



Multiple Sclerosis
Association of America

**MSAA Podcast:
Better Symptom Management through
Wellness – Episode 6**

Host: Peter Damiri

With special guests:

Mary Rensel, MD and Amy Sullivan, PsyD

Peter Damiri:

Hello, and welcome to the Multiple Sclerosis Association of Americas podcast, “Better Symptom Management through Wellness.” I am Peter Damiri, Vice President of Programs and Services for MSAA, and your host for today's program. Today's program is part of MSAA's 2020 MS Awareness Month, *The Mind, Body, and MS Connection* campaign, which has been made possible by the generous support of Biogen, Bristol-Myers Squibb, and Genentech.

I am honored to welcome our guest presenters, Doctors Mary Rensel and Amy Sullivan of the Cleveland Clinic's Mellon Center for MS. Dr. Rensel is an MS neurologist and Director of Wellness. And Dr. Sullivan is a psychologist and Director of Behavioral Medicine, Research, and Training. Thank you both so much for being here and sharing your expertise with us today.

Dr. Mary Rensel:

Thanks for having us. We're excited to spend this time with our MS community.

Dr. Amy Sullivan:

Yeah. Thanks so much, Peter. This is such a pleasure for us to be here this morning.

Peter Damiri:

Absolutely. Thanks. So, our topic for MS Awareness Month is the mind-body connection, which looks at both how physical wellness and emotional wellness are really integrated and so important in managing MS. Can each of you talk a little bit more about this?

Dr. Mary Rensel:

Sure. I'll start. This is Dr. Rensel. As a neurologist, you know, when we're training, we learn about the brain and, you know, the special organ that it is and how it makes us who we are, and we learn about how to support it or the day-to-day activities that actually matter. And that has become more and more clear over the years through research that folks living with MS, you know, all the little decisions we make throughout the day actually matter, like what we eat, and you know, how many people we see during the day, and who's in our social network. So, we're

all connected to our communities. We're connected to our friends. And it matters for our brain health. I'll let Dr. Sullivan add to that.

Dr. Amy Sullivan:

Yeah. I'd like to add to that, especially given what Dr. Rensel just said, with regard to how our social connections and our everyday environment contribute to our health and well-being. So, in psychology, we use a model called the Bio Psychosocial Model of Health and Wellness. And this is a model that really understands that people are biological organisms and so our genotype can really determine our behaviors such as wellness or disease. And so, this model takes into account, just as Dr. Rensel was speaking about, how our social and psychological worlds influence illness and disease as well as wellness. And so, we also acknowledge that there's an influence of individual culture, society, religion, activity patterns, individual differences, personality, cognition, and emotion. And why this is so important to us is that we know that this is linked to what we call the mind-body connection, or how, as psychologists, we can so readily help people shape their coping styles and how they deal with wellness and illness.

Peter Damiri:

Oh, great. Thank you. That's great insight. Appreciate that. So, let's start with physical wellness, which most people recognize as diet, nutrition, and exercise. I know at MSAA we're often asked if there's a specific MS diet to follow. Doctor Rensel, what do you tell your patients about diet, nutrition, and MS?

Dr. Mary Rensel:

Well, I always tell my patients my favorite study regarding nutrition and MS. And that's the one of Narconon. So that's a large study surveying many patients living with MS and asking them if they ever tried a healthy diet. And when they even tried a healthy diet, they had better physical outcomes, meaning they could move easier, walk easier. So, I always tell patients it's always worth learning and trying because even a little bit goes a long way. And what we know about the brain is it's made of billions of neurons and all those neurons need support. They need a lot of vitamins and energy to work. Our brain is metabolically super active. It's the most active part of our body. And so, we need to feed it well and give it healthy nutrition, which is hard for some folks, you know, living and dealing with MS symptoms every day because of the fatigue. So, a little planning and a little knowledge can go a long way. There is not one diet that every MS patient has to follow, but we would like people to try to follow as healthy a diet as possible.

The current recommendation is to follow a Mediterranean diet. That's what the Mellon Center, Cleveland Clinic recommends. And that's because there's so much literature behind that diet showing that it helps for at least systemic inflammation, so inflammation throughout the body. And it's great for heart health, et cetera. So, there are ongoing studies, multiple studies looking at different diets for MS, and there are books, et cetera. But really it is not known the "one" diet. But we do know that excessive sugar changes brain structure and how it works. We know we need healthy fats. So, fat is not the enemy, myelin is made of fat, so we know we need healthy fats like fish, avocado, et cetera. So, there's you know, there's a lot of nice, simple things we can do each day to support brain health through what we're eating at each meal.

Peter Damiri:

That's great advice. Thank you. Well, moving on to exercise, it's certainly understandable that people living with MS can experience difficulty with balance, strength, fatigue, and heat intolerance, which certainly can all hamper their ability to exercise. Understanding this, what are some of the safe and effective options for the MS community to exercise?

Dr. Mary Rensel:

Well, that is very true. It is very, you know, it can be very frustrating for MS folks. They, you know, I had a patient yesterday who kind of just threw in the towel. He said, you know, he's feeling weaker. It's getting more frustrating. And he can't find, he can't do what he used to do. So sometimes we need to, you know, pull in our health psychology partners and we have to reframe, you know, and talk about, you know, what it is today, what we can do today. And we have physical therapists and occupational therapists that can get to know that patient and structure a program, particularly for them. So, it's not supposed to be painful or horrible, it's supposed to be something that you can squeeze into your day. General health and wellness for somebody with or without MS, the recommendation is 150 minutes a week, at least, of moderate-level movements.

So, with MS fatigue, if there's any way folks can break that into bits and pieces throughout their day, that's fine. They don't have to do an hour and a half at a time or, you know, a really aggressive step class or something. If they have little weights in their house and they can do 5 minutes here and there or a little, you know, stroll through the living room, that's fine. If it's a stretch at commercials, I'll take it, you know, but some kind of movement really makes a difference. And there's been some really interesting research showing that physical movement also supports memory or cognition with MS. So when patients say, what can I do for my memory, I'm concerned about it. This is the best thing, physical movement to support. Because, you know, when we physically move, we demand more from our brain and the nerves have to kind of connect and they enhance their connection to each other, which we call synapse. So how the nerves talk to each other. So, the more we demand of it, the better our nerves work and the more they branch out to reach out to other nerves. So even though it's not maybe what it always was, some kind of movement really does matter.

Peter Damiri:

Right. And that does underscore that mind-body connection where you mentioned that it really can help in the cognitive aspect as well.

Dr. Mary Rensel:

Absolutely.

Peter Damiri:

That's great. So, I think we can all appreciate, though, that it's certainly easier said than done to eat better or exercise more. And, you know, certainly, life happens and life with MS can be challenging for sure. So, with this in mind, Dr. Rensel, what are some keys to creating and staying on your diet or exercise goals?

Dr. Mary Rensel:

Well, I think, you know, as humans we're hard to change, right? And so that's where evolving behavioral medicine or health psychology is important because, you know, we get in patterns, and we get in habits, and it takes some push to make new patterns or new habits. But once there are habits and they're yours, it's like brushing your teeth. You don't, you know, think about that every day. That's something that you do. But it takes some time to make something a habit. So generally, like we talked about that my favorite study is just even learning about what's good and even trying something. Sometimes then you can say, "oh, it's not that hard." But to change a human, we have to make it easy. So, if you're going to start exercising, you keep your shoes right by the door. You get your exercise clothes out the night before. You tell a friend, you know,

to remind you to let's go for a walk and do it together. Any way that you can make it easier for yourself, you're going to keep it as a habit, and then it will be part of your regular routine.

Same thing with nutrition. You know, I think in the morning we all have good intentions, but by night when we're tired, we say, "oh, forget it." So, it's good to make a plan in the morning. "I'm going to have this and this. I'm going to prepare my vegetables. I'm going to cook them early in the morning when I have some energy." You know, just little things can go a long way. And I think the other important thing is to know what does not help, you know, what does not seem to matter. There are a lot of false claims online, et cetera. So, I'm really glad you're doing this and taking the time to share this with our MS community because the simple things really do matter. You know, what we put in our mouths every day matters. And how we move or stretch every day really matters. And if we see friends and family and connect with people, that really matters to our brain.

So, we don't have to go to a store and buy, you know, \$700 worth of supplements and think that that's that, you know, and then sit down all day. You know, we need to do the things that really matter, and making it easy for yourself and having a plan can definitely change things. But I'd like to hear from Dr. Sullivan. She knows the key to making new habits and changing humans, maybe.

Peter Damiri:

For sure. I'd like to focus now on emotional wellness and its impact on MS. Dr. Sullivan, can you touch on how your mental and emotional state can impact a person's MS and overall quality of life?

Dr. Amy Sullivan:

I can. So, one of the things that I'd like to talk about first is that we've known a lot about stress, MS, and emotions throughout the course of the MS disease. So back in 1877, Charcot speculated that stress in MS was related to grief, adverse changes, and social circumstances, and related to one's MS. So, we've known since 1877 that there was a connection between stress and MS.

And then over the years we've seen lots of correlational studies that have shown a connection between stress and MS, specifically if we look at studies that have looked at people during wartime, and what these studies have shown is that during wartime more people were diagnosed with MS. And then more recently in 2012, this is one of my favorite studies to cite, Moore and his colleagues out at Northwestern completed the first Class 1 study on stress and MS, and they were really able to tie stress to MS. And so, in this study, the research team assigned 121 participants to one of two groups of people. So, it was either the intervention group or the control group. And in the intervention group, a stress management protocol was put into place for these individuals over the course of 24 weeks and consisted of 16 individual sessions. So, what they found over the course of the study was that compared to people in the control group, the treated participants developed fewer gad-enhancing lesions and T2 brain lesions.

But I think one of the kickers of the study, for me especially, was that once a person ended their stress management work, there were no differences between the two groups. So, it's very important for individuals to participate in active stress management and understand the mind-body connection. And so, for me, when I'm working with patients, we really work to teach people a series of stress management techniques, helping people to really understand their response to the sympathetic nervous system, helping them to really shut down that flight or fight

response, and helping people to combat the symptoms of stress, and therefore inflammation in the body.

Peter Damiri:

Oh, great insights. Very interesting study. Well, fortunately, there seems to be more awareness and acceptance about the importance of emotional wellness, especially when managing a chronic disease such as MS. But I am curious if you see situations of people having stigma or shame associated with seeking mental health treatment, and if so, how do you go about helping to kind of destigmatize mental health and bring about acceptance?

Dr. Amy Sullivan:

Yeah, I found that very interesting. I did most of my training in Atlanta and in New York. And so, these are big cities where people really accepted mental health and where everybody talks about their therapist. And then I moved to the Midwest where when I took this job at the Cleveland Clinic, and I realized that there was quite a stigma attached to mental health issues in the Midwest. And so really, I have been on a mission to change that. And so, on Twitter, I have this #normalizednotstigmatized hashtag that I think is so important. And I've seen so many people working to change that. And particularly in Cleveland, where we have the Cleveland Cavs, we've seen Kevin Love do some wonderful work around, you know, de-stigmatizing mental health. And I've just been really proud to see him and many of our other professional athletes and famous people coming out and describing their experiences with mental health that have been very helpful for normalizing.

With regards to our population, so our MS population, it's oftentimes depression, and anxiety, which can be both a reaction to but a symptom of the disease. And so, I think that when we describe depression and anxiety as a symptom of the disease, it's not as hard for our patients because they realize that it's not that they're weak per se, that in fact, this is just that, you know, MS has a symptom of depression or anxiety. And as a result, of that, we want to make sure that we manage that. So, our neurologists are very good with sending folks to see us right off the diagnosis. And they share that this is just a symptom of their MS. And so, one of the things that we say is MS takes so much from our patients we don't want it to take its joy as well.

And so that's one way that we try to destigmatize mental health issues here. But another way is that we are in the initial shared medical appointment at the Mellen Center. So, the initial shared medical appointment is for newly diagnosed patients. And this is an appointment that our patients come to with whomever they choose. And in that appointment, one of our neurology team members and one of our psychology team members, and so right from the get-go, we do a wonderful job of destigmatizing and just making this known that this is just part of their MS treatment.

Peter Damiri:

Right. That's great insight, and we often hear the difference between the physical symptoms of MS and the "invisible" symptoms, and certainly stress, anxiety, and depression kind of fall into that category. So, it sounds great that you're putting them both up front as these are the symptoms that you need to be mindful of with MS in that regard.

Dr. Amy Sullivan:

Yeah. Yeah, absolutely. And I think that when we talk about the invisible symptoms sometimes being more difficult for our patients to manage, you know, I think of the invisible symptoms such as cognition, pain, some of our mental health conditions, depression, anxiety, sexual

dysfunction, and fatigue, these are symptoms that are oftentimes more debilitating for our patients than some of their physical symptoms.

And so, I think it's imperative that we're treating those, and the invisible symptoms are things that we work so closely with. In fact, we have a group that we run here at the Mellen Center, one of our six groups. And we oftentimes talk about, "But you look so good," you know, and so many of our patients are really struck by that because they get discrimination because they look so good despite the fact that they're really fighting or struggling with some of these invisible symptoms.

Peter Damiri:

Yeah, absolutely. We hear that as well. Our people contact us through our phones or the programs that we attend. Yes. Well, you mentioned stress and stress management earlier, so, unfortunately, we all know too well that stress is an everyday occurrence. But can you give our listeners some helpful strategies or suggestions on ways to help reduce stress and anxiety and improve their mental well-being?

Dr. Amy Sullivan:

Yeah, and I appreciate what you just said right there, Peter, because you said that you recognize that stress is an everyday part of existence. And so, I think that one of the ways that we can help to destigmatize mental health is just by talking about the fact that many times people come to see us for stress management. And that's one of the things that I think we've done really well at the Mellen Center in terms of destigmatizing because we label our services as a four-session stress management protocol.

So let me tell you a little bit about our four-session stress management protocol here at the Mellen Center. So, I shared with you the Moore study, and that study went on for a little bit longer than I feel our patients can commit to because our patients are usually diagnosed in the prime of their life. These are individuals who have jobs, have families, and they don't have a whole lot of time to commit to us. So, what we wanted to do was pick out what we felt were the most important pieces of stress management to our practice and to implore those. And so, what we do is a four-session stress management protocol where we really help the patients to understand the autonomic nervous system. So, with that, we help them to understand the sympathetic nervous system, which is the fight or flight response, and the parasympathetic nervous system, which is the rest and relax response.

And so, it's very important for us to share with the patients what's happening to your body from a negative perspective when you're in a fight or flight, which many of us are on a regular everyday basis, and to help them then to recognize that they can turn that off and turn on the parasympathetic nervous response and the rest and relax response. And we do that by way of hooking them up to a biofeedback tool. So, they're actually able to see their physiological responses as they're working on these skills.

So, one of the next things that we do is teach the diaphragmatic breath and we feel like that's pretty much the key to learning the rest of the strategies that we teach. So, it typically takes some time for our patients to really understand this diaphragmatic breathing. And from there we work on that and then we teach something called serial three breathing. And this is a way to decrease the amount of breaths that one has per minute. And then next we move on to body scanning and visualization, and then finally we move on to a skill that I love, and it's one of the skills that I really base my own stress management on, which is mindfulness. And mindfulness really is learning how to be in the present moment. So, it's not looking ahead in the future where

you can have worry, concern about the unknown, and it's not regretting the past and being in depression or, you know, regret or remorse. It's learning how to enjoy the moment that we have at this time.

And so, when we do this, I think we get a lot of buy-in from our patients because, as we said, it's a four-session stress management protocol. We share with our patients their data over time. So, each time they come in, they can see how they're doing with their breaths per minute, and they can see how they're doing with their saturated oxygen. They can see the changes in their heart rate. And so, the patients really buy into this. And then this protocol lasts over the course of four to six months. So, we have them come in every four to six weeks over the course of four to six months. So, it's not a huge commitment in here, but it is a commitment outside of here because we want them to continue practicing these techniques.

Peter Damiri:

That's interesting and fascinating and that was going to be my follow-up, is - can they perform these breathing techniques and mindfulness at home and continue that through?

Dr. Amy Sullivan:

Yeah, that's a great question. So, you know, what we say is that we can teach you all of these skills inside these four walls, but it doesn't really matter what they do inside of these four walls, except to get the technique because their stress and anxiety occur outside of these four walls. And so, it's very important for them to be able to take what we teach them in here and bring it to the outside world.

And so, part of our protocol is that we want them to come back and report to us in the next four to six weeks how they've utilized these skills and in their stressful situations, because like you said earlier, we all have stress in our lives, but we want to know specifically how they utilize them. And then what's unique about this protocol is that we give them all of these tools, but patients don't always respond to each and every one of them.

So, what we find over the course of time, is that they've really held on to one or two specific relaxation tools or stress management tools that they can utilize. And what's interesting as well is that sometimes one skill will be for one situation. So, say a job meeting or something like that, and another will be for a home situation. So, our patients really learn how to tailor these stress management skills and skills of mindfulness to their everyday life.

Peter Damiri:

Oh, that's excellent. Very, very useful and helpful, I'm sure. So, we touched on this earlier, but I want to go back and moving beyond general everyday stress or anxiety might be a more serious issue of clinical depression, which is a common symptom of MS. So, Dr. Sullivan, can you help our audience understand clinical depression and effective treatment options?

Dr. Amy Sullivan:

Yeah, absolutely. So again, I just want to point out that when we think about depression, depression can be both a symptom of and a reaction to the disease. So, in our MS population, some studies will report that depression occurs in up to 50 to 54% of our patient population. So really, you know, one in every two people that have MS is going to have clinical depression at some point during their disease trajectory.

Now, this is very different from depressed feelings. So, both of them can be impactful, but clinical depression is more severe, and this is something that occurs when these feelings start to interfere with a person's daily functioning, when they're sad, depressed, or irritable more often than not when they see withdrawal. And I think that one of the things that I have noticed is that the patients' caregivers or significant others, family members tend to pick up on this irritability and sadness more than the patients themselves do. So many times, the patients will be referred to us because either their neurologist or the person's family member has said, you know, "I've noticed that my partner is really struggling with irritability. It's like walking around on eggshells." And so, for us it's important for us to evaluate "is this a clinical depression?" So, a more serious depression, or are these depressed symptoms? Either way, we like to put our eyes on them.

It's also important for us to recognize that screening tools can be very, very impactful in picking this up. So, our neurology teams as well as our PT and OT teams use the PHQ-9 before each session and they're able to really flag if somebody is struggling because we're able to graph this out over time and see how somebody's depression has changed over time.

So, it's something that I think is very important for all team members to be involved in. Here at the Mellen Center, we have an interdisciplinary team that works very closely together. But like I shared, really everybody is looking for depression because depression can really impact a person's ability to follow through with treatment, so adherence issues, as well as everyday issues in their own life. So, when we think about depression options oftentimes, we do get our psychiatry team involved or our neurology team involved and utilize some medications if they need it. And then oftentimes we are, up here, able to manage their depression by way of cognitive behavioral therapy or supportive therapy, depending on what the patient needs.

Peter Damiri:

Well, Dr. Rensel and Dr. Sullivan, you've both provided such great information and helpful insights today on this truly fascinating topic of the mind, body, and MS connection. As we wrap up our program, what are some key takeaway messages you want to leave with our audience today? Perhaps, Dr. Rensel, you can start?

Dr. Mary Rensel:

Well, you know, we're all born with one gorgeous brain. And there are things we can do each day to support it. And that is what we put in our mouth, what we eat, how many people we see throughout the day, the people we keep close to us, how we sleep, the medications we take, and how we exercise. So, there are things we can do each day to support that beautiful organ we have up there that makes us, us. So, we want to make sure we're doing everything we can and little things each day really make a difference.

Dr. Amy Sullivan:

Yeah. And for me, one of the most important things is really to normalize and not stigmatize. So, to make sure that we are talking about mental health issues, and so I really appreciate, Peter, that you pulled our team in and are willing to talk about this. Such an important topic because so many people struggle with depression and anxiety, but it is a part of a disease in many instances. And for us, we want to make sure that we're not taking anything else away from the patient. We don't want MS to steal anything else, especially a person's joy. And so just recognizing then as one has stress and an everyday occurrence, we can also provide these skills to patients to try to decrease their stress on a daily basis.

Peter Damiri:

That's great advice from both of you. We really appreciate your time and expertise here today. So, this concludes our podcast, "Better Symptom Management through Wellness." On behalf of MSAA, I would like to thank Doctors Mary Rensel and Amy Sullivan for their excellent presentation on this very important topic, Gradwell House Recording for hosting us today and producing the program, and our funding partners, Biogen, Bristol-Myers Squibb, and Genentech for supporting this podcast, as well as additional programs as part of our MS Awareness Month campaign. Please note this podcast along with additional information on multiple sclerosis, can be found on our website at mysaa.org. Once again, thank you for listening.