



Season 3 | Episode 32

How POT Syndrome Radically Altered Claire Walker's Whole Life

Claire Walker

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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.

Today we're joined by Claire Walker, a young woman who lives with a neurological disorder called postural orthostatic tachycardia syndrome, also known as dysautonomia or POTS. Although it is widespread and even growing due to COVID, this syndrome is rarely heard about, including among medical experts. Although life has never been the same since her diagnosis, listen in to how Claire is actually grateful for what God is doing in her life. Welcome, Claire.

Claire Walker:

Hi, hello everyone.

Crystal Keating:

So glad you could join us, you are joining us from upstate New York, right?

Claire Walker:

Yes, ma'am.

Crystal Keating:

I would love if we could start this conversation by sharing about when your health radically changed, you were a high school senior, a varsity basketball player, so that probably meant in great shape and active, and you had a desire to attend a Christian university. What happened that significantly altered your life?

Claire Walker:

When I was a senior in high school, I had gone to a small Christian private school with a class of 12, which turned out to be a blessing. A lot of kids, they prefer the bigger high schools, there's more opportunity, things like that, but we were just truly a family, and we got to study the word of God and go to school. And I did sports, I was in soccer, I did volleyball and basketball. I loved basketball, that was my favorite, I was a starting forward. And it was that year where we were so close as classmates, we were having a fantastic year. And especially in basketball, we were trying



to head toward championship, the big tournaments in March, and it was around that time when all this happened, and it all started, believe it or not with a routine oral surgery.

I had the luck of not getting my braces until around that year, and I had actually extra baby teeth in my mouth. There was five that they had to remove. So had to have oral surgery and it was in March; it was right around the height of our basketball season. And at the time I'd had strep throat, but I had been on antibiotics, but it was near the end, I think I only had a couple pills of the antibiotics left (and parents out there, I'm sure, are aware, it's very hard to get in for oral surgeries), so you usually book them months out. So the doctor thought that everything would be fine, because I was still on the antibiotics, I was at the tail end, no fever, nothing like that. So they went ahead and had the surgery, which I was put unconscious for because they had to remove so many teeth, and the virus ended up entering my bloodstream, and granted we didn't figure this out until much later.

I went home that day after surgery, I was very weak, but we thought it was just typical. I had anesthesia, senior year, very tired, but then that was not the case. That same day I fainted, and then I continued to faint. It was like all of a sudden, I just had this terrible chronic fatigue. I couldn't stand for very long, I had poor blood circulation, I'd get headaches, and I just started fainting. It was almost every day, sometimes twice, and then almost more than that. I would have so many close calls. I would faint standing, sitting, walking, et cetera. Most of the time I didn't even have warning because it would come on so quick, so especially if I stood up fast. And I went from varsity basketball player to daily wheelchair user to preserve what little energy I had, and to prevent episodes.

It was funny, my mom, she was a nurse at the time, but she gave me an ultimatum, she's like, "Okay, it's either a helmet, or a wheelchair. If you don't pick one of the two, we're going to keep you home. You can finish your senior year next year." And I just thank God for the school I was at, the principal and the teachers, because they really came alongside, and I thank God I have a twin brother, and because of him I was able to make it through classes. He would push me around in my a wheelchair.

Crystal Keating:

Was your school accessible?

Claire Walker:

No, no, at the time, because it was a very old building, I would just have to do the stairs, and I would hold onto his arms in case I were to pass out; he could catch me.

Crystal Keating:

Oh, Claire, my goodness.

Claire Walker:

Yeah, yeah.

Crystal Keating:

That's hard on so many levels as a high school senior, with all your dreams in front of you.



Claire Walker:

Oh yeah. And what was really hard too is, when you go through something like that, you quickly learn who your real friends are.

Crystal Keating:

I bet.

Claire Walker:

Especially with it being such a strange thing, a lot of students thought I was faking; I was being dramatic. So my brother-

Crystal Keating:

You had to give up basketball, right?

Claire Walker:

Yeah, and I lost 20 pounds too, in one month. Everyone always described me as very pale. I had what I call raccoon eyes, big dark circles... All kinds of rumors were going around about what's going on with Claire. And it was so hard, we even ended up going to tournaments, and I remember there was one basketball game I had to sit out of, and I stayed back at the hotel while the team went, and I just remember sitting there thinking, and crying, like, "Why is this happening to me? Why? I don't understand."

I had also finished a vocational program doing criminal justice, and I wanted to go into the FBI and be a part of the human trafficking task force, and then all of a sudden everything was coming to a halt, and I just felt benched. I mean, benched literally on the basketball team, but also with my life. Everyone's getting ready to graduate, go to college; I'd gotten a couple of acceptance letters, including Moody Bible Institute for a human trafficking program, and I had to turn it down because I didn't know what we were going to do.

Crystal Keating:

So you're dealing with the loss of your mobility and strength, but also the loss of what you thought was your future, the loss of dreams, the loss of the pursuit, even of can I do this?

Claire Walker:

And at first it was like, oh maybe this was just a weird fluke from my surgery, it'll just go away.

Crystal Keating:

Yeah, when's it going to pass?

Claire Walker:

But then the more days would go by, the more fainting episodes. It'd be like, once again I faint in English class, and everyone's watching me, and I had to be carried to the nurse's office, or put back in the wheelchair. And the worse I felt as the days continued, like I felt like I had short term memory problems. But I just remember being numb, because it's all happening so fast, so I'm in shock, but at the same time I'm in denial because I'm like, well maybe this will pass.



Crystal Keating:

Right.

Claire Walker:

So I would still try to do a lot of the same things, like go to practice, or try to play in a game, and then I would be benched or carried off.

Crystal Keating:

And you don't understand what's happening, and the people around you don't understand what's happening, and at that point, I don't think you had a diagnosis, right?

Claire Walker:

Right.

Crystal Keating:

You were on a journey to find a diagnosis, and you came to a place really of hopelessness, even believing that what you were experiencing was like, is this all in my head? I mean, what was that like, and how did God meet you in that dark place?

Claire Walker:

That was horrific because what really, really increased the hopelessness feeling was all the ER visits I'd go on, they just didn't know what to do with me in the ER. The nursing staff, the doctors, the residents, often I was just treated as, "Oh it's anxiety, oh it's hormones." And I even had staff look at me like, "Oh she's a faker, she's being a dramatic teenager, or she's trying to skip out of school," or I don't know.

Crystal Keating:

Wow.

Claire Walker:

So I saw cardiologist, and he even sat down with me and my mom and totally talked to me about how women are hormonal, many women pass out from their menstrual cycle and, "We'll just make sure you take lots of fluid and will give you salt until your ankles puff up, and then we'll take you off of salt. And maybe you should talk to a counselor," and it was very much, "Here, I'll do a psych referral," or, "Maybe you just need to go get on birth control and you'll be fine."

They even did a test that's actually a big test that they use to diagnose POTS, it's called a tilt table test. They strap you to this hospital bed that moves all the way up to a standing position. They strap you in, so you can't move, And then they hook you up to all kinds of monitors, blood pressure cuff, heart rate, all that, and then they slowly tilt you while monitoring what's happening with your head and your heart. And when I did that test, they actually took my mom out of the room, because we discovered later they were testing to see if she had Munchausen, because they even started looking at her thinking, "Oh maybe she's the problem."



Crystal Keating:

You needed someone to really believe you and hear you that something was going on in your body, something very dramatic, this was not a typical hormonal up and down. This was something serious.

Claire Walker:

Yeah. So they removed her out of the room, and when the bed was halfway up I blacked out. And it was obvious, I don't know how much more obvious it could be because even the nurse who was standing there doing the tilt table was like, "Wow, oh yeah, that's not good." And then her running out of the room to tell the doctor I fainted, and even after that the cardiologist was like, "Well, I don't know what to tell you, go see a counselor, go see this neurologist." So then we went to go see this neurologist, and my poor mom, she was denied, we were denied. The neurologist wouldn't even let me walk through the door when she heard my mom's account of my medical history and what's been going on; she refused to see me. She wouldn't even look at the chart, nothing. As soon as she heard it she just summed it up to, "Oh it's like panic disorder anxiety, I don't need to see her."

Crystal Keating:

Oh my goodness.

Claire Walker:

Yeah, so we were at her wits' end.

Crystal Keating:

It's another closed door.

Claire Walker:

Yep, exactly. And that was around that time, too, where I had to decline college acceptance letters, and I was even struggling to, can I even go to school, even if it's online? Because every morning my mom would sit me up in bed, she'd get me food and water, and then I would get up and get around the house, and then just getting ready for the day I'd have to go back to bed and take a nap.

Crystal Keating:

Yeah, we've heard from so many people that live with kinds of syndromes that are so exhausting, that taking a shower in the day, that's what your day is, you take a shower.

Claire Walker:

Mm-hmm, yeah.

Crystal Keating:

Because it's so exhausting.



Claire Walker:

And very many POTS patients, it wipes them out the rest of the day, or it takes them forever to get to a point where they can actually take a shower.

Crystal Keating:

So how did you finally get a diagnosis?

Claire Walker:

I just thank God for my grandmother. My grandparents at the time lived right next door on a small farm, and my grandmother, she loves the Lord, has gone to church her whole life, and she's a very dedicated believer, and she would faithfully go to her Bible study every Tuesday. And it so happened that during all this she went to Bible study, and there was a visitor there, this other grandmother from another state, and my grandmother shared the prayer request for me, and about what was happening, and this lady chimed in immediately, interrupted my grandmother and said, "Oh my goodness, my granddaughter went through the same thing."

Crystal Keating:

No way.

Claire Walker:

Yeah. And this was just a onetime visitor, out of the blue, they were traveling through the state, and she decided to go to this ladies' Bible study. So she told my grandmother, "Oh, she's doing so much better now, she had the same symptoms, and she went to this pediatric neurologist in Louisville, Kentucky, and he's a specialist in it, and it's called POTS." So my grandmother immediately wrote down all the information, brought it home, and then we started calling, and they immediately got me in. It was amazing. It was the tail end of the senior year, it was April, and I was so devastated because I couldn't go on the senior trip, because I was just too weak, they didn't have somebody to give me the support I needed, and teenagers, they're all going to run around, party, go to the beach. I'd be stuck in the hotel the whole time. I was so angry at that point, I was starting to get angry at God too because I was like, "Here I dedicated my life to you, I want to serve you, and now I'm going through this. Don't you understand I love you?"

Crystal Keating:

Yeah, you feel sidelined.

Claire Walker:

Yeah. So we take this trip and we went to Louisville, Kentucky while all of my friends got to go on the senior trip. So of course I'm not uberly excited about this, but at the same time I am because I'm hoping we find answers. We actually went with my grandparents, which was so supportive, and I went to this huge pediatric hospital, and they had a whole team set up: neurologist, cardiologist, even a nutritionist and dietician, and a psychologist; they covered all of the bases. So I was admitted for a 24 hour, basically an investigative medical study, I guess you can say. And I was put in this room, it had cameras everywhere, because it's 24/7 supervision, I'm constantly hooked up to monitors. And what was funny about this was they had get me to faint. So of course we're there, and I'm like, "Well I've been fainting every day practically, this



shouldn't be hard." But as we're going through this, it's taking a while, and I'm like, oh my goodness.

Crystal Keating:

Of all the days.

Claire Walker:

Yeah, and I'm getting impatient, and I'm like, "Come on, Lord, you can't even help me get diagnosed, what is going on?" So they had me get on a bicycle, an exercise bike, they had me exercise, they tried to get me to hyperventilate. And then what finally did it, after all that, after standing up from my hospital bed.

Crystal Keating:

Oh, something simple like that.

Claire Walker:

Right, yeah, which really shows you about POTS because-

Crystal Keating:

Unpredictable.

Claire Walker:

Yes, and that's part of the reason why so many get misdiagnosed. It's an autoimmune nervous system disorder at its core, and the triggers are viruses, vaccines, and an autoimmune basis. So basically, long story short, what happened with me was the virus entered my bloodstream and wreaked havoc with the nervous system. The parasympathetic and sympathetic nervous system, which is your rest and digest, and your flight and fight, get confused with each other. They malfunction, like how a computer fritzes, they often fight with each other. So for example, if you were chased by a tiger, your heart rate would increase, your blood pressure would elevate to help you run away, your adrenaline would kick in, all of that. In my case that might start to happen, but then the rest and digest jumps in and says, "No wait, I thought this was my job." Or they just get confused, so I pass out, I collapse. I get very fatigued, weak, my heart rate will jump way high, but my blood pressure will crash.

And I'm just so thankful for my neurologist, he is the sweetest man I've ever met, and he serves so many children and he still takes care of me, even though I'm past his age limit for patients. Me and my mom, and other people I've met who have POTS, are really educating our local area.

Crystal Keating:

Yeah. That's important, to be a voice for others who may not have been diagnosed yet. Well, and a new disability, or diagnosis, surely has the capability of threatening your faith in God, like you said, you felt angry, and I don't know about you, but I would start to wonder, who am I, what is my purpose? It threatens our identity, and yet God's word promises that he'll take these incredibly difficult circumstances and do a good work in and through our lives. Only God, right?



Claire Walker:

Yeah.

Crystal Keating:

So Claire, how have you seen that in your life and through your life to others?

Claire Walker:

Whenever I think about this I always think to Romans 8:28, where it says that, "And we know that for those who love God, all things work together for good, for those called according to his purpose." And at the time this was first happening of course I totally did not believe that anymore. I was like, "You know what? I was already focused on serving the Lord with my life, and I'd already realized that I need him in my life, that only in him can I find freedom, and then this happens. Part of me knew, yeah, Christians suffer, but I didn't think that it'd be in a way where I felt like I was not capable of being able to live my life or do anything.

Crystal Keating:

Yeah, it's that idea of subtraction. You think that God's going to continue to build on what you've already started, rather than taking things away.

Claire Walker:

Right, and I had twisted that one verse that talks about, "He'll give us the desires of our heart," which is true, but I kept thinking, "Well he knows I love of him, so he'll let me serve him however I want to," basically. So I began to see, slowly, and not at first, because I got treated with this new neurologist, I was finally put on a good treatment plan that put me in remission. Basically I was able to go to college at Word of Life Bible Institute my first year, with my twin brother and older sister, who was going for her second year.

Crystal Keating:

Oh fun, that's awesome.

Claire Walker:

Yeah, and I actually got to play on the volleyball team, which was incredible.

Crystal Keating:

Wow.

Claire Walker:

I didn't really get to finish very well, because that's after my remission ended, but God used that, and in our yearbook, it talks about our unity, surrounded by the fact that there was a girl on the team that passed out.

Crystal Keating:

Wow.



Claire Walker:

And we got to share the gospel, and during that year I didn't realize, sometimes we forget how people are also observing us in the sense that they're observing how we deal with suffering, and during that year I would get random letters in my mailbox saying, "Hey, I'm a fellow student, I've seen you pass out in the cafeteria," which was tons of times, and they'd be like, "Just seeing how you're handling it has really spoken to me, and I hope you know I'm praying for you." And I'd get letters like that just from anonymous people, and sometimes people who would come up to me and tell that. And during all that time I began to see, okay, God can use this. I mean, as Joni has said herself, "God conquered evil, he conquered death through suffering." And I was learning. It was still a big process; I was still dealing with denial and anger at times.

Crystal Keating:

Well, thanks for being honest just about the struggles, but also about when you are put on display because of a disability. I mean, we've talked to others who, once they got their wheelchair, people would stare. And so what do you do when you're in a wheelchair? Do you start to feel sorry for yourself? Or do you say, "I'm going to use this opportunity for God to shine through me. Lord, help me to do that, because I feel self-conscious." How do you turn those opportunities to start noticing others who might feel similarly?

Yeah, and you know, we have these stories, but we know we're part of a larger story. And the heartbeat of Joni and Friends is really to mobilize the church to welcome and embrace people with disabilities, and we talk about the importance of being a part of the body. We are a body, but we are also a part of Christ, and that our Christian life is incomplete without connection to other believers. How cool that you got to go to Word of Life, and then I know eventually you went to Biola, and we have the ability serve one another and pray for one another. What's it been like to live with POTS and also be part of a church? Have you encountered any barriers along the way?

Claire Walker:

I have one example that immediately pops to mind. When I was first going through all this everyone at church was praying for me, and then another Sunday would go by, then another, "Oh, how's Claire?" "Oh, still the same."

Crystal Keating:

Were they praying for your healing?

Claire Walker:

Yes, for healing, especially after I saw the neurologist, and then I was still passing out after I saw the neurologist, and then there was immediately questions. There was one man in particular who came up and asked my mom, "Well, why hasn't God healed Claire yet?" And that's when I learned the lesson that God operates on his own timeline.

Crystal Keating:

Yes, he does.



Claire Walker:

And suffering, what we go through, isn't necessarily a punishment either. And I even went before the deacons of the church and acted on, I think it's James chapter 5 or 6, where it talks about going before the elders, confessing your sins, asking for healing, and then anoint their head with oil, and I even did that. And that's when God taught me, "Oh, I'm healing you, I'm always healing you, just not according to your definition and according to your timeline. And by the way, I can still use you, and it's going to be a better plan than your plan." And through all of that I realized God was developing a more compassionate version of myself.

Crystal Keating:

And so even the barrier of helping those around you, who are praying for your healing, that God is doing a deeper healing, as Joni calls it, that he's working in your heart even to build compassion and patience, and sensitivity for others, and care.

Claire Walker:

Exactly.

Crystal Keating:

In 1 Corinthians 12, it tells us that every person, regardless of ability or disability, is a valuable and important part of the church, and every person has a spiritual gift. I say this over and over again, if you have the spirit of God, there is a gift or a manifestation of the spirit of Jesus that is given to you, and it's needed by the rest of the church. So Claire, how have you seen God use your gifts as a part of the church while living with your disability?

Claire Walker:

Yeah, that's a great question. For one I feel like God has used it like a bridge back to him and his truth, and he's used it as a reminder. And I mean, that goes both ways, a bridge for me and a reminder for me, but also those who are watching me, because sometimes, because we're fallible human beings, we tend to think that, okay, I'm God's child, I have the tickets of heaven too, oh, it's all about his blessings. We end up living for ourselves in a lot of ways. And I mean yes, God wants to endow us with many blessings too, but we're also here for a reason, there's a purpose. We are image bearers of God, we're, as Jesus says, salt of the earth, and salt is used to preserve goodness, to preserve things, and sometimes we can get carried away, but God uses suffering, he doesn't cause the suffering, but he uses it for his glory, and to also keep us humble.

I think I'd be a much different person if it weren't for POTS. I think if I did have my way, I'd probably be a callous, snotty-nosed FBI agent, if I even made it that far. So I just feel like God has used it in such a more powerful way, maybe subtle and weak in the world eyes, but there's so much behind the scenes I haven't gotten to see yet, but I know God's working.

Crystal Keating:

Yeah, and that takes faith that he is continuing to shape you. Well, and it reminds me of a minibook we offer at Joni and Friends called Go Make Disciples. We're always learning how to be like Christ, and we also are told to help others know how to follow Christ, and I know that's your heart, Claire. And so Go Make Disciples is part of our church training resources to lay a framework for starting a special needs ministry, or for personal learning when it comes to welcoming and embracing people with disabilities.



Just as your church has learned about your deeper healing and how God is shaping you to not be a snotty-nosed FBI agent, but to be compassionate, our Go Make Disciples mini-book focuses on mentoring and building mentoring relationships that invite people with disabilities to find their place of service and leadership in the body of Christ, and I think that's really important for us to remember that God is using you, Claire, even and because of your disability, to help other people be like Christ, as he's making you more like Christ. So for you, how do you think it's impacted your church to see you have an important role to play while also living with a significant disability?

Claire Walker:

I mean, I can't speak for them, but I hope the church sees how it's a gift and a tool, rather than an obstacle. We all think and operate under this medical model of, "Oh, if it's broke, it needs fixing. If it's sick, it needs healing." We want to remove all the imperfections; we want to get rid of the bad. But God uses suffering to point us back to his goodness, to his truth, just as Jesus had used suffering to conquer death and to point us back to him, and he couldn't have done it without suffering, taking on our fallen nature.

Crystal Keating:

Sometimes the visible physical disabilities can help us to really see our need for God, especially on the inside, the broken pieces and parts of our life, where we need God's healing, where we need God's redemption, forgiveness, transformation. Claire, as we close our time together, I would just love to open this up for you to share some words of encouragement to others who may be facing the shock of a new health challenge, or encountering physical hardships that don't yet have a diagnosis.

Claire Walker:

A big one for me, it's a verse I constantly go back to, because I do still have moments where I really struggle, it's 2 Corinthians 12:9, "But he said to me, my grace is sufficient for you, for my powers made perfect in weakness. Therefore, I will boast all the more gladly of my weaknesses so that the power of Christ may rest upon me." That's a big one for me, and God has done that in my life by helping me go back to school. I got my associate's at a community college, I had to live back home, and my parents took care of me so much, I still had to use a wheelchair, and God helped me graduate with my associate's.

I slowly got better over time. I don't pass out every day and I don't have to use a wheelchair anymore. I still have lots of close calls, and I still pass out, sometimes three to four times a month when it's really bad, and every day is still a struggle to get up in the morning, but God, he helped me through all of it. And then I ended up going to Southern California to Biola University and graduating with my bachelor's in criminology.

Crystal Keating:

Congratulations.

Claire Walker:

Thank you, it was totally the Lord. Those were the two best years of my life, so better days are ahead. Now I'm back home, I live with my grandparents, and I work full time for a nonprofit called AIM Independent Living Center, and we serve the disability community.



Crystal Keating:

Wow.

Claire Walker:

And God is bringing me more people in my area, including a very close friend, a best friend of mine, who has POTS now, and it's amazing how all of a sudden, especially this opportunity to talk with you all, God's like, "I have made you a voice, and the very heart you had for people when you wanted to go in the FBI, you still have that, you can still help people," and right now I work as an employment specialist helping people with disabilities be able to work, which was something I thought I would never get to work.

And so I just want to encourage everyone that yes, this seems dark and hopeless and horrible, and it feels that way, it is horrible, but this life is temporary, and are you going to choose to respond in a way like it's forever? Or are you going to recognize that we live for God, we only find happiness satisfaction and purpose in God, not in what we do, what we can and can't do, et cetera. Don't give up, pursue that master's or that whatever, that's what I'm doing now, master's in social work and theology.

Crystal Keating:

That sounds awesome.

Claire Walker:

And don't give up.

Crystal Keating:

What a blessing you must be to all who come through the door of that independent service that you are doing. You have a real story and a real opportunity to share the gospel and share the love of Christ.

Claire Walker:

Thank you, thank you so much.

Crystal Keating:

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