



Can Do MS Podcast

Finding Empowerment Through Self-Care and Accommodations

Episode 32

Host: Welcome back to the Can Do MS Podcast. I would love to welcome our guests today as well. Mental health professional Samantha Domingo, and young adult living with MS, Czarina Muñoz. We will hear Czarina's story about her life with MS and what it was like being diagnosed as a young adult. So now a big warm welcome to our guests. Thank you both for being here today.

Samantha Domingo: Thank you so much for that introduction Krista. I am really glad to be here with Czarina today, getting to know you a little bit. So, hi.

Czarina Muñoz: Nice to meet you, Sam. Finally.

Samantha: I know.

Czarina: I wanted introduction.

Samantha: Same here. So I am very curious about your story with MS. So if you can tell us a little bit about that.

Czarina: For sure. I was first diagnosed with MS my junior year of high school. What actually started the journey was I had a recent eye doctor's appointment during that time. And then after that I just started noticing some things that felt really off, mainly being able to go up the stairs. I thought I was having asthma because most of my family does have asthma on my mom's side. And so, we went to see a primary care physician about that and he had stated like "No, you do not. We can do more rounds of tests." And then the next week after my eye doctor's appointment, I went blind in my right eye. I was caught off guard because he did give me... I kept telling him that my eyes were itchy. I do not know what was going on and he said just put eye drops, and now I am just blind in my right eye.

Samantha: That must have been so scary.

Czarina: Yes. It was very scary. I was actually in lectures during that time because I was going

to early college program. I was freaking out. I told my mom right away. She said we will wait a day and then we went to go see my eye doctor again. He did about ten rounds of tests exams and then he stated like "You have done all my tests and every time I try to trick you it is not working. So, I believe you have optic neuritis." After that he told me that he was going to refer me to a neurologist. They would do an MRI and then after the MRI will decide where to go from there. The results came back when I went through my neurologist here in Dallas and he said "We cannot diagnose you with MS yet unless we are certain after we do a spinal tap." After the spinal tap, it confirmed that I did have multiple sclerosis and I was diagnosed two days after my birthday and the same day of prom. So I was at prom and it was just a lot.

Samantha: What was going through your mind then? I mean even just the terms you are using, optic neuritis, and spinal tap. Did you know what any of these things were?

Czarina: I actually had no clue what optic neuritis was. I knew that when we got home from my doctor's appointment with my eye doctor, my mom was very fearful thinking it was cancer in the brain. That was her first onset of fear, I guess, in a sense. On my mom's side cancer is prevalent as well so that was another thing that she was being more cautious of. Once we went through what optic neuritis could be, my eye physicians and the MRI will dictate whether or not it is a tumor or whether or not it is just a lesion or something of that nature, but we won't know until after the MRI and until after you go see your neurologist. What was going through my mind was very much... not fear, I would say just confusion because I was in my junior year of high school, I had prom coming up, and all of my regular activities of a normal teenager were being halted. I still had school, which for many who do not know what an early college program is, it is very stressful. So, not only are you taking high school courses but you are also taking college level courses. And so I had all those things to worry about on top of my diagnosis.

Samantha: Yeah, and all of this was in your junior year.

Czarina: Yes, my junior year of high school.

Samantha: Wow. I am sure a lot went through your mind. Did you share the news with anybody outside your family, friends?

Czarina: I actually was very closed off to sharing it with anybody. A lot of things had changed like I was wearing a backpack and now due to the spinal tap, which I got done the Friday, got two days on bed rest. Well, actually one day but kind of two days and then the Monday that I started carrying a rolling backpack everywhere. For a teenager, you kind of do not normally usually see that because everybody is wearing their backpacks and everything going across campus. And so, a lot of people started asking me as to why I am using this new backpack and just different things like that. I think as teenagers you do not understand, I guess you are still young, you are still going through your own emotions and things with high school. So you do not really understand what is going on as well within yourself. During that time I never shared or disclosed anything really with anybody. Maybe one person and at that point I just did not

feel comfortable because of just the onset of peer pressure and things of that nature. Only my immediate family knew and it was not until, I want to say, I graduated high school or my first year after college did I tell my family members and some friends of mine that I had MS.

Samantha: Yeah, it is definitely a difficult decision for even adults who are diagnosed whether they want to tell or share the information with family or friends. Given everything that you were going through and especially at that age, I can imagine why it must have felt like maybe it was not the right time for you. I am curious about if there is something that you wish someone would have told you when you were initially diagnosed.

Czarina: I think there was a lot of things, just the journey that you would have to go through by yourself in some form or fashion because my family did not know what it was. Another thing would probably be that there will be good days and bad days. Also, I would say the prevalence of what I thought MS was, was that many of the people who have MS are either in a wheelchair, use a walker, those things that are pretty stereotypical of what people would assume someone who have MS would use or utilize. I think that was one of the things that I was most fearful of, that I would not be able to do certain things, the things that I wanted to do. Some of it is true but some of it is actually not true. When I first got diagnosed, I was at Children's and so after Children's I would just see many people in the neurology department who were in wheelchairs and so my assumption was "This is what my life is going to be" until actually discussing with my neurologist and peer support groups that everybody who has MS, it is different for everybody. You won't necessarily be in a wheelchair, but you will have other limitations or accommodations that you might need.

Samantha: Yeah, exactly. I think that is so important for people to know and just learn about how differently MS can impact different people. Before I forget, did you end up making it to your prom?

Czarina: Yes, I did. I actually went to prom that day but there was a lot of things I was upset about with prom, mainly being that I could not feel my legs for that point of time. Nowadays, I do not wear a lot of high heels. I used to wear a lot of high heels and now with MS, it has been so much of a limitation on that, just because being able to walk and having my balance. I think that is more of a priority now. Like making sure that you feel comfortable in what you are wearing and your ability to feel confidence within yourself.

Samantha: I am glad you ended up making it. Did you have a good time?

Czarina: Yes, I did.

Samantha: Thank God. Okay, so you mentioned that you started an early college admission program. I am not really entirely familiar with what that looks like, but it sounds like you complete some college courses and then transition into your full night College University. What challenges did you experience as a result of living with MS?

Czarina: Majority of it was professors not understanding by accommodations and having to reschedule exams and more so, accommodations on test examinations. I think that was the struggle and having to talk to them. With them, I did have trouble like being able to get a day off because I either had doctor's appointments and things of that nature, spending more time off due to reactions of the medication that I was taking during that time. Also, I would say more lenient on assignments because the majority of professors are like, "This is the day I give it to you. I want it done by this time because I do so many other students as well." So I did have a lot of trouble with them, especially because for a lot of people who have MS, for people who do not, they have a stereotypical image of what it looks like. For me, I do look able-bodied when I do go to my class or my job. People assume things or even when I am with friends, they sometimes forget so it is kind of an adjustment. I think that was the hardest part, it was being able to discuss with my professor my accommodations and things of that nature.

Samantha: Were there any moments where you felt it was so challenging to get these very reasonable, needed accommodations done? Were there any moments where you felt like, "Well, I may have to just push through and pretend like I am like everybody else."

Czarina: Yes, there is a couple. I think one of them I actually did fell asleep in class due to one of the medications I was taking. The injection or the medication actually cause flu-like symptoms. During that time, my liver enzymes were going high. We were doing blood work pretty frequently on that and I would just nod off in class. And so I actually got kicked out from my professor's class because she thought I purposely meant to sleep in her class and I was not giving her attention. Even after discussing with her like "This is a medication. These are the side effects" she still would not have it. And so it is definitely a challenge sometimes to be able to discuss with my professors that on that able body part, this is what it looks like for you but this is what it feels like for me. It just depends on the person. Usually, professors are pretty accommodating and some people who have never had a student like that before do not understand, but I think it just takes a conversation.

Samantha: I am sure it can add onto the stress that you already are experiencing at school. One thing that I wanted to ask about especially in our current global situation with the pandemic is, how do you cope with any feelings of isolation that you may experience as a young adult living with MS? We can talk about it in terms of with pandemic and maybe before the pandemic.

Czarina: I think it is just the understanding of people who can understand you, not understand necessarily but empathize. A lot of my friends do not have a disability so that isolation is a different one in itself. Before the pandemic the retreat I went to, the conference with Can Do MS, which was held by Tennessee last year, was actually the first time I felt comfortable with other people my age, because usually the isolation in itself is people who have MS are usually a lot older, which is true here in Dallas. There are very few people that are my age who have it. That conversation or things that I might be struggling with at my age is going to be different for somebody who is 30 or 40 or 50. I want to say currently with this

pandemic, it was being an isolation because I am a social person. I like to be with friends, not all the time, but MS really does put in perspective I think for me self-care. In some sense, there is points of isolation where it can get lonely but there are also points in which I have learned during college that MS was the best thing for me in the sense that I was doing everything for everybody. I was running errands for everybody. And then once it hit, it was a form of self-care for me to actually say "Let us take a day for yourself today or like let us watch a movie because you normally do not do that." Just small things. Just small things.

Samantha: They end up adding up big time.

Czarina: They really do.

Samantha: Speaking of self-care and ways that you are coping with the current times, what are some other things that help you?

Czarina: For me, personally, it is my faith. I have an amazing family and amazing people in my life. So my faith is definitely something that grounds me, especially in this pandemic and the sense of uncertainty. I think that a lot of it is just also cutting out social media because we already get news every day and just to add on to that only retracts from your being able to be at peace with yourself sometimes. That is another thing. Trying to maintain, spending time with your friends, family members, if you can and also making sure that you spend at least one day out of the week for yourself, whether that be working out for yourself or whether that be cooking your favorite meal, just even things like that. During this time of the pandemic, I actually made a garden and it is something I have done for the first time with my grandfather. It was great bonding time with him, but also learning what it takes to be a gardener. I actually found a new hobby that I think I am going to enjoy for a while.

Samantha: That is really cool. What kind of things are you growing?

Czarina: I grow squash. I grew a little tomatoes. I grew some carrots and some chili peppers so we will see what grows this winter. I do not think anything will grow now, but I will probably try first spring.

Samantha: What is one piece of advice that you could offer our young adult listeners or perhaps any child who has been recently diagnosed with MS?

Czarina: I will say, first of all; it is not your identity. Make sure you also have a great support system for you along the way. But I will also note that it is okay to go to counseling. One thing that I did not do the first year or two, I would say two years, was I was struggling with my mental health a lot with college. For those that do not know what it is like to not have that outlet to go to, not only do you struggle with your disability, but there are also things that you have to go through on your journey as an adult. And so, just adding on to that is like two-in-one. When I started going to counseling it really helped me go through some of the challenges that I was going through, talk through them, problem solve and have that outlet

because for me, personally, growing up in the Latin community, it is very difficult to have those parents who are willing to discuss that with you because it is not really talked about. But actually going on campus and having a counselor on campus really assisted me. For any of the young adult listeners who are listening or for those who are just recently diagnosed, make sure you have a peer support partner, whether that be a friend or a family member, but also it is okay to go to counseling. It is okay to have that outlet to go through with whatever you are going through and just have that person to talk to if you do not feel comfortable talking to somebody else.

Samantha: Yeah, that is great advice. I might be biased because I am a therapist, but it makes me so happy to hear that counseling has been so helpful for you. And I know that it can be helpful for so many other people. Yeah, colleges and universities are great places to start. Lots of them already have their counseling center right on campus so it makes it really easy. I think now with everything going virtual, we have a lot more access to therapy than we ever did. Well, Czarina, it has been such a pleasure chatting with you and thank you so much for sharing a snapshot of your life, and for all the wonderful advice you had to gift our listeners.

Krista: Thank you to Czarina and Samantha for sharing your thoughts about being diagnosed with MS as a young adult. Thank you to our listeners for tuning into this episode. And of course, we would also like to thank 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 podcast episodes. We also now offer transcripts of all of our podcasts. If you would like to have a print version of this audio podcast to read along with. You can access these on our website cando-ms.org. Again, thanks for tuning in and have a wonderful day.

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