CAN DO MULTIPLE SCLEROSIS | PODCAST

Navigating a New MS Diagnosis

Episode 169 – Podcast Transcript

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[(0:23)] Stephanie Buxhoeveden: Welcome to the Can Do MS podcast. I'm your host Stephanie Buxhoeveden. I live with Ms and I'm also a clinician and MS researcher. This is episode number 169, and today we're excited to welcome our guest, Megan Hall. Megan is here to talk about being newly diagnosed and to share her perspectives on living with MS as a new parent and business owner. So welcome, Megan.

[(0:45)] Megan Hall: Hi. Thank you.

[(0:47)] Stephanie: You're welcome. Now, I think it's important to start by prefacing this conversation with the fact that you and I are friends.

[(0:55)] Megan: Yeah.

[(0:54)] Stephanie: And we met...

[(0:56)] Megan: We are.

[(0:56)] Stephanie: Yeah. We met a couple of years ago. And I distinctly remember, you are my hairdresser, and I sat down in your- in your chair one day.

[(1:05)] Megan: [laugh]

[(1:06)] Stephanie: And you asked me what I did for a living, and I said, I'm a nurse practitioner and a researcher in neurology, and I focus on MS. And that's what you [inaudible].

[(1:16)] Megan: Yeah. I said, holy cow and cried on the inside because I had just been diagnosed with MS like two weeks before that and I was so scared and terrified and I just felt like the universe brought you to me. [laugh]

[(1:34)] Stephanie: [laugh]. Because you had never met anybody with Ms

[(1:36)] Megan: No, I knew absolutely no one that had MS. All I had was Google to guide me and...

[(1:44)] Stephanie: Which is your worst enemy.

[(1:46)] Megan: Don't ever Google anything [laugh].

[(1:50)] Stephanie: Yeah. That's the first piece of advice is don't Google.

[(1:52)] Megan: Yes. Don't Google anything ever at all. [laugh].

[(1:57)] Stephanie: Yeah. And on top of this new diagnosis and being young, you are also a business owner, right? You own a salon, you run it yourself, and a single mom, correct?

[(2:10)] Megan: Yeah. And my- my kiddo at that time was barely one. He was still little. So I still am- am- am in like the throes of new motherhood and everything is scary when you're a first-time mom and they're little and you don't know what you're doing. And then to have that happen to get diagnosed, it was just terrifying.

[(2:39)] Stephanie: Yeah. It's kind of everything all at once, but also a very common story.

[(2:42)] Megan: Yeah.

[(2:43)] Megan: Coz I can't even begin to count the number of moms that I've had come in with their infants in their arms and I'm handing them that diagnosis. So definitely something I'm sure a lot of our audience can relate to.

[(2:56)] Megan: Yes.

[(2:57)] Stephanie: And so with you being a small business owner without access to private health insurance, right? Having to rely on Medicare, Medicaid, um, how was the journey of finding a doctor and starting medication?

[(3:13)] Megan: Um, it was a long one. And if you don't like making phone calls like me, it'll be even longer. [laugh].

[(3:21)] Stephanie: Yeah. [laugh].

[(3:22)] Megan: Um, yeah. So the doctor that diagnosed me, I don't even really know how I ended up seeing her, but she literally told me I had MS, gave me kind of a rundown of what that meant, and then handed me this stack of pamphlets and told me to look at them and pick a medicine [laugh]. And I was like, um, you know, I just don't feel like I'm qualified to make that choice. [laugh] And all of these pamphlets have nothing in them, but terrible, scary things. Like, this one will make your hair fall out, this one will make your liver fail. [laugh].

[(4:03)] Stephanie: Yeah.

[(4:03)] Megan: So I really wanted to find a new doctor, obviously, that could kind of help make a decision with me. Not for me, but with me on starting treatment. And I also was like kind of hesitant to start treatment at first because even though some things were happening that obviously sent me to this neurologist in the first place, I didn't ever feel sick or bad. I like had no... I had nothing going on that was stopping me from living my day-to-day life. So I was kind of like, well, why would I take these terrifying medicines when I feel fine? But then I met you and you kind of helped me find a doctor. So I'm very grateful for that. But, um, I did finally find one who I didn't love, but he was good enough for the moment [laugh].

[(5:03)] Stephanie: Yeah.

[(5:04)] Megan: Um, and helping me decide what to start with. And I tried a couple of different things. The first one were the injections, ended up being allergic to those, had to switch. And then the next one, I just could never remember to take the second dose. So obviously if you're not taking it correctly, it's not working. Um, but yeah. Then we landed on the third one and that's been great so far.

[(5:32)] Stephanie: Yay. And I mean, you touched on a lot of things in that...

[(5:37)] Megan: Yeah, sorry.

[(5:38)] Stephanie: ... [inaudile], which is... No, that's perfect. Um, because that is so true and I was a little bit on the other end of the spectrum where I was having trouble walking and seeing. And so from the start, I was terrified of MS and I was ready to hit it hard and hit it fast. But that's not the case for a lot of people. Right?

[(5:58)] Megan: Right.

[(5:58)] Stephanie: Sometimes it's a little bit of tingling, a little bit of blurred vision, but nothing like you said, that's scary enough to be so willing to just jump onto these medications and all of the scary side effects.

[(6:10)] Megan: Right.

[(6:12)] Stephanie: So that is a very relatable feeling of, I don't feel that bad. Do I really need these medications? And then through discussion and learning about, you know, MS being unfortunately uncurable at this point and realizing that medication is the best chance you have at slowing disease progression.

[(6:33)] Megan: Yeah.

[(6:34)] Stephanie: Um, that is something that a lot of- you know, everyone who's diagnosed has to go through. And then I remember saying to you, you're not marrying this first medication, right?

[(6:45)] Megan: Yes. Yeah.

[(6:46)] Stephanie: Yeah. And most of us will need two or three, and the reasons why we switch is often not because we get worse, but because we have side effects or like in your case, we're allergic to one.

[(6:58)] Megan: [laugh]

[(6:59)] Stephanie: Um, so being prepared to pivot and knowing that sometimes in many cases pivoting is inevitable. Uh, just preparing your mind for that I think is- is an important thing.

[(7:12)] Megan: For sure. I was so scared, like before I had to take these treatments, I didn't take anything. Like, at that point I didn't even take vitamins [laugh]. Like, I just didn't take anything [laugh]. So, you know, in my... I guess my anxiety was telling me like, "Oh, if you take this, you're gonna die," basically. Then it's....

[(7:35)] Stephanie: Yeah.

[(7:35)] Megan: Or you're gonna feel worse than you feel now. Um, but just in talking with you and with my doctor, it just kind of helped me to realize that yes, right now I feel great, but the whole point of it is to find something that keeps you feeling great for as long as possible.

[(7:51)] Stephanie: Yeah.

[(7:53)] Megan: So once I kind of got that in my head, it was like, okay, yeah. Let's- let's do something [laugh].

[(8:00)] Stephanie: Yeah. And to your point, you're right, your medication should not make you feel sicker than your MS.

[(8:06)] Megan: Right.

[(8:06)] Stephanie: And it took a couple of tries and a couple of pivots for you, but do you feel like you're in a place now where your medication...

[(8:13)] Megan: Oh, absolutely. Yeah.

[(8:17)] Stephanie: Yeah. And...

[(8:18)] Megan: I- I have zero side effects and not...

[(8:21)] Stephanie: Good.

[(8:22)] Megan: Yeah. [laugh].

[(8:22)] Stephanie: Good. And I think the other important thing is that you were honest and pragmatic in the, you know, I tried to take a pill twice a day, it's just not for me. It's just not something that works with my lifestyle.

[(8:36)] Megan: Nope. [laugh] Yes.

[(8:39)] Stephanie: [laugh]. And having the- the maturity and the honesty with your provider to say like, "Listen, it's not gonna happen. I'm only getting 50% of my dose and I'm just being honest." [laugh]

[(8:52)] Megan: Yeah. [laugh]. Yes. I think shame is such a hard emotion.

[(8:57)] Stephanie: Yeah.

[(8:57)] Megan: But definitely one we all feel. And I definitely did feel a level of like, "Oh my God, what is wrong with me? Why can't I not remember to take this really important medicine?" But at the end of the day, I just didn't. And the doctor that I was seeing, or with the team I was seeing, like they have, um, a pharmacist and she worked a lot with me too on the medication side of stuff. And she really helped like just take that shame away. Like, listen, this is what this is like. We have to find one that works for you and if you can't take it correctly, then it's obviously not gonna work [laugh]. So yeah. No point in wasting time on something...

[(9:43)] Stephanie: And money.

[(9:43)] Megan: ...that doesn't work for you. Yeah. And money.

[(9:45)] Stephanie: Yeah. And money. Uh, and I have trouble adhering to some of these medications and I myself have had to stop because either I was dreading doing an injection and I would put it off and I knew that was not good, but I was also feeling ashamed like, I'm a healthcare provider, I need to get it together, right? [laugh] The fact is like, it's a quality of life issue.

[(10:14)] Megan: Yeah.

[(10:14)] Stephanie: And it's a health issue. Um, so picking something you can adhere to and that fits in your lifestyle and that doesn't make you feel worse than your MS does all the most important key things.

[(10:25)] Megan: Yes.

[(10:26)] Stephanie: Now, of course, being hit with a huge life-changing diagnosis at a time where you had a baby and probably weren't sleeping, and probably your own health was the very end of the list of things you had to attend to.

[(10:43)] Megan: Yes. [laugh]

[(10:44)] Stephanie: And probably you didn't ever give your overall health a whole lot of thought before MS. Um, has that changed? Have you done anything to really work on your overall health because of this MS diagnosis?

[(10:59)] Megan: Oh, for sure. For sure. I... Um, you're totally right. I never, ever, ever cared or thought anything of that. And yes, that having the diagnosis of course kind of put it in my mind, but having it when I had such a small baby was like, "Okay, I gotta do something because I have a baby and I need to be around to take care of this baby." Um, so I've lost a lot of weight. I've lost like 70 pounds

[(11:36)] Stephanie: And you look fabulous.

[(11:37)] Megan: Oh my gosh. Thank you. I feel great. Feel much better. Um, next step is working on these muscles that I currently don't have. [laugh] that I'd like to have. Yeah.

[(11:55)] Stephanie: Yeah. So exercise, super important. Weight loss.

[(11:58)] Megan: Yeah.

[(11:59)] Stephanie: All of these things. Good for you. Good for your overall health.

[(12:02)] Megan: Yes.

[(12:02)] Stephanie: Like you said, will only set you up better and have some benefit for your MS as well.

[(12:08)] Megan: Yeah. And I- I- I don't focus on this a whole lot, but something I kind of keep in the back of my mind is inflammation. Um, just learning coz I know that's like such a huge part of MS. So just learning what foods make me feel inflamed and maybe not consuming those so much. [laugh]

[(12:30)] Stephanie: [laugh]. Yep. And you;ve worked on...

[(12:33)] Megan: I'll- I'll not say ever, but [laugh].

[(12:35)] Stephanie: Yeah. And I know we're not there completely yet.

[(12:38)] Megan: No, for sure.

[(12:39)] Stephanie: But we've... Yeah. But it's all a work in progress. And I, again, sort of the opposite experience. I was an athlete when I was diagnosed and my symptoms have made it hard for me to find, um, that same like level of fitness or the same ability to be as athletic as I once was. And I've had weight gain. And it's more of a like ever-present struggle to be in shape and take care of my body, but do it in a way that doesn't flare my MS up or trigger spasticity. So it's something I think that we all learn to read our bodies.

[(13:13)] Megan: Right.

[(13:15)] Stephanie: Um, and see what specific diet and specific exercises work best for us. I know we're working on maybe like quitting smoking.

[(13:24)] Megan: Oh, yeah.

[(13:25)] Stephanie: It's hard.

[(13:26)] Megan: There's that one. I do smoke and yeah. It's hard.

[(13:33)] Stephanie: And even though... Yeah.

[(13:33)] Megan: It's the worst possible thing I could be doing, not only for my MS but just in general [laugh]. Um, but yeah. One of these days will be there.

[(13:44)] Stephanie: But it's a work in progress you know?

[(13:45)] Megan: [laugh] Yes.

[(13:46)] Stephanie: And that's something we've talked about too, is you're only a couple of years into this diagnosis.

[(13:52)] Megan: Yes, for sure.

[(13:53)] Stephanie: And it's so much in your life has changed.

[(13:56)] Megan: And life is busy. Like I am in- I'm in my survival years right now.

[(14:03)] Stephanie: Yeah.

[(14:03)] Megan: I have a toddler, a business. Uh, things are crazy. We are just doing what we can and that is okay. Yeah.

[(14:12)] Stephanie: Yeah. Yes. And that is something we've talked about.

[(14:16)] Megan: Yeah.

[(14:16)] Stephanie: It is okay to focus on one thing at a time.

[(14:19)] Megan: Yes.

[(14:20)] Stephanie: You know that you have other areas that you need to work on, but that's okay. We can do it in steps.

[(14:29)] Megan: Yes.

[(14:30)] Stephanie: It's okay to take things one step at a time.

[(14:33)] Megan: Yes.

[(14:33)] Stephanie: And you don't need to just upend everything in your life immediately after having MS, right? We're all in this for the long haul and we're all works in progress. And if you can pick one thing to address at a time, you'll get there eventually.

[(14:49)] Megan: Yes. And I keep thinking of this dang emotion. Shame. Shame. I shame myself so much for smoking. Um, and obviously I don't encourage anyone to do so, but like I was saying, like I am so in my survival years right now. And it just... The thought of not doing it or of quitting is so overwhelming that I'm like, okay, you know what? I'm not ready for that. Like I will be, I'll get there, but it's not today. So I picked something else to focus on and that was my weight. [laugh]

[(15:30)] Stephanie: And you are killing it.

[(15:31)] Megan: Yeah.

[(15:32)] Stephanie: Absolutely. And there are so many other things. Right? And I think that's human nature, is to pick the one thing we aren't doing and to beat ourselves up about it while also losing sight of all the things we are doing right.

[(15:46)] Megan: Yes.

[(15:47)] Stephanie: Yeah. And two years ago you were completely overwhelmed, like you said, with just picking a medication and sticking to it.

[(15:56)] Megan: Yeah.

[(15:56)] Stephanie: And here you are, you've been stable on a therapy, you found something that works. You lost 70 pounds.

[(16:02)] Megan: Yeah.

[(16:03)] Stephanie: You're raising an amazing kid, you're running a business. Right?

[(16:07)] Megan: And both of those things are going so great.

[(16:10)] Stephanie: So great.

[(16:11)] Megan: So, you know... [laugh]

[(16:13)] Stephanie: So, it's okay to have goals.

[(16:14)] Megan: Yes.

[(16:15)] Stephanie: But also to just congratulate ourselves on everything that we've done right too coz there's so much you've done right.

[(16:22)] Megan: Sometimes if I'm feeling that way, instead of making like a to-do list, I'll make a to-done list, you know, just to go back and see like, okay, these are the things I have done. [laugh].

[(16:37)] Stephanie: Yes.

[(16:37)] Megan: Let's not forget that.

[(16:39)] Stephanie: A hundred percent. I have a brag folder on my computer, so every time I feel like an imposter or I don't deserve this or I don't deserve that, or I'm feeling ashamed of this, I just drop in like nice notes, accomplishments, things I feel proud of.

[(16:56)] Megan: Yeah.

[(16:57)] Stephanie: And then something that you can go visit on days where you're like, I am just failing it every day.

[(17:01)] Megan: I love that [laugh].

[(17:04)] Stephanie: Yeah.

[(17:04)] Megan: I think I'm gonna start a brag list. [laugh]

[(17:06)] Stephanie: I think everybody should have a brag list.

[(17:08)] Megan: Yes.

[(17:09)] Stephanie: [inaudible] reminds us of, you know, you're just- you're dealing with a lot of really hard things.

[(17:12)] Megan: Yeah. [laugh]. And that it's alright.

[(17:14)] Stephanie: Yeah. And it's okay. [laugh]

[(17:16)] Megan: It's okay.

[(17:17)] Stephanie: Life is hard. [laugh]. So as a mom and a- a young woman with MS, talk to me a little bit about some of the things that make you a little anxious or fearful in the future.

[(17:31)] Megan: Oh. Um, probably the biggest thing is just worrying about my own kid. Having MS eventually. Um, it's not something I'm super worried about right now because he's five [laugh]. Um, but that was... You know, the first year that was a huge thought that I had a lot. Um, because he's a boy and I guess men typically- MS I guess typically hits them a little harder than us ladies.

[(18:08)] Stephanie: Yeah.

[(18:08)] Megan: So I worried about that a lot. Um, I worry about the future all the time. Just, oh my gosh, what if I like can't walk one day and I can't be there for him? Or what if he's still little and you know, I can't do all the things that he wants me to do? Um, but I don't know, I guess it's just- it's been a little while now and I'm realizing it's okay. Like I'm- I'm okay right now. We're gonna bring it back to the- the present moment. Everything's cool. So just live in that and stay in that. And something else that helped a lot too was I actually talked to his pediatrician about it. Um, when I did get diagnosed at one of our checkups, I actually think it was his one-year checkup. I was just like, "Hey, I just got diagnosed with multiple sclerosis. Um, I'm terrified. Is my baby gonna have multiple sclerosis? What do I do if I can't take care of him?" And she was so great at just assuring me, just kind of telling me a little bit more about how that works and that it is just not something I need to be worried about anytime soon. [laugh].

[(19:32)] Stephanie: Yeah.

[(19:33)] Megan: Um, and that was... Just hearing it from her and again, not Google was very never Google, was very reassuring. [laugh].

[(19:37)] Stephanie: Never Google.

[(19:38)] Megan: Never Google. [laugh]

[(19:40)] Stephanie: [laugh] Yeah. And that's probably the first thing that my patients with young kids do ask me is, it's not about them and their own health and their medications and the plan. Gid I give this to my child?

[(19:52)] Megan: Yeah. [laugh].

[(19:54)] Stephanie: And I try to reassure them that the chances of them getting MS, because you have MS, are very low. They're not none, but they're very low. It's not a genetically inherited disease. There are so many resources out there. So talking to the pediatrician, great idea. And then as your children do get older and approach puberty, even just checking their vitamin D levels and making sure that their vitamin D is at a healthy level can help protect them against that slightly increased risk. Um, and then also how to parent. Right? So I know your son's very young, you haven't had a lot of conversations about MS.

[(20:36)] Megan: No, not yet [laugh].

[(20:39)] Stephanie: Yeah. But when- you know, when he is a little bit older and those conversations do come up. There are things that help you guide those conversations. Right? So the MS Society has great resources. There's some awesome articles. There's some books out there that you can read with them. We are gonna link those resources in the comments to this podcast.

[(21:01)] Megan: Oh, good.

[(21:02)] Stephanie: Yeah. And so that's something, you know, I think... Thinking about the future of parenting is very natural and normal, um, but there is a lot out there that does exist and help out. So now still being... Right, you're still technically newly diagnosed.

[(21:18)] Megan: Yes.

[(21:18)] Stephanie: But you have a couple of years. You have a couple of years under your belt now. And I did tell you one day, the day will come, which somebody will come to you and say...

[(21:26)] Megan: Yes.

[(21:26)] Stephanie: I hear you have MS. I was just diagnosed

[(21:29)] Megan: You did tell me that. And it did happen. [laugh]

[(21:31)] Stephanie: It happens to us all. It did happen, right?

[(21:35)] Megan: Yeah.

[(21:36)] Stephanie: So tell us what you said to that person or what you would like to say to somebody listening who may be where you were two years ago.

[(21:46)] Megan: Oh, it's just going to be okay. [laugh]. It's just... It's... The fir... You told me when I met you after a year, give it a year and you won't feel like this anymore. And when you told me that, I was like, what does this lady know? Probably nothing [laugh] despite all of her qualifications. [laugh]. Um, but it's just so true. The first like year is just so scary and you don't know what to do and there's so many... You have to find a doctor and you have to find medicine, and you have to get all these scans and all these things and it's so scary. But it's just gonna be okay because you just get to a point where it's like, okay, I have MS, so what? Okay. It's just something that I have, so I deal with it, whatever. It's just... Yeah.

[(22:39)] Stephanie: [laugh] It's sort of like all-consuming. The only thing you think about at first.

[(22:43)] Megan: Yes.

[(22:43)] Stephanie: Naturally.

[(22:44)] Megan: Yeah.

[(22:45)] Stephanie: But then life goes on.

[(22:47)] Megan: Yeah.

[(22:47)] Stephanie: And it becomes an important piece of who you are.

[(22:51)] Megan: For sure. Yeah.

[(22:51)] Stephanie: But not all you are.

[(22:53)] Megan: No.

[(22:54)] Stephanie: Megan, I wanna thank you so much for coming here, having a very real conversation about being newly diagnosed [laugh]. Absolutely. Um, if you aren't in the position where you have an MS buddy that you can call and text, um, you don't feel like you have a support group, we do have a Can Do MS program, uh, take charge program for the young and newly diagnosed. It's coming in August 2024. We would love to have you, we would love to be your community, and we will put a link to that in the podcast. So Megan, thank you so much for being here.

[(23:33)] Megan: Thank you for having me. This was fun. [laugh].

[(23:37)] Stephanie: Thank you for listening to this episode of the Can Do MS podcast. If you like this episode, please leave us a rating and review on Apple Podcasts or Spotify. We really appreciate your feedback. If you are newly diagnosed, please visit our website at cando-ms.org, which is cando-ms.org to get some additional resources and to register for programs. Lastly, we'd like to thank all of our generous sponsors for their support of this episode of the Can Do MS podcast. Until next time, be well and have a great day.

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