



MSAA Podcast - Episode 21: Beyond the Chart: Strengthening Self- Advocacy Through Communication – Part 1

Host: Shelby Bassili

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

Shelby Bassili

Welcome to Beyond the Chart, an MSAA two-part podcast focused on strengthening self-advocacy through better communication. I'm your host, Shelby Bassili, from the Multiple Sclerosis Association of America. As part of our MS Awareness Month theme - Your MS, Your Voice: The Power of Self-Advocacy - today we're digging into something that sits at the heart of good care. What actually helps create meaningful human connection between patients and their healthcare providers? This conversation isn't about having the perfect appointment or saying all the right things. It's about small shifts in language, mindset, and expectations that can make care feel more collaborative, more respectful, and more effective for everyone involved.

I'm joined today by two voices who bring different but deeply complementary perspectives. First off, 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, joins us with the clinical lens shaped by years of working directly with patients. And Kate Durack, Director of Communication and Patient Focus with MSAA, is here as a person living with MS and a patient advocate, bringing lived experience and insight into what it feels like to navigate care from the other side of the chart. Together, we'll talk about how self-advocacy shows up in real life, in busy exam rooms, during difficult conversations, and in moments when patients may not feel confident speaking up but know something isn't quite right.

Well, Dr. Howard, Kate, thank you both for being here. Dr. Howard, can you start us off and tell us a little bit about yourself?

Dr. Annette Howard

See, that's probably the hardest question you'll ask me. But let me just say thank you. I'm just so delighted to join you in this podcast today. And I have a long relationship with MSAA, so this is gonna be a very quite fun and enjoyable time we spend together.

So I've been doing MS for what we call a long time, reaching back into the last century. But actually, I've been practicing for, this is my 33rd year of doing neurology and taking care of MS patients. I'm from Houston. And this is where my practice is now, where I've been practicing the entire time. I grew up in Houston and then went to various schools. I graduated from the University of Pittsburgh School of Medicine in Pennsylvania and then returned home to Houston to do my neurology and internal medicine at Baylor College of Medicine. And then I joined the Department of Neurology as full-time faculty there. And then after eight years, went into private practice, which is what I'm doing right now. Most of the, I would say about 70% of the patients I see are MS and 30% are other kinds of neurologic conditions.

You better stop me or I could go on forever, but is that enough?

Shelby Bassili

That's great. Thank you so much. Kate, can you introduce yourself?

Kate Durack

Absolutely. And yes, thank you so much for having me. My name is Kate Durack, and I actually work with MSAA as the Director of MSIN Communication and Patient Focus. I have been with MSAA for three years, and I'm also living with MS. I was diagnosed 10 years ago. I am a mother of two boys. And my background is in disability support services and patient advocacy. I'm originally from Denver, Colorado, and I love the mountains forever. And now I live in Florida. So thank you for having me.

Shelby Bassili

Great. Thanks, Kate. So for the listener, during today's discussion, I will be asking Dr. Howard and Kate questions about self-advocacy to get their unique perspectives. So, let's get started.

Dr. Howard, when you hear the phrase self-advocacy, what comes up for you?

Dr. Annette Howard

Well, I think, so I probably wouldn't ever describe anyone or myself as a, or as a self-advocate, but I bet, you know, I think it's one of those words that you know it when you see it. But I think of that as a concept of where you learn how to take care of yourself, or you are experiencing and taking care of yourself. As it relates to being an MS patient, it's really about, I think, knowing, you know, what your MS is, being committed to doing the very best that you can in taking care of yourself and your MS and really thinking of it as just one other thing that we got going on in life, but that you are committed to doing the very best you can to be as whole and healthy as possible for this long life of living with MS. So it's, you know, it's kind of one of those things you can point to somebody you feel is practicing the best self-advocacy as possible. And that's what all of us, even beyond a diagnosis of MS, should strive to do in life.

Shelby Bassili

Thank you for that. Kate, what about you?

Kate Durack

Yeah, first I just wanted to comment. I love, Dr. Howard, what you just said about knowing what your MS is. And because everyone's experience is so different with MS, I think it's really important that we take the time to understand personally what MS is for us so that we can be appropriate self-advocates, right, and know what it is that we're supposed to be talking about. But for me in general, I think my key takeaway with self-advocacy is just giving myself permission to

speak up when I don't feel like things are going well, ask questions freely with my care team, and then trust that what I'm experiencing in my body matters and is real because I feel like we're constantly questioning that with MS.

Shelby Bassili

Thank you for that. Well, now that we've covered the basics of self-advocacy, let's get more specific. I'd like to start with preparing for appointments. We hear a lot from people living with MS about coming prepared for an appointment. I imagine that can feel empowering or exhausting. So, Dr. Howard, what would you suggest a patient do to prepare to see their provider?

Dr. Annette Howard

Well, the first part you said was that you ought to be prepared. And I think it's critical in times that we've been experiencing, you know, through the pandemic and after, where for most patients, I think the amount of time that they get to spend with the doctor or whoever their healthcare professional is, is more limited now than it's ever been. And so that requires you to be able to make the most out of whatever time that you have. And I think that starts with preparation.

So the day or the night before, take some time to sit down and think about what do I want to tell the doctor about how I have been since the last time I saw the doctor. For me, I always give my patients a frame of reference. "I last saw you" and I give them the date. And so that means don't tell me what happened before that. Let's start at that point and go forward. And so think about the things you want the doctor to know, what has happened to you since the last visit that you had. If it's been a year, I'm like, whoa, you better learn how to shortcut that, because you're not going to have that much time.

But just what are the things you really want the doctor to know? I'm usually more expansive than my patients are, but sometimes patients come to see me and I start out and I say, "okay, so what's on your agenda today?" And sometimes they say, "I don't have an agenda, Dr. Howard. I just came, it was my appointment." And so you know what I tell them? I say, "well, I got an agenda." And I start with asking them questions about, you know, what's going on with them, their body, their symptoms, how things are talking about the family and work and whatever. And so I can, I can pretty much get everything that I need just from asking a few of those kinds of questions.

But it would, you know, as the old folks say, it would behoove a lot of y'all to be prepared for these visits because of the, you know, they're telling us now that the average office visit is about 7 minutes. And so it may be a little longer or a little shorter, depending on if they have other healthcare professionals participating in on that visit. And so you got to have your stuff, you know, and I choose to tell people to write it down or put it in your phone, but be able to access it quickly so that you can get the important things that you wanted to discuss out.

Another one of my this is one of my pet peeves I share with you because everybody that knows me knows how I feel about this and know your medications. MS patients take a lot of medications. They may be prescribed, they may be supplements, or even vitamins, but have them written down. And I always expect you to call up the name of these medicines because they're hard. They're written in Latin and hard to pronounce. And, but have it written down somewhere that's easily accessible.

Now, why did I put that easily accessible part? Because here's another pet peeve of Dr. Howard. Don't say, "oh, you know what? I can pull it off of MyChart." So you know how long it takes to get into MyChart. And you know once you finally get into MyChart, you know what they ask you? To renew your password. And so you've wasted valuable time by not being prepared in that way. And some of you are just on so many medications.

Look, we don't really care how you taking the medicine. We want to know if you're taking, if it's something we need to scratch off the list or is it something we're thinking of that we may need to add, that you may have stopped, that we don't even know about. So it's called updating it and that is a step that needs to occur with every office visit is about updating your medication list because that may have some impact on some of the symptoms that you may want to discuss with the patient.

Y'all better stop me because I could go on and on.

Shelby Bassili

That is really good.

Dr. Annette Howard

Let me ask Kate a question. Kate, how do you get prepared for your doctor visits?

Kate Durack

Well, first of all, I need, so I lived in Houston for a year, Dr. Howard, and you're making me want to move back because I want to see you more often. You'll keep me honest.

Honestly, I have been, there have definitely been visits where I've been terrible at preparing, but I know that when I leave, you know, I'm just like, "well, that was a waste of everyone's time." So I've gotten a lot better about, I actually take photos of all of my medications before I go because I don't take a lot of medications personally, but in the moment, if you're asking me to recall my list of medications, guaranteed I'm going to miss something just because I'm going to go into some kind of brain fog and it's just going to be gone. So I actually take pictures and then I'll review those on my phone with my doctor in real time, and that's been really helpful.

And then I like to think about what do I need help with in the immediate, and then what do I need help with within the next six months before I see you again? So I kind of think about what's going on for me now and then try to project, okay, what's happening in life in the next six months that I might need to talk about. And then I write those things down and that's how I go into my appointment.

Dr. Annette Howard

I like that. And so, and you know what, I also like, Kate, is your honesty, because there's not a perfect patient. There's not a perfect doctor.

And I'll tell you what happens a lot. Patients will get in the office and say, "oh, Dr. Howard, I left the list in the car." And we're like, OK, well, we're not going to take time to go down to the car and get it. So let's just see if we can recreate it and review it and do that kind of thing. Everybody's not perfect, but it's working together and being sure the patient remains the focus of the togetherness that I think we can achieve whatever goals we're trying to work towards.

Kate Durack

Yeah, I think it's great that you talked about how you ask if the patient has an agenda and if they

don't speak up, that you'll ask them about details about their lives and just kind of recapping what's gone on since you last saw them. I think that personally that would help me jog my memory about maybe symptoms that have come up or times that I was too fatigued and I couldn't be outside and see my kids play soccer. You know, there could be things that would come up for me that would really help both of us in that appointment, just having you ask, you know, what's been going on.

Dr. Annette Howard

But you know what? That question can also be fraught with some, you know, some issues. Because if you ask somebody what's going on, you've got to be prepared to listen to what's going on. And I'm going to really be frank with you. There's some questions I don't ask because I'm not prepared for what the answer might be.

Here's a good example, because it always comes up in a broad discussion about MS symptoms, about people's sexual function. I really don't ask that question. And people will bring it up to me sometimes and we'll try to address whatever the issue is, but that's not something on my checklist. It's, you know, it's just a little bit private, but if they want to bring it up and, you know, we have to figure out what we need to do about some issues, we can. But I think sometimes doctors just leave out asking questions about things they are not comfortable with, whatever the answers might be. And I'm on that list of, there's some things I don't ask about, but if they want to talk about it, I can talk about it, but don't bring it up.

Kate Durack

Sure, so then that's where my job as a patient comes in, that I need to be expressing those concerns, no matter how personal to you, knowing that you might not be the one to bring it up.

Shelby Bassili

That is actually the perfect segue to our next question, which was about asking questions. So we hear a lot about not wanting to because a patient doesn't want to seem difficult. So Dr. Howard, what's your perspective on that? What are the right questions to be asking.

Dr. Annette Howard

So I really try to encourage asking questions. I'm not afraid of questions. And I actually, you know, I don't think, I tell patients, I don't think there's any stupid question. Maybe an uninformed question, but no real stupid ones. But I'm certainly okay with questions. I'm not afraid, it's not gonna take too much time. I like it. It helps me to figure out where your head may be, especially with newer patients. And it's just something that I encourage.

Now, here's what I think can happen, which is another reason why patients need to be prepared by writing. Write your question down. And, you know, in the old days, patients would come with, some patients would come with tablets of questions. We really don't find that happening that much these days. But, you know, sometimes the list would look so long, I'd say, "you know what, just give it to me and let me read through them." Because usually when patients write down and they've got pages and pages, it's repetitive and I can pick and choose and say, "you know, I see you're asking, how often are we going to do your MRI scans? Well, I can answer that one quickly." And then, especially if they let me hold on to the paperwork, I'll write it down annually, and if necessary. You know, so that way they get to get their paperwork back and then see me write a brief answer right next to it.

So I like questions, not afraid of questions. And I even, when family members are in the visit, I let them know you're going to get your chance. Let me hear from the patient first. And family members, I invite them to ask questions because often they have questions that the patient, will help the patient take care of themselves or even help to inform me about information the patient has not told me. So I invite that and I like it. But I think for the for most patients, they need to write their questions down. And then as the visit is ending, you know, look at your stuff and see now, did I get everything answered?

Because I'm going to tell you that once the doctor gets up from the chair and puts his or her hand on the doorknob, then it's beginning to get cut off, y'all. And once they open the door and go out, you're not going to see them again. And you might sit there and you say, "Oh, I just have one more thing. Could the doctor come back and I ask one more thing?" It's just not going to happen, okay? And so that's why I'm saying, write your stuff down, look it over before, "wait a minute, doctor, let me be sure that I asked you all my questions," so that you don't have to get into this, "Well, he didn't answer everything," or "I had a few more."

And if you do, the time gets cut short because you didn't get all your stuff answered. That's when you ask the question of, can I come back and ask the rest of my questions? Or can I e-mail them to you? Can I fax it to you? Can I leave them here and you get back to me, you know, in a week or so? Ask what are the alternatives for communicating after the visit is over? Because, you know, I just need you to understand that it's challenging and you're going to have to meet the challenge. Don't be afraid of the challenge, but figure out I got other ways to get what I need done rather than, you know, always this face to face in that, you know, few minutes of time that you've been granted.

Shelby Bassili

That's really great to know. Kate, what's your perspective on that?

Kate Durack

It's just so helpful to hear, honestly, from your perspective, Dr. Howard. It's really helping me think back on some visits that I've had and just helping me understand that even though time is short and it might feel a little rushed, it's not personal. It's just kind of the way the system works. So I think that's a good takeaway for me personally.

But when I'm in a visit, I always want to be a good, like I want to be the best patient that you've seen that day. I don't want to cause problems. I don't want to take up too much of your time. I want to come prepared. I want to seem like I'm educated about what I'm going through. And so that can end up looking like me being really quiet. You know, it's not that's not helpful. So let's say I'll pose this question back to you, Dr. Howard. Let's say you have a patient like that who's just not, you know, they're just like, oh, yeah, everything's fine. I'm doing great. You know, they're not really giving you anything. Do you dig deeper to try to get more information out of that person? What does that look like for you in the office?

Dr. Annette Howard

Well, that's not a common experience for me, but I have some newer patients who are just not prepared to have a doctor sit down, look at them in their eyes, and give you time to give a thoughtful response to a question. And so I have to draw them out with questions. And as I told you, I always have an agenda. And just so you know, what is the agenda? The agenda is looking at the patient and starting at the top of their head and working your way down to the bottom

of their feet and asking them questions about all those parts of the body that MS can affect. And, you know, I don't have to know that the dog messed on the car this morning. I don't need that as a part of the visit, but if we can hone down on how your body is being affected by MS, then I think, you know, we can get a lot of information. And usually when I've exhausted everything that I want to ask or that I need to know, that's when I proceed to the examination.

And, you know, and so you have to, for an MS patient, the examination is a critical part of that follow-up visit too. And so if you're not getting a thorough neurologic exam with your follow-up visits, then, you know, that doctor is not being complete or thorough enough. And so that's part of how you know, you know, what is the MS doing, whether it's staying the same, whether it's getting worse and progressing, you know, what is it doing? So the exam is another tool that we use to figure out how the patient is doing.

Kate Durack

I love that idea, excuse me, of a body scan when you're talking to the patient. I feel like between the time when I go into the exam room and then my neurologist comes in, usually, you've got a couple minutes to wait there. And taking that time to really tune in with my body and go from head to foot and think about, okay, "Have I had any MS symptoms that I want to bring up mentally? How's my fatigue? How's my vision? How has the numbness in my hands been? Have I been tingling in my legs? What are my feet doing?" You know, I think I've never thought about it in terms of like really thinking through and scanning your body for questions, but I think that would help me tremendously in advocating for how things are going for me during a visit.

Dr. Annette Howard

And come on, tell the truth, it's usually more than a few minutes.

Kate Durack

Oh, for sure.

Dr. Annette Howard

And you've been waiting, but it is. And so if that can be a tool that we talk about, I've never said that actually to patients, but if that's a tool to help you remember, then that's something that we ought to do. And then usually when, and one more thing, when I finish with the exam and patients are coming down off the exam table, I usually summarize what I find in the exam. Oh, this looks the same, or I see a little bit more weakness in that left hand today. Do you agree with that? So that gives us what we call in current time, what I think about the exam – and sets us up for what we may need to do if I see any changes.

Kate Durack

Yeah, I love that body scan as a tool. I think that's really cool.

Shelby Bassili

Yeah, this is a really rich discussion. I'm really enjoying hearing this. So moving towards the personal side, asking questions or talking about personal goals outside of MS. How does that impact care? I know it's important to bring up things like starting a family, new career decisions, or even hobbies or traveling. So I wanted to ask you, Kate, first, can you share a moment when you brought up a personal goal with your provider and how did it impact your care?

Kate Durack

Yeah, and I have shared this on our podcasts and webinars before, but it's really a highlight of

my MS experience, so I'll share it again. So I was diagnosed 10 years ago, and I had a wonderful neurologist that I worked with initially in Denver. Once I had a couple of MRIs and my diagnosis was confirmed, his first question to me when he sat down in front of me was, "what do you want for your life? Do you want to start a family? What do you want your career to look like? Do you want to go back to school? What does this look like for you? What are your goals?" And it wasn't, he didn't immediately jump into, okay, you have MS, we need to problem solve. It was more of like, "Let's talk about your life, and now let's transition into what are your options to do those things while living with MS, and how can I support you in that?" And I know that I am so lucky to have had that as my initial experience, and that doesn't happen very often. But knowing that that's possible has helped me mold my relationships with my other neurologists.

I've worked with four or five other neurologists at this point. It just kind of helped me feel better about having those kinds of conversations and knowing that those things that are important to me in my life outside of MS can actually be supported in my treatment and by my neurologist, and that they're important to talk about and that they all kind of feed into each other. So yeah, I mean, I strongly encourage people to discuss all of their personal goals with their neurologist. I mean, knowing that you have seven minutes with them, obviously. But I do think it's important.

Dr. Annette Howard

Well, you're right. If it's a scheduled seven minutes, then I tell MS patients, you make it personal for the doctor. They make them spend 15 minutes and be behind on everybody else, but know that you've gotten what you need. I'm going to tell you, so the first office visit for somebody to see me, I usually spend the most time I'm ever going to spend on that very first visit. And that may be an hour and a half to two hours, okay? Uh, I'm an MS specialist, so I got it like that. I have to take the time in order to get what I need in order to know what I need to do. And so I hopefully in that time have learned a whole lot about the patient, including their goals and their family and support, uh, network and, um, job, occupation, goals and issues so that I then know what we're going to do and how we need to do it. And somebody, a patient comes to mind right now who has been my patient for about 20 years now. She's doing very well, but she came to me in what we would call a hot MS mess, MS doing very poorly.

And I had to pull a kitchen sink approach on her. Try several things to do until we finally got to a treatment that seemed to stabilize her MS. But on her second office visit with me, she brought her children – ages 6, 8, and 10 at that time – with her and the husband was at work, but she had her mother and father bring all of them. And so, you know, you can then surmise that that crystallized what her treatment goals were about. And I saw her last week and she's still teaching school. Okay, 20 years later.

Kate Durack

Wow.

Dr. Annette Howard

The oldest son is going to be graduating from college this May. The second son is doing his first year in college, and the baby girl is graduating high school. Okay, so when you have children that small, sometimes I think my aspirations are higher for my patients than they have for themselves. But when I meet children, then I already know what the goal has to be. This mother has to take care of her children. And they've got to feel like they've had the best mother in the world. And my job is to not make them caretakers of their mother.

And so, we spent a lot of time being sure people can do what it is they want to do in life for themselves. I'm very honest with you. I'm about trying to make people do whatever it is they dreamed of doing before MS. Let's see, can we make those goals happen for you. And, like anything, we're constantly checking in on them and seeing how what the progress is or adjustments that we may have to make.

This person I saw last week is in a new school situation that's very difficult. And she's already had one infection since she moved to this new school several months ago. And so I had to lay it down that if you have another one, we're going to not finish the school year because my MS is important and we're not going to let anything interfere with that. Now, she happens to be in a situation where the husband can handle it all. But then there are some people where they just have themselves and no real strong support that could help them out financially in place of a job.

But if I didn't know this information, then I might not know how to act accordingly and put our strategies in place for, you know, so our current strategy with that particular, okay, let's get through May. We've got to get through May, but our sub-goal is going to be getting through spring break. And, you know, so I'm going to see her at spring break and then we're going to re-assess whether she can finish out the school year. Because if, you know, we've done so well in achieving a place where her MS had been in remission and we can't allow life to, you know, give her new status. I just don't want to do that. And if it's within my power to do it by watching her very closely and helping her and her husband make some tough decisions about how we're going to take care of her, then that's what we just got to do.

Why? Those three children, who are now almost adults. Believe it or not, they still need their mother. Okay. And if they're like me, my mother died in 91 and I still need her. Okay.

So, you know, it's just understanding MS is more than a condition, a disease, an illness. It's managing the whole person and those who care and support them.

Kate Durack

Oh my gosh, that was so powerful. So ,Dr. Howard – I don't know that you know all this – so, I am a single mom with my two boys and they are six and almost eight. Eight on Sunday, Happy Birthday, my sweet boy. So this hits home for me in a way that I don't know that you intended, but definitely wanted to cry while you were talking because I mean, obviously that's my main focus is these boys and being just an incredibly independent and strong and fun and energetic mom for them.

And it's my biggest fear to not reach that goal because of my MS. And I don't want to ever have them feel like they need to take care of me because I'm here to take care of them. And just hearing you say this as a neurologist is just, it's so... it's so nice. It feels very validating and refreshing. So thank you for sharing all of that.

Dr. Annette Howard

Well, did you tell your doctor that that's what your goals are?

Kate Durack

Oh, yeah. Yes, I have these conversations with her too. But, you know, I don't know that everyone, again, I don't know that everyone gets that experience with their neurologist. So, yeah.

Shelby Bassili

Well, thank you both for sharing your personal stories and perspectives. That's really powerful. It's becoming quite clear that communication and talking about your personal life and goals is very important and that MS care can look like working toward the quality of life the patient is aiming for. That's really great.

Dr. Annette Howard

You know, one thing, and it sounds like you got this, Kate, but we probably need to say it out loud, is that ideally, what you want to strive for is that whoever you have on your MS team, it needs to be a partnership with you, the patient, in the center, and everybody's focused towards that. And so that's why I early on like to include significant others and family members who are committed to, you know, the patient. Not everybody in the family. Not everybody that the patient has in their lives are committed towards the patient. So we gotta flesh that out quick and, you know, exclude people who are not on our team, include people who are. But ideally you want to have a partnership with your MS team.

And I let people know it's a partnership, but I'm the captain of the team. Okay, I'm the captain of the team. You're the patient, but I'm the captain. And I can quickly, easily, switch to dictator mode if I have to. And there are sometimes when I have to.

Kate Durack

That tough love, right?

Dr. Annette Howard

And it may be that the patient is having some issues with their MS or with other stuff or what we call life stressors disease, stuff going on in their lives, where I have to move from the partnership role to dictatorship to help them get back on track again. But it's not my desire to be in that role, but I can be because the patient needs to have somebody they know is, you know, can be in charge and in charge and, and you know, that that's what we have to do. But, you know, partnership until you make it a dictatorship. And, and I'd love to be in the, we on the same side, same team, kind of role here. So, you know, that's what I would recommend that people the kind of relationship they strive for. And remember, you can't expect to have that relationship out of the gate, get go. Like any relationship, it takes time.

Now, there are obviously going to be some situations where you know right away it ain't clicking. It's not working. And I don't recommend that you stay and make it work or I don't recommend that for people. Because I think there are too many options out there for you. But, you know, my mother would, told us when my parents separated, she said, I'm going to supply every need you have and most of your desires, but I'm going to take care of you. And, and that's what your relationship with your doctor should be about. They should handle every MS need you have. And, and then let's see if we can work on getting some of those desires met as well. So that's the approach I take into it.

And, you know, being honest, "no, I don't know how to handle that. I can't fix that one. No, you're gonna have to let somebody else do that." Or, "Mm, that is above and beyond my level of expertise." So I have the responsibility of being honest with you. And clearly, there are some times, it's rare with me, but there's some times when the relationship doesn't work out, you know, that I'm not the right doctor for somebody either. And, you know, they may decide to

leave me. And there have been some even rarer occasions when I have decided the relationship does not work with me and the patient. And so, you know, it's like any other kind of relationship. But I think for most people, they cherish the relationships with their doctors. They believe in them, they trust them, they care and want it to be reciprocated like other relationships. And I think that is a worthy goal to strive for.

Shelby Bassili

Thank you for that. I think you've touched on everything that we wanted to talk about, but we can dig a little deeper. This isn't technically our next question, but I think it's very appropriate for what you were just talking about, that self-advocacy doesn't just stop with providers. It also looks like communicating with family or care partners about MS. So Dr. Howard, we wanted to ask, like, what are some concrete tools that patients can use when they're trying to communicate about their MS with their care team or their family?

Dr. Annette Howard

So we spent a lot of time talking about this, about the care team. And if you want me to do more, I can. But let me talk a minute about family and significant others. I advocate for patients to let family members and friends know, okay? And if certainly if you're one of my patients you're also going to, however, whatever you tell them, you're also going to be able to tell them, but we got a plan and we're working on this, we're working on that, and I'm feeling better since I did this. So you don't just tell, you know, "hey, I got MS."

MS is no longer a death sentence. It's a disease you learn to live with. And so there are tools we have to help you live with it. And so you can share with them. "I'm not going to die of MS. I'm going to die with MS. As I might die of high blood pressure and diabetes and cholesterol and thyroid disease." You know, that's what MS has become in this era. So I advise truthfulness about the bigness of the disease, but on a day-to-day basis, I don't think it's of good value to, you know, I'll tell you a quick story, quick story.

So when I was in residency, I, you know, and I'm not going to tell you how they tried to kill me and I, you know, and but yet I survived, but that's true. But we, I was on call like every third night my entire residency because they would get rid of folks and you'd have to, you know, pick up the slack. And so my mother and I were living together and I'd come home on the nights that I came home and she was still up and she'd say, how you doing? And I would proceed to tell her of what I had been through and how bad I felt and how tired I was.

And she took it. She sat there, she listened, and she didn't have anything to say because she didn't know what to tell me about how to manage, you know, what happened in the hospitals. But she listened. And then one day I came home and she said, "How are you doing today?" And I said, I went into my tirade of how tired I was. And she said, "just one day, I wish you would come home and not tell me how tired you are. As a matter of fact, I am sick and tired of hearing how tired you are." Now, y'all, that was the truth. And coming from my mama, I don't know what kind of mama y'all got, but coming from my mama, that hurt my feelings. I was hurt that the woman who was put on this earth to take care of me did not want to hear how I really felt. She was sick and tired. So I thought about it all night long. And I came, I went to work the next day, thinking about it, thinking about it.

I come home the next day and she said, "well, good evening. How are you today?" And you know what I said? "I'm fine. How's your day been today?" See, that was a big lesson for me that

shouldn't, we got to get out of feeling the same way and letting people know the same thing every day. She pulled me out of a dangerous rut that I then passed on to my patients. People don't want to know. They don't care. They don't want to know.

And so why don't we put it on the back burner and then call somebody who does want to know, rather than thinking just because they love you and everything about you, how they are expected to accept you telling them this really bad stuff every day that you see them. So that's my advice. Don't tell them.

Kate Durack

That's super interesting. I want to speak to that for sure, if I can, Shelby. So for me, I mean, I definitely don't like getting into that loop myself with talking about my MS. I think it's really easy to fall into just when people ask you to just say, "I'm so tired and it's so hot out and I can't do anything and this is miserable." But at a certain point, I feel like personally, if I keep speaking to that, it's giving it power and I don't want to do that. So there are people in my life who know what they need to know and they know all of the details. And that's, my parents, my core group of girlfriends, they know about my MS and they know that I might have days when I can't meet them out for dinner, and they understand why. I don't have to get into detail.

But I've taken the time previously to explain to them what's going on with my body so that they have a point of context when I say, "Nope, not today," and we can just leave it at that. Also, as my boys have gotten older, I've brought them into those conversations as much as I feel comfortable so that it can be, this is my life, like this is our normal life and their normal life with their mom. And so they know that there are times when I'm not going to be able to go outside and do the things that they want to do, but it doesn't turn into a big to-do in our house. It's just a, "nope, that's not for me today." And then they're just like, "okay, mama." They understand because I've taken the time to explain to them why, because they're always asking why, and then they have that point of reference. So I really appreciate that.

I'm definitely the kind of person who doesn't want to give negative things in my life any extra attention. MS gets enough of my attention. I don't need to make it worse for me. So yeah, I appreciate definitely part of this.

Dr. Annette Howard

You know, when it comes to, you're using the term self-advocacy, and I want to say just advocating for yourself. I'm going to tell you the real true MS Ambassadors that I have learned from over the decades, who taught me and made me into the doctor that I am today, all of the real winners talk about understanding that MS is bigger than them. And, uh, they just kind of realize "once I figure that, you know, there's some things I can do that are within my control, there's some things that I cannot do that I cannot control and put that in the, you know, perspective and context of the rest of my life." The ones that truly make it to what I think the pinnacle of advocacy, they talk about having a sense of spirituality in something - faith in something. Doesn't have to be, you know, I'm a Christian, but it's not Christianity, it's not going to church every day, three times a week, but it's having a sense of faith in something that is bigger than them.

And, you know, I just give, you know, kudos off to those people who I really admire for you know, taking something and making the very best that they can out of it. And I'm just, I'm in awe of how they do it with what I call a lot of grace and courage that I don't know I could have had. And so I just, you know, wanted to share with you, I'm the beneficiary of being around for these

33 years true, you know, ambassadors of MS of conquering it in their lives. And I just, I couldn't leave this session without sharing that with you. We got a lot of those out there and they paved the way for current generations and, will continue to be beacons of light for those that come after, we get through this little period we're in now.

Shelby Bassili

That's a great word, Dr. Howard. Thank you.

That concludes part one of our Beyond the Chart podcast series. A special thank you to Dr. Howard and Kate Durack for their 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 MyMSAA.org. Thank you for listening to Beyond the Chart Part One. Be sure to tune in for part two. Until then, take care.