



Can Do MS Podcast Find Your Voice: Part 1 Episode 34

Narrator: Hello and welcome to the Can Do MS podcast. Today's podcast is episode number thirty-four titled, "Find Your Voice". I would like to welcome our guests, MS activist, Tyler Campbell, and neurologist, Dr. Mitzi Williams. I am excited to have you both on the podcast today. Thank you so much for joining us.

Tyler Campbell: Excited to be here.

Dr. Mitzi Williams: Absolutely. Thank you so much for having us.

Narrator: So, to get things started, I would love to kind of hand the microphone off to you two to introduce yourselves to our listeners.

Mitzi: Well, I am Dr. Mitzi Joi Williams, also known as the 'nerdy neurologist'. I am a neurologist and multiple sclerosis specialist and I live in Atlanta, Georgia.

Tyler: My name is Tyler Campbell. I am a die-hard Texan. I come from the great state of Texas, by the way, of Austin. I am an MS advocate and traveling by Zoom nowadays, Mitzi, as a public speaker and a professional speaker. It is an absolute honor and privilege of being a national MS ambassador from the MS society for quite some time now. I am excited to see where we are and have a conversation, Mitzi. Let's go.

Mitzi: Awesome. Looking forward to it. All right. Let us just cut to the chase. Let's jump right in. So, why do not we start kind of when we are thinking about this journey of MS. One of the biggest parts of it is actually getting that diagnosis, and oftentimes, when I talk to people living with MS, they remember the day, the time, and all the events that led up to it. Why do not you share with us a little bit about your journey to diagnosis and how that happened for you?

Tyler: Yes. Like so many other people, mine came without warning, right? There was no preparation for this whole MS phenomenon taking place. I was a college student at San Diego State University in 2007 playing football on a football scholarship. And literally, after playing a football game, Mitzi, against BYU, last game of the season and I went to sleep absolutely normal that night with no problems whatsoever. I promise. I woke up routinely at close to five

o'clock in the morning like I always do. Instead of getting out of bed and rising to my feet and walk to the bathroom, Mitzi, I fell flat on my face. Do you hear me? It is something that we all take for granted, right? We all expect to be able to just get up, wake up, and walk. I lost function in the limbs on the right side of my body and I had slurred speech. It was completely gone. And I had no idea what this was. Nobody. No trainers. No team doctors at the University. They had no idea what this was and I was shipped to Scripps Memorial Hospital La Jolla, Mitzi. And if you end up in La Jolla, California, that is like a place you want to visit. You want to go see the sea and you are trying to go get to the beach. You do not want to go there to go to the hospital.

Mitzi: Right. You want to have a good time.

Tyler: You want to have a good time at La Jolla. My introduction to La Jolla was going to the hospital and getting there, I was sent to a neurologist. I had never heard of what a neurologist was. I did not know what that was. And as soon as I walk in, Mitzi, nobody looks like me. I am twenty-one. I am in the best shape of my life I'm two hundred and thirty pounds. I checked in. I am limping. I am dragging my right foot noticeably. And I sit down next to an elderly white woman and she says, "Son, what are you doing here?" I said, "Ma'am, I have no idea." She says, "You are too young to be here. You do not belong here." And as soon as I said was trying to get the understanding or tell her why I was there, the lady came through the door. It was the nurse and she said, "Mr. Campbell?" And I limped on in the back. I was administered a lot of equilibrium tests, right, Mitzi? I stand on one leg trying to walk in a straight line. I had speech impediment issues, and I will never forget it, her name was Dr. Naira Kocharian. She said, "I think this may be something called Multiple Sclerosis."

Tyler: And I said, "What is that?" I am African-American, so, a black man. I am used to high blood pressure, sickle cell anemia, high cholesterol, and diabetes. I never heard of this thing. My mom was a former ER nurse. And she asked me, "Where are your parents?" I said, "I am out here in college by myself at San Diego State University. I have no family here." She said, "Call your mother." And she tells my mom she thinks I have MS. They are going to administer a spinal tap. It was not supposed to hurt. That is what she said, Mitzi. She said it was not supposed to hurt.

Mitzi: She fooled you. She fooled you.

Tyler: She said, "What we are going to do is we are going to get in the fetal position, and it is not going to hurt." I said, "Okay." As MS patients, you do not know what you are walking into with this, okay, right. I did not know any better. My mom told me to listen to everything that she says and my spinal tap results came back. I was sent to an MRI. I had lesions on the left cortex of my brain, which was why I was having so many issues on the right side of my body. I was diagnosed very quickly which we will talk about today. This is abnormal a lot of times in MS diagnosis. I was diagnosed the next week. That is not always the case with Multiple Sclerosis and there is a major shift in my life, Mitzi, from that day forward.

Mitzi: Right. I love that you brought that a lot of people are not diagnosed as swiftly as you were. A week is an extremely short period of time. I have a lot of folks or people that I have seen or interacted with, who have been waiting years for a diagnosis and who have been having these symptoms and nobody knows what it was. Fortunately, you are young enough where MRIs are very accessible, but back in the stone age, it was very difficult to get an MRI. Your doctor had to have a very high suspicion of something for you to get it and good reasoning to get it. So, once you got that diagnosis though, I have a lot of folks that deal with uncertainty about the future and they do not know what was coming. How did you grapple with that? And how did you learn to adjust to your new normal? Whatever that was. Did your symptoms completely go away? Tell me about that process.

Tyler: It got worse. I think that was the heartbreaking thing for me. A lot of times, we get an answer as to what we have and we feel like the healing can begin. And it can, but there was a delayed gratification that would come from my healing. It did not take place. I continue to lose the functioning of my limbs. I ushered into the world of senior nurses and learning how to administer my own IVs, steroids, and medication. Going from just being a college student to now, I am pricking myself, Mitzi. There is this whole world. My limbs continue to worsen. I developed what was called drop foot, right? It is where the blood was not circulating. My right foot was, literally, you could not lift it up and you could not lift it down. My world literally changed, flipped, and turned upside down. I thought things would get better and they did not initially. You kind of reflect back on the things that matter to you in life when you are at your most vulnerable state, I feel. What was important to me at that time was my college education. I told you earlier, I was a college student.

Tyler: I had experienced a relapse in the middle of finals at San Diego State University. I had no functioning in my right hand. My right leg is dragging. I am having to take all my finals with my left hand and what it did for me though is it showed me that if you have a sense of direction, a sense of things that you want to accomplish or do with your life, those are the things that are going to propel you to keep going no matter what adversity that you are faced with. My education mattered to me, Mitzi. So, I found a way to uphold my education, not fully understanding what MS was, but the fact that I had a path towards what I wanted is what got me through and down the path of recovery. So, that is actually what started it for me. It was understanding that MS has stricken my body, but I am not going to let it take away from the things that I want to accomplish with my life. Whatever those things are.

Mitzi: Right. That is so key because what I hear you saying is that you had to look at what are the foundational things that are important to you, right? Because I heard you saying that you were playing football, right? For many who may get diagnosed and let us say they had weakness on one side and they were athletic, they may have said, "Well gosh, I cannot be this athlete so that means I have no purpose." right? What you were able to do was kind of distill down, "Okay, I cannot do this at this point, but this is what is really important to me and I am going to focus on this." It also sounds like I hear you saying that support of your family was extremely important to help you to kind of work within the healthcare system and to encourage you to listen to what the medical professionals that you were working with were

telling you. So, tell me a little bit about kind of how you distill down to that thing that is important or the importance of focusing on what is important to you even if you cannot do everything that you used to be able to do.

Tyler: Right, and I think that is so key. When I was laying there, I think there was a lot to be said. The human mind goes to so many different places when there is silence and when there is no miscellaneous noise. A lot of times when we are diagnosed, we are trying to figure out what the heck is going on and what the next steps are going to be. And a lot of times, that is in isolation, right? In my isolation, my mind literally began to carry over and helped me understand that football was just a small portion or piece of my life. Football was nothing more than a talent and a lot of times we all have talents. This is something we are all gifted with. Mitzi can do some amazing things that Tyler Campbell cannot do and vice versa.

Tyler: Listeners, you all have qualities that you can do. I learned that football was just a small avenue or piece for me. That is not who I am. There are many other gifts that I have. There are other things I love to do. I listened to a message by Dr. Martin Luther King talking about purpose, sense of somebodiness, your own sense of self-worth, and understanding those things that you are called to do. What is that thing that you have been called to do with your life? The only way you can get there is if you spend some time with yourself getting to know you. We get caught in so much of the hustle and bustle that we forget to give our self some time, some love, some energy, and some compassion, right? And in doing so, I have learned that there are more qualities to Tyler Campbell.

Tyler: Football is just a small stepping stone. And a lot of that was for my voice to be lifted and utilized. I found out that utilizing my voice, MS cannot take that to me, Mitzi. Mitzi, MS can take this body. I felt like I had a leg up on MS because it cannot take something away from me. In doing so with my voice, I learned to get another sense of comfort and confidence in myself. Yes, my limbs are taken. Yes, I have speech therapy. Yes, there is chronic pain. And yes, you are worried about how you may be perceived. People were looking at me funny because they cannot figure out what is going on with me. What set me free was I found my purpose, Mitzi. And finding that purpose of speaking allowed me to make myself more vulnerable and open up to my family to be able to receive help, because we cannot do it alone, right? I was doing it alone in college trying to do it all by myself, but life is a lot to carry by yourself. Your privacy will keep you from achieving your destiny, right? You cannot hold everything to yourself. It is when you open up about your MS diagnosis that the fruits of life can start to manifest and you can start growing. Why? Because you will meet somebody like a Dr. Mitzi. You will meet somebody like Can Do MS. You will meet people who can dive in and help you, and then watch this, it gives legs to your purpose and can take you further. Mitzi, I cannot meet you if I do not have MS.

Mitzi: Yes, that is so deep. I liked what you said about your privacy is keeping you from your destiny. And so, I spend a lot of time educating about this need for help. We all need help. We cannot accomplish anything solely by ourselves in this life. And so, it is a very hard thing for many people to do. We have this sense of society that you are supposed to be self-sufficient,

pull yourself up by the bootstraps, make it happen, and work till you pass out. All of these things and all these tropes that are kind of ingrained in us, but I think that situations like people being diagnosed with MS, or even people dealing with a pandemic and having to totally shift gears, really gives us an opportunity to not only ask for help but to see how many people we have around us who are absolutely available and willing to help that we just were ignoring the whole time. Oh my God, that is so good. But I also like the fact that you were able to look and say, "Okay, I love football but this is a part of me." I think so many times when we try to reach a certain goal, I think for myself I spent years and years to become a doctor, right? And so, I remember that moment when I finally stopped saying, "I am going to be..." Because for the majority of my life, I kept telling people, "I am going to be...I am going to be...I am going to be a doctor. I am going to be a neurologist. I am going to be an MS specialist." And then, once I achieved it, I was like, "Oh, well, what do I do now?"

Mitzi: And even partway through my career, I came to this realization that, yes, I love seeing patients and I love touching people one-on-one, but I had a sense that my purpose was to reach beyond just the exam room and to be able to reach and educate people on a broader scale. That was when those doors opened up so that I can do things like advocates like you and others, and to really work toward my passion which is taking care of people, but also, serving my community. And so even for us who do not necessarily have a chronic illness, it becomes important for us to really kind of look at these moments these 'aha' moments, and refocus ourselves, dig in, and find out what exactly we should be dealing with.

Tyler: I love it, Mitzi.

Mitzi: That was so good. Okay. So, now that we have been diagnosed, right? We have connected with a healthcare team. We have kind of opened ourselves up to say, "Hey, I need some help to be able to deal with this." Let us talk a little bit about self-advocacy. This is a huge thing for me. I think one of the biggest difficulties that I have seen as an MS specialist is that many of my patients do not recognize that they have a voice, right? That they have a say. That they are part of the healthcare team. And unfortunately, many people have gone along and continued on treatments that were not effective, have continued to decline, and do not really know that they have a say-so. Tell us a little bit about how you found your voice and the importance of self-advocacy. As well as, what tips you may have for people to become advocates for themselves or their family members?

Tyler: Yes, no problem, Mitzi. My family is from the country, right? I grew up riding horses and being in the country. That is my family. I always think back to watch my Uncle Willie plant peas, right?

Mitzi: I have an Uncle Willie too.

Tyler: Really? Okay. Everybody has an Uncle Willie. My Uncle Willie would plant peas and watermelons. I looked at it and Uncle Willie could not get to the final product of reaping the harvest of the vegetables and the fruits until he did what is called 'disking or turning the soil'.

A lot of the listeners listening who are from the country get where I am going with this, right? And so, what I learned from it was like, "Yo, Uncle Willie could not get the final product until he flip turn the soil upside down. He had to do something different to the soil in order for us to eat these watermelons over the summertime that we so desperately were looking forward to." right? When I looked at my MS diagnosis, Mitzi, to get down that path of kind of a bit like having a voice is like, "Yo, I found my voice." Why? Because my world got flipped turned upside down just like Uncle Willie used to do with those watermelons, right? And then, I receive that final product of understanding what my voice is, and that voice meaning that, "I, little old Tyler Campbell, out of the million people are diagnosed with MS in this world, I have a voice." And my MS diagnosis is unique. Why? Because there has never been another Tyler Campbell and nobody else can tell it, share it, or walk through it as I can.

Tyler: And a lot of times we get caught up as if we are just another number in the long list, but in all actuality, we are a valuable number. I do not know, Mitzi. It could be me just making that stuff up, but that is, psychologically, what I did. I said my MS diagnosis matters. And by me lifting my MS diagnosis and becoming an advocate for my story, it could possibly help somebody else maybe get to a diagnosis faster than a week for me, Mitzi. Maybe there is somebody who gets diagnosed the same day because they picked up on some of the things that they learned from my own. And so that is what really prompted me to get out there, was to share it and to talk about it, because somebody else could reap a harvest even faster or I could put down a road of recovery even faster. That is what help maneuver me, was Uncle Willie playing watermelons and mixing. Long story short, Uncle Willie from Tyler, Texas area code 903 is who got me to look. It is amazing what you remember as a kid to help form your own advocate.

Mitzi: Exactly. That is so important and I think everybody has their own analogy or things that kind of spurred them on to that point. But I think, for me, it was seeing so many people who were not doing as well as they could because they did not know that they had a say. I think it is so important for us to know that within this healthcare system, we are really moving a lot toward what we call 'shared decision-making'. I do not sit down with people to say, "This is what you are going to do because I know what is best." right? Although I have a level of expertise, you know what is best that works in your environment. You know how your body works. You know your schedule. You know what your lifestyle is like. And so, we have to come together and make these decisions as a team. I think it is extremely important for people to recognize that their family members and care partners are also an extremely important part of the team, because not only can they be that extra voice, they can be your memory and write things down for you during visits while you are paying attention to other things. They also can provide insight into how you are doing. I really encourage people to have their care partners as part of our team because sometimes they will notice things that you may not notice, right? They may see things that you may not see and they provide that extra perspective that really helps us to move forward.

Mitzi: Right before we leave, that last piece is accountability. When we talk about care partners, I have a lot of folks that come in, right? The husbands and the wives, right? I ask the

husband, "Hey, Mr. so-and-so, how are you doing?" He is like, "Great." And the wife is like, "Uh-uh." There also has to be a level of accountability where you have people who are offering help but who are also holding you accountable to do the things you are supposed to do. To take your medicines or to do whatever exercise regimented routine. Why do not you talk a little bit about accountability?

Tyler: Absolutely. For me, I think it is that point of making that stepping-stone to allow yourself to be vulnerable and to be transparent. It is like we have that wall in front of ourselves where we do not want to put ourselves out there because we are fearful of what people may think. We are fearful that it may disgruntle a marriage. It may hurt a relationship. It may cause tension on our job or to possibly lose our job. We let people know that we have a mess. But in all actuality, Mitzi, you can attest to this. A lot of times when you say what you are going through, that is actually when the healing can take place. I feel like our pain points are there but when you are able to seek the healing, that is when the recovery really starts mentally, physically, and emotionally for yourself. You are able to free yourself of that "stress", Mitzi, because we have been fighting the battle alone. So, I just encourage people like what I did was I said, "I am going to do a new thing. I am going to do something different and I am going to go against what goes on in this house stays in this house. I am going to throw my MS at your feet and see if we can both be educated together." And because I rallied the troops of my family in the country, in rural east Texas, let them know about what this MS thing is? Your family shows up in a different way of love because they see. People cannot know how to help you until they know that you need some help. That all goes back to everything you said. It opens you up to an avenue of love and support. There is something so powerful about somebody calling just to check on you to see how you are doing.

Mitzi: Absolutely.

Tyler: To tell you they love you. That is powerful.

Mitzi: And that makes such a difference, right? Because healing is not just about medications. Healing is about community. Healing is about love, understanding, and trust. It is so much more than just going to see the doctor. So, I love it.

Narrator: Thank you for tuning in. This episode of the Can Do MS podcast was brought to you by our sponsors Biogen and Genentech. Make sure to listen to part two of this podcast where Tyler and Dr. Mitzi Williams continue their conversation. The next episode is available now wherever you listen to your podcast. Once again, thanks for tuning in.

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