrich's ataxia is progressive, communication has also become more challenging. And I just want you to know how much we appreciate your sacrifice to join us on the podcast today.

Stephanie Magness:

Thank you, and hopefully I said something that will resonate with someone.

Crystal Keating:

I'm sure you did. Thank you for sharing your story with us today.

Stephanie Magness:

Thank you.

Crystal Keating:

Thank you for listening today. If you've been inspired, please send me a message or leave a five-star review on your favorite app. That's a great way to help other people find encouragement from these conversations.

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