MSAA Podcast – Episode 26

MS in Your 40s
The MS Journey: Stories and Strategies for Women Across the Decades

Host: Kate Durack, MPS

With special guests:

Dimika Cavalier

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Kate Durack

Welcome to the MS Journey: Stories and Strategies for Women Across the Decades, a series from MSAA exploring how multiple sclerosis intersects with every stage of life. In this episode, we move into the 40s, a decade often marked by long term career establishment, evolving family roles, and a deeper understanding of living with MS over time.

We'll hear from Dimika Cavalier about her lived experience in this stage, and we'll be joined again by Dr. Mitzi Williams. Together, they'll explore what it means to live in the middle chapters of MS where experience, adaptation, and long-term planning come together.

Welcome to Dimika and Dr. Williams. I'd like to start with some introductions, if we could and, Dimika, how about we start with you? Can you tell us a bit about yourself?

Dimika Cavalier

Yes. Good morning. It is great to be here sharing my journey with MS. Now that I am entering my 50s, it is great to reflect on what living with MS was like during my 40s.

To provide a little insight about my journey, I began having symptoms with MS in my early 30s. I was having symptoms of vertigo, fatigue, muscle, and joint pain. And progressively, those symptoms were getting worse.

At that time, I always thought that it was something with an inner ear issue. So, I was sent to an ENT specialist, and I was diagnosed with vestibular migraines. I was treated for that for several years. I did have an MRI when I was 40, and at the time, the report read - the radiologist interpreted the report as the lesions that I had to be less likely due to a demyelinating disease and so I just continued the treatment for vestibular migraines.

I moved to Memphis a couple of years after that, and I had a new care team. My primary care doctor at the time explained that my symptoms weren't making sense to her, so she sent me to a neurologist. And at this time, I was 43. I had an MRI, and it was, I had enhancing lesions at that time, and that's when I was formally diagnosed with MS.

So, it's been quite a journey. But I'm glad that now I have an answer and I can just do the things that I need to do to make sure that I live my best life with MS.

Kate Durack

Well, thank you for sharing all that. It's so great to have you. Dr. Williams, do you mind doing a brief introduction for those people who haven't had a chance to listen to our previous episodes?

Dr. Mitzi Williams

Absolutely. Thank you so much for having me, Kate. And it's such a pleasure. Looking forward to this conversation with you, Dimika. My name is Dr. Mitzi Joi Williams. I am a board-certified neurologist and fellowship trained neuroimmunologist who specializes in MS, and I've been practicing for almost 20 years in Atlanta, Georgia. My work really focuses on many various topics, but most important, teaching patient self-advocacy and making sure that people know what good care looks like.

So, I'm really happy to be a part of this conversation.

Kate Durack

And we are happy to have you. I am Kate Durack. I'm the Director of MSIN Operation and Engagement with MSAA. I am living with MS myself, and I will be your host today. I'd like to start us off talking about what might make the 40s feel a little different than the 30s.

And so, with that Dimika, can I start with you? Specifically, what feels most different about life in the 40s than it does in your 30s?

Dimika Cavalier

My 40s became the decade where I truly discovered myself and my purpose. There were a lot of pivots and adaptations during this time. I finally had an, you know, the answer in my 40s as to what was causing my symptoms, but there was still so much uncertainty.

I pivoted from a career as a forensic scientist approximately two years prior to my diagnosis, because I believe that the stress from a toxic work environment was contributing to my symptoms since by that point, I had done everything differently. I did dietary shifts, increased physical activity, and still nothing was making me feel better.

In the beginning, professionally, it was difficult because I felt like I was losing everything that I had worked for so far, and the plans that I had for my life had seemed to be slipping away. Physically, things were steadily changing. I was not rebounding as easily as I did in my 30s. I began noticing steady disability progression versus temporary attacks. But during this time, I also discovered my own resilience. I learned how to advocate for myself and how to demand the care that I needed, and I began utilizing my lived experience for advocacy and volunteer work. I also began to just prioritize my well-being during this time.

Kate Durack

Thank you for sharing that. It's interesting that you were diagnosed in your 40s. I was diagnosed at 30, so it's a little bit different for me. I can only imagine what that would look like, you know, 13 years later to be diagnosed at this stage in my life.

I bet that was a big shift for you, but it sounds like you really saw...well, I think your age probably helped you see some clarity in it that maybe you wouldn't have had in your 30s.

Dr. Williams, what are you seeing happening in the 40s compared to the 30s?

Dr. Mitzi Williams

Yeah. It does depend on when you are diagnosed, right? So, if someone is in their 40s and maybe they're ten years into diagnosis, things that we are hearing in the clinic are people are trying to learn how to best balance, manage their energy.

We talk a lot about energy conservation, right? “If I'm going to do this big event, maybe I can't do ten things before that, like I could do when I was 30.” So, it's really about kind of shifting that perspective.

We talk a lot about saying “No” in the 40s, because our capacity may not be as robust as it was even if you don't have MS, but having a chronic illness on top of that, we talk a lot about saying “No” and gaining clarity.

So just as Dimika said, gaining clarity on what's really important, what do I want to focus on, and making sure that I'm focusing on those things. For people who are newly diagnosed in their 40s I think, again, we deal with some of the same issues at any point with a new diagnosis. Uncertainty. Many people are mid-career, and that may cause them to shift to do other things.

So, it really just depends on where they are in their journey. But I think definitely a big theme is focusing on what's important. Gaining some clarity on what we feel like we should be doing and letting go of those things that we shouldn't, so that we can make sure we have the best energy to focus on the things that are important.

Kate Durack

That makes good sense. Thank you, Dr. Williams. Dimika, I'm going to go back to you.

How has your relationship with your body and symptoms evolved over time, especially considering your later diagnosis?

Dimika Cavalier

Yes. So, I am more in tune with my body. I wouldn't say that I overthink everything, but I definitely pay attention to what my body is telling me, and I don't shrug it off like I used to. I listen, I monitor, and I report when necessary.

I will have to say, I love the fact that all of my providers have an electronic portal so that I could send in my questions and things like that, and concerns, as they happen. It just makes it easier for me to keep track of what's going on and then I have that to refer back to when I have my follow-up appointments.

The one important thing I would say is that I've learned that I need to be more descriptive when discussing my symptoms with my care team. I find that the more descriptive I am, the recommended treatment seems to be more effective.

And so, I just allow myself plenty of grace, and I'm constantly telling myself that “It is okay. I will get through it. It may not get easier, but I will adapt to the changes.”

Kate Durack

I love that idea of being more descriptive. I'm a very matter of fact person and I don't know that that works well in the clinical setting. I think we do need to take the time to honor our body and what we're experiencing and give it the words that it deserves.

Dr. Williams, what are you noticing with the changes in relationship with people's bodies and their symptoms as we move forward in time?

Dr. Mitzi Williams

Yeah, I think that, you know, we're in the 40s. People are, you know, well aware of what their bodies are used to doing and when we're outside of normal. I think that, very much so with MS, people are often kind of at a point where they're like, “Okay, this is my regular ebb and flow, I did too much, maybe I stayed out too long at the barbecue or, I stayed on the beach too long.” But they also have that sense of, “Okay, usually I should recover by here, and if I haven't, then I need to be reaching out to somebody.” So, I think that people are much more comfortable with their bodies that they're trying to understand.

I think the difficulty then becomes that when we factor in aging -and for our ladies, when we start factoring in perimenopause and, you know, all those types of symptoms- it can muddy the water some.

So, we do reach a point, especially in those mid to late 40s, where we're really trying to figure out “Okay, is the brain fog from MS? Is the brain fog from the perimenopause? Do I need to see the OBGYN?” And so, that's something that we have to navigate together as a care team.

Kate Durack

Yeah, I think it's kind of a nice phase. Being comfortable and confident enough in yourself and what you know your body is capable of living with MS. I feel like it maybe opens the

doors a little bit more for self-advocacy than it did in the 30s. I don't know. Are you experiencing that, Dr. Williams? Do you feel like people are more open with what they're experiencing and asking for what they need?

Dr. Mitzi Williams

Absolutely. But I do find really that many of my MS patients do that. I think that the landscape of knowledge and understanding and access to information has really changed, particularly over the past ten years in this age of social media. There are people that are able to see patient advocates and hear their stories. I feel like overall, my community advocates for themselves much more and if they can't, their care partners and loved ones are looking at things and advocating.

But certainly, in the 40s, again, people have that clarity. They are often in the crux of their career or raising children so they're used to advocating for someone and so they also advocate for themselves.

Kate Durack

That's good to hear. I am going to pivot back to you, Dimika, and we'll talk about career a little bit, if that's okay.

How are you balancing career stability, energy levels, and long-term planning?

Dimika Cavalier

Yes. So, as I stated previously, I actually transitioned from my career prior to my diagnosis, and I kind of was changing my path prior to receiving a diagnosis. But while I was still employed, I took advantage of FMLA. I tried shifting to less stressful, less demanding jobs, and I also tried shifting my work schedule just to see if any of that would help with me to be able to remain in the workforce.

And so, reluctantly, I did have to leave the workforce and currently I receive Social Security disability benefits. And transitioning from the workforce has been both financially and mentally challenging, but advocacy and volunteer work has provided a fulfilling, fresh sense of purpose for me.

So, even though my work hours are not so traditional, I just feel like this was my purpose. I enjoy doing what I do with volunteering and helping with MS advocacy organizations and

things like that. So, if I could provide one takeaway, I would say your story is not unwritten. Don't associate changing careers or changing your path with failure.

Kate Durack

So great, I am very appreciative of it. I was connected to you through that next career phase of yours, so I am very thankful for you and all that you do in this space, for sure.

You did touch a little bit on accommodations in the workplace when you were still employed. And I'm wondering, Dr. Williams, what are you seeing in terms of accommodations at this phase in life?

Dr. Mitzi Williams

I think that this is a really important topic, and perhaps an area where people maybe don't advocate for themselves as much as they should. I think that sometimes there is this idea which we want people to function as highly as they can. We want you to, you know, I always say we have this no pain, no gain idea in our society. But when you have MS and you keep pushing through, you pay for it.

I think that sometimes, or oftentimes, people wait too late to ask for accommodations. What I encourage people to do is if we're on the front end and we're not having any trouble, you know, let's not wait until we get a bad evaluation. Let's not wait until we're getting written up. Let's try to get those accommodations beforehand, before we get in trouble, so we can make sure that we're helping you to function optimally.

And so, I think that that's an area where we need to do probably a lot more education and awareness in the community. That it's okay to ask for help. It is not a sign of weakness. It doesn't mean you'll always need it, but we always want protections in place so that when you are having a bad day or having a relapse, that you have those protections in place beforehand so that we don't wind up coming to the point where someone’s getting fired, or getting disciplinary action, when we could have gotten ahead of it.

Kate Durack

Do you have specific recommendations for things like COGFOG on the job?

Dr. Mitzi Williams

Typically, what we do is every visit we talk about what are the major issues that are interfering. So, I encourage people to just be honest. Sometimes depending on, particularly if we're high functioning, we can just, as you said earlier Dimika, push things to the side. So, it's like, oh, well, I'm just having a bad day. But if we're having like 30 bad days in a row, then we probably need to talk about it.

So, typically one of the things that I really recommend everybody do is intermittent FMLA. Whether you're asymptomatic or whether you have 100 symptoms. Having intermittent FMLA on file at your job helps protect your job so that if you have a relapse or you're having an issue, you know that you have that time allotted for where you can be off and it doesn't just seem like you're lazy or not able to do your job. That's something I recommend for everyone across the board.

Then, of course, as we're in the course of our visits, if we're starting to notice things like cognitive changes or COGFOG, we talk about different ways that we can allow, that we can adjust, if there are different lifestyle modification factors. I think that's a really big issue. In our 40s, we can't function like in our 20s and get three hours of sleep. You've got to get those six hours or more or you're not going to be able to think straight. So, we spend a lot of time educating and counseling on that. And then of course, there are other options.

And if there is a need for accommodations and we talk about what can we do that's practical? Maybe decrease your workload, get some electronic material for you to have a scribe, those types of things. And so, we just try to talk through the process at each visit so that as we're encountering problems, we're dealing with them rather than waiting for it to snowball.

Kate Durack

That's good, and these are you're having in real time during a visit.

Dr. Mitzi Williams

Absolutely. Absolutely. I'm like, "Hey, intermittent FMLA, right? Let's get it done." You know, so we don't, again, want to wait until we have an avalanche. We want to try to handle it when we see the snow trickling down.

I don't know why I'm thinking about snow. It is very hot in Georgia right now, but snow is on my mind for some reason.

Kate Durack

Well, I think that's good to know. I think it's good to share that your neurologist is a source for that and that those are conversations that you should be having if you're having those issues at work.

We've talked in the past episodes about vocational rehabilitation and using other resources outside of your neurologist and MSAA can always connect folks to that as needed. We also spoke earlier about care partners, friends and family who are helping advocate with us, for us.

And with that, I wanted to go back to you, Dimika, and ask how your family dynamics or caregiving responsibilities have changed for you in this decade.

Dimika Cavalier

Yes. I have to say, I have so much respect for people who are raising children because I could not imagine having to do that and deal with, and balance, my life with MS.

I was married, five years - I'm sorry - five months before my diagnosis and so I gained a stepdaughter who was in high school at the time. What has been challenging for me is feeling the guilt of him having to take on a caregiver role so early into our marriage.

That's something that I struggle with constantly, and just feeling like I'm a burden. I mean, he's very supportive and I have a very supportive support system with family and friends, but it's just hard feeling like I'm a burden and then also seeing their faces, like when I'm explaining things to them or talking about my symptoms and things like that. It saddens me to see that they have this concern, and it's nothing that they can do. Right?

And you can just see that they feel helpless, and you see that helplessness and you kind of feel sad about that. But for me, my caregiving is not as intense as others may have in their experience. And so, I appreciate that, you know, that my path was different, but I just had have so much admiration for individuals who are caregivers to others while they are on this journey.

Because it is very challenging and I don't have any skills to offer for that because that's not my journey. But, like I say, hang in there and ask for help.

Kate Durack

Yes. I mean, I feel like that is the key takeaway, right? And I am, I am sorry to hear about your feelings of guilt. I also carry those and I am sure, Dr. Williams, we are not the only two living with MS feeling this way.

What are you hearing about family dynamics and caregiving in the office?

Dr. Mitzi Williams

Yeah. So, it's difficult, right? MS primarily affects women, and women are used to taking care of other people and taking care of themselves on top of it, even though often we put ourselves at the bottom of the list of all the people that we take care of.

And so, the biggest hurdle that I find for many of my patients is just asking for help because they don't want to feel like a burden, they don't want to feel like they are causing extra stress on their family, etc., because people have life, which is life, so to speak, and then you got the MS on top of that.

However, what we also find is that open communication is really important. And oftentimes when people do reach out and ask for help, the people around them would love to be able to do anything to help them, right? Because in many cases they can feel helpless. And so, if there's something small they could do, like take somebody to school, or pick up the groceries, or cook dinner, those types of things, it actually strengthens that communication and that relationship because they feel like they are contributing to taking some of the burden off of this disease that they can't fix, if that makes sense.

I think that those roles and dynamics can be very difficult to navigate, particularly depending on the level of disability or ability that someone has. I'm a very big advocate of mental health engagement throughout the process. So, at the time of diagnosis, I think it's really important to deal with uncertainty. And then certainly when we reach certain marks in the disease where maybe there are symptoms where you do need more help or you do need assistance, just kind of revisiting. I look all my patients in the eyes and I say, “There's nothing you did to cause your MS.”

I think that even though they have that guilt, it's a disease that you can't control. So just being able to kind of manage that mentally and also engage in conversations with care partners is extremely important.

I think the other piece that's important is having family members and care partners participate in the medical process, right? Because oftentimes there will be questions that

the doctor can answer and if anybody has ever had a boyfriend, or a husband or wife, you know that you can tell them something and they won't believe it. But if somebody else tells them the same thing you told them, suddenly it is the most fantastic and amazing idea that has ever been mentioned, so sometimes it's having that reinforcement.

The other thing that's really important is community. I encourage my patients with MS to engage in some type of community with other people living with MS, and their care partners can meet other partners. And then that way when they build community, they'll realize that they're not alone. That isolation, I think, is one of the biggest issues. And the lack of communication. So, those are some of the conversations that we have.

But certainly, mental health care is extremely important and engaging in community and also participating in that medical process so that in some cases, partners or loved ones realize, "Okay, you're not ignoring me. This is cognitive dysfunction from your MS," or "You're not just lazy, this is fatigue, which is a real symptom." And hearing the medical professionals say that can really change a perspective and change how they engage on the day-to-day level.

Kate Durack

Yeah, I think that's great. Thank you. I think it's important that we're pulling other people in and building a team as we go through this, and everyone needs a team, regardless of if they have MS or not.

Dr. Mitzi Williams

You are the most important part of your team, and your care partners are also the second most important part of your team, because they see you every day and your doctor only sees you every six months or every three months.

Kate Durack

Yes, I'm always in my appointments. I'm always looking over and saying, "Keep me honest, am I getting everything? What am I missing?"

Dr. Mitzi Williams

The truth tellers, that's what I call them, truth tellers.

Kate Durack

Yeah, definitely. And I love the idea of you telling your patients that they have done nothing to cause their MS. I think that's really powerful.

I would love for everyone to just take a pause now, that's living with MS, listening to this. Look in a mirror and say that to yourself. I think it's incredibly powerful and a good reminder so that we can stop feeling that level of guilt for no reason.

Dr. Mitzi Williams

Absolutely.

Kate Durack

I'm going to go back to you, Dimika, is there anything that surprised you about living with MS that you weren't anticipating?

Dimika Cavalier

There are so many things. Top of mind is, just the lack of research around aging with MS and specifically women aging with MS. And how difficult it can be to maneuver the healthcare system has been very, very surprising and frustrating at times.

Kate Durack

Yes. I definitely hear that and see that often, especially with MS where we could have, you know, we need to go see four different specialists in order to manage our care. It can become really, really tricky. Or we're taking a medication that we use a patient assistance program for, so you have to navigate that part of it and insurance and everything that comes with it.

And when you're living with something that causes extreme fatigue, it makes it that much harder. So, I hear you, and I am sorry about that.

Dr. Williams, what are you hearing about things that are surprising folks living with MS?

Dr. Mitzi Williams

Definitely engaging with the health care system. It's really difficult, you know, it is really difficult. Insurance can be difficult to navigate. You call one office and they're telling you this, you call somebody else, you're on hold for two hours. You know, the doctor is saying this, they're saying this, I mean, so it can be really hard to navigate for anybody. For me, it's hard to navigate. And I am a doctor, so I can imagine my patients, who are not in that system every day, are really having difficulty.

I think the other thing is just kind of grappling with the uncertainty about the future. I think that is something that is really underestimated. I find that often, my patients with lesser physical symptoms may have more difficulty than my patients with lots of physical symptoms because they're scared they're going to have lots of physical symptoms. That can be really tricky to navigate.

I think that that's something that people underestimate, which is again, I think we're going to talk about mental health at some point. But that's why it's really important. So, it's just that kind of cloud like even if things are going well, it's that kind of cloud of “When is the other shoe going to drop” and trying to navigate that and live as well as we can so that... the shoe may never drop, but then if it does, we wasted all of our good time waiting for this shoe to drop, you know, so to speak. So, I think that those two parts are really, really hard and that people underestimate those.

Kate Durack

Yeah, and we've talked about this in the biggest episodes. I feel like that comes and goes, for everyone, you know, we kind of come to a place where we're at peace with what's going on, and we can find ways to live fully and live well in the moment and then all of a sudden, it hits you like a ton of bricks, that you're living with this and you don't know what's going to happen. And that is a really difficult thing mentally to navigate. So that mental health support is, is huge.

Dr. Mitzi Williams

Yeah. Now something that I would say, because you asked me slightly differently, something I would say would be surprising is that many people do find a renewed sense of purpose or talents they didn't know they had and they're like, “You know what? I'm going to seize the moment,” you know? And they may be artists, or make inspirational books, or write a book.

And so, I think that the other thing that's been really cool to see is the renewed sense of purpose or the new sense of purpose that some people develop and then also their willingness to go after the things that they maybe have been thinking about but were kind of scared or hesitant to do. And so, seeing the fruits of that has been really amazing.

Kate Durack

Absolutely, Dimika, you're nodding a lot. Did you want to add anything to that comment?

Dimika Cavalier

Yes. It's interesting because the fear... I'm not as afraid as I age with MS because of that. Because my outlook has changed and it has afforded me that opportunity to do things that I just didn't even realize were possible.

You know, this opportunity is a great example. Just sharing my journey and things like that and the other activities that I just appreciate so much more because when I can enjoy something, it just means so much more to me that I have those days when I'm able to just experience life in the world.

Kate Durack

Yeah, I am going to go straight into that mental health question, Dr. Williams and that is what role does mental health play for you in this stage Dimika?

Dimika Cavalier

So, fortunately for me, my primary care doctor recommended that I see a mental health professional soon after I was diagnosed. She realized that I was grieving my pre-diagnosed self and it was an emotional rollercoaster.

The therapy is very important to me. I will say that all therapists are not the same. You know, there are good or better physicians. You kind of have to find someone who is good for you, and you may have to switch depending on what season you're in. I know one of the things that I found really beneficial was finding someone who was skilled in dealing with someone with chronic health conditions.

That treatment was different than what I received previously. So, you know, it's a process, and I am in a much better place. But, you know, I still have my times where I have to have my little pity party, and I cry, and then I move on from that and, you know, life is good again. But I just allow myself plenty of grace and I allow myself to be in those moments.

But I try not to stay there too long, and I notice within myself if things are lingering, I know that I can reach out and get help.

Kate Durack

Yeah, it's great that you established that it's a cycle and, I think it's also healthy to know that when you're doing well, there is probably going to come another point when you're not doing so well and putting up those guardrails so that you have a plan in place for when things aren't feeling so great.

I thought it was really interesting when you said that if you find a therapist who you've connected with, they're not necessarily going to fit you for every season. I think that's really important because we talk a lot about being patient and finding the right person for you in therapy in general, and how that can really take some time and effort on your part.

But the idea that once you find that person, they might not always be the best fit for you is really important and interesting. I don't know that I've given that enough thought, but I really, I like that you said that.

Dr. Williams, what do you have to add about mental health?

Dr. Mitzi Williams

I mean, I think that Dimika covered most of the bases, right? I think that it is a partnership. So, you have to have someone you feel comfortable with. I encourage people who say, “Well, I went to a therapist and I didn't like them, so I just quit going,” and so my analogy always is okay, well, if you go get a bad hairdo, are you never going to get your hair done again?

The answer to that is no. Are you not going to go back to that person that did a bad job on your hair? Yes. You're not going to go back to them, right? But you're not for the rest of your life never going to get your hair done again. And I know it's a very simple analogy, but I'm like, if we have that tenacity about hairstyles, then we should definitely have at least equal tenacity about taking care of our mental health, right?

Which helps us to get through. Maybe the hairstyle contributes to the mental health, but you know what I'm saying? So, I think that making sure that we're taking the time to find that right person is extremely important. And again, different seasons may require different things and so I love what Dimika said as well.

But I think that we also can adjust how we look at mental health and look at mental health and therapy as maintenance. It doesn't always have to be I'm getting therapy because my life is so bad and I'm in a bad place. It's like, okay, well, I'm doing good. How do I stay good?

It's okay in good seasons to also seek that support to maintain the good season and not just look at it as something that we do in crisis, but it's something we do. Like when we go get a checkup every year with our primary care doctor, whether we're having problems or not, we should still go get a checkup.

Kate Durack

Yeah. For sure. I think that's really important to do. And I want to just honor that we've taken the time to talk about this, and I think that it's something that is just a recurring theme throughout life. And I think that it's something that we should kind of work with where we're at in our life phase in order to target it in different ways and address it in different ways and make sure that our care team is on that page with us too, when appropriate and it feels comfortable. So, thank you both for that. I want to talk about something else that comes up all the time with MS, which is fatigue.

So Dimika, how do you manage fatigue alongside the demands of work, home and relationships?

Dimika Cavalier

I have to say this is still... fatigue is one of my more challenging aspects of the journey because there's still this guilt, right? When I have to decline an invitation or if I need to cancel plans because I just no longer have the energy to do anything.

I manage fatigue by breaking tasks into smaller, manageable steps, and I had to definitely reshape my thoughts about this. So, I've stopped tying my sense of accomplishment to checking off every box on my to-do list.

I rely on reminders to help me keep track of things. Sometimes I have backups to my reminders because it...yes, just staying focused and being in the moment is very difficult. I use - like if I'm doing a task, I would use the Pomodoro method and so that helps to keep me focused.

I add reset days to my calendar, and I am very intentional about what gets added to my calendar because I have to monitor. I have to add things according to how they deplete my energy. And so, it's very intentional.

Talking about it, it almost seems like it's draining just to manage the fatigue, and it is. But these steps kind of help make it all better to deal with and be able to do the activities that I would like to do.

One important lesson that I learned in therapy is that it's okay to have a plan B sometimes you may have plan C, D, and so on. That this does not equate to failure. And so, I just remind myself constantly that, you know, it's okay to adapt. You're going to have to adapt in order to be able to do the things that you want to do.

And so, I find that being honest with myself and communicating my needs and limitations to others really does help the need to be able to manage to do everything that I need to do with the limited amount of energy that I may have on a particular day. It is still a work in progress. But I'm working on not feeling guilty when my answer is no.

Kate Durack

I am just floored by how much you've put into this, and I'm jealous that I haven't done the same, it’s amazing.

Dr. Mitzi Williams

I’m taking notes now

Kate Durack

Seriously! the idea of you redefining what it means to have accomplished something is fantastic. I love that. And I love that you've taken the time to really sit back and reflect on your personal experience with MS, and understanding your body enough to know your limitations and being okay with the idea that plan E might need to happen, and it might turn out better than plan A, we never know, right? And just kind of being able to go with the flow with that is great.

Dr. Williams, I don't know how you're going to follow that up, but what would you like to-

Dr. Mitzi Williams

Yeah, there's not much for me to add, right? So, I think it is really about doing the work. I think that changing perspective is extremely important, with the goal not being to continue the same level of exhaustive things that we've been doing.

Because sometimes the thought is “I've got fatigue, so, fix my fatigue so I can keep doing exactly what I've been doing.” And I think that's where the problem comes in. It really is a matter of changing perspective. Like, how do I prioritize what's important. You know, maybe what's the one thing I've got to get done today instead of like the ten things, right?

Then figuring out what other type of lifestyle modifications we can do: reminders, working on the sleep, staying hydrated, taking rest when we need it. How can we modify our lifestyle so that we can function optimally at the things that are most important to us, instead of trying to continue the same level of activity and putting Band-Aids on things and then being exhausted because we're trying to maintain a level that's not sustainable.

Kate Durack

Yeah. And I think asking for help comes right back into play with that. Obviously for me too, fatigue is my biggest issue and I'm a mom of two boys. They are seven and eight, so they take a lot of energy.

But one thing that I've done is I've slowly integrated them into part of my care team. They don't know it, but they are part of it. I feel like they're at the age now where I can say, “Hey, can you go run the laundry” or, you know, “Can you clean up the sink?” or whatever it may be. I am pulling them in and I'm asking for help, and I'm using the support system that I have when I have it.

It's not as easy because they are little and we're still getting there. But I think it's important to use what you have and make sure that you're reaching out to other people who may not

live with you or, you know, have what seems to be very busy lives of their own and ask them for that help, because they do want to help more often than not.

Dr. Mitzi Williams

Absolutely.

Kate Durack

Great. So, I'm going to ask. Actually, we're going to go ahead and just ask our last question for today. Thank you both so much for this.

Dimika, what does quality of life mean to you now? We touched a little bit on it.

Dimika Cavalier

Yes. So, for me, quality of life means doing everything within my power to experience my best life in spite of the challenges I face from day to day.

It means taking advantage of the resources available that make my life easier and more fulfilling. It means sometimes being more self-centered because that's needed for me to make it through each day.

When I hear someone say, “Oh, it must be nice that you're getting a massage,” or “It must be nice that you're still in bed or still in your pajamas.” I'll always say, “Yes, it is” but what I tend to leave out is that, “Yes, it is nice that I had to forego something else to pay for a treatment that significantly helps with muscle spasms and pain. Yes. It's nice that today my body decided not to cooperate, and it's too painful for me to get out of bed or my vertigo is so intense that I have to bounce from wall to wall while walking around my home, or that I am so fatigued that my muscles feel weak, or that once I finally got out of bed, I no longer have the energy to change out of my pajamas since walking to the bathroom and standing my brushing my teeth has expended my energy for the day.”

And so, for me, quality of life requires that I be unapologetic for doing what is best for me to exist in that moment of my journey.

Kate Durack

That's really, that's really powerful. I love that. Dr. Williams?

Dr. Mitzi Williams

Can I add something to that? So, I love that perspective. You know, I love that 'and' part. And I think that on the one hand, we absolutely don't have to explain ourselves, if we don't want to.

But I think in some instances, depending on the relationship, that we should add that 'and', right? Because there are assumptions. And again, when you're talking about dealing with a chronic disease, oftentimes there is this feeling that we have to look strong, that we have to look like nothing's wrong, you know? But if sometimes we just let people get a little peek behind that curtain, that may change their perspective as well.

And they may still say it could be nice, but they may think twice about it. And, you know, I think that sometimes adding that second piece and not having to be the strong person that says, "Oh, okay, well, I'm just going to pretend like it's because I wanted to and not because I had to." I think that that vulnerability also opens communication and also opens other avenues for people to say, "Well, how can I help you?" or "Is there something I can do?" Or, you know, maybe just think twice before they make that comment that assumes that you're just kind of lounging around because you don't have anything else to do.

I don't know if you were going to ask me the same question, Kate, but when I think about quality of life, it's going to be different for each person and so I think that's why it's so important to have a health care team that listens.

So, I'm like, "What do you want to get out of this?" and I try to be as honest as I can about things that I think are realistic about what we can accomplish and what we can try to do to help people accomplish their goals.

But that quality of life is really going to be different for some people. It may be "I want to stand and brush my teeth." For somebody else it may be "I want to go see my kids at the baseball game," you know? And for someone else, it may be "I want to be able to work from home or do this."

So, I think that that's going to be really individual. But it's important to have that team around you, to support you, and to communicate that, so we can try to help you achieve that in living well with MS.

Kate Durack

Thank you so much for that. I really appreciate that. Dimika, I think we are all going to aim to live unapologetically now.

Dr. Mitzi Williams

Absolutely, very wise advice indeed.

Kate Durack

Seriously. Thank you both so much for your time today. This has been a great discussion. I appreciate it so much. Thank you for being here.

Dimika Cavalier

Thank you.

Dr. Mitzi Williams

Thank you for having us. My pleasure.

Kate Durack

Absolutely. Thank you for listening to The MS Journey: Stories and Strategies for Women Across the Decades. I'd like to thank Dimika and Dr. Williams for sharing their insights about MS in the 40s.

I'm grateful for their openness and insight and it was such an awesome conversation. Thanks again to Gradwell House recording for hosting and supporting the production of this episode. Support for the decades podcast series is provided through an educational grant from EMD Serono.

This podcast, along with additional resources and support, can be found by visiting the Multiple Sclerosis Association of America's website at MyMSAA.org.

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