



**MSAA Podcast - Episode 12:
Finding Joy in the Process:
Managing Mental Health in the MS Journey
Part One: Mental Health and MS**

Host: Yahaira Rivera

With special guest: Amy B. Sullivan, PsyD, ABPP

Yahaira Rivera:

Hi. My name is Yahaira Rivera, and I'm the Director of Mission Delivery and Program Development for MSAA. You are listening to MSAA's MS Awareness Month podcast, "Finding Joy in the Process: Managing Mental Health in the MS Journey." This podcast series of three episodes will discuss the importance of mental health in MS care and how to improve your life through the power of positivity and supportive connections.

Today's episode explores the topic of mental health and MS, and we are excited to have mental health expert and board-certified clinical health psychologist Dr. Amy Sullivan guiding us in this important conversation. Dr. Sullivan is an associate professor of Medicine, Director of Behavioral Medicine and Research at the Cleveland Clinic Mellen Center for MS, Director of the Neurological Institute Engagement and Well-Being, and Chair of the Institute's Diversity and Leadership Development. Dr. Sullivan is an expert in mental health and psychological factors impacting multiple sclerosis and is also a member of MSAA's Health Care Advisory Council. Welcome, Dr. Sullivan. We're so happy to have you.

Dr. Amy Sullivan:

I'm so happy to be here. I must say, MSAA has been so near and dear to mine and my patients' hearts since I started this career back in 2010. So, I was happy to do this. And of course, mental health is also something of huge importance to me and I'm happy to talk about this today. Thanks for having me.

Yahaira Rivera:

Of course. Thank you for being here with us. Dr. Sullivan, in your experience working with individuals that are living with MS, what are some of the common symptoms that impact mental health, and how do you recognize those symptoms?

Dr. Amy Sullivan:

Yeah, that's a great question. I think, you know, mental health is a very complicated disease. We have, you know, so many different domains of things that can be affected by mental health. From my perspective, when patients come to talk to me in my office, we talk a lot about the invisible symptoms. And when we think about the invisible symptoms, there are really five invisible symptoms that people are sometimes more concerned about than the physical symptoms. So, let's talk about them first. So, the invisible symptoms would be cognitive function, sexual dysfunction, pain, fatigue, and mental health. And of course, mental health is what I'm very connected to with my patients. And oftentimes, especially the fatigue and the cognitive symptoms and the mental health symptoms, people will say to us, these are much more debilitating or much more difficult to manage than their physical symptoms.

And I think that that's really important that we listen to what our patients are saying and we address those and we treat the patient and a multidisciplinary or, you know, integrated care type of model, which is what we do here at the Mellen Center. So when I talk to my patients about fatigue, they will say that this is so depleting because they feel like they have the flu 24/7. Or when they talk about cognitive symptoms, they will say, you know, it feels like I'm just not able to connect the dots in the way that I used to or I can't remember things in the way that I used to. And when they talk about the mental health symptoms, it's very difficult for people because depression and anxiety are very prevalent in individuals with MS. In fact, we see the prevalence at 3 to 4 times that of the general population. So an individual that may have depression, we see that in about 54% of our patients. And those are just people who meet full criteria for a major depressive disorder or dysthymia. These are not people who just have symptoms of the disorder, but these are people who actually meet full criteria. So, we think that the prevalence is actually higher.

And just let me say one more thing about anxiety before we can kind of reflect on that. I think when we think about anxiety in an MS population, it's kind of like your little brother being carried along with you. It's something that we are always looking for. Usually, when somebody has depression, they will likely have some symptoms of anxiety. And I think when we talk about these statistics, they're exceptionally high. But what's important, again, for me to stress is that these are people who are meeting full criteria, not necessarily people who are just experiencing the symptoms. So the symptoms are likely much more prevalent than the numbers that I've discussed. And I think it's just really important that we take some time to talk about these symptoms and we take some time to just bring awareness to the fact that people with MS likely have some type of mental health, at least symptoms, happening.

Yahaira Rivera:

So now that you mentioned some of the symptoms and the prevalence and the percentage of people living with MS and having mental health challenges, what is your advice for someone who might be experiencing these mental health challenges and symptoms and wants to take action, but doesn't know where or how to start?

Dr. Amy Sullivan:

So there are several things. I think, first and foremost, as neurologists and people who see people with MS, I think the neurological care team has to assess for this. So in Mellen Center, every single appointment that an individual goes to, so either neurology or what the advanced practice providers or the physical therapists, the occupational therapists, the speech therapists, of course, when they see us, individuals are given what's called a PHQ-9, and that stands for a Patient Health Questionnaire, it's a nine-item question, and it assesses the symptoms of depression. So let me go through what the symptoms of depression may be.

We assess that by using an acronym called SIGECAPS. So, the S stands for sadness or loss of interest. So does a person have some apathy, some sadness, some loss of interest? That also includes in our MS population, irritability. Believe it or not, depression isn't always about the tearfulness that you see on TV or in movies. It is sometimes just simply that irritability and we see that a lot in our patients because they're irritable, because they can't do the things that they used to do. It also includes, the "I" is interest. So, has the person lost interest in things that they once enjoyed? That's incredibly important. So sometimes fatigue takes away interest, sometimes depression takes away interest. So, we want to make sure that people are still able to do the things that they used to do, that G stands for guilt. So, do they feel guilty about their situation or is there anything they feel guilty about?

The E stands for energy. So, have they lost energy? And you're starting to see kind of a trend here, too, that some of these things are actually symptoms of MS as well. The C stands for cognition. So, are they noticing cognitive difficulties or are they complaining about cognitive complaints such as memory, attention, etc.? The A is for appetite. So, have they seen an increase or a decrease in their appetite? That P is for psychomotor agitation. And the S is for two things - sleep: so, have they seen an increase in their sleep or a decrease in their ability to fall asleep or stay asleep? And the other S is for suicide. So, are people feeling like they would be better off dead?

And so, when people are in our offices, they're taking the PHQ-9, which assesses for all of these symptoms. And we're particularly interested in capturing the people who have even moderate levels of depression. We want to make sure that we're seeing them in our practice. And so I feel from my perspective that they have to be screened first, so that our physicians know to send to us, or the therapists know to send to us. If they're not in an interdisciplinary care practice, such as Mellen Center, there are also ways that they can seek help. So, their insurance will be able to direct them to a psychologist or social workers or therapists or psychiatrists. Their doctor should have referral sources. I know MSAA and NMSS also have referral sources. And so, these are really important.

And finally, there are support groups. So support groups are kind of everywhere nowadays. One of the greatest things that happened during the pandemic was that things started to go virtual. And although that's very difficult for some people because life has turned inward, for support groups, it's been a really wonderful thing. You can find support groups on almost every social media medium. I know at Mellen Center we hold multiple support groups for those who live in Ohio, and I'm sure many other states would have support groups that are associated with chronic disease, caregiving types of things. So, I think there are lots of ways that we can direct people to get help. But I think it really starts from the neurologist's office onward. And people need to be aware that they're having these symptoms. And so, somebody needs to recognize that depression, again, is not what it looks like on TV. It's not sitting in your room, in a dark room with the blankets up over your head all the time. Our MS patients are very functional. These are some of the most resilient people that I have ever met. It can simply just look like irritability, so people have to be aware of changes and sometimes the best person to identify that is either a spouse or significant other, parents, people who are around them on a consistent basis. So just, you know, first and foremost, being aware that these symptoms are occurring.

Yahaira Rivera:

And also care partners, right? Because they're on a daily basis with the individuals living with MS and sometimes they can recognize those symptoms. So, it's important to recognize the symptoms. It's important to get the screeners, to have those conversations with your providers

and also to seek help. So now let's talk about strategies. Do you have recommendations about strategies that can help to cope with mental health and MS at the same time?

Dr. Amy Sullivan:

So, I think what a good psychologist would tell you is that it's not a one-size-fits-all all, but I do think that there are some things that we can teach people to put in their toolbox. For example, we have a four-session stress management protocol that is highly effective. In fact, we just got our data back, which shows us that people are really responding to the techniques that we're teaching. They're responding in both a subjective way, such as in the form of their screeners, again, so anxiety and depression screeners. But they're also responding, so, we're giving them a biofeedback tool, and they're also responding in a physiological way. So an objective way. So we're able to see that the sympathetic nervous system is perhaps dropping and they're going into parasympathetic nervous system response by way of looking at their heart rate. So people's heart rates are coming down. People's breath work - so their breath per minute is coming down, and then their saturated oxygen is increasing. So, it's a fascinating, it's just a fascinating study that we've been able to do.

So we want to give people tools to fill their toolbox, and my favorite skill is mindfulness. So let me explain mindfulness in the simplest of terms. Mindfulness is being in the here and now. So, when we think about the here and now, it's hard to think about, you know, maybe what may happen five minutes from now or five years from now. So, our MS patients oftentimes come in and say, Well, what if in ten years I'm in a wheelchair? There's a lot of fear in the future. And so, what we focus on with mindfulness is being in the here and now. It's also very difficult to focus on the past, which can be filled with regret, remorse if you're focused on the present.

So, when we teach mindfulness, the skill that I love the most is learning how to be in the here and out. Now, that even means, you know, if somebody says, So, what do we have going on this weekend? The answer should be, I'm focused on where I am right now. You know, where are my feet? So, "be where your feet are" is what I like to say to my patients. So, my feet right now are in Cleveland, Ohio, at the Cleveland Clinic in the Mellen Center doing this podcast with you. I am completely into this podcast, not thinking about what happens at 10:00 when I have to go round, or what happened earlier this morning when I forgot to pack a peanut butter and jelly sandwich for my child and one of my children was very upset with me, right? So, I could think about the past and have a lot of guilt or remorse about that, or the future, like I have to get over to the hospital. But instead, I think it's really important to focus on the here and now. So, and I'll say it again, I think it's really important to be where your feet are. And try to use that tonight, too, just to see how that works for you and your family, be where your feet are.

The second skill that I love, so we talked a lot about stress management earlier, but I think there are several stress management techniques. Mindfulness is certainly one of them, but mindfulness encompasses a lot more than just stress management. Mindfulness is kind of a way of living or a way of being. Stress management is like your breathing skills. So, what I'd love to do with you is just teach you a quick breathing skill that I think people can utilize when they're in their everyday life. I don't recommend this if you're driving, until you get the hang of it, because I think that eventually this is something that we can use kind of all the time.

But the first skill that we teach is just diaphragmatic breathing. And so, diaphragmatic breathing is learning how to breathe from your diaphragm. And I know you can't see my hands in this video, but your diaphragm, if you think about your lungs and that upside down U, it's above your belly, right under your lungs, that is your diaphragm. And so what we do is we teach people how

to move their breath from their chest into their diaphragm. So why that's so important is that most of the time when people are freaking out or they're anxious or they're having a very difficult time, they're chest breathing. And chest breathing leads to panic, it leads to our brains not getting the oxygenation that they need so they're not able to think clearly. It also leads to us not being able to oxygenate the visceral organs. So, we really need to work on that ability to move our breath from our chest into our diaphragm. And so one of the skills that I would love for us to practice and maybe you'll do this with me right now, is just the diaphragmatic breath.

So put one hand on your chest.

Yahaira Rivera:

Okay.

Dr. Amy Sullivan:

And one hand on your diaphragm.

Yahaira Rivera:

Okay.

Dr. Amy Sullivan:

And all I want you to do is just recognize where your breath is coming from. Is it coming from your chest or your diaphragm?

Yahaira Rivera:

My diaphragm...

Dr. Amy Sullivan:

Your diaphragm. Yeah. So, people who are really good at this and just keep doing this as I talk, but people who are really good at this are people who [do yoga] or people who practice meditation, people who are wind instrument players, people who sing and choirs. So people have been taught this skill, but they don't recognize that it's a stress management skill.

So, learning how to breathe from your diaphragm versus breathing from your chest is one of the greatest skills that we can teach people how to accomplish. Now, there are several iterations or several things that we can do in advance. I think that'll be a fun podcast for another time. I know we don't have time to cover that, but some of the things that I love, my favorite breathing skill is Serial-3 breathing. So, it's learning how to breathe, learning how to develop a nine-second breath. So, it's a three-second breath-in, a three-second hold, and a three-second out. And that's a really powerful breathing skill to utilize.

And then there are other techniques such as visualization. So, some of the things that we do in our practice are we tailor visualization to our patients. So if a person really loves their backyard on their porch, we have them go through their five senses and really describe to us what their relaxation spot looks like, or some people love the beach or some people love the mountains, whatever that looks like to the person, we have them describe through their five senses their favorite place to be, and then we take them through a visualization.

And then finally there are things like body scanning and progressive muscle relaxation. So there's lots of ways that we can teach people how to shut down their sympathetic nervous system, so the sympathetic nervous system is the fight or flight system, and how to turn on that

parasympathetic nervous system, so that rest, relax, recover, which is so very important for us when we're treating people for symptoms of depression or anxiety.

A couple other things that I just want to mention. We had talked about groups earlier, but I think connection is vitally important. So, I think people with depression or anxiety, they want to pull away, but it's actually the opposite that we need to do. We need to encourage people to connect. So, I think groups are really important for that. And then finally, just kind of knowing yourself and knowing what works for you, I think it's important to push ourselves a little bit, to make ourselves do things that we, you know, depression takes away our interest and our motivation. So, we want to make sure that we're planning things on a regular basis, but knowing what works for you. So, there's a whole toolbox of skills that I gave. But some of those will work for some and some will not work for others.

Yahaira Rivera:

Thank you, Dr. Sullivan. I love the breathing exercise. Thank you for sharing that with us. We appreciate all the important information and all the strategies that you shared with us about mental health and MS. The main takeaway for me today is that our mental health is as important as our physical health, that knowing ourselves is important, recognizing those symptoms and seeking help. It's okay to ask for help. And I love what you said about being present in the here and now. Thank you, Doctor Sullivan.

And I would also like to thank Gradwell House Recording for hosting us today and producing our program. Once again, thank you for listening. We'll be back with our second episode of this series, and we'll chat with Dr. Sullivan about the power of positive thinking. Stay tuned.