



Season 2 | Episode 28

Thriving with Spinal Muscular Atrophy During COVID-19

Tracey Motoda

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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 welcome and include people impacted by disability in your community.

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August is Spinal Muscular Atrophy Awareness Month, and I'm thrilled to be joined today by my friend and coworker, Tracey Motoda. Tracey Motoda is joining us on the podcast to help us celebrate Spinal Muscular Atrophy Awareness Month, and I'm so happy to have my friend and coworker on the show with us today as she talks about thriving with SMA through COVID-19. Welcome to the podcast, Tracey.

Tracey Motoda:

Hi, Crystal. Thank you for having me again.

Crystal Keating:

Of course, I'm so happy to be talking with you. As we start this conversation, can you briefly describe SMA, spinal muscular atrophy, and the impact this has had on your everyday life?

Tracey Motoda:

Sure. Spinal muscular atrophy is a motor neuron disease, and it causes your muscles to atrophy over time. It cuts off the communication from your brain to your motor neurons, which control your muscles, so they don't quite get the message. Over time, they atrophy, and you lose the ability to use them.

For me, that looks like, I walked until I was five and then I started using a power chair as soon as I hit kindergarten. I have been in a power chair now for about 36 years. And so, it has greatly affected my mobility, but hasn't really held me back in other ways. That's for sure. I do definitely require a lot of assistance.



The only thing I can really move are my hands and I do have good net controls. I can be expressive with my facial expressions and whatnot, but otherwise, I'm pretty dependent on others for care. But it hasn't affected me throughout life. I was able to go to college and get a degree, start a career, get married, just really have a lot of fun throughout life.

Crystal Keating:

You really have. If anybody has seen a picture of Tracey, you know that the one thing that stands out is her big smile. You are well loved, and you are full of joy, my friend.

Tracey Motoda:

Well, thank you.

Crystal Keating:

But I just have to say, I'm trying to picture you as a kindergartner in a power chair. That would have been fun to see.

Tracey Motoda:

I think probably many people thinking of putting a five-year-old in a power chair, that sounds a little scary. I was a mature five-year-old if that helps, but I do know that the first time I got my power chair, my parents took me to a parking lot. Put me in it, and said, "Try it out," and I had that freedom. I ran away. I had never been able to run before. And so, shortly thereafter, my parents learned where the speed control was on my chair and slowed me down. But now as an adult, nobody's slowing me down. I keep it on full speed all the time.

Crystal Keating:

That's not just your wheelchair, you are a high-pace, detail-oriented person. And I love working with you. Well, many of us know and love your husband, Mike. Affectionately known as Mikey. I want to talk a little bit more about him. How long have you two been married? Tell us about your relationship with him.

Tracey Motoda:

Yeah. We have been married now for a little over 12 years. He is amazing. We met 18 years ago now and we had a long-distance relationship for several years. Then we got married, and it's been an amazing ride. We have certainly had our challenges. We have lived in three states in those 12 years, and had a lot of changes that we've faced together. Yet, we've grown closer and closer together with each one.

He is this super kind and compassionate man, where I tend to be an overly emotional person. I'm an extrovert. He is my level-headed introvert, and we compliment one another very well in that respect. He likes to say I do all of the organizing and he is the doer. That looks like with groceries, I plan out the menu, I write the grocery list and he does all the cooking. I help him by you're going through the recipe, letting him know what's next.



He is my hands in so many ways and not just with cooking, but he takes care of all of my personal care needs as well. From the time I wake up in the morning, he is helping me get ready, helping me get dressed and put together for my day. He turns me over at night to ensure I'm comfortable. He takes care of all of my physical needs throughout the day and night.

Crystal Keating:

Well, you guys have a really sweet marriage. You enjoy each other and you really have a spiritual bond that God has strengthened. We love and appreciate Mikey. Well, how has life changed for you two during this extended season of sheltering in place? You guys have been doing this for over five months, right?

Tracey Motoda:

Yeah, since March. It certainly does look different. Life is very, very different than it was a year ago today. Mike, he has a full-time job. I work full-time at the ministry. We had a great routine, and we had a very rich social life outside of work as well. We have a lot of friends. We have a wonderful church. We were involved in a small group and Bible study, so we were on the go quite frequently.

We would come home for dinner, and then oftentimes, we would go out again. Or where we would have friends over. And so, life has definitely changed. We have been pretty isolated in our home since March. Just the every other week grocery shopping trip, the occasional car ride, perhaps the nice socially-distanced outside greeting with a friend or neighbor. But otherwise, for the last five months, it's been Mikey and I doing life together pretty isolated.

Crystal Keating:

Yeah. That isolation I know has been especially hard on you because you are such a social person. You have so many friends, you love to be involved and it's been a challenge for Mike as well because to help protect you, he's chosen not to see his friends and family. Have you two talked about how that affects him.

Tracey Motoda:

Yeah. It's funny, I think I mentioned before that I'm the extrovert to his introvert. In many ways, he does certainly miss his friends and family. Yet, he actually is content with being home and being just us. He has felt safe and comfortable and confident in the choices we've made to maintain safety.

Crystal Keating:

Yeah. Well, that's good. I'm glad to know that he is happy to be with you and you guys have found creative ways to continue to stay in touch with people. I think maybe we need to really talk about the reasons why you have chosen to really shelter in place and be staying safe at home. You've stayed in touch with a few of your key doctors. What's been their advice for you during this coronavirus epidemic, especially since evidence has shown that people with underlying health conditions may be at greater risk of serious illness from COVID-19? This has really affected your decision to stay sheltering in place for these last five months.



Tracey Motoda:

Absolutely. Yeah. For someone with spinal muscular atrophy and so many other disabilities that affect the breathing muscles, all right, or your lungs, the need to shelter in place and avoid the virus at all costs is higher. I spoke to my pulmonologist when we first began this, I guess in April. He [crosstalk 00:00:08:37]-

Crystal Keating:

The pulmonologist is the doctor that really focuses on your lungs and breathing, right?

Tracey Motoda:

Yeah.

Crystal Keating:

Okay.

Tracey Motoda:

Yeah. He focuses on my lungs. His recommendation was, I absolutely need to be working from home, staying at home, wearing a mask at all times if I must go outside of my home and maintaining distance. I asked him, because at that point we had been doing this for about a month and I was itching to go to the store. I wanted to just go grocery shopping. It was such a normal routine for us. To be honest, Mikey wanted me to go grocery shopping with him as well, because I'm the one that knows where everything is in the store.

And so, we asked him, "Can I just go to the grocery store, wearing a mask and all of that, making sure I wash my hands?" He hemmed in hard a little bit, and he said, "I really would rather you not." He said, "It's not so much about I don't ..." I trust that you will wear your mask and do everything right. He's like, "I just don't trust that everyone else is doing the same." So, his suggestion was that I continue to just stay at home, shelter in place and really limit my contact with people who don't live with us.

Crystal Keating:

Yeah, and you've been very diligent about that. Maybe you can talk more about how SMA affects your breathing and your lung capacity. For coronavirus, a virus that typically affects the lungs, what would that look like for you? I mean, I remember two years ago when you got the flu, it was awful for you. You had to use a cough assist machine just to help you breathe.

Tracey Motoda:

Right. Yeah. It's definitely a bigger risk for someone with a complication like spinal muscular atrophy. It's not that my lungs are unhealthy, I have healthy, normal lungs. It's that I have a very weak diaphragm muscle. You use your diaphragm to cough, and when you get sick, even a common cold can really knock me down and be very dangerous. Because, if you aren't able to cough out anything that ends up in your lungs, it can then turn into pneumonia.

And so, the risk is high. That is why I have, yeah, like you mentioned, the cough assist machine. I typically use that anytime I get a cold or yes, when I had the flu two years ago. What the cough assist machine does is it forces pressure into your lungs, and then it quickly reverses and sucks that pressure back out, helping you cough.



And so, it's a very uncomfortable machine to use and I am not really great at it. It takes some practice for sure. On top of that, every night, I sleep with a breathing machine. It's called a non-invasive ventilator. That way it helps my diaphragm muscle rest, and I can truly get the good sleep I need. So, there's a lot of complications surrounding my lung function. My lungs work at about 50% of what they would be expected to work at as my age. That's simply because I cannot take a deep breath in and forcibly blow out.

Crystal Keating:

Well, the diaphragm muscle is one muscle that I have definitely taken for granted. Well, and on that note where the doctor trusts that you and Mike would take careful measures to protect yourself, what's been your response to people who do not seem to take the potential harm from COVID-19 as seriously as you do?

Tracey Motoda:

Yeah. It's hard. It feels like it's keeping me from participating in society. We've been called to sacrifice for our neighbor, to love our neighbor as ourselves. And because my doctor and many, many other experts have said, "Masks work. Please wear your masks," for me, someone wearing a mask, even though it's uncomfortable, shows me that they care about me. I do know that, for me, it's very obvious I live with a disability. You see my wheelchair. You can wonder what else is going on, but you at least know I live with a disability. I know that there's others who have invisible disabilities. They may have been an organ transplant patient. Or they may be battling cancer. We can't walk by them in the store and assume they're healthy and, "Well, we don't need to wear a mask around them." So, it's been hard for me, for sure.

Crystal Keating:

You're a woman who presses into the Lord. There's been a lot of times where you are just saying, "Lord, give me hope, give me joy and let us make the best of this time." I've heard from a few families that this time of sheltering in place has actually been a blessing for them. They've been able to spend more time together, maybe how Mikey feels.

Tracey Motoda:

Yeah.

Crystal Keating:

It's been a time to refocus priorities and values, to plan ahead on how individuals and families want to spend time together in the future. So even through the downside of isolation, have there been any eureka moments for you and Mike? Any unexpected blessings or realizations?

Tracey Motoda:

Well, certainly have appreciated and enjoyed the time that this has given us. It's even just the amount we'd eat lunch together every day. It's expanded that joy in being present for one another. Not just present, Mike is here with me, helping me with things I need throughout the day, but just that comfort level of having your beloved spouse with you next to you, working throughout the day. That's a big blessing. Something that people may take for granted is your ability to just even use the restroom throughout the day at work.



Now I can drink tea in the morning and not worry about it, because I can have a restroom break throughout the day. Another blessing I've noticed is, I have back pain and hip pain from scoliosis and surgeries I've had. And so, if I'm having a painful day, I take advantage of my lunch hour and I lay down and I stretch and relax and rest. That is really given me so much more energy throughout the week, if I've been able to just have that downtime in the middle of the day that I couldn't have had in the office.

Crystal Keating:

Well, how has this time impacted you spiritually?

Tracey Motoda:

I think one of the things that I have noticed is, it's just has expanded our prayer life. I could speak for Mikey and I with this one. I feel like constantly, we're going to the Lord in prayer. Like you mentioned, praying for hope, praying for joy. It has caused me to be so thankful and express gratitude so much more openly with the Lord over things that certainly we took for granted. We laugh and we say, "If we would have only known that was the last time doing A, B or C, how much more grateful would we have been?" And so, I feel like this time has given us time to focus on prayer, focus on our relationship with God, draw closer to him, because it really truly is him and us. It's the three of us and we're doing this life right now.

Crystal Keating:

Amen. Well, Tracey, you and I work together on the response department and we get over 1,000 contacts a month. Many of us who write to our ministries, especially in the last few months, have expressed what great fear and anxiety during this time of uncertainty. So many unknowns. Also, those with certain types of health challenges, like we've talked about, and disabilities, are especially vulnerable to the virus and its affects. Have you wrestled with any harder emotions through this time?

Tracey Motoda:

One of the things that I feel like I have wrestled with is just that distance from loved ones. I feel like I've always been a homesick kind of person. I'm not from California originally, I'm from Oregon. My family, all live in Oregon and Washington. And so, we're some distance away and it has, I would say it's exacerbated the distance. It makes it feel like we're even further away, because you just don't know when you're going to see them the next time.

There's that uncertainty, and so I have dealt with some sadness over that. My great nephew started walking and I haven't seen him before he was crawling. And so, those milestones that we're missing out on, I feel a deep sadness over that time lost.

Fear and anxiety, I certainly understand that. We want to be able to make the right decisions and be wise. God did not give us a spirit of fear, but of power, love and self-discipline. And so, I feel like going to that and remembering the choices that we're making, that we feel are wise, there are God-given and directed, I am trusting and turning away from the fear, but I have had a lot of sadness.

Crystal Keating:

Yeah. Well, you're very close with your family. Your parents were your main carers until you married Mikey, and they're going through their own challenges and you're away from them. I know that's been hard and I know a lot of families can also relate-

Tracey Motoda:
absolutely.

Crystal Keating:

... with not being able to visit loved ones in nursing homes or those who-

Tracey Motoda:
sure.

Crystal Keating:

... are in the hospital. It is so hard. I just love your posture to spend this time with Mike praying together for your own marriage, for your loved ones, for those that you can't stay in touch with the way that you would like.

Tracey Motoda:
Sure.

Crystal Keating:

When you talk about fear, how do you manage some of that fear or stress during the pandemic, both practically and spiritually?

Tracey Motoda:

Yeah. I mean, I think that's probably really what has driven us to a stronger prayer life, is that uncertainty, the anxieties that can come up with something that is really unprecedented. None of us know how to live within a pandemic like this. Mikey was just talking about this last night, that we have the hope of heaven. We have the hope of something bigger, something so much grander, so we don't grieve. We don't sit in fear. We don't linger there. We refocus our thoughts and our hearts on God and what he has promised us.

Crystal Keating:
That's good.

Tracey Motoda:

Practically, we each have our own individual hobbies. Mikey is a video gamer and I love to crochet.



Crystal Keating:

One of the things that I appreciate that you've done practically is also taking a break from watching the news, taking a break from social media. Because there's a lot of information out there. Information can be good, but it can also increase our fear and anxiety.

Tracey Motoda:

Yeah. At the beginning, I remember I was watching a lot of news. I was following the numbers really closely. I was learning as much as I could learn. Then, as the time went on, I realized, that's not going to change my current circumstances. The maintaining of the numbers or even the flowing of the numbers, my doctor's still not going to be comfortable with me going back out and going back to the office and doing life as we knew it. Not anytime soon. And so, I decided it wasn't really helping me. It was discouraging me, in fact. And so, I did decide to turn off the news. I stopped watching it.

I stayed informed just on a very few, limited number of sites so that I wasn't ... I knew what was going on, but I wasn't hearing lots of different sides. I was just trying to focus on the facts. Social media, I took a small break from social media. That was a hard decision as well because, as I mentioned, one of the deepest sadnesses I felt during this time is missing my family and my friends. And so, it was a balancing act of maintaining that contact and yet, not being flooded with negativity or distractions.

Crystal Keating:

A wise woman you are. Speaking of social media, you're pretty well connected with others who have SMA through Facebook groups and other messaging boards. What are you hearing and reading from others who are having to adjust during this time of uncertainty, especially those with SMA?

Tracey Motoda:

Yeah. SMA is a very rare disease, so it's a small, tight-knit community of people. It's been really helpful to stay in contact with them and just learn how they're navigating this new normal, as it were. A lot of people who rely on caregiving staff have been really struggling. Number one, it's hard to find caregivers right now, people that can come into your home. Number two, when we think about people coming into our home, that raises our level of risk of exposure.

And so, there's a lot of things at play for people who do rely on those caregivers. And so, that's been a big challenge in the community throughout these last few months. One of my friends, she ended up in the hospital in April, not COVID-related, and she was not allowed to bring her fiancé. He had to drop her off at the door, and she is only able to move a few fingers on one hand. So, she's pretty much a quadriplegic. She's ventilator-dependent, and she was put in a hospital room by herself for a few days and had to call a nurse when her phone rang.

One of the things she mentioned was, she just wanted to be able to answer the phone when her doctor called. She couldn't even do that. The nurse had to come in to feed her, to help her use the restroom. All of these tasks that were used to being cared for by someone else. The nurses were already stretched, and they had to put on new PPE every time they came into her room.



Crystal Keating:

And they don't know her. They don't know her routine. Maybe they're not especially familiar with SMA.

Tracey Motoda:

Absolutely. It really causes a lack of care, a lapse in care. That can be detrimental on our health. Every attempt to petition on her behalf, whether it came from her or someone else, for the hospital to make an exception, it was denied. They stuck to the no-visitor policy, but really that's not a visitor. That was one-on-one care. I think her story is exemplary of many people living with disabilities, very disabilities that-

Crystal Keating:

Sadly.

Tracey Motoda:

Yeah, that were experiencing illness during this time and isolated without their normal care routines in a hospital. My heart goes out to both those people and the nurses, because, like you said, it's a whole new routine when the nurses are already stretched to the limits. That scenario was very hard for me to follow. That was probably the one time throughout these last few months where I really did feel fearful, because I was putting myself in her position. What would happen if I got sick and I was in the hospital and when I'm laying down, I can't move anything but my hands? Those thoughts went through my head a lot and I had to just bring those to the Lord and wrestle with them and ask him to give me peace.

Crystal Keating:

Amen. Well, your friend actually became well. She left the hospital.

Tracey Motoda:

Yes.

Crystal Keating:

There's a good ending to this story, thankfully.

Tracey Motoda:

She is a wonderful advocate. She actually even spoke at the legislature and told her story, advocated for a change in the rulings and was successful. Every legislator that voted that day voted in favor of a change. I love that she took such a devastating experience that was quite traumatic and turned it around to help others who may face it in the future.



Crystal Keating:

What a powerful story. For us who are listening, we really need to remember people with disabilities, specifically SMA, who are facing some difficult health challenges that are unrelated to COVID-19. Who are having to go to the hospital or who are without the kind of caregiving that they're used to, and that they need. We need to pray for God's strength and grace and peace for all. This is a challenging time, but God is still on the throne. We can take comfort in that, and we really need to pull together as a Christian community to step in when needed, when appropriate and to take those risks to get out of our comfort zone.

Speaking of the Christian community, Tracey, your church has been a huge part of you and Mikey's life. You guys entered this church, you were received with open arms very quickly, you got involved, and so many of our churches have transitioned to online services. As we close our time together, how have you stayed connected with other believers from your own church during this time?

Tracey Motoda:

I was actually so excited to see how our church adapted so quickly. We're a small church and we didn't even record our sermons before. There was no videos of our sermons. Yet, within the week of the shutdown happening, we were online having our services.

Our pastor did a great job. He said it was so hard to preach to an empty sanctuary. It was not the same looking at a camera lens, but he truly brought us messages of hope throughout this entire time. He refocused us on trusting the Lord and seeking his wisdom.

We did a whole sermon series in James, and that was really, really encouraging and convicting. They also pivoted and put our Bible studies online through Zoom. That was wonderful. We could continue with our Thursday night Bible studies and see the same people chat with the same people that we were used to spending our evenings with. Our small group, continued to meet.

We used to gather one Sunday every month for dinner. Now instead, we're gathering over Zoom and keeping each other updated on our lives and how we can be praying for one another. We miss seeing those people. We miss greeting everyone and handshakes and hugs all around. Yet, we certainly don't feel isolated from them. That is a blessing.

It's wonderful to see a church community adapt and really take into consideration the safety and wellbeing and spiritual needs of everyone involved. My birthday happened to be in the middle of all of this. One day I was sitting at my desk, and I saw our pastor and our associate pastor pull up out front. They came to sing me happy birthday from the sidewalk. I just-

Crystal Keating:

I love that.

Tracey Motoda:

It made me feel such a part of a community. That's the blessing of the body of Christ, is that, I know with my whole heart that should we need them and we called upon them, they would be here. That has gotten us through a lot of this challenging time.

Crystal Keating:

That is such a blessing. Your church truly is the expression of Jesus Christ. Tracey, it's so good to talk to you on the phone. I can't wait to see you in person. I've got a running list of things we're going to do. The first thing is, I'm going to hug you. I can't wait.

Tracey Motoda:

Yes. Absolutely. Then we're going to go out to eat.

Crystal Keating:

Yes.

Tracey Motoda:

Because I cannot wait to eat in a restaurant again.

Crystal Keating:

Such a blessing to have you on the podcast today, Tracey. Thank you.

Tracey Motoda:

Thank you so much, so much.

Crystal Keating:

Thank you for listening today. If you've been inspired by our conversation or have a comment about something you heard, please drop me a message at podcast@joniandfriends.org. I would love to hear from you. You can also find all the resources that we've mentioned at joniandfriends.org/podcast.

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