



Can Do MS Podcast

Advocating For Yourself Through Life Transitions

Episode 31

Krista: Welcome to this episode of the Can Do MS podcast. Today on the show, I am happy to welcome psychologist, Meghan Beier from Johns Hopkins, and guest, Julie Stamm.

Meghan Beier: Well, Julie, thank you so much for being here. It is really nice to meet you. Love to learn a little bit more about you. Can you tell me a little bit about yourself?

Julie Stamm: Yeah, sure. I was diagnosed fourteen years ago, in one month it will be fourteen years. It feels like such a long time now and I say that but it still feels pretty new to me. So, yeah, I consider myself a patient advocate and I am trying to normalize disability and I am working pretty hard at it.

Meghan: How awesome. Can you tell me a little bit more about your journey with MS? Where did it start and how has it progressed up until now?

Julie: It took a really long time to get diagnosed. It started in 2001. I was living in London and just everything was going right in my life in terms of career, in terms of relationships. Everything was perfect except for my health. I was like, "What could this be?" The doctors kept dismissing me saying it was travel and just stress. I did not feel stressed so I just was dismissed by so many doctors. When I finally was diagnosed, I was relieved which most people get upset when they are diagnosed but I was like, "Oh, thank God," I know what it is and I can do something about it. They told me, "Go home. Have Christmas, then come back, and we will figure out your treatment." That is pretty much it. It was just so quick and unlike other people, I was really happy to just know what it was and just know who the man behind the curtain was and then I can fight and do something.

Meghan: It is interesting because I talked to a number of people who have similar reactions. Some people get really stressed out when they are diagnosed but there are quite a few people I have talked to who just feel relieved because they have had symptoms from so long and have been going through so many tests that finally they have an answer and they have sort of a plan of attack, would you say that it was kind of true for you?

Julie: Absolutely. Just knowing that it is not in my head. Knowing that these symptoms were

real and that I am validated. Even though it took a long time, it just took one doctor running an MRI to figure it out, but it was all the other symptoms that you go to the doctor and you say, I feel like I have a UTI all the time, and they are like, "Well, this is just stress. Here is an antibiotic and go home." I think what it taught me when I speak to people now is to be your own advocate. You know your body better than anyone else. So, if you go to a physician and they are dismissing you, it is time to look for another physician. You know your body, you know how you feel and if something feels off, you need to be your own advocate and fight for answers.

Meghan: Oh, yeah, absolutely. I one hundred percent agree. I often tell people the same thing. If you are not feeling like you are being heard by your provider, it is always worth a second opinion. I know you said you felt sort of relieved after getting the diagnosis but did life change for you after your diagnosis? And if not right away, has it changed since you have been living with it for some time?

Julie: My life completely changed. Because I used to work in finance, immediately went on long-term leave the day of diagnosis. They put me on long-term leave. So that was not by choice. I did not want to do that, but I could not really do the job that I was given. I worked really hard to get where I was and it all just went out the window. That took a little while to get my head around and then once I did, I realized that was my purpose in life now, but I had something that was going to be more rewarding and I think I am grateful that-- I think I would have been good at that. But I think I am way better at what I am doing now. I think I can sleep easier at night knowing that every day, I am working to make someone's life better. There was no amount of numbers or trades or anything that would make that as satisfying as knowing that I will help a newly diagnosed person feel better about their diagnosis.

Meghan: That is really interesting. I work with a lot of people who are going through transitions with their work either having to take steps back in their job or even having to leave their job completely and that can be really disappointing, really frustrating, really scary, what was that transition like for you?

Julie: I think, initially, there were a lot of tears and a lot of uncertainty because I just did not know what does this mean. I had gone to school for this. I had planned that this is how my life was going to play out. I was going to have a career doing what I was doing. And then when that was taken away I had to kind of reimagine where my life was going. It is one of those things that at the time when I look back I am like, "Wow, that was so stressful," but now, "Okay. Well, we [inaudible] pretty well." You do not want all those message boards and you talk to other people that are going through it, but it really takes you reevaluating what is important to you. With MS, you have to look at your day and say, how do you want to allocate your energy and your everything? With diagnosis, I decided, "Okay. So, what is important to me?" I always liked working with people. It was very important to me. Relationships, friendships, those are all important to me so how can I make that something that would be a career or something that would be comforting for me at night and knowing that I am contributing to society and not just at home feeling bad that I do not feel well. I think we are

all going to have really bad days, especially in the beginning when you are learning going through all the medications and side effects and that does not work. Then you have to have an MRI and then you have to get your results. In the beginning, it is so much harder.

Julie: Years down the road, it is a lot easier. You just navigate the system because you have done it for so long. So, everyone that gets diagnosed, needs to give himself a learning curve and just be forgiving and say, "I need this time to figure out what I am going to do to stay strong long-term," because the short term, it is hard to get wrapped up in but I think the long-term is the focus.

Meghan: Absolutely. What are some of the things that have helped you stay strong over the course of the last fourteen years?

Julie: I think friends and family. I really think relationships are a big pusher. I was married for a number of years, but that relationship served a purpose. It was there during my diagnosis, he was wonderful and we got through it and we traveled, we still did everything we wanted to do just a little bit different but then that relationship ends. Everyone in your life at a moment for specific reason and I think enjoying those moments and not dwelling on whether or not they worked or are they successful? Now, I am in a different relationship for eight years and this is where I am supposed to be, where I am happy. My body and my mind thrive currently because I am with someone that encourages what I need and hopefully, I do that for him.

Meghan: Can you tell us a little bit more about your family? I mean, how did things change? I hear so often that roles change after people are diagnosed with MS. Some of the things that you are taking on you might not be able to anymore and so that has to shift. I imagine that shifted with your ex-husband and maybe even things are shifting and changing in your new relationship.

Julie: Yeah, when we met, we just had different-- We did not plan on having children. It was not planned. He was my greatest thing and I would do anything for him. He is my life. He is four. It was not like that is why we stayed together, but our relationship definitely has changed. We went from going out to dinner was our priority and going out and having a good time. Now, we are at home with a four-year-old and playing Legos all day, which is very different. But his role definitely has changed. I would not say that he is a caretaker but he does care for the family just as I care for the family. We just have different roles. There are certain physical things, pre-COVID, when we were having big parties or whatever and people over, he would be responsible for the vacuuming and the things that would exhaust me and I would be responsible for the [inaudible]. We allocate what drains my battery the most and he takes the bigger stuff, the physical stuff and I could take more of playing with my son on the floor is in his favorite thing. And I love them. I could do this for days. He could vacuum and wipe everything down and I am like, "Okay. This is a good designation of who gets to do what."

Meghan: Absolutely. How else does has MS played a role in your relationships either in your immediate family or your extended family or friends? What I am thinking of is I heard

somebody else recently say that they had to figure out who to go to for what after being diagnosed with MS. I would love to hear your experience with that.

Julie: Yeah, I think that is really true. You have certain friends that you are going to go to for advice. Some is going to make you laugh is different than-- So, my sister also has MS. She is my go-to person or whatever because even though we had very different symptoms, she understands that each day is a little bit different and the stress of it and not knowing. She can feel that. Whereas, my mom is like, "Drink apple cider vinegar. You will be fine." And I am like, "If only I knew that is all it took then I would be cured." Everyone has different-- Some Facebook people like, "Have you tried a new diet?" I am like, "Yeah. I tried everything." I am doing what I can so you just-- I find that when it is a particularly hard day, I go to someone that I know can actually empathize with what is going on instead of trying to fix the situation because I think just in general, good advice is sometimes people just want to talk and do not want advice. So, if I go to some of that I know, they always wants to fix the situation. That is just going to frustrate me. So, I know who to go to but I definitely agree with allocate- decide which one you are going to choose to go to depending on what the day brings to you.

Meghan: Absolutely. I would love to hear a little bit more about your son. Is it son?

Julie: Son. Yes, Jack.

Meghan: What it is like to be a mom with MS?

Julie: He is four and a half. He just turned four and a half on December 1st. He is a perfect. Honestly, I do not know what I did in life to get such a good-- I do not know how he came out. So many things go wrong like in terms of health, like my appendix just burst two weeks ago. Everything was wrong. With him, everything is right. He is just everything to me. He was not planned but my God, he is a blessing and he has changed my whole perspective of everything. He sees the world in MS differently and I think parents with MS raise kinder, not that people without MS [inaudible] just kind of children, but I do think that the children are more aware of what is going on around them. I always say that my son if we sit down at a table, he will always make sure everyone has their plate because he is always just looking. He is always observing. When I walk in his room in the morning, he always just evaluates how I look. At first it had me like, "Oh, my gosh, is it Bell's Palsy? Is something wrong?" But he just evaluate what the day is going to be like and just at that young of an age to have such a kind heart and just sit and look at his mom and care enough to change the course what he has got planned in his mind for the day, whether or not we are going to play Pokémon or we are going to do board games or whatever it is. He really adjust so I got very lucky with him.

Meghan: Well, I am super interested to hear your perspective on this next question because I work with a lot of young people that have MS and do not have kids and many of them both men and women have described not really wanting to have kids or being afraid to have kids because they are afraid of how MS might impact their ability to parent. You lived with MS for almost ten years before your son was born. And so I wonder if you ever had similar thoughts

or how did life change and what kind of advice would you give those individuals who maybe have that fear?

Julie: I think that is a great question and it is one that I struggled with for-- I had tried with my ex-husband to have children and it just did not feel like it was in the card. So, I had resigned myself saying, "We are not having children. I am okay with this. I like my life. I am going to stay strong MS-wise." My doctors had told me not to have children. It was not advised because of my symptoms and the course of my disease but accidents happen. And, yes, but I do think that it will add challenges and there are going to be parts of it that are not-- After you have a baby, it does have impact on you. It is different for every person. Some people feel amazing during pregnancy. Some people do not feel great after pregnancy. It varies from person to person. For me, I was telling a young woman or young man, if it is something that you wanted to do before MS, do not let MS be the reason not to do it. Say, you end up in a wheelchair, let us say you are only here for ten years of the child's life. You are going to give them enough love. Your life expectancy is not less with MS. But there are certain things but you will overcome the obstacles just like you have during the diagnosis as you do individual. As a parent you will also and you will come up with the strollers are really good walking aid. As long as you can give the love and just provide them with comfort knowing that, "Hey, we might not look the same as every other parent but we are going to be here and we are going to fight for you and we are going to be good parents. It just going to look a little different," because every parent has something whether it be MS or depression or diabetes or whatever it is, but every parent has something and we all have guilt. We all feel like we are not doing enough. I do not think MS should be a reason to stop you from that.

Meghan: Right.

Julie: In my opinion, I am not a medical expert, obviously. I am so grateful that I did not miss the opportunity because of all the things that I have done in life, this is the one that matters the most. I could do everything in the world, but he is what is making my term on earth worth it.

Meghan: I love that. As a mom of a three and a half-year-old, I especially love that.

Julie: Oh, thanks.

Meghan: You also wrote a children's book. Can you tell us about that?

Julie: I did. I was looking for materials for him. I am very transparent about having MS. Everyone that meets me, I have MS. It is not a big deal to me. I am very open about it. I decided from a young age to be very open about it with my son. But I wanted to look at what other children were being introduced to it. How it was being introduced to them and I did not like it. I thought they were great materials for a little bit older. I thought their age group that I wanted to get from that zero to six. I did not feel there was something that I would read to a child, any child. I am not negating that there are resources out there and they are great. They

are just not something that I wanted to give to my son so I created one. I took my Cry Myself to Sleep, I read him notes. So I took my Cry Myself to Sleep mom moments where I was like, "This is the worst. MS sucks. This has ruined my life. I am ruining my son's life" and then I talked to him about them and I said, "How did you feel on that day?" And he saw them completely different. My worst moments were adventures for him and I was like, "Wait," now we got it. Now, we know what we are doing here. The book is every page is based on a day we have lived. Those are bad days for me. Those are terrible days for me but not to him. That is what is important is that we have to remind ourselves to stop and talk to them. They are smart little guys and girls. They know what is going on. They are aware even if we do not tell them. They are aware that something's a little bit different so we might as well embrace it and comfort them. Just like coronavirus, we could not play on this but we have to just remind them it is going to be okay. We are going to get through this and this is something a little bit different. We cannot anticipate what is going to happen next but just support and comfort with what I think is most important for them.

Meghan: Well, just like coronavirus, I think that kids may adapt differently than we think they will. For example, I have an aunt who said, "How is your daughter dealing with wearing a mask? This must be horrible for her." My daughter plays with her mask. She will pretend to play, imaginative play with her mask on because it is just normal. It is part of life for her now. Her perspective is very different than our perspective and I would imagine that translates to other things like MS and any other medical condition that somebody might be living with. Because he has lived with you and has lived with this his entire life, his perspective may be very different than yours or even other people in your life.

Julie: Right. It is really the truth because the things that we feel so guilty about-- You are a mom. You know everything. "My goodness, did I give him enough vegetables? Did I do this?" They just see everything differently. We are perfect to them, even though we are not perfect but to them we are perfect. So, I think we should just all be a little more forgiving of ourselves. It is easier said than done believing.

Meghan: It is easier said than done, for sure.

Julie: For sure.

Meghan: What kind of response have you got so far with the book? Because I imagine that this is a really helpful resource to many moms or parents with MS.

Julie: I self-published because I wanted it in his hands really quickly. I wanted it in his hand while you can appreciate it. I did not really think that-- I knew that there was a market for it, but I did not really know how much I wanted to run with it. I just knew I wanted a copy for my son, but luckily it took off. We got very lucky and a publisher heard about it. They picked us up. So, we are coming off the market December 31st and being relaunched with a publisher in the fall, which is super exciting. It is going to be my dream because when I self-published, I could not do it the way I wanted to. I wanted it to be a board book, but it is very expensive

without the finances of a publisher behind it. But now we have everything, it is going to be my absolute dream when it comes out. People are using it as a tool to tell their kids for the first time. That is my favorite. And then just around the world, I am getting pictures of people, you know in Ireland, Scotland, in Italy, and India, just little kids around the world loving the book. I am doing school readings which is really exciting, but just sitting and talking to kindergarteners and what pages their favorite and how they read the book like, "Wow. I think it is going to make a difference."

Meghan: That is really fun. Do you have any plans for any future books?

Julie: Yes, I wrote book two and three. So, yeah, they were picked up also. So, that is exciting. Once this one is out in the fall, then the book two will be coming out the next fall so 2022.

Meghan: Okay. Oh, that is so cool.

Julie: Yeah, I am excited.

Meghan: Earlier, you had mentioned that you do advocacy, can you tell us a little bit about that?

Julie: Yeah. I have always volunteered. When I was in London, I volunteered with the UK MS Society and then when I came back to the US, I started volunteering with the New York Chapter. I was always at the finish lines at the races to answer questions for people that never heard about MS but want to just ride through the city. They have the MS bike that they can ride through New York. So I have always tried to and you know, I have been a speaker at [inaudible] and stuff. Just try to put a face to what MS can look like because I think people pictures certain thing and then it is not really-- I do not want people to be scared. It is a totally different disease that it was fourteen years ago. So, if I were diagnosed now, yes, it would be very upset. I am not negating that you should be upset about it, but it is a completely different disease. There is so many more treatment options. I wish I was diagnosed now instead of fourteen years ago. My whole life would be different. So, I think my big advice for people is just to be your own advocate. I wish I did that sooner and I wish I found the right medication. That is also like the big thing for people with MS. If it does not work, do not stay on it too long, like switch get something that works.

Meghan: How did you eventually find the right medication?

Julie: Well, it took a really long time. I just kept getting worse. So, I do think finding the right medication is the most important thing. Some people are completely against medication. I personally am not but just find what works. Find what keeps you healthy then I do not care what you're on, just do something. Do not not do something. Even if it is your diet or whatever you feel is helping you, do something to help yourself because this disease can be relentless if you just let it run rampant.

Meghan: Yeah, absolutely. Medication is a really good point and I often tell people that if you want to try a medication and again, your provider is not open to it, you can always get a second opinion and see if you are hearing the same thing. You mentioned try something, and I am wondering beyond medication, what other things do you do that kind of keep you well? You had mentioned previously diet, that you tried all the diets or exercise, meditation, all kinds of stuff, I mean, are there any other strategies that you use to keep yourself well or stable?

Julie: Wine. No, I do not know. I do have a lot of wine. No, I really think trying to eliminate stress is my biggest tip and I should do more exercise than I do. I have like a move it or lose it alarm on my phone so I have to do twenty minutes a day of whatever it be. I do think doing stuff that makes your heart happy is the most important for me, personally. As long as I feel better knowing that I am on a medication that is going to stop it. Staying on top of my medication and getting rid of as much stress as possible. And then just like coronavirus help with this too is focusing on who matters. Even now, I will get text messages from people and it is really nice but sometimes I am like, "Am I going to waste thirty minutes of my day responding to some peripheral friend?" Instead of just, "Hey, it would be great to catch up on the phone one day." I think I just want to allocate my space and my time a little bit better and I think coronavirus is actually helping that.

Meghan: Yeah. Well, it sounds like you really devote your energy to what matters and who matters for you.

Julie: Yeah, that is my priority. Yeah, unfortunately, you have to kind of [inaudible] back in sometimes because you lose track of it but it is a goal to just stay focused on what is important.

Meghan: Yeah. So, you said you have bad days and as a psychologist, I always have to ask about mood type things. You are saying that you try to eliminate stress, how do you manage stress or the ups and downs that MS can bring to your mood?

Julie: It is hard. There is no one way to answer it. Depending on what the issue is that day. If my leg is particularly weak, the mental weight on me, it just weighs on me. I feel like my mood is ruined and then if I am in a bad mood, it radiates everything else. I really try not to let that affect me but eventually it does. I do think taking a walk is my greatest relief of just clearing my head space, breathing, and not like it is such a big deal. Just get out, get fresh air. Even if it is just to the roof for ten minutes, just to have a minute of like, "Okay, it is going to be okay. This is a bad day better, tomorrow will be better." If it is not, you will adapt because everything-- If you look back at your life, my favorite part of MS is that you forget most of it with cognitive issues like all the bad stuff. I am like, "I totally forgot about that. Thank, God." Sometimes I wish I did not write so many notes because then I would be like, "Oh, I completely forgot." I [inaudible] and did that. Cognitive issues are thing but I also like them a lot because I forget some of the bad stuff.

Meghan: I love that perspective.

Julie: Yeah, it is kind of nice. I am like, "Oh, totally, it is fine. It is not a big deal. It is okay. It is done." But I do think just trying to remember the stuff that was so overwhelming in the beginning, how it just a blip on the radar now. So, everything new that comes eventually is going to be a blip. Just like I have to use catheters. I am very vocal about it. I do not care. I am not going to be embarrassed. I am not going to sit there and make someone feel-- If someone feels uncomfortable because I have to use catheters and that is on them. I do not care. Those were all, like to me, the end of the world when they told me, I was like, "I do not want to live. This is it. I am not going to make it. End of the world." Now, I am like, what an idiot that girl was. Of all the things you have to overcome with them as that is nothing. I think just trying to bring it back to perspective and looking at all the things that were like, "This is the end of the world," and they turn out not to be is kind of a good way for me to get through the bad days.

Meghan: Yeah. Absolutely. I love that. I sometimes think about getting diagnosed with MS or even some of those setbacks or those progressions as completely new learning experiences. You have to kind of think about how I am going to learn to live with this new symptom which can be very disappointing and it is totally okay to be disappointed and frustrated and then also get back in there and figure out how I am going to deal with this. It sounds like that is what you are saying.

Julie: Yeah, exactly.

Meghan: Is there anything that I have not asked you that you think would be helpful to know about you or your family?

Julie: I think our family life will keep evolving. I think my priority is just to make sure that my son knows that he is loved and that will never go short in supply. I think as long as I can keep doing that then I am successful in life. So, I think there is going to be more ahead in all of our lives and just focusing on the exciting stuff and had to get through those tough days is the important thing.

Meghan: Okay, awesome.

Krista: Thank you to Julie and Meghan. So, thank you both for sharing your thoughts and ideas with our listeners. Of course, thank you to our listeners for tuning in to this episode. Lastly, thank you to our 2020 online program sponsors for making this podcast possible. Thank you to Bristol-Myers Squibb, Biogen, EMD Serono, Sanofi Genzyme, Genentech, Novartis, and Mallinckrodt Pharmaceuticals. Be sure to check out our other podcasts episodes on our website, cando-ms.org. We also now offer transcripts for our podcast if you would like to have a printed version of this audio podcast.

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