



MSAA Podcast - Episode 22: Beyond the Chart: Strengthening Self- Advocacy Through Communication – Part 2

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With special guests:
Annette Howard, MD
Kate Durack, MPS

Shelby Bassili

Welcome to Beyond the Chart Part 2 of MSAA's podcast focused on strengthening self-advocacy through better communication. I'm your host, Shelby Bassili, from the Multiple Sclerosis Association of America. We covered several tips and strategies during part one of this podcast series. Today, we're diving in more to what happens after the doctor's appointment and how to keep the conversation going beyond the chart notes. Once again, I'm speaking with Dr. Annette Howard, Medical Director of the Multiple Sclerosis Institute of Texas in Houston, Texas, and a member of MSAA's African-American Advisory Board, and Kate Durack, Director of Communication and Patient Focus with MSAA, who is here as a person living with MS and a patient advocate. Let's rejoin the conversation.

We've talked about what someone can ask during our doctor visits, but what about communication between doctor visits? Dr. Howard, can you give us some insight?

Dr. Annette Howard

So in between visits, okay, this is what my expectation is in my office: that you'll contact me about anything that I need to know that has to do with your health care. So if I'm the MS doctor and the cardiologist changed your blood pressure medicine, I need to know that. So call the office and say, "cardiologist changed my medicine or took me off or added this."

I have a patient who fell at a grocery store yesterday. MS patient fell at a grocery store yesterday. And six weeks ago, she had a knee replacement. She hit that knee and the incision opened back up.

Kate Durack

Oh, no.

Dr. Annette Howard

So she went to the hospital. The doctor who did the knee surgery saw her and scheduled her

today for an arthroscopic procedure to look inside and be sure that nothing had been damaged with this new knee. So she called yesterday to say it happened. She called today to say uh it's going to be at 9:00 and I'll give y'all a call after I get out of the recovery room.

I want to know that. She knows that I'm concerned enough about the rest of her that I want to know. And so the problem with me in this office, is if you have stuff happen and you don't tell me about it. That's when the dictator side of Dr. Howard comes out. So here I welcome, I want to know what is going on with things that may not even have to do with MS.

I tell the story all the time that MS patients don't generally call you right away when something is wrong with their MS. They go through all kind of motions with maybe I'll get better, maybe it'll go away, maybe it'll be all right, and sometimes wait until it's Friday at noon to call you about their MS only to find out that you close the office at 11:55 and then they have to go through the weekend and be calling you at 7:55 on Monday morning. So MS patients don't contact the office like clockwork. So I don't always expect to hear from patients when something happens. They want to see how it's going to do over a period of time before they contact you. But they usually do end up calling you. And so I'd rather know sooner rather than later so that perhaps we might not have to go through the weekend. It may be that we need to tell you, "why don't you go give us a urine sample so we can rule out that it's a UTI." Or "why don't we give you three or four days of some prednisone pills and maybe that'll make you feel better," you know, so that by Monday we don't have a bigger problem. We've, you know, got to manageable problem that can wait until we can get you seen in the office in the next couple of days.

So we want to know, hear. So that's that. And if your doctor is not one of those kind that really want to know, give him the information and make him tell you that he doesn't want to know. You supply the information anyway. And if you find out that they don't really want to know or seem like they care, that's another clue that you may need to find a doctor that would be interested in knowing.

Shelby Bassili

Do you have any thoughts on that, Kate?

Kate Durack

I was just thinking back on our initial question and about how knowing your MS and understanding your MS helps you with all of this advocacy. Because when I hear you say that, Dr. Howard, I think there's no way I'm sending my neurologist a note every time I get a new like twinge in a hand or my vision gets blurry or I mean, I am not the kind of person that would do that for every little thing, but I am aware personally with my MS thus far what is something to be of concern and what is not, and what can wait a few days to see if it goes away and what should not. And I just think taking the time to understand your body and your MS and having those conversations at the beginning, at the outset of your establishing a relationship with a neurologist is really important so that you do know when you should be reaching out and how frequently.

Dr. Annette Howard

And you know, you bring up a good point. So, Kate, you are what's called an MS veteran. So you've had it long enough that you kind of know what the twinges might be and then when it's something that's not the usual. And I think most MS patients know that. And that may be where you need to clue your family and friends on something. Because I'm going to tell you, I can hear

from family members, "well, I saw you wasn't walking right last week." And they sometimes can be helpful in cluing you in that maybe it's a little worse than you thought.

Kate Durack

That's such a good point.

Dr. Annette Howard

And so that goes back to we all on a team.

Kate Durack

Yeah.

Dr. Annette Howard

But for me, I find family members to be very helpful. I really don't see them getting in and trying to manage. And coming in my office, but trying to be sure I'm aware of some things that the patient just may not have felt was as important. And so it's a clue sometimes.

Kate Durack

Definitely.

Dr. Annette Howard

And so I offer appreciation and, you know, we kind of joke through it all, but I understand those family dynamics and, you know, we just, but we still need them to be on the team.

Kate Durack

For sure. And I don't have, I mean, I definitely go to most appointments by myself, so I don't have that, but I will share this and hopefully, Shelby, you don't mind. So Shelby and I have been working together for years and we've worked together at MSAA for two years, but we actually worked together previously before that. So she and I have a pretty close relationship. And so I do share some MS symptoms with Shelby.

And recently I have started getting dizzy in the mornings and that's new for me. And that one is very unusual and something I need to talk to my neurologist about. And Shelby is aware of this new symptom. And as my coworker and friend, I think it's important that she is aware of this symptom because it can impact me at work as well. So she knows this, but I feel like I have that kind of relationship with Shelby and with other friends and family that they would keep me honest, right? Like they would say like, "I don't know, Kate, remember how you told me that this new normal might be happening for you, that you're now waking up dizzy? You need to talk to someone about that." And that's really, I need that. I need that push sometimes to share that information.

Dr. Annette Howard

I agree. And the first question your doctor is going to ask you is, "well, when did this start? How long has that been going on?" And you know what we hate? "Umm..."

Kate Durack

That's my answer, though.

Dr. Annette Howard

Not too long.

Kate Durack

Yeah. And I just shoot Shelby a text, and I say, "when did I first complain about this?"

Dr. Annette Howard

We hate those questions. "Not too long."

Kate Durack

Well, this was really helpful. I also think that you brought up in your answer, Dr. Howard, that if these types of conversations aren't happening, it's another clue that you should be looking potentially at a new provider.

And I myself have experienced some pretty unfortunate things with neurologists where it only lasted for one appointment and I immediately was just like, never again. I am never going back. They didn't listen to a thing I said. They did not, I didn't feel respected. I felt like a number. It didn't even register with them that I work in the MS space and that I might have some context about what I'm living with. I was treated like I knew absolutely nothing about my experience and my disease, and that's happened several times for me, so it's unfortunately probably happening to a lot of people.

With that, I know I would strongly encourage people to get the energy to go find another provider – and I'm using those terms specifically because it's exhausting. It is exhausting to go through the process. It is exhausting to try to find who's covered in your insurance. It is so time-consuming when everything else is also happening in your life. But once you find someone who you click with and you feel respected by and you have that relationship with where you're both communicating equally together, it changes everything. And I have been lucky enough to find that person. And I hope she doesn't go away for a very long time because I feel like we're finally on a good trajectory with my care. And I know that I'm being listened to and taken seriously.

Dr. Annette Howard

I think that for those of us who work in the MS professional space or healthcare entities at all, and find our way on the other side of the desk as a patient. What I want to encourage you to do, Kate, is to, in that moment, be a patient. I'm a patient now, and I'm clearly aware of what it's like to be in the doctor side of the seat, the nurse side of the seat, and to be in the patient's seat. And you can be with fear and anxiety and trepidation and all that. I felt rushed. I felt that there wasn't enough time. I felt we did a ton of testing, but you still ain't told me why I have this fast heart rate. Wanting to scream that as a doctor, he got up and left. Like, well, everything's okay in that. Good. Go back to work. You're fine. And yet, left with the answers.

Uh, and I thought, split second thought, I ain't coming back to this doctor before I realized that my own training as a neurologist really works. I do detective work, you know, trying to find what's going on with the brain, the spinal cord, the nervous system. Not all doctors are trained like that. Their job is to, I guess be sure there's nothing getting ready to kill you. And, if the test says normal, then you are normal. And yet in the neurology world, that's not how we operate.

The test may be normal, but the patient can still be abnormal. How do we bridge that gap between, you know, I hear you, I see you, I know you have a problem, but yet I also know we've ruled out, you know, 200 possibilities and yet we still don't have the answer for you. This is what I recommend we do in that, with those circumstances. And I didn't hear that from a truly phenomenal doctor. And so, it's both sides of the coin and maybe being patients helps us be better informed healthcare professionals. So that's...

Kate Durack

Yeah, I think it's good to put on both hats for sure in that moment. I mean, my experience is personally, there was one visit where I didn't even get a physical exam. No, she never touched me. She never asked me to walk. I mean, it was incredible. And she never reviewed my MRIs. It was absolutely unbelievable. She was on the phone with another patient during the visit. I mean, it was just red flag after red flag where I just said, "Okay, this is not for me. I need to find something else." And I think that putting up that boundary, finding someone that works for you is the best thing that you can possibly do no matter how stressful that process is.

Dr. Annette Howard

And then you know what? We know many a patient who remains stuck in a situation they should have gotten out of a long time ago. And so we have to just kind of leave them alone and hope the light bulb goes off one day, but, you know, keep feeding them information. You know, hope that they come to another dinner about, you know, learning a new drug or that, you know, might be helpful for them. And so we just have to, you know, we still keep them in the family, we still keep them close, but we stop beating them over the head about it because MS is such a weighty, all encompassing life issue that it's hard to make those kind of decisions about treatment, about doctors. It's just hard.

And we kind of need to give people grace in sometimes as they try to, you know, do the obvious. And so we just, we just got to go, "okay, all right. Still there. Okay. Well, stop asking me the same questions you asked me last time. It's okay." You know, we just have to keep our arms around them until they do.

Shelby Bassili

Thank you both for those insights. As we prepare to close, let's briefly circle back to where we started. So if self-advocacy had a new definition after this conversation, what would it be? Dr. Howard, what do you think?

Dr. Annette Howard

Take care of yourself. Put yourself first and make a commitment to do everything that is within your control to manage your MS for this long lifetime journey that we're going to have to live. Take care of yourself.

Shelby Bassili

Kate?

Kate Durack

I think for me, I really would like for, well, my takeaway is just that I need to focus less on perfection and more on progress and just doing what I can in the moment and knowing that it's never going to be perfect. And living with MS doesn't look perfect. And just knowing how to navigate that and really listen to myself and continue to listen to my body, knowing that it's going to continue to change. And so I have to be open to those changes and ready to pivot at a moment's notice, you know, personally and with my care team.

Dr. Annette Howard

So, you know, the teacher in me can't let this session get away without plugging the need for MS patients to continually grow their education curve. MS is changing every day. I used to be

able to read and feel like I was pretty caught up all the time. But now there's so much information that comes out every single day about MS. I no longer can stay caught up. And this is what I specialize in.

So, uh, I know that patients have to be bombarded with, you know, all kinds of information, good and bad, that you have to learn how to sift through. Patients sometimes bring me stuff. And say, you know, "Dr. Howard, what do you think about this?" Or send me stuff or email me stuff that, you know, they want to be sure that I read or what do I think about it? And so you're going to have to stay in a posture of learning about MS. Just because you've got a good drug, it's working for you, that doesn't mean you have to say, "already done, got everything done. I'm good to go. I'll just see Dr. Howard three months from now." No, you still got to stay plugged in and learn new information and try to stay conversant about MS so you know what you're talking about.

And I would warn you against, you know, getting into what we call – you probably got a better word for it, Kate – but those bad sources of information. MSAA is one of the most credible sources for good, reliable, reproducible information of any kind, from symptoms to treatment to research. And I want you to focus in on what we call the good healthy stuff. I'm not so interested in the 10 probiotics good for MS. I'm really not so interested in that. We can talk about it, but we need to stay focused in on what can be helpful for you on this MS journey. And so that teacher in me had to plug the value of never-ending learning about MS. Even if you're in a good place with it, I still want you to stay educated about what's happening in the MS world.

Kate Durack

I mean, I'll say that obviously I live with it and work in it every day, and I still feel like I'm the same way, Dr. Howard. Like, oh my gosh, there's so much more to learn. It's amazing. And I do feel the more I learn, the better I feel about how I'm managing my MS, regardless of whether or not it directly pertains to me in this very moment, just understanding the broader picture of MS is very helpful.

Dr. Annette Howard

And if you have a good relationship with your doctor, you can bring information, you know, you can challenge them. "Dr. Howard, did you know this?" Because I may not have seen it or heard of it, particularly on the research side that patients seem to hear so much more about research than even I know. And so share it, send it to them. Just drop it in the mail to let them know that you are keeping up. That's advocating, too. You're keeping up. So I want my doctor to keep up as well.

Shelby Bassili

Those are really great insights. Thank you both. So that concludes our time together today. Thank you both for being a part of this conversation and for sharing your perspective so openly. One key takeaway from today is that self-advocacy doesn't have to be loud or confrontational. It can begin with clarity, curiosity, and small moments of honest communication.

Dr. Annette Howard

And humor. Don't forget about humor.

Kate Durack

True.

Shelby Bassili

Do not forget. When patients and providers work together, care becomes more human, more effective, and more empowering. A special thank you to Dr. Howard and Kate Durack for your insights and for helping bring this topic to life from both the clinical and lived experience perspectives.

I'd also like to thank Gradwell House Recording for hosting us and producing today's program. This podcast, along with additional resources and support, can be found by visiting the Multiple Sclerosis Association of America's website at mysaa.org. Thank you for listening to Beyond the Chart. Take care.