



MSAA Podcast - Episode 24:
MS in Your 20s
The MS Journey: Stories and Strategies for Women Across the Decades

Host: Kate Durack, MPS

With special guests:

Stephanie

Mitzi Joi Williams, MD, FAAN

Kate Durack

Welcome to The MS Journey: Stories and Strategies for Women Across the Decades - a series from MSAA exploring multiple sclerosis through every stage of life. In this episode, we begin in the 20s, a time of discovery, independence, and unexpected change. We'll hear from Stephanie about her early experiences with diagnosis and identity, and we will be joined by Dr. Mitzi Williams. Together, we'll explore what it means to navigate MS at the start of adulthood, from uncertainty to adaptation and everything in between.

I'm Kate Durack, the Director of MSAA and Communication and Patient Focus with MSAA, and I'll be your host for this episode. Welcome, Stephanie and Dr. Williams. Thank you so much for being here. I'd like to start us off with introductions. Stephanie, do you mind telling us a bit about yourself and your diagnosis journey?

Stephanie

Yeah, my name is Stephanie. Thank you so much for having me today to discuss my journey. I was diagnosed in 2020, so it has been about six years of being diagnosed, and I was diagnosed at 23. And before we start, I would just like to acknowledge that I am inherently privileged to have access to great medical systems, specialized doctors, and to work as a nurse. So I do know how to navigate the healthcare system.

Kate Durack

I appreciate you sharing that very much. Thank you for being here. Dr. Williams, how about you?

Dr. Mitzi Williams

Yes, I'm so excited to be here to speak with you and Stephanie. My name is Dr. Mitzi Joi Williams. I am a board certified neurologist and fellowship-trained neuroimmunologist in Atlanta, Georgia, and I am the Medical Director of Joi Life Wellness Group here in Smyrna.

Kate Durack

And just to share a bit about my personal connection with MS. I am also living with MS, and I was formally diagnosed 10 years ago at age 30. So I'll probably be sharing bits and pieces of my journey as we chat. And to set the stage for this podcast, I'll be leading our discussion with some key questions. And I'd like to start out with a question for you, Stephanie. So what were your earliest MS symptoms and how did you make sense of them?

Stephanie

Yeah, so my story begins in April 2020. So at the height of the COVID-19 pandemic, I had come off a stretch of night shifts and I woke up unable to focus my vision on my phone unless I closed one eye. So I shook it off as fatigue, but over the next few days, I realized that I had begun to have just the slightest double vision when I looked to my right side. So it wasn't even full frontal, it was only when I looked to the right side.

And sadly, I noticed it while I was watching the show House, so I haven't been able to watch it since, which is just a shame because it's a great show. But so when I say slight double vision, imagine those shaded letters on a Word document slightly above where they have the shadowing. And that's kind of how things looked to me when I had looked to my right side.

I was due for an eye exam, but it had gotten canceled due to the pandemic. So I had reached out via e-mail just to let them know that I had this new symptom that was kind of concerning to me. They had instructed me to go to a specialized eye emergency department that was located near me. I went in to be examined and they looked at every part of my eye and they couldn't find anything structurally wrong with it. So at this point, the next step was to get an MRI and see if there was anything going on with my brain.

And at this point of my nursing career, I had been an oncology nurse. And so you can only imagine how scary that felt to me because I was like, oh my gosh, is it going to be a brain tumor? So I went into this MRI trying to remember every little thing I could from nursing school while simultaneously trying not to panic. And they let me know later on that they had found two lesions, demyelinating lesions on my MRI and the suspected diagnosis.

Looking back, I do remember having intermittent doubling of my vision even a year prior when I was really tired driving home from work but I didn't think anything of it. And so they then referred me to an MS specialist. I got a lumbar puncture, lots of blood work, and a prescription for a hefty dose of steroids.

I remember going to the pharmacy to pick up those said steroids and the pharmacist giving me trouble because the dosage was so high and I didn't look like I had a reason to need them. And now I wouldn't have thought twice about that interaction, but in the moment while I was still processing and in complete disbelief, it felt like the worst thing in the world. So that was a little bit about how everything started for me.

Kate Durack

Well, thank you for sharing that. Oddly, my journey to diagnosis is incredibly similar to that. And

so I've shared in the past about mine as well, but same vision issues, retina specialist leading to MRI, leading to diagnosis. And so I think what would be helpful is Dr. Williams, is this a common story?

Dr. Mitzi Williams

Absolutely. So I'm listening to both of you and I'm saying this is one of the very common scenarios that we see when people are first diagnosed.

But I would like to point out that the things I think that stood out about your story, Stephanie, or your journey, is that you did that follow-up. And sometimes people get lost in that follow-up period between when you see that something's wrong and when you get maybe a referral to one doctor and then they order all these tests, some people may say, "Well, you know what? It's gone away. I feel better. So maybe I won't get that MRI or maybe I won't go see that second specialist." And that's often where we see people accumulate disability, but it is not uncommon for young people to develop visual problems. Sometimes you go to the eye physician and it may be optic neuritis, but in your case with double vision, sometimes there's a problem in the brain in the back of the brain.

And so again, it's that persistence, right? When you have that symptom and something is wrong, if we don't necessarily get the answer with the first visit, making sure that we follow up and follow through with those second, you know, imaging tests or that second specialist, because that's often where the diagnosis happens.

Another common symptom that we see is people may have things like maybe their legs are dragging, you know, maybe they have a little weakness. And again, when you're young and otherwise healthy, people may blow it off and say, "I was tired. I did a long shift. I was walking around a lot." You know, maybe it was nothing, you know, but it is never normal for us to be weak. It is never normal for us to not be able to see. It is never normal to have double vision. And so I think the most important thing is if something is wrong, get that checked out and follow through.

Kate Durack

Yeah, self-advocacy is huge and just not questioning your body and go with your gut. I think that's probably the best route for everyone. But hard to do in your 20s when you think you're invincible.

Dr. Mitzi Williams

Very hard, very hard. I get lots of folks that come in and say, "Oh, my memory was bad. I thought I was getting old." And I'm like, you're 22. Like, why would your memory be bad? Like your memory should not be bad at 23.

Kate Durack

Yeah. Okay, my next question, Stephanie, I'll start with you again. What support network did you have when you were diagnosed, friends, family, or peers that really stepped in to help you out?

Stephanie

Yeah, that's a great question. I had a really good support network of friends, a supportive partner and family, but when you're in that moment, no one really knows what you are feeling or even how to support you. Even to this day, it's hard for people to truly understand the mental

load that comes with a chronic illness and that even though I don't present with physical symptoms, I still have fatigue, brain fog, anxiety, et cetera, that I'm constantly working through on a daily basis on top of just managing regular life mental load of like, what's for dinner? What am I following up with at work? It can be really challenging, especially when you're well-appearing.

I did find it really helpful to have a care coach that was assigned to me through my insurance. Her name was Misty and I just will always remember her because there was one point where like we were both crying on the phone and she just like helped me process a lot of things. I just feel like that's an undervalued resource that is typically free with insurances. A good therapist helped a lot. Someone to just be an unbiased, not throwing positive things at me constantly and letting me sit in those feelings. And access to online support groups at the time.

I actually met one of my best friends in an online support group. She had been diagnosed in December of 2019 and we have really been able to support each other through things when it feels like no one else understands. Yes, we're crying over blood work, even though we get it twice a year. But over time, the scar tissue adds up, especially if you're getting infusions. And when they fish for a vein, it hurts.

And it's not fair. It's not fair. And something like that may seem so trivial to someone, but it's not when you know it's for the rest of your life.

Kate Durack

Thank you so much. I know this is a podcast so you all can't see us, but Dr. Williams and I were nodding very strongly along with everything that you said.

Dr. Mitzi Williams

Absolutely.

Kate Durack

That's so wonderful that you have that support system. And I know I wish I had somebody in the same age group that was going along this journey with me. I think that would be incredibly helpful. And Dr. Williams, what role do you see social support playing in general for people that are coming into your office?

Dr. Mitzi Williams

So it's extremely important. And Stephanie, I mean, you hit the nail on the head. You hit so many important points. And as Kate said, I'm so happy that you had access to these resources and that you had the wherewithal to connect with the coach, to connect with the therapist, because oftentimes people are really overwhelmed and just may not even have the bandwidth to try to reach out to get those resources, which will make them feel better and maybe decrease, increase the bandwidth, so to speak.

But support is extremely important because, as Stephanie said, nobody knows what it feels like to have MS, except for someone else with MS.

Even as a specialist who has been seeing people and diagnosing and treating people for over 20 years, I don't know what it feels like to have MS. And so that sense of community with people who understand I think is extremely important. So I do encourage everyone when they're newly diagnosed to get involved in some type of community.

Now the difficulty is every community is not for everybody. You know, I have some people with some of the in-person groups that said, "Gosh, I feel so bad complaining because these other people have more physical symptoms than I have," or "I don't feel like I can relate to the people in this group." So it's really kind of finding your tribe and your group of people.

The other thing that's a little bit more difficult for my younger patients is that often because they don't have as much physical disability, they're working, they're moving around, they're doing the things, right? So they don't necessarily have time to meet at a support group in the middle of the day on a Wednesday. So it is, trying to find, that group of people who have that, or trying to create spaces where people who are young, and moving and doing things can get together.

So that support is extremely important from the very beginning, but not just family support or friend support, but also the support of people in the MS community. And, as was mentioned, the support of our coaches, our mental health patients, because it is a lot to take on, right? Life is a lot, period. And then you add a chronic disease on top of that. And it's like, okay, this is a lot for anybody to handle.

And I think, I tell my patients, listen, if you weren't having trouble when you got diagnosed, I would think something was wrong with you. Like if you just said, "Okay, no problem." I mean, so we expect that people will deal with some difficulty, you know, and you know, there is that thought that "This is gonna be for the rest of my life." We don't have a cure. What are these treatments gonna mean? How much, you know, there's just a lot that, you know, that comes with diagnosis. And so all of those support systems are extremely important for people to live well and to thrive with MS.

Kate Durack

Yeah, absolutely. I think that is key. And also just having people around you outside of direct lived experience who you can talk to, who will be your sounding board, who will go to those blood draws with you, who will go to those infusion appointments, will help you pack your bags, get your bedroom set up so that you can recover nicely when you get home, get all of those pieces into place just to take some things off your plate. That helps tremendously.

Dr. Mitzi Williams

Absolutely. And sometimes it's your chosen family. It may be your blood family, but sometimes it's your "family" as people call it. So, just finding those people that can be that support, whether they're inside or outside your home, is extremely important.

Kate Durack

Absolutely. And there's actually a level of beauty and freedom to that kind of support system, Dr. Williams, because I know that I feel like less of a burden to my friends that are coming in to support than my family. I don't know how to make sense of that, but it just feels like I can call on them when things are hard. They know me at a different level than my parents do to a certain degree. And so they can understand maybe how dealing with these things at my age specifically, because they're also in my age, could impact my daily life and then they can step in smoothly and help out where needed.

Dr. Mitzi Williams

Absolutely.

Kate Durack

Yeah. Well, thank you both for sharing those things. Stephanie, I want to ask you about, I mean, you're a nurse, so that's huge. But can you tell me about how you needed to change how you navigated your early career decisions with MS?

Stephanie

Yeah. So my diagnosis made me think of my long-term career plan because working three 12-hour shifts and rotating and all of that with fatigue and brain fog and the anxiety of potentially making a mistake and harming a patient, it just, that was the spiral that my brain was constantly in after being diagnosed. And it kind of made me look towards like what would be sustainable in a worst case scenario.

At the time it had led me to take on a more administrative role, which I don't regret because it gave me a ton of great experience, but I am now in a role that is part administration with part clinical responsibilities. So I'm back to like taking care of patients and supporting an inpatient unit, which I find way more fulfilling in my current phase of life. But I think that my grief and depression made me feel like I had to make career decisions immediately. And luckily it's all worked out that I'm in a role I love and see longevity in it no matter what happens.

But I do think like if I can give any piece of advice, it's that you have time. And people like, there's people who get into car accidents who have death of a family member and their life trajectory is completely thrown off kilter too when they pivot. And you can pivot to when the time is necessary. So I just think that's important because I think like in the heat of diagnosis and grief, like I was just completely catastrophizing a little bit. And so now I'm in a better spot and happy with decisions I've made, but in a better spot where I enjoy my career again.

Kate Durack

I love that you said that. I've really never thought about that. But same, I definitely did the same. I think when I was diagnosed, it was like Chicken Little and the sky was immediately falling. And I was 20 years ahead and I was thinking through future marriage and kids and what does all this look like and what do I need to do to get my life set up so that I can still support everyone in a meaningful way, and not become a burden and all of these things, and it hits you like a ton of bricks.

And I'm guessing, Dr. Williams, this happened, you probably see this happen in real time, right?

Dr. Mitzi Williams

Absolutely. So I do see this happen. And in many cases, there is time and room to make decisions, to kind of take a step back as we're recovering, and decide what to do.

But in some cases, unfortunately, due to the symptoms a person has, due to their level of recovery or their level of disability following a relapse, some people do have to make an extreme pivot. So I've had people who, for instance, did not recover from visual loss and you can't be a real estate agent and show people around the houses if you can't see, right? Or if you're a truck driver and you are weak in your driving leg, then you probably can't do that anymore. So, I think there's a wide range of ways that people deal with this.

But the first thing is, to first kind of take a step back, because for many people who do the spiraling, sometimes they're completely normal, right? So they had to relapse and then they're completely back to normal. And those are the ones where I'm like really kind of talking folks off the ledge, like, okay, it's gonna be okay. Let's get this plan in place.

But I think that's where the support team comes in, particularly working with the therapist to kind of talk through these things and kind of talk through these issues, seeing what we can do now if there are limitations. Sometimes there are no limitations and then sometimes there are extreme limitations where we have to completely pivot and say, "Okay, well, I definitely can't do that anymore, but what else can I do?" And I've seen many people find an amazing purpose when they've made that pivot. And so, you know, my encouragement is always, you know, we may not be able to do what we used to do, but you're still here, there's still purpose. So let's figure out what the next step is and how we can move forward from there.

Kate Durack

Yeah, that's wonderful. I did want to make mention in my past life before MSAA, I actually helped with disability support services and I helped people with all kinds of disabilities find employment. There are programs in every state with vocational rehabilitation that can help support anyone who needs that kind of transition in life.

So if something happens for you and you weren't you didn't have the proper education to shift gears with your career or you're not able to do something physically that you were once able to do and you need to shift your career, vocational rehabilitation can definitely be a good resource for anyone.

Dr. Mitzi Williams

I love that you said that. And one more thing that I would add is also, working really closely with your specialty team for accommodations, right? Some people, when they are diagnosed, some people get into a little bit of pride and it's like, well, I'm not going to tell anybody I need help because I've never needed help. But oftentimes we can keep people employed and doing the things that they love with some adjustments. And so not being afraid to talk to your healthcare team about, you know, are there adjustments that we can make? Are there work accommodations that we can do where I can take breaks or I can sit. And if we reach out and get those things off and we can keep people active and employed and doing the things that they love to do.

Kate Durack

Absolutely. That was actually my favorite part of that job, Mitzi, was going into the workplace and figuring out accommodations for people. Wonderful.

Well, thank you for that as well. Stephanie, we talked about relationships a little bit, but how did your relationships change and shift with friends specifically with your diagnosis?

Stephanie

Yeah. So honestly, I feel like my diagnosis made me reevaluate a lot of my friendships. I cut a few people out who I felt weren't adding to my life, or sparking joy as Marie Kondo would say, and when I was diagnosed, I felt like some of my friends were afraid of me. They were afraid to ask how I was doing and talk about it and that kind of hurt. And I realize now that they probably didn't know how to respond and were unsure how to support me, even though in that moment,

like I just needed to be talked to about anything else. You didn't have to ask me about that, but anything else.

A huge thing for me was that I had significantly cut back drinking due to a medication I started on. And just for overall wellness, inflammation control, from doing my own research. And not drinking at 23 is pretty far from the societal norm, at least on the East Coast, I don't know how it is everywhere else. So I constantly had to be vulnerable and explain why I wasn't partaking.

Luckily at 29, Drinking isn't the center of all activities anymore, so hooray for that. And I feel way more confident in the fact that my friends love me and want me around, whether I'm drinking or staying sober. And they all support joy now. So it really did help me refine those friendships. And I do feel like I have, my friends now are my lifelong friends and are super supportive.

Kate Durack

Yeah, I definitely have very similar experiences. Do you have a way, if you meet somebody new and you're thinking, "Oh, this could be a great friend," do you have a way that you talk about your MS? Is there something that you do to communicate what they might expect if you're out playing volleyball on the beach and you get crazy fatigue and you have to leave immediately?

Stephanie

I do find this to be the hardest part. So by nature, I'm a person that I typically don't disclose things about myself immediately, in my personal life. Obviously here, I'm just laying it all out. But in my personal life, that's not how I approach friendships. So typically, once I see that I can trust them, I will casually just be like, hey, you know, I do deal with this. It's not something that I let define me. However, sometimes I have to make adjustments accordingly because of it. And typically, like, that's all it takes.

And they're like, "Oh my gosh, no problem. Like, you can't be in the heat all day. Let's go back to the hotel. Let's go to a museum." Like, so I feel like seeing that then makes me be like, oh, okay, this is a friend I want to have. And when people respond otherwise, I'm just kind of like, okay, you're not someone I think I want to continue to be friends with or not further a friendship. Maybe you're a coworker friend, maybe you're an acquaintance.

Kate Durack

Yeah, that makes good sense. I can't keep my mouth shut. So I'm an oversharer, not like you. And so I'm definitely, I think it's hard now because my career is my diagnosis, is my lived experience. Everything has blended into this thing. So if someone were to Google me, the first thing they're going to learn is that I have MS. So it's just kind of something that I shout from a mountain whenever possible. I definitely respect the way that you approach that, though. It makes a lot of sense.

And I think that it's really helpful for you to be here talking like this, for anyone sharing their lived experience to just normalize all of it. Just sharing as much as we can to just say, this is what this looks like. This is what this looks like, right? And there's probably people that you're walking by on a daily basis that also are experiencing these things and just keeping that in mind as we go about our lives.

Dr. Williams, I didn't want to skip you for this topic. Do you have anything you'd like to add?

Dr. Mitzi Williams

So obviously you guys have the lived experience. What I would say from a physician standpoint who's seen many people be diagnosed, the disclosure is the hardest part. I have some people who come to their visits and see me and nobody in their family knows they have MS. Not their children, not their spouses. Nobody knows.

I've seen other people who maybe disclose to one or two people, and maybe their job doesn't know. And so I think that decision is very individual, but I do encourage people to disclose to someone, because no one will know you need help if they don't know what's going on with you. And I love the approach that you said, Stephanie. when you meet new people, deciding to talk to them, and then if they are willing to kind of come along and accommodate, then great. If not, then they're not the person.

And so, what I often do find is that people are afraid to tell people when they're having issues or challenges they have because they fear that they will either slow people down or they may not go places. Like "I just won't go on vacation or I just won't go here." And I'm like, the people that love you, they will make a way for you to be there. They will find a scooter. They will find whatever, a fan, a cooling necktie, a vest, whatever they need to do because they want you there.

And that has been the experience. And it's been really beautiful to see people finally be vulnerable and say, "You know what? They were having a card party outside and they brought the fans and all this and I had a great time and they made sure that I was okay." So the people that care about you will make sure that there are accommodations, you know, if they're needed for you to be around.

And so, you know, that decision to disclose to people, that decision to engage in that support and be vulnerable often has a lot of rewards when you have the right people around you.

Kate Durack

Absolutely. And this was not included in our questions beforehand that I sent to you both, but I can't help myself because we're talking about our 20s - people are dating. I think that this advice, Stephanie, your tactics for friendship can go right along with the dating scene. Do either of you have anything you'd like to add about dating in your 20s and potentially navigating an MS diagnosis?

Dr. Mitzi Williams

I'll let Stephanie go first.

Stephanie

I, you know, I just think that it's like kind of going back to what Dr. Williams said. I think it's just disclosure is just hard, right? Like you, don't want to, at least I can't speak to the dating scene, but I can speak to like, I don't want that to ever be the first thing someone perceives about me or the first thought they have about me.

I want to be known as being kind. I want to be known as being resilient. I want to be known as a hard worker. I don't want to be known as the person that has MS, right? It's not who I am. It's something I have. So I think just navigating it in that way goes a long way when you're navigating new relationships of any sort.

Dr. Mitzi Williams

Yeah, so I would agree, and I've seen many different ways that relationships have gone, even marriages, right, after diagnosis. So there, I hate to say it, but sometimes there wind up being two very extremes, right? Somebody gets diagnosed and the person is out the door, right? Whether it's a boyfriend or a girlfriend or a spouse, right? I've seen spouses like up and just leave.

And then you have the other person that's with you to the end. Like, I mean, they will roll you around to the basketball game and do everything that needs to be done and make sure you have an amazing life. And so it's almost, it's hard to know who's going to be that person. But I think that again, you have to make sure that you get to know people. And I think that it is important at some point in the dating game to disclose, right? So I wouldn't want somebody to just go ahead and get married and nobody knows they have MS, right? Because you can have a relapse. So I wouldn't recommend that.

But I do think that also that cautious approach that you have, Stephanie, is certainly very reasonable, but everybody's gonna be different. Some people are gonna be like, I'm gonna say it up front because if you start acting crazy, then I already know I'm wasting my time. So, you know, it can really go either way.

Kate Durack

Thank you both for that. That's great.

Dr. Williams, I'm actually going to ask you a question based off of something you just mentioned. You said having a partner who, you know, potentially is going to wheel you around with the basketball games. I mean, I love like that's the level of support that we're all aiming for, right? In general, outside of MS, like that is what we're looking for.

Dr. Mitzi Williams

Because anything could happen to you, right? Whether it's MS or the car accident, anything could happen. You can get any kind of, you know...

Kate Durack

Yeah. So in that, when we're diagnosed with MS, I think that even if we're not experiencing physical symptoms regularly. In my head, I'm always thinking about how I want to maintain independence for as long as possible, but I also have to ask for help. I have to ask for help. So what strategies do you give people to kind of balancing the independence and the need for support?

Dr. Mitzi Williams

Right, so I think that this applies to anyone, right? I think it applies definitely to people who have chronic illnesses like MS, but I see people who are moms and working, struggling with the same things. "When do I ask for help? When do I do every, or do I just do everything and act like everything's okay and slowly have a breakdown in the kitchen?"

I think about that video that I see on social media sometime where the person is like, I'm in the middle of a breakdown, right? And they're like crying, you know, sliding down the refrigerator and then somebody comes and asks for a snack and then they open the thing and then they go back to their breakdown and then somebody else comes and asks for something. And so they're just stopping their breakdown. you know, every few minutes to help and do something for somebody when they should be taking that time for themselves. So it's like that person is,

you know, not taking time for themselves and to take care of themselves and they're still in the midst of a crisis stopping to take care of somebody.

So balancing that independence really looks like, you know, getting people involved in your care. So when we talk about your healthcare team, you are the most important person on your healthcare team. And then your family members and care partners are also extremely important people. So I encourage people to bring people to their visits. If they can't come to your visit, call somebody on the phone. We'll FaceTime a friend or a spouse and they'll listen to everything that's been said so that they know what's going on because a lot of MS, as Stephanie mentioned earlier, is invisible. So people have these invisible symptoms and on the outside they look okay, but they're so exhausted that maybe they can't get up and go to the park or do this or do that. And so having people involved in that healthcare process normalizes what's going on with you.

I think also I encourage people to bring family members to events. If your center is having a patient day or if there's a talk that there's dinner or something like that, just kind of hearing those experiences from multiple people normalizes what's going on with you and then they have a bit of a better perspective and maybe more proactive in reaching out and more open, to, offering that help when someone is asking for it or when they need it.

Kate Durack

I love that. I think... I'm trying to put myself back into my 20s. I turned 40 this year, so this is a while. But I think that what was hard for me when I first experienced my symptoms because I was in my late 20s when that happened. It was hard for me to open myself up to needing that level of support and asking my parents to come with me because I felt like I had just gotten my independence.

I had just started my career. I had just got my first house. Like I had done all of these things independently and now I'm like reversing and I need all of this support. But really looking back at it and knowing what I know now about living with MS and anything else that you're living with, is that support doesn't go away. Like you always need that. I need my mom and dad just as much, if not more now than I did then. And so I don't want anyone, I hope out of this conversation people are hearing that asking for that support is not you giving up that newfound beautiful independence and strength that you have in your 20s, that can still be embraced when you're asking for help and support from your friends and family.

Dr. Mitzi Williams

And asking for help is not a sign of weakness. That's something that I really stress. It is not a sign of weakness. Everybody needs help. My mom still comes over, she's 80, and sometimes she'll help me fold my clothes. I mean, I need help. I do not have MS right? All of us need help from somebody, and so it's not a sign of weakness.

But if we want to be balanced and we want to live well, then we have to, pull sometimes on the resources that we have and that are available to us. And oftentimes when you ask, people are very willing and they want to help. They don't want to see you suffer and they don't want to see you have issues, but they're not going to make you. They're not going to force themselves upon you.

Kate Durack

Absolutely.

Dr. Mitzi Williams

Most of the time. Some people will force themselves on you, but others.

Kate Durack

Yeah, that's a fair point. Stephanie, did you have anything to add?

Stephanie

Yeah, I think that, you know, we're talking about mom and dads and parents, but that support can look like anything. You know, that could come out of a group, that could come out of your peers that, you know, not everyone is lucky... has parents that are involved or that can support them. So I think that just also recognizing like your support may not come in that form and that's okay. And still don't be afraid to ask because even though they didn't bring you into this world, there's people who still want to help and support you.

Dr. Mitzi Williams

Absolutely.

Kate Durack

Absolutely. Yes.

Okay, I have two more questions for us for this episode. And I think I'm going to go back to Stephanie. What wellness strategies helped you manage fatigue and stress?

Stephanie

So I would say staying physically active. I enjoy hiking, walking my dog, doing some Pilates or yoga here and there. I'm by no means like going to the gym every day, but I'm doing activity to stay active and to support my wellness and then staying mentally active as well.

I'm constantly trying to stimulate my mind with new hobbies, new experiences, and constantly working to learn something new. And then some of the more obvious ones are like staying hydrated, eating well. Although I am not one of those diet persons, I think everything in moderation and I will never fully give up McDonald's.

Dr. Mitzi Williams

Because the fries are good.

Stephanie

Because the fries are good and the Big Macs even better. Going to therapy as needed, good sleep hygiene - there's a lot of links between your sleep health and your brain health. Spending time with loved ones, music, taking my vitamins so it doesn't end up that I'm taking other pills. Those are all kind of things that I do to support my overall wellness.

Kate Durack

You hit on so many good topics there, but I'll let Dr. Williams speak to what really resonates...

Dr. Mitzi Williams

Stephanie's saying all the good things. I mean, I wish. My model patient. I'd be like, "Stephanie, do like Stephanie's doing."

Stephanie

I don't do it all the time. Don't let me fool you. I try.

Dr. Mitzi Williams

All right, so first thinking about fatigue, right? One thing that's really important to recognize about fatigue is that it's multifactorial. So what I tell people is that a lot of my job when we sit down and talk about fatigue is kind of sorting out how much we think is related to the MS, and how much we think is related to other things.

I'll give you an example. I have someone that comes in and says, "Dr. Mitzi, I'm so exhausted. I can't get anything done." And I say, "How many hours are you sleeping a night?" And they say "Three." And I'm like, "Okay, so what makes you think you can survive off of three hours of sleep at night, right?"

So when you're in your 20s, you feel like you're invincible. And perhaps at some point when we're studying for exams and things like that, we can get a couple of hours of sleep and be able to function, but we can't do that long term. So the first thing is recognizing that we've got a little bit of a different body now that we have this diagnosis. And so we have to adjust a little bit and sleep is a really big one that I spend time talking to my young folks about.

So not that you can't stay out and maybe party like a rock star, but maybe we can't do that four days in a row. Maybe we can do a day and then maybe we need to take a nap and rest the next day. Or if we do two days on, then we need two days off. And so just trying to find that balance is extremely important. So we talk about sleep.

We also talk about things like hydration, which can, if you're dehydrated, that can cause fatigue. We talk about medications because some of the medications we give for symptoms like spasticity or nerve pain can make you sleepy. So we just really kind of sit down and spend some time sorting out how much do we think is MS, and how much do we think is other stuff.

And then in terms of wellness strategies, you know, exactly as Stephanie said, you know, the sleep is extremely important, getting some type of movement in, and again, thinking about re-framing exercise. So perhaps before diagnosis, exercise may have been going to the gym four days a week and working out for an hour with your matching outfit on. Maybe now it looks like walking for 30 minutes or maybe going to the gym two days a week and doing that long workout and doing some short things in between.

So we're always looking at how we can modify and how we can adjust according to where we are now. But all of those elements are extremely important, not just to wellness, but to your brain health. We know that if you engage in those activities, it keeps your brain healthier and better able to combat any injury that it may incur related to MS.

Kate Durack

That's really good. I appreciate both of you sharing that so much. I mean, I'm gonna just share this little tidbit. We might end up cutting it. But I mean, even at the gym today, I've started doing weight training since my diagnosis and I've really changed that up and I enjoy it very much. But there are days when two sets are done. And then I say, "I must leave now. I need a nap," because my fatigue will kick in out of nowhere.

And so I think that we get into this new normal when we get diagnosed, but then we also need to keep in mind that it's going to shift daily. And being okay with that and not just sticking to this one-size-fits-all approach when you get diagnosed, you figure out your MS and your experience

and what works for you, that can't stay stagnant. It needs to change and flow with what you're experiencing.

Dr. Mitzi Williams

And that also changes as you age as someone who is closer to 50 than I am to 40. There are some days where I can lift those weights and there are other days where I'm like, yep, the knee is not kneeling.

Kate Durack

For sure.

Dr. Mitzi Williams

So we just can't do it, right? So again, listening to your body is extremely important and that's something I've really stressed with all of my patients as well.

Kate Durack

For sure. My final question, is a little bit, I think it's something that's really important because a lot of this topic is just so heavy and it's hard to think about being diagnosed with something like MS at such a young age. But I did just want to ask Stephanie, do you have anything positive that's come out of this diagnosis for you?

Stephanie

Yeah, definitely. I met, like I was telling you guys earlier, one of my best friends through the support group and we've traveled internationally together, been a part of each other's big life events and have been there as someone that we can really depend on for each other. So it's really helped me create a wonderful relationship.

I've learned to not worry about tomorrow as much and to be more present, which I'm not perfect at, but I'm still trying. And it's honestly, since the diagnosis, it's gotten a lot better and easier to be present and enjoying my current state. And then I've been able to meet some wonderful people in the healthcare system who've taken care of me with such compassion and respect and my health anxiety is a bit lower because I'm getting checkups so frequently. So that's great.

And then I have been able to tell my story and support other young, newly diagnosed people to hopefully make them feel a little less scared. Because I know how I felt and it was horrible to be in that spot. And I do understand the mental health behind it and the depression and the grief and everything that goes into processing this diagnosis because I've done it. And so to be able to help support someone else to see if they can relate to anything I'm saying is something that brings me great joy.

And then I was able to adopt to a healthier lifestyle at a younger age than most people, just because I was more cognizant of it due to this diagnosis. And that will hopefully only benefit me in the long run. So, you know, there's quite a few things that I've been able to find light out of such a dark time for me.

Kate Durack

I appreciate that so much. And I feel so similarly. I mean, there was such a time of sadness and depression and really mourning the person I thought that I was and the thought I was going to be. And don't get me wrong, that still comes and goes. I mean, that's not just a one and done situation. So yes, therapy is still a big part of my treatment plan. But I feel the same way.

I mean, it's amazing to me the change that I've been able to go through, I think faster than a lot of people, because I do recognize that nothing is promised tomorrow. And that was instilled in me very early on. I think that people get there eventually, as they get older and life goes on and they see other people maybe having to deal with big shifts.

But to have that diagnosis in your 20s, wakes you up in a way that I don't think a lot of people experience. And I think that it's incredible. I'm very appreciative that I've had that and also been able to use it hopefully for good as this has gone. Dr. Williams, is that something that you've experienced as well?

Dr. Mitzi Williams

Absolutely. And I would say, I encourage people in the beginning to go through the emotions, to go through the feelings, right? You have to deal with that grieving process. But many times, once we get past that - not fully, but the initial, shock and impact of it - I've seen people go on to do amazing things and I think that it makes people cherish the things that they accomplish even more.

When we have that baby and everybody in the office is like, "We want to see the baby, bring the..." you know, or when we get that degree and all of us are cheering you on like, okay, we did our accommodation for school, you know, it makes people cherish those things so much more because they did it in spite of. And I think that it also, as you said, can be a very big wake up call for people very early on in life to not take things for granted and to continue to experience and love life to its fullest.

Stephanie

I would just like to add too, I think that, we can say this now, right? Being I'm six years out of it. I don't know how far out of it you are, but like if you're someone that's going through this currently and listening, like there was a time that like nothing made me happy, nothing made me sad. Everything just was and I just was and this would all sound way too positive for me right now. And that's okay too.

Like it's okay to be in that spot and like there will come a day or even a moment where you will feel like a long thunderstorm is clearing and the sun is finally coming or it's been a long winter and spring is finally here. And when that day comes, just remember that it never defined you. It was okay to process the way you did. And there is a light at the end of the tunnel.

Dr. Mitzi Williams

I love that. And I tell many of my patients, I wish I had a camera kind of in the corner of my office because, when people are diagnosed, we go through so much, and your healthcare providers are right there with you. Like, I think that if you are working in the field of MS, you're doing it because you love people. I don't know anybody who's doing it because they just want money because that's not the field that we're in, but we do it because we love people. And we don't, I don't want to see people suffer. Like it is hard, for me to experience, even secondhand the things that you're going through.

But it brings me so much joy when we come back a year later or after we start that treatment and maybe those first 10 visits, we cried the whole visit, right? But when we come back for that 11th visit and you're like, "I'm doing well." It is one of the greatest joys of my life as a doctor to be like, "I told you, look at that." You know, like let's have a social visit. I always tell people my

goals are social visits where we talk a little bit about your MS and then we talk about where you went on vacation.

Stephanie

I love a good social visit.

Dr. Mitzi Williams

I love social visits, right? And so, you know, to see that transition and to have seen it so many times just gives me so much hope, you know, for the future and gives me, you know, the ability to say, "You know what, it's a rough time. We're going to process it. If we got to cry, I've got boxes of tissue, but we'll get through it and it will get a little bit better. We know that it will get a little bit better."

Kate Durack

Thank you both so much for this. My grandmother always used to say, "This too shall pass." And I have a little sign in my office that says, "This too shall pass." But yes, I think, Stephanie, I think it's such a great point to validate that you are potentially in this season of depression and trying to make sense of everything and that's okay. That's okay. And it will pass even if it doesn't feel like it's going to, everything does.

So thank you so much for sharing that. And thank you in general for sharing everything you have. You've touched on so many important things that we talk about in the MS space all of the time. So you've been an amazing guest. I really appreciate you. And Dr. Williams, amazing to have you as usual. hope that we get to connect soon in the near future.

Thank you for listening to The MS Journey: Stories and Strategies for Women Across the Decades. I'd like to thank Stephanie and Dr. Mitzi Williams for sharing their thoughts about MS in your 20s. I'm grateful for their openness and insight.

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I look forward to our upcoming episodes of this series as we explore the topic of MS throughout the decades. Thank you for listening and take good care.