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MSAA Podcast - Episode 17:

If I Knew Then:
Reflecting on an MS Diagnosis – PART 3

Host: Kate Durack

With special guests: Claude, Anita, and Lizette

Kate Durack:
My name is Kate Durack, and I am the Director of Communication and Patient Focus with MSAA. Welcome back to 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 about how to communicate with your healthcare team and other aspects that arise when you're newly diagnosed with MS. In part two, we were introduced to three incredible individuals living with MS, Anita, Lizette, and Claude, who shared their stories about when they were first diagnosed. Now, in part three, we will hear the conclusion of my discussion with Anita, Lizette, and Claude as they share more about how they have navigated their own MS journey since their diagnosis. We're going to move on and talk about what strategies we have found helpful in our journey in advocating for ourselves and making sure that our concerns are heard by our healthcare teams. Let's start with Lizette.

Lizette:
Well, I think a way to manage and to navigate my appointments with my doctor, I try to keep, you know, a list of things that come up. You know, it's quite a while to see the doctor It's about, what, six months? So I try to keep up by, you know, writing down, having some notes before I go. So, you know, a list, keeping a list of those questions that I have, because that appointment creeps up pretty quickly, so... But, then you forget, you know, memory issues. You forget what happened three months ago or what you felt, so I think just being prepared for those appointments in terms of, you know, keeping track of symptoms or anything that I feel differently. It might not be correlated, but it's always good to ask that question. So I think that's how I keep up. And I keep up, you know, I see my doctor about every six months, and he's great.

Kate Durack:
Yeah. I'm similar in a lot of ways with that. I do, I keep notes, even if there's, you know, a little tingle in my right pinky finger. I'll write it down, mark it on the calendar, and then note how long it's been occurring. And then share that with the team after, you know, at my next check in. How about you, Anita?

Anita:

A thing that I found best that worked for me in terms of advocating for myself, and I do agree with both of you, obviously with Lizette and with you, that being prepared and taking notes is a huge part of that, but one of the things I found was asking myself the question: “What would I like the end result to be?” So, when I'm going to my doctor or whoever it is, whether it's the neurologist or if it's any of the other complementary healthcare professionals, the one thing I want to ask is, at the end of this particular appointment, “What do I want the end result to be?” Because I don't want it to simply be an appointment where I'm simply saying, “okay, this and this and this and this are happening,” and then leaving that up to the healthcare professional to really lead that. So, for me to think to myself, “what do I want,” that helps me bring everything, one, mainly back to the center for me and reminding myself that it's okay to put myself in the center and to say, “what do I want?” And too often I think we don't think about ourselves and what we want. It's more about survival or what do we need. And so, asking myself what I want to get out of that really helped me to advocate for myself and to speak up for myself, because I knew that there was something that I needed and wanted to have at the end of that appointment or meeting.

Kate Durack:
And, you know, that's going to be my personal key takeaway from this meeting with you. I love that so much. And I actually have an appointment coming up in a month, and I will be using that as I prepare for it. So thank you. How about you, Claude?

Claude:
Oh, I'm the worst person to ask for advice on this, for a couple of reasons. The first being, like, it's a slightly different dynamic with me, just because of stuff we've talked about already. But also, when I go and see my neurologist and her fellow, who are both fantastic and just so patient with me, so patient. I don't want to be there, because it's a reminder that I have to deal with this. And I don’t want to deal with it. So then, I don't go to my... I don't go to my appointments with, like, “what do I want to get out of this?” I go to my appointments with, “How can I get out of here as quickly as possible?” So, you want to cut this part out of the podcast, and no one should be listening to this advice.

I think, speaking in general terms, I love what Anita said. And I think, for me, my issue was... I actually this is maybe one useful thing I can say about this and advocating for myself that might be helpful to others. Every time I needed extra help with something, whether that was dealing with the fatigue or whatever it may be, some of like the anxiety and sad episodes you might get, I would see that as a failure, that I was in some way failing, that I wasn't able to just overcome this by myself. And that's a really... it took me a while to get through that attitude. And I would just encourage other folks who may have similar personalities to myself that it's not 0 to 1. It's not “you either succeed or fail.” There's a lot of middle ground, and it's okay to advocate and accept help in addressing some of that middle ground. And so, approaching and advocating for yourself in that fashion is constructive. Taking the “Claude approach” that I just articulated - destructive. Do more of the former, less of the latter. That would be what I recommend to the group, but I don't have the best answer for that.

Kate Durack:
No, I appreciate your honesty. And, you know, actually Dr. Hendin spoke about that a little bit too. Just, you know, I feel like... what I'm hearing from several of us is that we put a lot of pressure on ourselves to be a good patient. And so that probably leaves a lot of things unsaid, potentially. Right? We're not asking for help in the ways that we should and not self advocating as much as we could be. That's going to be an ongoing thing that I'm going to need to work on, that's for sure. So I appreciate all of your honesty. I think for our final conversation, I think let's turn to mental health and talk about what you all have found to help manage the emotional

aspects of the diagnosis and what advice would you give to others for this? Anita, can I start with you?

Anita:

Oh, absolutely. I am just all about mental help. Like you, I was diagnosed with depression before I found out that I had multiple sclerosis. And that also happened to me when I was in college as a junior. And so there was probably about a 20-something year gap between my first diagnosis with depression. And what I have found with MS is that a mental health aspect of what goes on with us had been so severely neglected for so long, and it is so important that we address this and take care of it, it's just as important as the physical part, because regardless of whether my depression was earlier or before my MS diagnosis, being diagnosed with MS can make you depressed. It can make you sad. Whether it's from biological reasons, there are just so many things that go with having MS that you have to deal with on a daily basis. The pressures, dealing with, as Claude talked about, insurance, dealing with your health, trying to schedule things, making sure that you're writing down symptoms that you have, or "is this a symptom or is this going to be a relapse?"

There's just so much mental exertion that goes into simply living with MS and taking care of our mental health is essential. I recommend, if possible, therapy, for people that are living with MS, the ability to work through that with someone who is a professional, that can help meet whatever your mental health needs are. But mental health, and I'm glad you brought that up, Kate, I cannot say how important it is, and that is the MS hill I'm going to die on is that we must, must take care of ourselves emotionally and take our mental health seriously, regardless of what family or friends or society or community, regardless of what those other voices are. Please, I really just implore people to take care of your mental health and take it seriously.

Kate Durack:

Thank you, Anita. And I really appreciate all of that. And, my background before working for MSAA was actually working in mental health. So, I hear you and I appreciate it equally. Lizette, how about you?

Lizette:

I think for me, just because I've already been with this for so many years, I think I've navigated that already, and I got through it. I came to accept it. Now, I feel like it comes up a little bit more in my head. You know, now that I have a family, that I have kids, I think, you know, like, "oh, my gosh, what's going to happen?" You know, "what route is this going to go," even though, thankfully, I haven't had a relapse or anything. But, you know, "what can happen later on, or how's my body going to react later on?" But mentally, I've accepted that and I'm aware of it. But I do try to kind of keep my head clear. There's so many things - work, life, it all comes together. So, the mental health aspect of it is from so many different angles, not just from the disease, and navigating all of it and just trying to get through it, it's a lot.

But, I do have a great family and parents, husband, kids, brother. They all help me through it. Right? They help me mentally. I feel like just exercising, taking walks, just to kind of keep me more calm whenever I can. I'll try to do some yoga. So more the meditation side. That's where I turn towards for this. Thankfully, I haven't had depression or anything, but life, you know, can take you in different directions, and it could happen at any moment. And I do have those moments, unfortunately. But I've learned how to navigate that and how to get through it. But in terms of the disease, I think I got through that a long time ago, but now it's coming back a little bit now that new thoughts are coming about because of family and kids and what can happen in the future.

Kate Durack:
Yeah, I definitely relate to that, Lizette, I think about my kids and, you know, for me, in terms of mental health, I definitely have a counselor. And, it varies how often I need to see her. And it kind of ebbs and flows with where I'm at with, you know, life and with MS and my journey. But I also just have friends that I know I can call and I can just vent everything and anything, and they're not going to judge me, and they're going to listen and they're going to take me seriously.

And then additionally, with my kids, you know, they're little, they're five and seven. But with them, I'm finding that it helps me with my mental health if I'm open and honest with them about things. And so I share with them, you know, to what the degree I feel is appropriate. But sometimes, “I'm really tired and I can't do X, Y and Z.” And I am living with MS and it's, you know, “it's nothing to be scared of. But there are definitely things I need to do to take care of my body.” And just knowing that I, being honest and open with them helps me feel better because I'm not holding everything in.

Lizette:
Absolutely. I feel the same way.

Kate Durack:
Not always easy to do, because you don't want to admit that you're not the strong mama that you always want to be. But important for sure.

Lizette:
But they understand more than we think, sometimes.

Kate Durack:
They really do. They really do. There's definitely, you know, my boys have been so sweet, especially with heat. They know that I can't do everything that I want to be doing outside. And so, they know, and they'll say, you know, “mama, we know we can't go do this today because you can't be outside in the heat, but maybe we can do this instead.” So, they're already offering different solutions for me. It's the sweetest. But I think that that's only happening because I'm being open and honest with my feelings and my experience. Hopefully in a way that is not scary. That's always my goal. Claude, how about you with mental health?

Claude:
Yeah, there's so many complex things to talk about with regards this.

Kate Durack:
For sure.

Claude:
We’re in a generation, first of all, where you can actually talk about mental health. So that's the first thing is like even generational attitudes have changed towards this. I come from a culture, and this is going to be a sweeping generalization, of deep repression of emotions. The British people have the phrase: “keep calm, carry on.” So, like, when I moved to America nine years ago and everyone's talking about their feelings and stuff, I was like, “what is this, what's going on here? I'm not used to this.” So culturally, for me, even acknowledging mental health was challenging. That was like my first barrier to overcome, is like accepting and being okay with that kind of stuff.

My picture around mental health is also slightly more complex in that I have mild OCD, very well controlled, actually very useful for my career in healthcare and medicine. It's good to pay attention to things and make sure they're done correctly and stuff. But you know, so there's sort of a balance of how I look after that, as well, and the anxiety it can cause. And that was something I was already working on before I started to think about mental health with regards to multiple sclerosis. And, you know, it's tricky because a lot of people would be like, “well, of course you're depressed, you've got MS.” Or the alternate way of looking at it is if you look at my frontal lobe on the MRI, it's like someone's, you know, taken a hole-punch to it about 20 times. So, I'm not working with the best situation here.

So, my attitude towards it when I sort of came to that realization was like, “okay, so I'm like on the wrong side of the bell-shaped curve of like how much resilience I have. So why don't I try and, like, afford myself strategies to get myself to at least the middle so that I can cope and have a better sense of how to manage this and grieve it,” like you were mentioning Kate, and in my case, let go of some of the anger I had, which I don't have that anger anymore. So, you know, 100% recommend speaking to people about this stuff. If you are fortunate enough to have access to a therapist or an MS specific therapist, why not? What's the worst that can happen? You'll have a chat with someone, you don't like it, don't go back. You do like it, you keep going. If medications are right for you, I see no issue with helping yourself out on that. You know, again, you're dealing with a bad hand, so your brain is not working as well as, like, the average brain. So totally fine to do that.

And then the last thing, and this is something that's quite personal to me, is community. So I've lived in the US for nine years and my best friends from home I've known since, the earliest ones, like six, seven. So they now have kids that are as old as we were. And we’re still very, very close, this group of ten of us. And I was never able to find a similar community to that in America. And that's something I've really been trying to work on, because the community fabric is really quite frayed across society, in general, I think. There's a great book about why America bowls alone now, and that's a big problem for society. Worth checking out. And the cause of it. And we know that being lonely and being socially isolated is so bad for your health. It's like smoking a pack of cigarettes a day, apparently. So, like, creating and making sure you have a strong community around you of your friends and family, I think is a really important, like mental health without the mental health. So like not over medicalizing it in that sense, that I have found really helpful to try and prioritize - pursuing my hobbies, putting myself out there, building relationships with people, and building a community here that is local rather than just lamenting the fact that my friends that I've known since I was seven aren't here. It's okay to actually, like, branch out and build those things. And I found that extremely helpful as well for me.

So, you know, in summary, because I've rambled, cultural old stuff is stupid. Don't do that. I would 100% engage with a therapist, if you have access to it. If your psychiatrist recommends medications, I don't see an issue with that. I would 100% lean in there. And then community, build community around yourself. Try and have community even if you're more introverted, because I kind of a, almost bipolar in terms of my extroversion to introversion. I like both in equal measure. And so, but even introverted people need people, so like, try and build that community around you, and spend time pursuing that, I found to be very helpful strategies.

And then the last thing is like, just coming to terms with the fact it's okay to be sad. Like sometimes it's okay to, like, sit on the sofa, be like, “you know what? Having MS sucks.” And that's okay. That's fine. You can just sit with that feeling and be fine with it and allow yourself to feel that feeling and explore it. There's nothing wrong with that. Like, again, don't do what I do and just bury it down, like, let it ferment, and... what I used to do, I should say. Let it ferment and experience it, because that will ultimately lead to a much better, sort of, long term outcome for you, because if you don't take care of your mind, it doesn't matter what medications and stuff you're on, like, that stuff really impacts you.

Kate Durack:
And I think that's great. And I do... I really like what you had to say about medication, and just allowing yourself to be sad. I think that those things are important to talk about. And then I do just want... if we can all take some time to talk more about building community, I think that's really interesting. And, as someone who's almost 40, I have found it really difficult to build community. I have moved.... So, I lived in Colorado for 28 years, and then I moved to three different states. And so, I have just been kind of bouncing around and I'm now very much settled and want community. And I want to feel engaged with something outside of my career and my kids, even though I love them so much. But I want that other level of connection and fulfillment. And so, I just would love to hear from the three of you how you have built your communities and how you continue to grow them, because I feel like that is very difficult. Anita, do you want to share?

Anita:
Certainly. I have a very different experience, I think, from the three of you, in the sense that I did not grow up with a large community. My family moved a couple of times. My father was in the military, and then he became an attorney. So, I never got grounded with a group of people like Claude had that have been friends since seven. With as far as Lizette, my parents divorced when I was younger, and so I just had a very intense, very small family of three people, my mother, my brother and I. And so for me to build community took a lot of effort. But in terms of multiple sclerosis, I needed to build that community from the ground up. And my community's actually virtual. So the people that I have around me, that support me in MS, are people that I have met through the various projects that I've been able to work on and the organization. So I, you know, chatted with people through a couple of meetings and then just sent an email, hey, let's chat, called them up, and all of a sudden, you know, there's that person that's a friend. And that's how I've built my community, was sort of brick by brick with the people I've been able to interact with in distance.

So my entire MS community is virtual. I don't have a local MS community because, similar to something Claude had said before, I'm not a group therapy kind of person. Some of the groups that I did try to go to in the beginning were cry fests and how terrible it was to have MS. And I did not need that sort of, you know, oh my god, my life is terrible energy around me at all. And so that's how I did it. I just simply got to know people through various organizations and things that I did. And that's what I would encourage people to do who are more very introverted like... I'm an introvert... introverted, is to join various programs. So, it might be an online program here. Something to do there. And just sort of do it that way. Just stick your head out a little bit and build it that way. So, I've been able to create this virtual community, and it is possible to do that for people who don't have immediate family, a large group of friends or people that are physically close to them.

Kate Durack:
Yeah. I had a very similar experience with a MS meetup group in my town, and did not... I went once and never again because I do enough in my own head thinking about all of the downsides to living with MS, I didn't need that in an MS community. But what's interesting about that is I would love to connect with other people living with MS, who have, you know, similar perspectives to the three of you. And I'll be really honest, and we can cut this out of the podcast if we want to, but this is the closest I have ever come to talking with three other people living with MS that are like-minded and sharing our stories in a meaningful way. So I just wanted to

thank the three of you for this. I really, really appreciate it. Lizette, is there anything that you have done to build your community outside of your immediate family?

Lizette:
I would say the same thing you said. I've been out of it. The only time that I did anything in the MS community was 20 years ago when I attended some of those talks about the medications, and never again. So, been out of it. But, working in this project and also meeting all of you guys in this talk today, the closest to... the most people I've talked to with MS. Same with... the same... the very, very same thing that you said, Kate, for me. And it's very refreshing.

Kate Durack:
It does feel refreshing, doesn't it? Claude, did you want to add something?

Claude:
You know, so... Okay. I'm in a similar age bracket to you. I'm too self-conscious to to state my exact age. And, this Zoom AI filter is doing a lot of work right now. The Zoom AI filter is doing all the work I need. It's wonderful. But, it's the whole male loneliness epidemic, like being a guy in his midlife, trying to make friends with other blokes, or women, like, it's hard. It's really, really challenging. And I think about community outside of MS, actually, I don't just think about the MS community. I think that's great, and I find meaning from our work and this stuff, like Anita was mentioning, like you mentioned Kate, not a fan of group stuff. But like just having community, full stop. It's a challenge, and it's... and I just want to be clear when I answer this as well, I would not put myself as a success story with regards to this. I would grade myself at like a C-minus in terms of how I've built community. But I would encourage people to treat this, like, as important a thing is like going for your... going to the gym, or like, cooking your meals or eating healthy, like it is a garden that needs to be tended, like, building community. It is not just something that happens magically, so it requires effort.

The closest I've come is a motorcycle club I'm a member of, but even that is like, at best, like a garage with a sofa in it where I occasionally speak to other people. So it's tough. It's really tough. So you have to put the effort in. It's really the only advice I could give on this, which is like, you know, schedule the fun. Schedule, like... or come up with ideas in terms of things that you've always wanted to do, where you will potentially meet people like, you know, book clubs, sports, competitive sports, whatever it is. But like, things that you can do to like, have a common shared interest and lived experience, is always a good start to like getting through that awkward phase and then finding people who are your people. And it's hard with kids. I mean, I don't have kids, but like the amount of time you all have, I don't know how you do it. Got a job, got the kids. It's like, when do you do anything for yourself? So it's really hard that you got to try and find and carve out that time for yourself to build that. That's all I've got.

Kate Durack:
I really like that idea of community and being just as important as any other aspect of our wellbeing. And to me, it's probably my biggest struggle in terms of my wellness. Like, I can do the eating right thing most of the time, and I can do the exercise thing when my body is playing along. But community is hard. It takes... especially living with so much fatigue, just like, "oh my gosh, I have to go out and do what?"

Claude:
It's the last thing you want to do is get up and go out and meet a bunch of people. Like, you already feel like four hours jet lagged.

Kate Durack:

Yeah, and then you make plans and you want to cancel them last minute because, you know, you're tired or, you know, something changed.

Anita:
And I think it's also important to decide for each of ourselves what community means. I have... this has been an incredible, incredible conversation that has a depth to it that I haven't been able to have before. And so when I talk about community, for me, it's other people that are living with MS that, not necessarily that I reach out to in terms of having a group therapy, but there are people that I know who understand what I'm going through. And so if I need to just call and we just talk, that's great. Actually, I don't think I ever talk to my community about the MS symptoms and having multiple sclerosis or anything of that nature. It's just that it's a friendship or an acquaintanceship kind of thing where you can just talk to someone, they have MS, you just know... there's that unspoken communication. But community can mean anything for a lot of people. It can mean, you know, a bigger group of people, and some are extroverts, and they actually go to group meetings and group events and do things of that nature. So, it's also important for each person to define what community means and not to try to do what they think they're supposed to be doing as far as having support around them.

Kate Durack:
Yeah, I appreciate the diversity and what we define as community. And yeah, that's a good point to bring up. Definitely. So, anything else that you all wanted to share that you wish you would have told your newly diagnosed selves?

Lizette:
Give yourself grace and time. Time will tell what happens next, pretty much.

Kate Durack:
Yeah. Dr. Hendin and I were talking about about that very thing, was that and how, you know, the way that MS is treated now and what we know about it, you know, we are going to be okay. You know, I think it's important to know that it's just a different outlook than it was 20 or 30 years ago. So, there's definitely a lot of positive things to be said about living this way. We are able, I mean, like, as you said, Anita, we've connected with each other and we have an underlying understanding of what we're living with. And we've been able to have this very robust and meaningful conversation. So, yeah, I think giving ourselves grace and also just knowing that this is just another step in our journeys and it's affording us, honestly, some wonderful opportunities in life as well. Anything else from any of you?

Anita:
Yeah, I just wanted to say that I would have told myself “Be as nice to Anita as you are to everybody else.” And that would have made, I think, the biggest difference. And that's along with what Lizette said about grace, is that the kindness that I extend to other people, I needed to extend to myself a lot sooner than, I can even say, I do now. But that's the goal, is to be as nice to myself as I am to other people.

Kate Durack:
For sure. It's a great reminder. How about you, Claude?

Claude:
It's hard to go after that. Anita said it perfectly.

Kate Durack:
I know.

Claude:
Plus one. Yeah. You know, and just it's okay. It's okay to feel annoyed or upset and yes, we're going to be fine. It might not be the normal that you thought you would have for the rest of your life, but it's your new normal, and there is plenty of nuance between 0 to 1 in terms of how you accept that and accommodations you can make to have a very fulfilling life that, you know, aligns with your core values and is meaningful for you. Yeah.

Kate Durack:
Wonderful. Once again, I want to extend a very special thanks to Claude, Anita, and Lizette for their valuable contributions to this discussion. We spoke a lot about community in this episode, and for more information about MSAA's online peer-to-peer forum, My MSAA Community, please visit mymsaa.org/community. Also, I'd like to thank Gladwell 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 three of our series, “If I Knew Then: Reflecting on an MS Diagnosis.” Take good care!