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Multiple Sclerosis Association of America

MSAA Podcast - Episode 16:

If I Knew Then: Reflecting on an MS Diagnosis – PART 2

Host: Kate Durack

With special guests: Claude, Anita, and Lizette

Kate Durack:
Hi, my name is Kate Durack, and I'm the Director of Communication and Patient Focus with MSAA. You're listening to part two of MSAA's MS Awareness Month podcast series, "If I Knew Then: Reflecting on an MS Diagnosis." In part one, we spoke with MSAA's Chief Medical Officer, Dr. Barry Hendin, and explored key areas for those newly diagnosed with MS, including how to communicate with your healthcare team and the emotional aspects of navigating an MS diagnosis. Now, in part two, we'll hear from three incredible individuals living with MS as they share their personal experiences. We'll hear the lessons they've learned, the challenges they faced, and what they wish they had known when they were first diagnosed. Let's dive in.

I am honored to be here today with Anita, Lizette, and Claude, each of whom are navigating their own MS journey. Welcome to each of you. Can you please take a moment to introduce yourselves? And I think, Lizette, let's start with you.

Lizette:
Hi, I'm Lizette. I'm from Houston, Texas. I am a wife and a mom.

Kate Durack:
Thank you. How about Anita? You?

Anita:
Hi, I am Anita Williams. I live in Aurora, Colorado, and I am really passionate about my beta fish.

Kate Durack:
Thank you so much, Anita. It's so good to see you and to have you here. Okay, and Claude.

Claude:
Hi, there. I'm Claude. I am living in New York City. I am a husband to my wife and a dog dad, and yeah, I'm really happy to be talking about our journeys today.

Kate Durack:

Wonderful. Thank you. And just for full transparency, again, I am Kate. I am also a mom, I'm a dog mom, I am in Saint Augustine, Florida, and I have been living with MS for almost ten years now. So it is wonderful to have each of you here all with our very own journeys. And I am just going to kind of run through a few prompts for us to guide our discussion today. And I think what we're going to start with, Claude, actually, if we can go to you, I would really like to talk about when you were first diagnosed and ask that you share your initial thoughts and emotions.

Claude:

Sure. So, I was diagnosed in late July of 2022, so MS is still pretty new to me. Coming on a three-year anniversary. And basically, I was actually in the UK at the time, and I noticed that my eye, my right eye in particular, really hurt when I was looking in certain directions. And it's probably worth mentioning at this point, I'm a physician. And despite that, and despite clearly having signs of optic neuritis, I gaslit myself into thinking I've strained my eyeball really hard, that otherwise is physiologically not something that is possible. But, you know, that was my process. And so, I dealt with that for a few days. And then when I got on the flight, I noticed, going back to New York, I noticed that my vision was getting a bit blurry, and I said, “Oh, my eyes must just be really dry from the flight.” So again, continue to ignore it. And then thankfully, my better half convinced me to go to the eye hospital in New York, and so she took me over there.

And despite having a visual field loss, I was still like, “Oh, maybe I'm just going crazy.” Maybe I'm just making this up. This can't be anything wrong. But then the blurriness continued, and I started to actually lose sight in my eye. So off we went to the emergency department in New York, and I had enough knowledge to know that based on the symptoms and signs they were seeing on examination of me, that MS was probably the best-case scenario for a diagnosis for me at that point. So, in a really perverse way, I was kind of hoping it was going to be MS, that's to say instead of a blastoma or something horrific. But, yeah, I got an MRI and then I was diagnosed in the corridor because they had pushed the results to my MyChart without actually having a doctor review them first. So, I logged on in the corridor and saw the results and got my results and my diagnosis that way. And I actually think that's a really good teaching moment just in general for the medical professional, that when you're expecting a life changing diagnosis to put a hold on the reporting from these things so that people don't receive their diagnoses in the corridor. And then an attending doesn't have to sort of awkwardly shuffle over and be like, “Oh, so you've seen the results,” and not kind of know how to handle the situation.

And my immediate emotions were devastation. So my knowledge of MS, because I haven't... I went more on the business side of healthcare and have done for ten years, I haven't practiced since 2014, and my knowledge of what MS was is like from knowledge from 2007, 2006, when I was at medical school. And, in my mind, it was still kind of like a pretty big death sentence, actually, in terms of like my quality of life is going to be awful. I've maybe got 10 or 15 good years and then screw it, I'm out.

So that was my initial reaction is like, “I'm dead.” And I immediately wept, my wife, Sarah, was with me, and immediately went to thinking, “how am I going to make sure she's okay before everything's finished?” But then, after sort of the initial steroids and they got me up into the water, I did a quick Google and had a lot more hope, actually, afterwards. So, I was like, “Oh, okay, this is very different from when I started,” and medicine has come a huge way with regards to this. So, I had a lot more hope there. And, understanding that with the right care, I could probably lead a fairly normal life, for the most part. So yeah, I, you know, you do the whole range of emotions, though. It was initially shock, devastation, a bit of hope. I can talk to sort of afterwards or if you want me just to stay on the initial sort of 24-hour period.

Kate Durack:
I mean, I have so many things that are similar to that, and many things that are quite different. But I do have one question for you. From you first recognizing your vision challenges to diagnosis, how long was that?

Claude:
I would say, so I got the vision changes on a Wednesday, and I was diagnosed on the Tuesday the following week. So that's six days.

Kate Durack:
That's so fast. Wow. Okay.

Claude:
And I had always been clumsy. So I, like, the previous summer, which was particularly hot in New York, it was over 40°C. I still don't do Fahrenheit. Sorry, folks. And, I had like, fallen a bunch and broke my ankles three times in the space of two months. I had like a really bad year. So I'd always been clumsy for years. So basically, I'd been masking having had it, from the MRI they think I'd had it since I was like in my mid 20s and I'd been masking having it. But you can justify, like, a forlaying or feeling tired. You can't really justify going blind. And that's kind of a medical emergency as well. You need to get the high dose steroids very quickly. So, I basically waited till that point to get diagnosed versus being several years earlier, being like, "Maybe I should get checked out as to why I'm falling all the time, and I feel so tired all the time," and all that kind of stuff. I just kind of plowed through.

Kate Durack:
I mean, I was the exact same way, but it took me a lot longer to get diagnosed. But, mine was the same. I had... I didn't really listen to my body fully until I started having vision issues, and then I thought, oh, this cannot be normal, I need to go get this looked at. But when my dexterity or my strength was a little iffy, I never... I, you know, I just thought, like, "I'm really tired today," you know, or "I need to definitely go lift weights a little bit more so that I don't struggle to do these things so much." But yeah, once that vision starts going, it's kind of hard to ignore.

Claude:
Yeah.

Kate Durack:
Well, thank you for that. Lizette, let's move on to you and your initial diagnosis.

Lizette:
Well, my story is a little different. Very different actually. I was diagnosed about 20 years ago, and I was young, really young, and I did not really know what was going on. I remember having my first symptoms in high school, my senior year in high school. I was writing in a journal, and I could see that I couldn't write. I got to a point, so I had numbness. So, I had radiating numbness throughout my body, and it got to my hand. And when I got to my hand, my writing hand, I couldn't write. I remember that journal. I still have it. You could see the progress of great writing to horrible writing. And I remember and will never forget my teacher saying, "Hey, you need to get that checked." But I didn't think too much of it, you know, at that time, like, "Oh, something's going on, it's going to go away."

So we went on and then I started college and, in college, it still continued, you know, and I remember walking, my campus from one side of the school to the other, and then when it hit my legs or my feet, my gosh, you know, I was walking weird. But I didn't think much of it either. But, at the clinic at the school, I went ahead and made an appointment. Before that, my parents had taken me to local doctors and they're like, “Oh, you have anxiety,” you know, “you're stressed out,” so they gave me medication for it. But then in college, I'm like, “Let me try it again, let me go to another doctor here.” And they, you know, I'm telling you, it was like 20 years ago, so there wasn't a lot of information, like Claude said. So, they did a lot of bloodwork. They continued with the anxiety bit, unfortunately. I can't blame them. But eventually they referred me to a neurologist, and I was diagnosed then. So that took about, I would say like 3 years, 2 or 3 years. And before that, you know, in high school, I was a cheerleader. So, I was in the heat a lot. So that could also, you know, I don't know if that could be correlated. And I live in Texas, so it's hot.

But that's a little bit about my journey. I did start medication right away, one of the first medications back then. So, I would say that that helped. But then, as time went by, I was in college, so, like many people, you just, you know, you're like, “I feel better”. I got to a point where I just felt better, and I'm like, you know, “I'm fine. I'm fine now,” you know? I don't have anything. I was a college student, so my journey right there, you know, was like, difficult for medications and keep up with things. And I was just like, “You know what? I feel better. I'm just going to be a noncompliant patient.” And I just kept on with my life. And then, in my 30s, I got pregnant with my first son. And my doctor was like, “You need to go to a doctor for this,” because you know, you could have a relapse after... I didn't really have relapses. I probably had symptoms here and there through that timeframe. But, you know, I didn't think much of them. Now my doctor tells me, he's like, “Yeah, some of those things are correlated to just the lesions that you have.” So, my journey has been very different. And now, you know, I see an MS specialist and I keep up with medication and everything, but that was my journey because I started so early, you know, and I was young and became non-compliant at some point too.

Kate Durack:

Yeah. Well, thank you for that. There's a couple things that you said, you actually talked about anxiety, and I definitely have experienced depression. And so, you know, we talk a lot in MS about how those things can go hand in hand. So you never really know, you know, if that is part of your MS or not. Definitely not something to, you know, turn your nose up at. Definitely something to bring attention to. So I thought that was interesting because I experienced depression way before I was diagnosed. So I don't really know what the correlation is there, but it definitely was apparent for me.

And then talking about just how all of a sudden you start feeling well, I still experience that, you know, after ten years. It’s like, “Well, I'm doing pretty good, you know, no disease progression. I've been on the same treatment for eight years. Maybe I don't need this.” And then I very quickly go, “No, no, no, Kate. Stay on track. You need this. It's going to be OK”. So yeah. Thank you so much for sharing that, Lizette. Anita, let's move on to your story of diagnosis.

Anita:

Yes. There is so much in Claude’s story that I can identify with as far as being diagnosed in the hospital, but my story is very odd. I found that I had MS because I had a nosebleed. I had a nosebleed on a Saturday night and on Tuesday, after they had cauterized and packed it Saturday, I took the packing out and I thought, “Okay, my face is a little bit swollen, probably from the packing, don't worry about it.” But I had people in my life who cared about me who said, “Go back to the emergency room, get it checked out just to make sure.” So, I reluctantly went back to the emergency room, and when I got in there, the doctor told me, “Your face isn't swollen, the other side fell.”

And so, the first thing you think of is, “oh my gosh, I had a stroke.” But I was in there chatty, just super “WOO,” like I usually am. And they said, "We don't think you had a stroke, but let's put you in and get a CT scan just to be sure.” Put me in there. CT scan came back. They said, “great news, you haven't had a stroke. It’s Bell’s palsy. We have a medication for that. It’s going to be fine. However, we think we see something else. So, can you do, you know, an MRI?” So, they went ahead, put me into an MRI machine. And I've been extremely fortunate along my entire journey, and this was one of the first things - they had got an MRI machine for someone who was larger just seven weeks before I was there.

So they put me in the MRI machine, listening to my 80s hair metal, and pulled me back out. And as I'm sitting on the exam table, a doctor came in and he said to me, “We think you have multiple sclerosis. You are not going to die. I see that you have your phone with you. Why don't you take a moment to look a few things up while I go take care of my paperwork?” That for me, was one of the best things that happened with my diagnosis, was the fact that he was, one, very upfront. He didn't give me that, “Oh my gosh, you're going to die” look, and the fact that he told me right away that I wasn't going to die. And the third thing was the research, and that's how I got into the research end of MS, because I sat on the table after I took my two pictures saying, “wow, this is pretty significant.”

And I went and I just started looking up some information on multiple sclerosis, on, you know, how many people had it, what the expectancy was, what I could expect to happen to me. And I didn't have a very long time to do research, but it was enough to let me know that I wasn't going to die, that there were therapies out there. And so, I jokingly say that I went from a nosebleed to MS in two and a half hours. And the weird thing about that, though, is unlike most people who have different symptoms, I had to work backwards, because I did not have a history of perhaps going back and forth for three or four years with different symptoms and doctors, like Lizette saying, “Oh, you know, it's all in your head. There's something else going on.” So, I didn't go through that particular journey. So, mine was backwards.

So once I did, I found out that, things like... I called it “Sparky Jaw,” but it's actually called trigeminal neuralgia. I have had that for as long as I can remember, but I didn't think anything of it because I thought that was the sensation people felt when they bit into a lemon, and they just like... I thought, okay, that's it. Did not recognize the severity of it. I also have tinnitus, which again, I've had for a long time, but my tinnitus was off and on. And so, whenever they talk about people having tinnitus, it's always, “Oh, it's the slow buzz that goes on continuously.” So, I didn't make that connection. But then again, as I went back through history, I saw these different things that happened. So, I thought... I went through a period of time in junior high where I actually fell uphill, you know, and I used to... and I was clumsy when I was younger. So, my MS symptoms seem to have happened a little bit here, a little bit there. But nothing so consistent was standing out that would have taken me to see a physician on that.

So that's been my journey. It's been a little unusual, and it seems that at least once a year I find something else or some other connection to what may have been happening to me in the past. My first emotions when I was diagnosed, I was confused. I was confused. I was like, “Where did this come from?” Because it literally came out of nowhere for me. So, I was really confused. I was scared, because I didn't know what that was going to mean for me long term. What does it mean short term? I was curious, obviously, because I wanted more information about what was going on. And so those were my really main... being confused and being scared, because I didn't have enough time to really delve into what it was. I just knew that I had a serious chronic illness, a disease, and that I wasn't going to die.

Kate Durack:

Yeah. Thank you for sharing all of that, Anita. It's interesting again to hear the overlap in stories, but also all of the variation, which, you know, speaks to MS, for sure. All of us are experiencing it in different ways.

Claude:
I have a follow-up question, just from a couple of the stories, and maybe, Kate, if you're comfortable, you could share a little bit about your situation. Lizette, like, what you talked about with things being blamed on anxiety is a very unfortunate, gendered thing that occurs in medicine. And, it is towards the female gender of which I am not part of. I just wondered, I know, Kate, you mentioned that you had had a delay in diagnosis. I don't know, Anita, your situation was slightly unusual in that you sort of accidentally went into it, but did you guys, or did you ladies, rather, experience like, a lack... I mean, Lizette you already mentioned that you did, but like, was it because you were unable to, like, have people take your symptoms seriously that your diagnosis got delayed, and it was just blamed on anxiety? “I will give you some Lexapro, whatever,” but instead of, like, I don't know, we should actually take your symptoms seriously. Because, I didn't have that issue. And part of that is because my wife happened to work at the hospital in the emergency department I was diagnosed in.

Kate Durack:
Well, that’s hand handy, Claude.

Claude:
So, it was very, very easy to advocate for myself. But, I guarantee part of it is because I am a guy. So, therefore, my symptoms would have been taken more seriously. So I just wanted to ask you about your sort of experiences around that and how you managed to navigate that. I think that could be really relevant for some folks listening.

Lizette:
Yeah, I think with me, I don't know about the gender side, but I was young, I was in college, so it was easy to kind of blame it on that. Right? Blame it on, “you’re a young student.” Either, you know, I think I did go to the doctor in that in-between time of college and high school, and they're like, “Oh no, you have anxiety.” They prescribed medication. And we went on from there, but it just kept going, right? Nothing happened. Nothing changed. But yeah, I feel like... and like I said, it was 20 years ago, so there was less information, and kind of going with what Anita said, that her doctor made her feel so comfortable with her diagnosis. I felt the same way, because I never, ever thought that something bad was going to happen.

Maybe when I started attending kind of events where I would meet other people, I'm like, “Oh, something could happen.” But I don't know if I was too young to understand or, or what, but I felt like... I didn't feel like it was a death sentence at all. So, my doctor was pretty good. And he just told me, “Oh, you know, kind of be careful with this, careful with that.” Like, kind of like... foods. And I guess that was the thing. And if you went online back then, there was nothing online, so there was just a little bit here and there, there was a lot about, kind of anxiety, you know, keeping track of yourself in that aspect.

So, I'm like, “Okay,” I kind of learned how to deal with it. A lot about memory issues, which I did have. And I was a college student, so I really had to keep up with that. Right. Kind of learn how to have checklists. And then once I started working and everything, still today, it's still part of my process, right? Because I forget a lot of things, or because that mental state is not all there at times to get me through the day, in terms of just like, “Oh, these things, these things.” And as a woman and working... all those things just kind of come together. But yes, I do feel that it was...

they just didn't pay attention to it as much. But it could be that that was a time in the world that it was just not something that they thought about right away.

Kate Durack:
Yeah. And I'll hop-in, too, Claude. Thank you. And Lizette, similar with me, you know, there's definitely just tips and tricks that you pick up along the way. And then you wonder, like, “Oh, maybe that's helping me because I have MS.” Like, I am such a list person. I have to rewrite my lists every day.

Lizette:
Absolutely. Me too.

Kate Durack:
But for me, for my diagnosis... So, I was diagnosed when I was 30. And looking back on high school, which is when I was first diagnosed with depression, I also had just like a lot of just general... I would get dizzy spells at night. In high school, I had a lot of, back pain. And I've probably, you know, now looking back on it and as a mom, I don't blame my parents for this, but they were kind of just like, you know, “Suck it up. Keep moving. You're young. You're fine.” And then it wasn't until college, when... Anita, this goes back to what you shared, I started falling up the stairs a lot. Not down, but up. And, I definitely had some changes in vision, but nothing too dramatic. And my depression kicked in to a much higher gear during my sophomore year of college. And that is really when my parents started paying much more attention and saying, “Okay, this is something that we need to look at.” So that was kind of the mental health aspect for me was the first thing that I found support in.

And then through my 20s, I got married, I had two kids after diagnosis. But, you know, eventually I was a wife, I was a mom, I had all of these things going on. I had my career. I got my master's degree. There was just so much going on that I just thought, “Oh, I'm tired. So, all of these other things just make sense. They come along with that.” I figured they were just normal for everyone else, so I don't know that it was that I was ignored by anyone or pushed aside. I think it was more that I didn't self-advocate probably as early as I should have until, like you said, Claude, things really became a problem because I couldn't see right anymore. And so, it had to escalate to that certain degree for me to bring that much attention to myself, to say, “Oh, wait, wait, now I need help. Like I've been helping everyone else and now I really need help.”

Lizette:
And in that time frame, you know, when I didn't see a doctor, every time I would feel something, I would try, you know, I'd go back, you know, to, like, “Hey, you know, I'm feeling something, something wrong.” And, and it just kind of... I never found the right doctor, I think, after my initial doctor and never went back, you know, never really found a good doctor. So, I didn't feel comfortable. And I imagined starting over every time. But, yeah, I felt the same way. Any symptom, you just, you would be scared of what was happening.

Kate Durack:
Yeah. Yeah, I actually, and, you know, shout out to my mom because, she helped me with my MS diagnosis. She happened to be connected to an MS specialist in Denver, and I was able to see him really quickly after my vision did not improve with steroids. I was basically just nonresponsive to steroids, with optic neuritis, and then had an MRI ordered, and then that was eventually transferred over to this MS specialist. So thankfully I had that connection, was able to be diagnosed in that way - fairly quickly. But overall, probably much longer, I had been symptomatic much longer than I knew.

Okay, well, I'm going to move on to our next question. And, Anita, I'm going to go back to you for this one. So when thinking about everything that we've all shared, and that you have shared, is there anything that you found during initial diagnosis that helped you feel less overwhelmed? I know you mentioned just doing research on your own, but was there anything outside of that that you found to be helpful?

Anita:

I found it to be helpful as far as not just the research, but actually connecting with people in the organizations, because once I did find information, I did call. I called just about every MS organization to find out more information about either the disease, about options. Just anything. I just soaked in as much as I could from that. And in that, I made really great human connections with people and being able to just know there were other people out there that had MS, that were sharing information that was relevant to me.

But in addition, for me, joining iConquerMS helped tremendously, because the people that I met there through the organization who were people from just across the country that were just doing different things, whether they were in pharmaceutical, if they were in hospitals, nurses, etc.. Those people were incredibly wonderful and very supportive on that journey. So it wasn't just other people living with MS. It was other professionals and people who were concerned and cared, that also provided a tremendous amount of support and information, and that helped me to feel more comfortable, because I knew that there was a greater MS community, that was there to be supportive in whatever way that I needed, whether it was, answering questions, providing resources, anything along those lines. So it was the greater community that was really helpful to me.

Kate Durack:

That makes really good sense. Claude, how about you? Anything that you found to be helpful?

Claude:

In the short term, no. I actually had a challenging experience in that being all too well aware of, like, the healthcare industrial complex. I was really worried about how much this was all going to cost, whether it would be covered by my health insurance plan. So I spent a lot of time acting as my own, like, health insurance coordinator. And... I say “I.” Let's give credit where credit is due - my wife, Sarah, spent a lot of time doing that. And, I did what I could as well, because I was still recovering at the time, but, and that was actually very stressful, not having a good sense of what would be covered, what wouldn't. And then also like just coordinating other things, like, you know, “Are my vaccines up to date? Do I have good titers for like mumps, measles,” for all the stuff that you should, like, make sure before you're going to be quite severely immunocompromised that you've got under control? So that was really stressful, and challenging.

And the other thing was that I had not prepared myself for how tired I was going to be every single day of my life afterwards. I always describe it to people as feeling like you're four hours jetlagged. Not five, not eight, not two or three. Four. Just enough to be really annoying, but not enough to be unfunctional. So, it's just like you can work your way through, but it's not fun. Every day is just like that. So, that was like my initial kind of, like, what would have been helpful, I think, in that phase, would have been understanding those two things. What I subsequently found helpful moving forwards was talking through stuff. Now, you know, for some classic toxic masculinity, I had zero intention of speaking to a therapist, speaking to other people, getting any help whatsoever, I was going to toughen up and get on with it. At least I'm not dying. But what I noticed is I was more angry. I was struggling to come to terms with the fact that I had MS, and that that meant I couldn't do the things I used to do before.

And what would often happen is I would just refuse. So, like, I'm kind of a fitness person, so, like, you know, I would go out running in 40 degree Celsius heat, even though I knew that was going to destroy me because I didn't want to accept things. So, what I found helpful more longitudinally and subsequently was taking that more whole person-centered approach and actually speaking to someone who specializes in MS about sort of things in my sort of zero to one approach on things and how ambiguity in getting used to the new normal is okay. And, you know, I tried group meetings for a bit as well. Some of that was useful, some of it less so. I think, you know, different people have different responses to that. But, yeah, the ability to talk to people about what was going on and have them understand was really helpful because a lot of the time, all my friends and close family, and I don't blame any of them for this, you know, when I think about something happening to my dog, which is not even a human, like, my whole being collapses.

So as a parent, I imagine all you want is for your kids to be okay, right? So having your heart on the outside of your body, it's a whole thing, as Lee says. And like my parents, and I don't blame them for this, and my friends, all they wanted was to know I was going to be okay. And actually what I had to train them through is actually, you know, I'm not ever going to be “okay,” but I am okay with this new version of me, and I need you to be okay with this new version of me as well, to support me versus wanting me to just be, “fixed.” And like that dialog and working through that has been extremely helpful to my overall dealing with this situation, I found.

Kate Durack:
Yeah, that's super interesting, Claude. I'm thinking about my own diagnosis with my parents and how hard it was on them to hear that I had MS. And, you know, I think there's definitely, like, they went on their own journey after my initial diagnosis and they, I'm sure they were mad at some point. Definitely a denial phase happened where “you're okay, you look okay, everything's fine.” And then kind of more of an acceptance. And so, it is interesting that as you're navigating it yourself, you're actually watching everyone around you also navigate it. And it was really hard for me to experience it myself, because I just wanted to assure everyone that I was going to be okay.

Claude:
Yeah. Oh God, Kate, I couldn't... Sarah was telling me, she's like, “You know, it's okay to tell people you're upset about this.” And I was like, “No, no, I just want everyone to be chill and okay with it.” I like planned to call... I was going to give my sister and my parents, before I did, I had like the key bullet points. I did the whole, “Hey, I've got news. I sat down. It's not good news.” You know, I gave them the warning shot. I mean, I had my monologue and I was like, “I'm going to tell you what I have.” And blah blah. I was so concerned with, like, cradling their emotions that I didn't even acknowledge my own in that immediate space.

And then for a while afterwards, I was so concerned with them just feeling like I was okay, especially because I live here and they're all the way over in a different country as well, which makes it even more challenging. And same with my friends, I just wanted them to be like, “Oh, he's okay.” I wasn't, but now I've come to terms with a much more mature emotion of like, “No, I'm not okay, you guys understand that I'm not. But I'm okay with this new version of not being okay, which is okay.” A lot of okays in that okay, but I think you follow.

Kate Durack:

Absolutely. That's so funny. I was the exact same way. And, during my diagnosis, I had the most wonderful neurologist, and, I brought this up with Dr. Hendin too, I had an experience where he asked me what I wanted for my life. And so, the same day that I was diagnosed, we started focusing on: "We're not going to talk treatment, you're going to need it, but let's talk about do you want kids?" And so, then I was able to very quickly adjust my focus to I need to have a family, and I need to do it quickly before I start treatment. And so that was easy for me to push back the diagnosis emotions and just say, "Here's what I have in front of me. I can control this. I can do X, Y, and Z. We'll think about the treatment and the aftermath later." So, I definitely don't have good strategies that I used back then. There's definitely things that I would have done differently. But yeah, Lizette, I know, you experienced it 20 years ago. So, was there anything back then or more recently that you think would be helpful?

Lizette:

Well, back then, I mean, there was a little bit of information, you know, fatigue, but not as detailed as it is today. There was like fatigue, memory, you know, you might forget things. I remember, so my resource was my doctor, right? It was the only person. I was not telling people about this, to be honest. Like, it was kind of me and my family, my parents, my brother. So it's not like I was even telling, you know, anyone outside, so I can't say I felt lonely, but, it just felt like, you know, it was just something... because I looked normal. Right? Even my parents, a little different than you, Kate, you know, they're like, "You're fine, you're going to get through this." You know, it was very... "You look fine. You know, it's nothing." It's going to be something. And I don't know if it's Hispanic culture, you know, that we feel that medicine is going to fix us. Right? But it was like that.

And then another kind of thing that used to happen then, which I believe still happens, pharmaceuticals have, you know, like events to talk about the medicines. It was kind of new then, I would say. But, and that's where I would kind of meet people, and I would go with my mom or my dad or both of them, and, you know, so they would hear stories from other parents there too, you know, or older individuals. And I felt too young at times. I mean, I was 20, but I still felt, you know, like young. But yeah, I felt that.

And then I kept a lot to myself, like the fatigue factor. I feel like I never said much and it was always there. And in my 30s it was worse, I think. I remember waking up, sitting on the couch and just staying there, especially like on a Saturday, right? No work, no nothing. Just sitting there and say, "I'm not doing anything today." And as time goes by, you start also identifying, like, you know, the more movement you do, the more active you are, that helps. And once I had my kids, I just didn't even feel that anymore. Or if you do feel it, you just can't do anything about it. You just have to keep going. Right? But that was a big factor, I think, the fatigue, the people. And I remember at the time when I did start telling people, friends and family, they're like, "Oh, okay, well, what is it?" And even when you explained it, I don't think they understood very well what you were talking about.

So, it got to a discouraging point where I'm like, "You know what? This is just kind of staying with me. And, if I meet people who have it, they'll understand it, you know?" And, as I started my career, I kind of... I worked in healthcare my entire career. So, like, I got to meet a lot of people, was more comfortable talking about it. So that maybe was the changing factor in my life, you could say. I wish I, in a way, took it a little bit more serious and I think the people around me, but I can't blame anyone. It was such a long time ago, you know, I can't even blame myself. I was young and just did not understand it completely, to an extent that I should have. And because I had never heard about someone, you know, handicap or, you know, or having any of those really tough issues, I was experiencing a little bit of it, but I'm like, "I'm going to get through it." And I used to get through it, you know, because the numbness went from my legs to my arms.

So it was just like, “Okay, I'm good now, right? It's just over here now. So, I can walk fine now.” But those were kind of the things that I experienced. But, if I could tell myself in the past, I would say, "Just keep going and just be compliant and things are going to get... they're going to be well, you know, it's not like you're not going to have a family or kids.” I didn't even think about that then, that I wasn't going to be able to or anything like that. I did not even consult my doctor about those things.

Kate Durack:
Yeah, it's really interesting to look back. I mean, you're looking back 20 years and lots of life experiences later. And, Anita, what do you think looking back on your initial diagnosis, do you wish you would have handled anything differently?

Anita:
I would definitely agree with Lizette and say that I wish that I had taken it a little more seriously. I didn't fully understand everything about MS, and even though there was a lot more information, I had questions about being an African American woman with MS and how that presents. And there was no information ten years ago about that. And so that was a concern. And I do wish I had. And actually going back to something that Claude had been saying about, and you as well, about the people around you and wanting to comfort them to put, you know, a nice little blanket around them and spend time telling them, you know, “I'm going to be okay. I'm going to be okay. Don't worry. I'll be okay.” Because there's obviously a part of them that wants to fix you, that wants you to be better. And so sometimes people become kind of obsessed, in a way, with that.

My father took my diagnosis so well that he was just like, yeah, whatever. But my mom really took it hard and is still taking it hard. And, as a parent, from her perspective, it's always been, “What did I do? Did I do something when I was pregnant with you? Did I do something when we moved here? Did I do something that... was it something I cooked? Was it...” you know, and all of that. And even ten years down the road, at my advanced age, she is still having those concerns about was it something that she did or when I'm going through issues, you know, or going through problems that my MS causes, like with my arms, there's always that concern - “Okay, is it getting worse? Are you okay? Is it going to get better? What's going on with this? What's going on with that?” And so, that would have been something I think I would have changed, would have been to have coddled people a little less and coddled myself a little more.

Kate Durack:
I completely agree with that one, Anita. And it's still hard for me, though. I mean, I know that I should have done a better job taking care of myself and focusing on me. But there's definitely still part of me that thinks, like, I don't know... I feel so selfish. It's hard to get into that brain space of like, “No, this is what's important. This is your body. If you don't take care of you first, you know, you’ve got to put your seatbelt on before you adjust anyone else's seatbelt.” So, you know, that's kind of... it's very much easier said than done. But I do think that that is an important takeaway. And it sounds like all of us are kind of saying the same thing here, is that we wish we would have taken it more seriously. I personally wish that I had grieved it more, sooner, because now it creeps up and it does at least once a year, and all of a sudden, I'm just hit with this burden of “I'm living with MS, oh my gosh, what's going to come next?” And so, I feel like I just have to keep reprocessing that. And I don't know if that would have been easier if I had been just more honest with myself and educated myself more when I was first diagnosed. I definitely missed the boat on that one. So, Claude, anything you wanted to add?

Claude:
I think we all did the best we could. It's... just listening to all of us, we’re all so hard on ourselves about how we dealt with others and ourselves around the diagnoses. I think we did the best we

could with what we had at the time. And being kind to oneself about that is also just as important. I think that's allowed at that point.

Kate Durack:
Thank you. As special thanks to Claude, Anita, and Lizette for their valuable contributions. Also, I'd like to thank Gradwell House Recording for hosting us again today and producing this program. This podcast, along with additional resources and support, can be found by visiting the Multiple Sclerosis Association of America's website at mymsaa.org. Thank you for listening to part two of our series, “If I Knew Then: Reflecting on an MS Diagnosis.” Stay tuned for part three of my conversation with our panel of guests coming soon. Take good care.