



How We Talk to Ourselves and The People That Support Us: Best Practices in Communication and Self-Advocacy

Presented by: Susan Eggly, PhD, FACH; Sheila Yarbrough, PhD; and MS Community Member Anita

Marie LeGrand:

Hello and welcome to MSAA's live webinar: How We Talk to Ourselves and the People that Support Us. I would like to take this opportunity to thank you for joining us. I am Marie LeGrand, Director of Education, Healthcare Relations, and Grant Management for the MSAA and your host for the program this evening. Before we begin our program I would like to take this opportunity to thank Genentech and Johnson & Johnson for making this program possible through educational funding.

Please make sure to visit our Virtual Display Hall which is listed in the chat box on your screen along with the link. This online resource details some of the products and patient services that are offered by our selection of sponsors and we would like to thank Biogen, Genentech, and Sanofi Genzyme for taking part in this new virtual opportunity.

We are extremely grateful to have MS community member Anita Williams, Dr. Susan Eggly, and Dr. Sheila Yarbrough with us this evening, who will be presenting on this very important topic. We are so pleased to bring you this program that will explore patient provider communication from the perspective of a patient and learn how the experiences of African Americans may impact a patient's approach to self-talk and self-advocacy. This program is for educational and informational purposes only and does not constitute as formal recommendations. Please do speak with your doctor or healthcare provider if you have any questions or concerns.

As you may know, MSAA is a national non-profit organization dedicated to improving lives today for the entire MS community. Some of our free services include a national helpline, equipment and cooling products, as well as MRI funding, an online community, webinars, and many more free programs available to people living with MS all across the country. Please do visit our website to experience our COVID-19 and MS Pathfinder tool, which provides ongoing updates and resources on the coronavirus. Also, please know that MSAA has expanded our helpline hours to 8:00 PM Eastern between Mondays and Thursdays. To learn more about these and all of the ways in which MSAA improved lives today, please visit our website at mymsaa.org or you can also call us at 1 (800) 532-7667.

Throughout tonight's program you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit questions throughout the program and we'll do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future programming and content.

Now before we get started, a few housekeeping notes - throughout tonight's program you will have the opportunity to participate in polling questions. When it's time for an audience poll a window will pop up on your screen. If you have any questions for the presenters, please do share via the chat function which can be found at the bottom right hand corner of your screen. Likewise, if you have any technical questions or difficulties during tonight's program please use the chat box and a member of our team will respond.

Without further ado, I would like to introduce our first speaker for this evening, Anita. Anita was diagnosed with MS in 2015 and began her advocacy work soon after. She is co-chair of the engagement committee for "I Conquer MS", a member of the Minority Research Engagement Partnership Network, and co-chairs the Equity, Diversity, and Inclusion subcommittee. Anita is vice-chair of the board of directors for Stride Community Health Centers and is a member of the Colorado Black Health Collaborative. I will now turn it over to Anita. Anita, welcome.

Anita:

Hi Marie. Thank you very, very much. What I wanted to share was my story and the importance of communicating with your provider. "Have you ever considered gastric bypass surgery?" Those were the words spoken by my new neurologist before he said hello or talked to me about multiple sclerosis. It was that moment that really spurred me to more action; to be an advocate for my own health care, because after all I should be the person who cares about my health most of all. Now, in my past I have had doctors and other medical professionals who would ask me questions or say things but I was too afraid to really ask them questions or perhaps push back on things I might not agree with. But when my neurologist said that to me, it was an indicator that I needed to do more to be a leader in my own health care. And so I decided that that's what I was going to do - that I was going to lead a team on my journey towards wellness.

So the first thing I did was educate myself. I read as much as I could about multiple sclerosis, about the therapies, and everything involved, because I wanted to be able to ask questions that were important to me and that were relevant to me. And during that process, I decided that I would have that approach where, if you look at a hand, I am the center of my health care. Everyone else is part of my team - neurologist, physical therapist, behavioral health - everyone else was there to help me in that journey. And I always look at it as a journey, because there is no definite end or destination; it's everything you do along that path. So, after I educated myself, I took away the fear that I had in terms of speaking to medical professionals, because I knew that I was invested in my own health care; that I was the leader of my own team, and that this team of people that were with me were there to help me and I would guide them in that way, but I always knew that when I turned around, these people had my back.

So once I found that approach, I was able to be more direct with my health care providers and open that stream of communication that goes back and forth. And once I did that, I was able to really take control of my health care and know that I'm leading the way; that I'm the person who knows the most about me; I'm the person who knows the most about what's happening with me physically, emotionally, mentally, and therefore, I'm the best person to lead. So, that's just a small part of my journey towards being an advocate. I first read, educated myself, learned as

much as I could. I erased the fear that I had in speaking with people who were only there to help me and to move me along in that journey.

So once I had that education and I lost the fear, I was able to move forward and be an active participant and leader in my health care, and I hope that we can provide that for all of you. I want everyone who's in this webinar to have the same confidence that I have when I approach my neurologist or my general practitioner. I want everyone to be able to know that they lead, no... you, you lead your own health care. You know yourself best, and on that journey, I hope that we can show you how you can be the person in front and have that team behind you. Thank you for listening to my story. Marie, back to you. Thank you.

Marie LeGrand:

Thank you so very much, Anita, for sharing your story with us. Our next speaker for this evening is Dr. Susan Eggly. Dr. Eggly as a communication scientist has conducted several communication interventions to improve patient provider communication and has ongoing NIH-funded research focused on clinical communication and outcomes related to clinical trials, health disparities, and treatment decision making. She is also Professor in the Population Studies and Disparities program at Wayne State University. I will now turn it over to Dr Eggly. Dr. Eggly, welcome.

Dr. Susan Eggly:

Thank You Marie. But more, thank you Anita for sharing that story. I have all those credentials, and I've got years of experience as a researcher in the area of patient-doctor communication, but I am not a person living with MS, and nobody can speak to it the way Anita can, and the kind of empowerment that you talked about in the journey that you went on, Anita, was just incredibly inspiring to me, so thank you for that.

As I said, I'm not a person living with MS, but I have had a lot of my own personal experiences communicating with physicians. And I've also been a student of patient-physician communication for many years, and I've been working on ways that we can not only understand the communication process, but improve it. Oops! And I can hear my little dog barking in the background... sorry, he's working on his communication process. So, what I... if we can move to the next slide... what I'd like to show here is that communication is the center of the relationship that you have with your healthcare professionals, in fact, it's the center of really all your relationships. And so, what you can see here in this graphic, is that patients and providers - when I say patients, I mean your family members; the people who support you: all of these people and also the providers and that, you know, the physical therapists, the physicians - everybody comes into the interaction with a whole background, all kinds of things.

So, you might have, you know, a level of education, you might come from a certain part of the country, you might have spoken a certain language when you were a child, you've got a religious affiliation and different kinds of beliefs, you also have feelings about the person who is your health care provider. And those things influence the way that you communicate with your doctor or other professional. But, remember that providers also have that. So, they were raised somewhere, they spoke some language when they were a child, they've got religious affiliations, they've got feelings, they're busy, they're confused, they're tired, they're all the same things that patients are.

And so when they walk in a room, they've also got all that, too, including, I mean, what you just said about the walking in the room and asking you if you've ever considered a gastric bypass surgery - that came from somewhere. You know, it came from something about that physician

and a bias, or a feeling, or a thought that in some way he or she thought that was helpful. But these two things come together into that room and there's either just a fantastic chemistry, where you just really like each other and you know you're going to work well together, or there's some awkwardness, or some tension. And, based on how that communication process goes, the provider will make recommendations to you, you'll make decisions about whether or not you want to do those, and based on that you will have, you know, better or worse course of your treatment.

So, I just want to sort of... this is a process that goes on; it doesn't just happen automatically. So, in my career I train physicians about communicating with patients, but I also train patients about how to enter that interaction in a way that's powerful. And, Anita, you spoke to it really well, but keep in mind that these biases are on both sides; these feelings and these thoughts about each other are on both sides. Can you go to the next slide please? One of the things that we know and that I know from my own research and you probably know also from your own experience is that people of color, and especially black people and their family members, have historically received very poor treatment throughout the history of the United States, and it really boils down sometimes to the communication process. In some ways, this poor treatment has led patients to be mistrustful. And they may walk in the room and not really be ready to speak up and to be a partner at that table in their own care. It may be because they're mistrustful or skeptical, it may be that they're a little scared or intimidated, which I think you spoke to, Anita. Doctors may just walk in the room and just barrel right over you. So, there's that, too, and there may be a lot of things that you know from your experience where you walk in, and you become confused, you become intimidated, you might even become angry and you say nothing. And as a result, you're not the partner that you could be in your own care.

So, what... can we move to the next slide please? One of the things that we can do, you know, when you walk in the doctor's office and you're just... you're confused, you're upset, you're maybe... you couldn't get a good parking spot, or it's raining like crazy, or you had a fight with your partner, or something happened and you don't remember any of the things that you wanted to talk to the doctor about. So, one of the things that you can do is the few days before your visit with the doctor, you can prepare - you can start writing down questions, you can pull your thoughts together, maybe look some things up on the internet, maybe even talk to your friends and family and say, "What are the things that you think that I should put front and center before the doctor in that visit?" Keep a running list. You know, oh, and your friend might say, "Oh, you know, I noticed that you've been having this particular symptom that you wanted to remember to mention to the doctor," and you say, "oh yeah," and you write it down and then you take that list of questions with you into the doctor's office, so that you have it and you're prepared.

And you can even bring a notebook, in fact it makes you, honestly, it makes you look organized, and I think... honestly, from my own research, I know that it improves the communication process. Doctors want you to be a partner, they want you to speak up, they want to know who you are. So, it's really your job and your role to speak up, be prepared, give yourself that little boost before you get in the room. And then, when you're in the room, stay focused and ask those questions using your question prompt list.

So, what I'd like to know, I can see there's lots of things in the chat. I can't really keep up with it very well, so... but, if you... can you move to the next slide? Because what we'd like to do is give you an example of a patient and a doctor in a room together. The patient is Jasmine, she's a black woman living with MS. She's in her early 30s and she's married with two young children, and she works full-time remotely and loves her career. But, she's meeting with a new doctor now, Dr. Smith, because she didn't really feel like she could get on the same page as her

previous doctor, and she's specifically wondering whether her treatment plan approach is a good fit for where she is with her MS journey. Dr. Smith is a white man who's been practicing medicine for over 33 years. He cares deeply about his patients and he wants the best for them. His practice changed to digitized health charts about seven years ago, but he still finds it awkward to look at the charts on the screen. His office manager called in sick today and there's a waiting room full of people. So, there's a lot going on when these two people walk in the room together. So, I'm going to call on my panelists to kind of read through this scenario with me. So, you're ready? Sheila and Anita? Jasmine's waiting for her new doctor in the exam room and she's thinking to herself:

Jasmine:

"I wonder what's taking so long. I'm so nervous about this appointment. If I don't find a good doctor, what's gonna happen? Hopefully this goes well. I do have my handwritten notes and questions."

Narrator:

The doctor knocks and enters the room.

Dr. Smith:

"Hi Jasmine. I'm Dr. Smith. It's nice to meet you."

Jasmine:

"It's nice to meet you."

Dr. Smith:

"Jasmine I see from your chart that you were diagnosed with MS last late last year, and what exactly brings you in today?"

Jasmine:

"I'm looking for a neurologist who can help me..."

Dr. Smith:

"I get it, I get it. Um, looking at your chart, i think we can help. We'll need to send you for some additional testing, but I'm thinking..."

Dr. Susan Eggly:

The doctor thinks out loud, running through a variety of options and next steps. He's semi-turned away from Jasmine and he's looking at her chart on his computer. Jasmine feels overwhelmed and confused by what he's saying. She wants to make sure she gets-in the questions she wrote out beforehand, but she thinks she shouldn't say anything or question his approach because he is the doctor. There's a lot going on here, so we're going to ask you, as the audience now, to vote. What do you think that you would do if you were Jasmine? Would you A) tell the doctor you have a few questions. Would you B) not say anything and hope that you get your questions answered the next visit. Or, would you C) wait to see if you like the doctor and then, if you do, let him know about your questions and concerns. So, please go ahead and vote.

So, I can't... oops, I can't see the poll. Oh, okay. Well, I think we've got an overwhelming majority here who said they would tell the doctor that they have a few questions. I was hoping

that's what you were going to answer. So, that's great. So, moving on, Jasmine speaks up and interjects as the doctor continues to talk about the medication options.

Jasmine:

"Dr. Smith, thank you so much for explaining all of this to me, but I'm feeling a bit overwhelmed. Could I share with you some questions I put together? I think some of them may impact next steps of my treatment."

Dr. Susan Eggly:

Dr. Smith turns to face Jasmine and this puts Jasmine at ease. Jasmine goes through her questions and concerns one by one. Dr. Smith and Jasmine review next steps. Dr. Smith asks Jasmine to think about what they've discussed today and schedules a follow-up appointment next week. Both acknowledge that they can work together on a plan for Jasmine's treatment and care. After, hearing how Jasmine's appointment with Dr. Smith went, let's reflect as a group here on this situation with our next polling question. So, this is your chance to vote again.

Would you... do you think that the doctor should listen more? Ask Jasmine to explain more about herself? Turn toward Jasmine throughout the visit instead of looking at his computer? Ask Jasmine if she has any questions? All of the above, or something else? Go ahead and vote.

So, everybody says... well not everybody, but 86 percent of you said All of the above. So, I couldn't agree more - the doctor has some responsibilities, and I think that it's important to hold doctors accountable, and even tell them if you, say, you know, "Doctor, I appreciate what you're saying. I need you to listen to me, though, before we go any further." I think that we can hold them you know responsible for the communication process in the same way that we as patients can be responsible. So, that's really great. One more poll - as we move to Dr. Yarborough's presentation on Self-Narrative, let's reflect on the way that Jasmine spoke to herself during the doctor's visit. How much did preparing herself and the self-talk... how much do you think it changed the appointment and how well it went. Was it a little, a lot, or it didn't really matter?

Pretty much everybody, 81% of you say that it really did matter. And I hope that is your experience every time you go to the doctor. You know, think ahead. In fact, keep notes between the doctors appointments. Also, you know, physical therapist, ... everybody. But, keep notes... keep a running notebook of your thoughts and things that you might do to empower yourself. as Anita said. Ways that you can be a good partner in your own care. And take that list in with you to the doctor's office and, you know, take responsibility, take control. Remember, as Anita said, you are the center of your own care, you are very much the person that matters most.

Again, to summarize, find a doctor that you're comfortable with. If you've tried that doctor once or twice and you're not comfortable, it's time to find another doctor. Think about your questions beforehand so that you feel confident when you go in. Remember, though, that you can't ask 45 questions. You can ask, you know... set some priorities - two, three, four. Not a lot of questions. You might write down 45 questions, but pick the ones that are most important to you and consider bringing someone else with you that can help you think through your questions and to remember the information that you learned.

And, with that, I'm going to pass this back to our other panelists and to Marie, and thank you so much for listening and for your work out there as empowered patients.

Marie LeGrand:

Thank you so much, Dr. Eggly, for your presentation. Thank you very much Dr. Yarbrough, as well as Anita, thank you so much for your wonderful acting skills, I'm sure the audience truly appreciated that, so thank you again. Our last speaker for the evening is Dr. Sheila Yarbrough. Dr. Yarbrough is a senior level higher education administrator with over 20 years of experience in communication, and she is Academic Dean at Rasmussen University. Throughout her career, she has been engaged in communication related work, including crisis communication, virtual communication, and intrapersonal communication. Welcome Dr. Yarbrough.

Dr. Sheila Yarbrough:

Hello everyone. It's great to be here with all of you and to follow Anita, and to follow Susan, to follow Dr. Eggly. Anita, your passion and your drive and your willingness to focus and share your own experiences, helps and informs all of us. Dr. Eggly, thank you for helping us sort of giving us a lens to look at where the provider might be coming from as they work with their patients. And I think it's always important to consider how we can empower ourselves. And I saw a chat pop up that... yeah, we don't always have a choice in who our providers are. When we can make changes, we definitely need to make those changes, if we're not feeling comfortable. But, let's take a minute to look at our self-talk and, we've also... we've already shared a bit or heard a bit of how Anita's self-talk changed the dynamics of, you know, in the scenario.

But, in real life, could you... let's take a minute to think about the messages that we've heard today. How many messages have you heard about how you should or should not be? Have you heard messages about how you should feel or how you should not feel? And have you heard messages about how you should or should not think? Sort of, let's just sit with that. Like, how... what messages have you heard and what was the source of those messages?

So, what messages actually came from others and what messages came from you; came from that voice inside your head, the voice that we all have inside our heads? That's what we're talking about when we talk about intrapersonal communication. So, why should we be concerned about this? Our intrapersonal communication is important because giving words... we give words power - our thoughts, our beliefs, our biases. Dr. Eggly talked about the fact that we may come with biases that have come from our background, from the voices or from the information or the values that we've collected over time. Anita pointed out how a message or a voice from a provider triggered where she started moving on her own path to empowerment. So, words have power and when we're thinking about our intrapersonal communication, the intrapersonal communication that we have, that voice inside of our heads, we can give it a lot of power.

We can give the voices that are based on our experiences, that we've learned from our childhood, that we pick up along the way in our journey through life. Those words, again, can have a power and affect us, and the messages coming from others, especially those that are not positive. When we're in those moments, for instance, if we're seeking health care, if we're working through our own health care concerns and issues while we're dealing with life, right? The rest of life. We are still... we are still having that conversation with ourselves, those conversations with ourselves, and those messages, again, have power. So that means that it's even more important that we take some time to sort of focus inward and understand where the messages that we're getting are coming from. What is the base of those words, or where the basis, how are they based, how long have they been with us, and how are they impacting the way we work through getting the care that we need? How do they impact our ability to communicate with our providers.

So, some of the things that can happen when our intrapersonal communication is sending us, or when we're focusing on our self-talk and it's negative and there's so many messages and so much information coming our way and our stress is high, we can get caught in the sort of circle or the cycle of simply thinking too much - thinking too much and saying things to ourselves that we might have never said to others. And it's something that, you know, whether it is a wrong or right, I don't sort of value it either way, but saying things to ourselves that we wouldn't say to anyone else and then using those terms, or having those terms sort of sink into our being, and sink into us when we need to be as empowered as possible.

So, what do we do with that voice that's inside our heads? Or what do we do with our self-talk? It's a part of us, we can't shut it off, right? Those messages are still there, but what we can do is interrupt that negative story, interrupt that negative self-talk, and find other ways, or other positive messages, that can replace how and what we're saying; we can reframe. So, if there is negative self talk about, you know: this doctor or this experience, I'm ready to give up, I can't move on, this is too frustrating - reframing that with: I need to reach out for help to find another source, I need to do some research. And it sounds like, Anita, you shared that's exactly what you did - reframing and stopping the negative story to create a different, more positive story that can lead to empowerment and help us as we sort of... it doesn't change reality, right? But, it can change and empower what we're thinking and how we're feeling at the time to help us move forward, to gain momentum and to try to sort through all that is coming our way.

So, here's another scenario that I'd like for us to focus on for a second, if you don't mind. And I'm going to move my screen. So, Jasmine, the patient from the last scenario, is on a Zoom with her friend Heather. Heather is an MS Community advocate that she recently met and they stayed in touch. Heather connected with Jasmine because heather had gone through similar things and was diagnosed with MS in her 30s, while juggling a career.

Heather:

"Jasmine you mentioned in your direct message that you're stressed about your upcoming follow-up doctor's appointment, what's going on?"

Jasmine:

"The beginning of my last appointment was awful. Dr. Smith totally ignored me. I should have stuck with Dr. Jones. Change is hard."

Heather:

"It can be really hard to see a new doctor."

Jasmine:

"It really bothered me that he interrupted what I was saying at the beginning. He didn't even look at me. He totally took over. It's exhausting!"

Heather:

"Oh, I hear you... that's a lot to deal with that's not acceptable. Let's talk about some ways I might be able to help you."

Dr. Sheila Yarbrough:

So, let's take a moment to hear from the audience, and we've got another poll for you. What do you think works well about what Heather just said to Jasmine? A) It acknowledges what

happened. B) It was a supportive message C) it was a solution oriented message D) all of the above, or E) I don't think that anything Heather just said helps the situation.

So, we're waiting for the polls to come in, and the results are... D) all of the above - it acknowledges what happened, it was a supportive message, it was solution oriented. So, all of the above. And, it's important as we're sort of thinking through, and that's exactly right audience, that if we're from a self-talk perspective and from a self-empowerment perspective, reaching out for help, talking with someone else who can acknowledge how we're feeling, and if you don't have anyone to talk to, writing it out, using a notebook... that notebook that Dr. Eggy talked about, and writing what you feel - the facts down and the emotions that you're feeling, and acknowledge what happens. And then look for support. So, finding a supportive message and then also using and, those feelings of empowerment, to look towards something that is solutions oriented. So, the conversation between the two hit all the markers for how we can sort of reframe the story and reframe those negative thoughts and move forward.

So, before we see how the rest of the scenario plays out, I'd like to hear from the audience again. Could Heather's support help reframe Jasmine's self-narrative about the situation with Dr. Smith? A) yes B) no C) unsure

Alright, fantastic! And I know I sort of moved forward or ahead a bit, but I think we can hear easily what the positives were in that message. Again, acknowledging how the other person feels, acknowledging and also... so, being supportive while acknowledging, and then focusing toward a solutions-oriented goal, sort of moving forward or again reframing that story.

So, let's take a moment to see how the rest of the conversation goes, let's get back to Jasmine and Heather. Thank you audience.

Jasmine:

"I guess, but that doesn't stop the doctor from treating me poorly. I can't handle this change in my life right now, there's just too much going on - work, the kids, school. I don't have time for this."

Heather:

"I hear you - there is a lot going on, but I know you can do it. Is there someone who can come with you to the appointment? Or, if your doctor's office has COVID restrictions, maybe someone to wait in the car, so when your appointment's over, they can go over the next steps while it's fresh in your mind? Or even someone who could be on FaceTime or speaker phone when you're in the office with the doctor, someone to support you?"

Jasmine:

"I'm not sure I can get anyone on such short notice for next week, but I'll try - I like that idea."

Heather:

"Don't be afraid to ask for help Jasmine - people are more willing to help than you think. Let me know if you want my help in any way - I'm here for you."

Dr. Sheila Yarbrough:

Alright, excellent, excellent, thank you! So, as we hear what Jasmine and Heather discussed, it sounds like Heather's messages of support... they're helping Jasmine, and she's practicing her own self-advocacy. I'd also like to reflect a moment on Jasmine's self-narrative scenarios. So, thinking about both scenarios, how would you describe Jasmine's self-talk and her self-narrative; how she talks to herself? That piece. Please type-in any words in the chat box that you'd like to.

I see some coming in as they're popping up. So "a little unsure," "she doubts a lot," "she was doubtful." Yes, so doubt is definitely a main component - she's got a life, she's got stress coming in, right? There are stressors, there's so much going on, there's fear, there's hesitancy. She's looking at trying to figure out how to take care of her own needs and she's also trying to sort through this maze of medical care providers, right? So she needs some self-assurance, as you say, Jackie, thank you. She needs self-assurance, and yeah, it's new, right? It's a new world and she's finding herself, but she's getting empowered, and as she talks with Heather, as she reaches out for assistance, she is starting to feel more empowered.

And that is where we all have to come, whether we are seeking the help of care providers, where we are seeking to help ourselves, our self-talk, yes, can help determine... Nicole, I see what you've written... can help determine how we view and how we're able to navigate and interact the systems, the medical systems, that we have to navigate, right? It doesn't bend or change reality, but our focus on our self-talk and our trying to find those places where we can reframe our story to a more positive point can lead to our own support and help us with building our self-assurance, gathering information... Anita talked about doing research on her own so she would have the words to talk to her doctors, to talk to others so she'd have the information to find what she needed and to be able to, again, navigate the system. Those things interrupt the story of negative self-talk, those kinds of actions are solutions-oriented, and they can also help an individual see, or feel, more empowered and definitely more self-assured.

And I see someone said they're very good at telling your own story, and that's fantastic. So, interrupt. What can help? Interrupt the negative story, speak your positive story. Try, because it feels more encouraged to try, and in trying there's empowerment.

Thank you. And I think I should hand things, at this point, over to Marie.

Marie LeGrand:

Thank you so very much, Dr. Yarbrough, for the wonderful presentation, and once again, thank you to Susan and thank you Anita for doing such a great job with the scenarios. There were definitely a lot of comments in the chat box and I can see that we have quite a few questions coming up as we speak. So, we're now heading into the Q&A portion of our program, and the first question that I have is for Dr. Yarbrough.

So, "Dr. Yarbrough, sometimes I find myself saying I should do this or I should do that. How do I get out of this habit?"

Dr. Sheila Yarbrough:

So, those should lose... you know, I get it, we all get into those. They're easy to get into the loops of what we should do. Sometimes, when I... one of the things that I found, and others can definitely weigh in if they'd like to, is writing out, you know, those messages that I have. The "should" things that can wake you up in the middle of the night, or if you get up, that sort of keep

you up and keep you from going back to sleep and getting a good rest. Writing down what those comments are, what the "shoulds" are, and then looking through and rewarding, and responding, and changing that self-talk, talk about the things that you have done, the things that you have done... the things that have worked well.

Give yourself the credit, treat yourself well for those things that you've done and then really look at it - are some of those "should messages" messages that are coming from you, or are those older story lines when other people were telling you what you should do or what you should not do. So I believe in writing out the messages, looking at, sort of, the fact versus the feeling, acknowledging, right, the feelings. And if there are things on that "should list" when you look at it, that you think... should that... when you see those things that you know that you might choose to do, that you want to do, that you select because they are in your best interest, then those are the things you want to move forward with. I hope that was helpful, and if anyone else wants to weigh-in on the panel, feel free.

Marie LeGrand:

Yes, absolutely. Anita, did you have any thoughts that you want to share?

Anita:

First, I want to say Dr. Yarbrough and Dr. Eggly, their comments about writing down your questions are so very, very important, because I had those "oh, I should have asked this," "they should have done that," "oh, well I should have responded in this way or responded in that way." And, but when you have that list of questions, one, it kind of takes that feeling of "oh, I missed it."

But the other thing is when you're able to go back at those questions and look at "oh, I should have done this, should have done that," if it's possible, take that opportunity to get back in contact with your healthcare provider. maybe through email, or if you're able to, you know, leave a phone call or message, so if there are things on that list that you felt like you should have asked that, as Dr. Yarbrough said, you went back over and said, you know, this one's really important, you can always reach out after the appointment in some way and get back to those questions. But, that negative self-talk, "if I shoulda, shoulda, shoulda, coulda, woulda" - I had to learn to let go of that and to give myself some space and some real forgiveness for being a human, and, you know...

Dr. Sheila Yarbrough:

Yes. Oh, thank you so much. I'm so glad you said that. Forgive yourself for being human. The "shoulda, woulda, coulda" pieces - the door isn't closed, and sometimes we may feel that way out of embarrassment, we may feel that way because, you know, we might think the other individual, well, you know, you have that opportunity, there's still opportunities again. So, if you're feeling like, or you believe that that is something that is crucial, that question, or that information, or whatever it is that you might need to do, then move forward and ask that question, make another appointment, leave a message, or whether it's a voicemail or an email message.

Marie LeGrand:

Doctor Eggly?

Dr. Susan Eggly:

Yeah, I would even add that those "shoulds" or feeling like we are not doing all the things that we should do, can prevent us from really getting good care. I know that patients will sometimes say, "well, I don't want to go back to the doctor because the doctor told me that I should do x, and I haven't done it. And so, I'm not going to go back to the doctor." And instead of going back to the doctor and saying, like, "that's not something that I can do, it's not something I'm willing to do."

So, those "shoulds" can actually really get in the way of getting care. So, yes, forgive yourself. Go back to the doctor, go back to whoever it was that said it and say that's not gonna work for me. I know I should and I don't seem to be doing it... we all have those, right? We should be exercising more, we should be eating better, you know... whatever it is. Those "shoulds" though, when they get in the way of your relationships, especially with your health care providers, then they're very destructive.

Marie LeGrand:

Thank you.

Dr. Sheila Yarbrough:

We can ask what are other options; perhaps I can't do that now, but what are some other options or alternatives?

Marie LeGrand:

Thank you so much for sharing. So a question from one of our audience members:

"What do you suggest when you have a question and the doctor, perhaps, does not acknowledge your question?" Dr. Eggly?

Dr. Susan Eggly:

Yeah, I was just thinking when you said that, because it happens all the time where I will encourage, you know, people, patients, family members, to ask a question, and they'll say "well, I asked that question, I've asked that question, I've asked that question so many times. The doctor never, never, gives me an answer." And so, what I think, that doctors, like the rest of us, sometimes don't understand the question, or we're not communicating in a way that is as clear as it should be. And I think you need to hold the doctor accountable - "I'm sorry, that didn't answer my question. I mean, what I really want to know is... you know, what I can do. I don't..." You know, maybe you guys can prompt me with some questions, but we know, you know, "how long I should have to deal with, how much is this gonna cost, how bad is this gonna get? You know, what are some things that I can do? Ask "I just I need you to answer the question because I either, I didn't understand you or you weren't clear, but I need to go back to that, I need to revisit it and I need you to be a little bit clearer with your answer." Hold them, hold their feet to the fire.

Marie LeGrand:

Thank you Dr. Eggly. Did any of the panelists have any thoughts?

Anita:

Yes, there have been times where I have asked questions and doctors have ignored them. And the thing, one, to remember is that the doctor may either, one, may not have heard you. I, unfortunately, have low volume speaking and so there are times where I simply didn't speak,

literally, loud enough. But the important thing to do, in a way, that generates good communication, is to circle back and say, "you know, Dr. So-and-so, or Susan, I asked this question about this, I don't know... sure if you heard me, but can you please respond to this question?"

When you do that, and I said please a lot, and I would say please at the beginning, but if it's obvious that this particular healthcare provider is not being respectful of you and your needs and your questions, then that's a point where I personally have looked for a different healthcare provider. I have had that situation happen quite a bit, and I noticed Christine, in the comments, mentioned that she had a doctor that scolded her for weighing too much, and blamed that for being able... why she couldn't walk normally. And I empathize, you know, I didn't walk nine miles a day like she did, but I was more physically active, and at that point, when you have a healthcare provider, who I think is disrespectful of you, your needs, your experiences, your journey, that's the point where I believe you need to find someone else with whom you can connect, because it's difficult to connect with a provider who, one, has said something that is dismissive or is unkind.

We need to learn our healthcare journey, and if you look back at your team, you can't have somebody on your team who, while you're walking with your torch towards wellness, you can't have somebody who's, like, throwing apples at your back. You need someone who's going to be there to support you. So again, if you have a provider who is disrespectful, who does not answer your questions, who is not there for you to support you, that's where I would look for someone else who can be that support person for your team, because, again, your journey is... everybody's journey is different, but we need people that are going to be there for those bumps and for those issues and they're going to support you. So, please don't be in a place where you are disrespected and treated unkindly.

Dr. Susan Eggly:

Can I also add... something that Anita mentioned - make sure that you're phrasing your questions clearly. I mean, sometimes you might be beating around the bush just a little bit, like the doctor is. You know, maybe they don't want to give you an answer, maybe you don't really want to ask the question, and so it... maybe it's getting a little confusing, and you're almost giving the doctor a way out.

So, instead of saying things like, "yeah, I wish I knew..." Then, say right away, you know, "please tell me." You know, make sure that your questions are clear and ask them one at a time - don't have a barrage of questions, because if you ask five, you're going to get an answer to one. So, be careful at how you phrase the questions as well, so that you're going to give them the benefit of being able to answer. Direct questions get direct answers. Thank you.

Marie LeGrand:

Dr. Eggly, that was actually going to be one of my next questions is - I'm shy, especially around doctors, so any tips? And you covered that, so thank you. Going back to your MS journey, Anita, how would someone, perhaps open more and start speaking about their stories?

Anita:

One of the things is friends. In our scenario, Jasmine had Heather, someone that she was able to confide in. So, one of the things I've done when I was nervous was actually, literally practice. Find someone to listen to me, you know, with my mom or friends, and I would say, "okay, you know, I have to go into this doctor, I'm nervous, I'm not sure about this issue, I don't know how I

want to bring it up." And so, I would practice, just actually, just call up someone or just speak to them and say, "hey, I'm going to the doctor, you know, let me practice this... you know, saying this to you."

And once you do that a few times, it gets to be almost automatic, and that can erase some of the fear, because often, if we're walking into a new situation and we haven't kind of prepared ourselves, as the doctors have talked about, then that just adds more stress, more anxiety, makes it harder to say something. But I would definitely recommend practicing ahead of time. And, if you're by yourself, speak those words out loud - don't just always keep them in your head. And I believe there's power in the spoken word, so if you have your questions and what you want to bring up, speak those words out loud. And that's helped me in my time of nervousness or being shy about approaching one of my healthcare providers about a situation.

Marie LeGrand:

Yes, thank you Anita.

Dr. Sheila Yarbrough:

May I just add a bit more?

Marie LeGrand:

Sure! Yes!

Dr. Sheila Yarbrough:

If you're alone, and quite often it's great when you have the support, or someone that you can turn to, but, as you said, when you're alone, still, whether you're speaking it to yourself in the mirror, recording, writing your questions down, recording and practicing, it can make a difference. If you're anxious in any forum, I think practicing can help. But if you're alone, write those questions down, record them, practice saying them, and, as you said, we speak power to words. Thank you Anita for saying that.

Anita:

And, just as aside, I had a tremendous amount of anxiety coming into this webinar, and so I did sit with myself, and I practiced what I was going to say about my journey, I practiced the parts of Jasmine, and I did that alone. So thank you Doctor for pushing out. So yeah, that helped me in this situation. You guys aren't health care providers, but it's still anxiety going into a new situation.

Marie LeGrand:

Thank you Anita. Talking about anxiety, Dr. Yarbrough, do you have, perhaps, any tips or suggestions for someone who may be dealing with anxiety in certain stressful situations, as well as, perhaps, any other thoughts you can think about when it comes to negative self-talk that would help?

Dr. Sheila Yarbrough:

Well, I think the piece about anxiety... we all feel anxiety, right? Well, there may be someone who doesn't, so I won't say "all" and generalize everyone. But anxiety is a natural human feeling, you know, it's tied to a stress response, we're transitioning, perhaps, into something new, we're tackling something... I felt nervous, too, getting ready for this. And, you know, it is falling back on practice is one of those things that I have found that personally helps me. Writing out, practicing what I want to say, I think, it's important.

Also the recording piece. And I think the other thing that we can do is look at those places where you know that you've done well; remind yourself, interrupt that story of "I'm so anxious", that I can't do this... remind yourself of the things that you have done. And also, you can be anxious and still continue to get the information and the services that you need, and part of that is the preparation piece, right? The anxiety may stay with you, it may diminish a bit. And if it stays, and you have your questions written, and you're talking with your care provider, those questions are there for those moments when that anxiety may be overwhelming, you know, when it sounds like the doctor, you may feel like the doctor or the provider is not listening. But, you've got your written questions, and they're there as your support; as your, sort of, your extra... your extra piece.

If you are in a telehealth, I know a number of individuals who are involved in telehealth, and who might have relatives or a support person there with them, having that person nearby, if it's that situation. But again, and with the anxiety, know that it's natural, know that you can still, you know, move forward with it. If the anxiety is at a point that it becomes debilitating, then that might be something that you want to talk with your provider about, if there's some assistance with that.

But I also believe in practice, and in the preparation piece; to prepare for those moments when I need to be the best that I can be to get the information I need, and I might... and having something written down definitely helps, and being able to fall back on practice that I've done, so that memory, can fall into place and help us or support us when we're feeling anxious.

Marie LeGrand:

Thank you so much Dr. Yarbrough. So, one other question for Dr. Eggly. So, "Dr. Eggly, sometimes it seems like the dynamic between me and my physician seems to change; each visit feels different. Is it that what we bring to our conversations changes over time, or is it that it can change based on the day? I can only imagine how busy my physician is before me."

Dr. Susan Eggly:

You know, that's a really great insight. I do think that our relationships change over time, all of our relationships. And you may have noticed even with your own friends and your family, sometimes things are going well and some things that aren't going. Well, people come to me sometimes and they say, "you know, I had a horrible interaction with my doctor. I think I'm gonna leave." And, you know, we'll talk about, well, are all of your interactions awful or was it just this one? Because, you know, maybe she had a bad day, honestly, maybe the patient before you really gave her a hard time, or you know, maybe her kid's having some problems. I mean, you know, I do think that, you know, you got to look for a pattern over time.

I also think it's not a bad idea if things aren't going well to address it, and say, you know, let's take a step back here - I feel like there's a little bit of tension. I just want to make sure that, you know, we're understanding each other, And are you okay? I was thinking about your comments about anxiety, I think sometimes it does help to understand that they've got a life too, you know, and so it's, you know... although you are truly the most important person to you at that moment, you have to realize that they do have lots of pressures, lots of patients, a personal life, and things like that. So I'd like to think that you should be patient with, you know, the ups and downs of a relationship with your health care providers. Having said that, though, if it goes on too long, I agree with my other panelists - time to find somebody new.

Marie LeGrand:

Right, right. Thank you so much Dr. Eggly. So now, since we're coming to the close of our program for the evening, I just wanted to hear from each of you any last thoughts. We'll start with you, Anita.

Anita:

One, I want to thank everyone that has participated. This has been an absolutely amazing, inspiring experience for me. I'm inspired by the doctors, I'm inspired by the comments in the chat - people just sharing their experiences, being open in what I consider to be a safe space. And I have learned things that have been mentioned in chat, and I just want to thank everyone that's participated. MSAA for the support and sponsoring. And for our other sponsors for the program, thank you. I just feel really fulfilled and excited to continue to advocate for myself, as well, because I have moments where I'm not doing so well. So, thank you to everyone, this has just been an incredible, fortunate, and blessed time. Thank you.

Marie LeGrand:

Thank you so much Anita. Dr. Yarbrough, any last thoughts?

Dr. Sheila Yarbrough:

Well, I want to add my thanks. Thank you to everyone, it's been a fantastic journey to be able to get to know you and, Anita, to get to know you, Dr. Eggly, Marie thank you very much also... it's been wonderful. And I appreciate, as Anita pointed out, the sharing in the chat, that you're willing to be vulnerable here in this space and to share your stories. I'd like to add that one of the things to take away is interrupting those... anything that comes negative, because it will come our way, right? Interrupt those negative stories and know who you are and speak words that give power and add power and positivity to your lives, because there is so much more to us and we... just the negative stories that might come our way, continue to fight, and be who you are, and thank you so much for sharing.

Marie LeGrand:

Thank you so much Dr. Yarbrough. And Dr. Eggly, any last thoughts from you?

Dr. Susan Eggly:

Just again to thank MSAA and the panelists, whom I've never met, but I certainly hope that someday I do meet you. But also, mostly, to the audience. These... I have learned so much, and the kinds of messages that you're putting in the chat and the kind of advice that you have to help each other as you go through this journey, but also as you honor yourself, and understand that you do have more power than you think, that you do... and to own your journey in ways that maybe will not only help you but maybe help other people, and to understand and have compassion, not only for other patients, but also for the providers that are doing their best to help you. So, thank you all.

Marie LeGrand:

Thank you so much Dr. Eggly, thank you Dr. Yarbrough, and thank you Anita for sharing your time with us. This concludes the final webcast in our New Directions Series. Tonight's webinar was recorded and will be made available on our website at mymsaa.org. Please do visit MSAA's calendar of events for our upcoming webinars.

On behalf of MSAA, we would like to thank Genentech and Johnson & Johnson for making this program possible, as well as our Virtual Display Hall sponsors, Biogen, Genentech, and Sanofi Genzyme.

We would also like to thank Anita, Dr. Eggly, and Dr. Yarbrough once again for the great presentations and your acting skills, you guys were on point, and to Anita for sharing her MS journey with us, we truly appreciate it.

We would also like to thank our partners at Impact Education in delivering this program. And thank you audience members for joining us this evening, thank you for participating, thank you for all of your questions and suggestions and insight, we truly appreciate it. Please participate in the participant evaluation which will appear on your screen momentarily.

Know that we are thinking of the entire MS community and hope that you and your families continue to stay safe. Thank you and have a good night.