



Can Do MS Podcast Find Your Voice: Part 2 Episode 35

Narrator: Get ready for Episode number 35 of the Can Do MS Podcast. Today we welcome Tyler Campbell and Dr. Mitzi Williams back for part 2 of the podcast titled 'Finding Your Voice.' If you did not listen to part 1, please go back and make sure to listen to Episode number 34. We definitely do not want you to miss out on part one of this great conversation. So now, welcome back.

Tyler Campbell: Hey, excited to be here. If you missed the earlier part, you missed something sweet, you hear me? Better go back and hit that playback button.

Mitzi Williams: Exactly, because we are having a good time and talking about some really, really important stuff. Okay. So now, let us switch gears Tyler, and let us talk about wellness, right? So, coming from the aspect of an athlete, I know you know a lot about wellness. Tell me what wellness means to you.

Tyler: For me, I like to always think of it in three different stages, right? Of course, being an athlete, I was introduced to physical wellness from a standpoint, but as MS came into my life Mitzi, I am going to be real. I learned there is also a mental wellness standpoint and there is also for me, I think the last one is kind of like a face standpoint for me because there's a lot of hope, a lot of uncertainty. You do not have to lean on something in your own facet of where you are with MS, so the body, you only get one of these, right? You got to treat it the best way that you can, so with MS, I was obviously cultured to just start doing a different thing. We cannot be eating Bojangles all the time. I cannot be eating a burger on the west coast all the time. I cannot be at Whataburger in Texas all the time, you hear me? I am just being open, this is me, this is where I was. Tyler had to make some shifts and some changes from a physical standpoint.

Tyler: You may not be able to hit the gym all the time, but there is something to be said about being able to stand at times throughout the day. There is something to be said about being able to walk to the mailbox, those little things. I am not talking about marathon wonders, but there is a greater attention to be able to play towards your physical health and watch this, we can control that. It does not take a doctor visit to do that. That is a decision you make up in your own mind to make some adjustments like we talked about earlier. From a mental

standpoint, just knowing that hey, you may need to talk to somebody about what you are going through. Your overall mental approach to how you handle this disease is very, very big. Depression is real Mitzi.

Mitzi: It is very real and very common.

Tyler: Yes, it is not a figment of the imagination, and your faith, whatever your faith endeavor is, lean on that because it gives you that hope, and that hope will create determination. Determination is a positive attitude, right? We talked about how your attitude plays into so much, and when we have hope, it creates that positive attitude, and when we have a positive attitude, there is no limit to your altitude as a human being and what you can do. I break it down into those three parts but they are... Your wellness is everything.

Mitzi: So important, and there is so much to unpack there. Okay, so let us start with the physical. I love what you said about recognizing small gains, right? When I talk to people about exercise, oftentimes especially if they have some type of physical impairment from their MS or if they are dealing with fatigue, I tell folks you have to reframe what you think of as exercise, right? So, a lot of times we think of exercise, we think you go to the gym, you put on your Ivy Park or Adidas outfit, you work out for an hour or thirty minutes on the treadmill, thirty minutes on the weights, but walking to the mailbox two or three times, right? Parking a little further away in the grocery store and walking further, right? Every little bit counts, and so we have to reframe our thinking, and again, adjust, so that we think just because I cannot do this does not mean I cannot do anything, right? All of us can do something.

Mitzi: I had one patient who was so remarkable. She was a woman who had been living with MS and unfortunately had lost the use of her legs and only had the use of one arm. Every time she came in my office, she needed to lose some weight, and she was getting skinnier and skinnier, and I said, "Well, what are you doing? You can only use one arm." And she said, "Well, I changed my diet right?" So, just because I cannot do that, does not mean there is nothing I can do. And so, that power of our mental thinking and our mental state is so hugely important. The other thing is to recognize is that you already said, is that our mental thought process significantly affects our physical outcomes, right? So, if we keep telling ourselves we cannot do it, you are not going to be able to do it. And so, making sure that we use that community support, making sure that we get that help, the help of a counselor or therapist or a faith-based counselor. Whatever that help is that we need, seeking that out is extremely important to our success and to the look of wellness, and to use one of my "Dr. Mitzi-isms" as I call them.

Tyler: Here they come, you all. Here they come. Get your platform ready.

Mitzi: You know they are coming, right? Get ready. So, there is a part you play, right?

Tyler: Yes.

Mitzi: There is a part you play and there is a part medicine plays. No medicine is going to take away the part that you play. Once you get that diagnosis, once you get on a good treatment regimen, that still does not mean that you just sit on your hands and do nothing, right? You got to be doing that physical exercise, engage in that community, etcetera, to try to move forward. Now, when we think about wellness, a big part of wellness is the physical part, and oftentimes, especially throughout different points in that journey of wellness with MS, there are a lot of interactions with the healthcare system. When people get first diagnosed, they see me a lot. Once they are doing good, I might see them every six months or once a year, but there are some communities, Tyler, where some people's interaction with the healthcare system is not necessarily positive. Let us talk a little bit about trust. One of the biggest parts of being a health care provider is that I have to establish trust with my patients. And so, kind of what does trust look like, and what are maybe some of those examples where people interact with the system and do not necessarily have as positive outcomes.

Tyler: Yeah. For me, I want people to remember I was twenty-one years old, I am young. The healthcare system is not something I really navigated to outside of getting annual physicals which is nothing major until you have to get to a point of really treating an ailment or a disease, so, a lot of trial and a lot of error experienced on my part, but it is actually through navigating the healthcare system in terms of making my own phone calls, Mitzi, and maybe not getting the answer I wanted to that day may have taken a week, may have taken even a couple of months on a medication especially when talking about financial pieces, but it is learning that there are programs, there are initiatives that are out there, and there are a lot of them to help you get the adequate care that you need specifically when it comes to paying for pharmaceutical remedies that you need to treat your MS, and the different support groups that are available.

Tyler: But like you said earlier, there is a list of things that we have talked about in self-advocacy and all those things and adjustments that allowed me to get to that point. And so, when I had navigated through trial and error, figuring out okay, there are programs out there, because there are trial and errors with my MS medications, I was not on just one MS medication, Mitzi. Hello, sometimes it may take doing a couple things before you find it out. I hope it is not for you, but that is what it took for me. What it did was it allowed me to approach a neurologist and let a neurologist know what I want, let a neurologist know what I need, so a neurologist can give me guidance and direction as to how we go out and get there, you know.

Tyler: So, that's the thing, I think there is something to be said when you are interacting with people in the healthcare system, with you having an agenda for your own self-advocacy and awareness of what you are looking for because your diagnosis of MS is not like the patient walked in the thirty minutes before you are getting to see him. You have a different level, you have a different body. And so, those are the things kind of creating my own MS world of what I want my pharma or what my healthcare interaction to look like, and then the professionals were able to usher me. My neurologist was able to usher me, but my neurologist could not usher me until I voiced what it was I was looking for, you know, so, go ahead.

Mitzi: Yes, so that is so good. When we talk about your relationship with a neurologist, I think that this is extremely important, because one of the reasons that I chose MS is because I am a people person, and I love people and I love being on this journey with people. I love seeing people go from diagnosis, where they may have been kind of dealing with the difficulty of it, dealing with the uncertainty, two-three years later they are showing me baby pictures, they graduated from this. I love to see the other side of that, but it really is important to have a trusting relationship, and I think that one thing that people need to know very early on is that if you encounter maybe that first neurologist and you do not feel like you have that trusting relationship with them, it is okay to seek a second opinion, and I have seen a lot of people. It is okay to seek a second opinion, and I have had a lot of people run into difficulty with that and maybe not go on treatment because maybe they interacted with that person and they gave them a handful of pamphlets and they are like, "Well, I do not want to do this." Be persistent.

Mitzi: What I heard you saying throughout a lot of what you were just talking about was that you were persistent. If you did not get the answer this day, you call back another day. If you did not get what you needed here, then we looked over here for it. And so, you have to be persistent when it comes to your healthcare. If you are with a healthcare team that you do not feel confident in, then find another one, right? Find another one, and I tell people even who see me, "Listen, if you do not have confidence in the decisions that we are making together, I am not going to be offended if you look for somebody that you think fits you better." Right? There's nothing wrong with that, there is nothing offensive about that because it really is a journey, right? And when we talk about treatments and telling people things about yourself that you would not tell anybody else, you need to have that trusting relationship. Then, another piece that I think is extremely important when we talked about self-advocacy was that you talked about resources.

Mitzi: There are many, many resources that are available to people with MS, not just with pharmaceutical companies, but also with our advocacy groups like Can Do Ms, like The MS Society, like the MS Foundation, and you do not know about those if you are not connected, right? I think connection is another extremely important aspect of self-advocacy within the healthcare system, connected either to a support group, connected with some of these foundations or other groups, or connect it with advocates such as yourself, because that is where you find out information like networking where you try to get a job or you are trying to get in somewhere. It is about who you know, and so when you know people who know things, then you know things too. And so, I think that that is the extremely important part is connecting with the MS community in whatever way that looks like for you.

Mitzi: I think one of the challenges especially for underserved communities, whether those are people of low socioeconomic status, in some cases people of color like us, sometimes people do not have positive interactions with the healthcare system. Sometimes people may have delayed diagnosis, so they may experience bias or discrimination within the system. Tell me about kind of how you have either help people navigate or deal with that or maybe some of the things that you may have either dealt with personally, or had people that you know

with MS who dealt with some of those issues and how they have overcome them.

Tyler: To be honest, Mitzi, I am going to be real. I looked at what I have. I looked at my family. I looked at who I am and what I come from, and then I looked outside of my family, to get a greater understanding. What I mean by that is I looked at my family tree, I looked at what I come from. I have a grandfather who was present on D-Day, he was a part of the black Army Air Corps. I looked at my father, was an NFL Hall of Famer and a Heisman Trophy winner. I looked to my mom and my dad, first-generation college students, came from absolutely nothing to make something of themselves. And so, I looked at my family tree and it is like, whoa, it was not about having money, it was just about having a will, and about having people who have a desire to just do something with their life, so I said, "You know, I am gonna do something with my MS."

Tyler: And then, I looked at my history of people, I looked at the culture, I looked at my ancestral heritage of people that I come from, I looked at W. E. B. Du Bois, I looked at M.L.K., I looked at Markus, I looked at all these people, I said, "Yo, I come from something." And so, with that, you say, I can do something with this MS journey, and watch this, it is going to be hard, it is going to suck, it is not going to be fun. Matter of fact, I am going to probably hear "no" more times than I hear "yes", so just get comfortable. But I come from a history of overcoming something, and it is like we always have a story to tell when we overcome.

Tyler: So, I was constantly looking for that one day when I can tell and share that story of overcoming, but I know of what I come from, so, if your inner family ain't that great, cool. Look at ancestral heritage, find a story that you like with people who do not even look like you if that is what it is got to do, but you create what it is that you are looking for and what you want and you go out and have it for yourself. So, I said, Mitzi, I come from heroes, and a hero is not going to give up just because somebody says you cannot get treatment here, or because we do not offer that service here. I am going to walk into an infusion clinic and I am going to ask other MS patients in this infusion clinic that may not even look like me "how did you get to where it is that you got, how did you find?" and then you start building your own book. You are a best-selling novel yet to be written, I am telling you all.

Mitzi: Yes. I love it.

Tyler: You know what I am saying? So, that's kind of what got me... I created my own imaginary world. That is what I did.

Mitzi: I mean, that is so deep and that is so good, because I love this thought of if it is not in my immediate surrounding does not mean that it is still cannot be a reality for me. I think that mental process of persistence and unwillingness to give up, it is so key in this journey, not just with MS, a chronic disease, but just in life, right? Because we all encounter times when people tell us 'no', we all encounter other instances where we may not get the answer that we want. I have many people who come to me who said, "I just knew something was wrong and I am going to keep searching until I found the answer." And so, that persistence in that stick-to-

itiveness really pays off in the end. And so, I think it is so important for us to express to people to not give up and to not quit. If you do not get the answer you need today, keep pressing, you will get the answer, and maybe try going somewhere else if you do not get the answer you need in one place.

Tyler: Nothing wrong with it.

Mitzi: I think that is so huge. Nothing wrong with it, right? Nothing wrong with it. Finally, just, you know, you have given us so much good information and so much knowledge about how we can advocate for ourselves and how people living with MS can advocate for themselves. If you had to put it down into like three top tips you would give people living with MS to advocate for themselves within the healthcare system either for themselves or their families, what would those top three be?

Tyler: My top three tips would be to number one: Do not let your MS just be yours. Make your MS open to your family. We have a tendency to that woe-is-me attitude, we feel like that is negative, we do not want to share our problems. There is something to be said about "hey, I do have MS", and your ability to be vulnerable opens up the pathway for people to help you. I am not here on my own accord, Mitzi. I did not get out of the wheelchair on my own accord. There are tons of people who are not on this podcast that had helped me get to where I am, and in doing so, I think that there is something to be said when you are on this path of MS to navigate it in such a way to where you can also share what you have been going through with somebody else with the hope of helping other people with MS, to make yourself visible.

Tyler: Those are my biggest things, and again, those are free. You do not have to go somewhere. It is a choice that you literally make up for yourself, that you are going to be open, that you are going to be willing to be transparent. So, that is when the true healing can take place. We have gone through the pain, which is when you go through those painful experiences that you really look, and true healing can really actually start to take place in the midst of your pain of getting diagnosed. That is kind of what is big for me is just being transparent and being open about your diagnosis.

Mitzi: Wow. Yeah, so that is amazing. So, being transparent and open about your diagnosis, asking for help, and then using your MS as a voice and as a way to kind of help others and to also help heal yourself. That is amazing.

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Narrator: And that is it for our show today. This episode of the Can Do MS Podcast was brought to you by our sponsors Biogen and Genentech. If you enjoyed this episode and you would like to help support the podcast, please share it with others, post about it on social media, or leave a rating and review. You can also follow us on Instagram at Can Do Multiple Sclerosis. Thank you so much for listening.

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