Managing Stress with MS to Improve Mental Well-Being

Presented by:

Amy Sullivan, PsyD, ABPP

Marie LeGrand:
Good evening, everyone, and welcome to MSAA's live webinar: Managing Stress with MS to Improve Mental Well-being with Dr. Amy Sullivan. I would like to take this opportunity to thank you for joining us this evening. I'm Marie LeGrand, Associate Vice President of Mission Delivery, Health Equity and Education for MSAA and your host for the program.

Before turning it over to our speaker this evening, I would like to take this opportunity to go over a few of the services that MSAA provides and some housekeeping items. As you may know, MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the entire MS community. Our services include a national helpline, providing English and Spanish services Monday through Friday from 8:30 a.m. to 8 p.m. Eastern.

Additionally, MSAA also provides equipment and cooling products that are designed to improve safety, mobility and also help with heat sensitivity. We also offer an MRI access program to help cover some of the costs for individuals with MS who qualify for assistance. And we provide a variety of educational programs, such as this, that includes webinars and on demand videos, online tools, publications, and digital resources, which includes the ultimate MS Treatment Guide, which is now available on our site. This interactive guide describes and compares 19 FDA approved MS treatments and will help people living with MS make informed decisions and choices. MSAA offers support through community connection to help you stay connected with other members of the MS community.

MSAA has also partnered with Talkspace, which is an online mental health service, to create an innovative pilot program for individuals with MS to receive three months of online therapy at no cost. Talkspace connects people to thousands of dedicated providers via a secure and confidential, HIPAA-compliant platform. To learn more about this and Messiah's programs and services. Please visit our website or you can also give us a call and speak with one of our client services specialists. Or you can also send us an email at MSquestions@mymsaa.org.

As a reminder, throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit your 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 programing and content. A link to the survey will also be included in the chat box.

Please note that MSAA strives to provide useful up to date information on matters of concern to people living with MS and their families. This program is for educational and informational purposes only and does not constitute as medical advice. For diagnosis and treatment options, you are urged to consult your physician. Please speak with your healthcare team if you have any questions or concerns.

What we're covering tonight will, with Dr. Sullivan, will address the impact of stress on MS. She will discuss how acute stressful events and chronic stress can influence and impact MS in the short and long term. And we'll also talk about the reciprocal relationship between stressful life events, MS symptoms, and MS exacerbations. Dr. Sullivan will go over the connection between disease progression and emotional distress and the risk for further progression. Dr. Sullivan will inform us about the prevalence, impacts, and treatments for stress and mood disorders in people living with MS.

Without further ado, I would like to introduce our speaker. Dr. Amy Sullivan is an Associate Professor of Medicine and the Director of Behavioral Medicine and Research at the Mellen Center for MS. She's also the Director of the Neurological Institute Engagement and Well-Being and the Chair of the institute's Diversity Leadership Development. Dr. Sullivan's work has focused on mental health in people with chronic diseases and their family members, as well as physician burnout and diversity empowerment. Her work in academic medicine intersects with teaching, mentoring, programmatic development and strategic initiatives. She is an expert in group dynamics and curriculum development, as well as psychological factors impacting multiple sclerosis. Dr. Sullivan is a member of MSAA's Health Care Advisory Council, and we are so glad that she's able to join us this evening. Welcome, Dr. Sullivan.

Dr. Amy Sullivan:
I am so pleased to be here with you today. Thank you so much for inviting me. So the hardest part of my talk is going to be right now when I try to share my screen. So let's hope that I do this right. Put this in slideshow, from the current slide. And did I share my screen? Have I been able to... Not yet?

Marie LeGrand:
Not yet.

Dr. Amy Sullivan:
Okay. Let's see now. Have I shared...? Okay. And do you see the right screen?

Marie LeGrand:
Yes. Perfect.

Dr. Amy Sullivan:
Wonderful. Well, that was fast for me, so I will walk you guys through how I managed my own stress with that here in a few minutes. So I'm so pleased to be here tonight. There's so much that I would love to cover with you, but in a short period of time, I've picked what I felt were the most impactful things to cover with you all today. So we're going to start by doing an In Vivo patient experience. So if I were with you tonight, I would ask you this in person, but I guess

since we're virtual, I'm going to ask you to think in your head adjectives of how you would describe a person that has MS. So just take a moment and think about that. And I bet some of the adjectives that you describe are invisible symptoms, things like depression, fatigue, anxiety, sleep problems, pain, cognitive symptoms, family, family and partner issues. And I've done this enough times to to realize that most of the time when people are discussing what is the most difficult for them with MS, it is typically their invisible symptoms.

So let's talk a little bit about invisible symptoms. So we put them into five categories. So fatigue, as you all know, probably very well, is a kind of like a 24/7 flu. In the literature, it shows us that about 90% of people with MS experience some sort of fatigue. Cognitive symptoms are present in 40 to 65% of individuals with MS. And they specifically affect processing speed. And what we know also is that depression can affect or exacerbate cognitive symptoms. Pain is prevalent in up to 86%. This is actually my research. 86% of our patients. Sexual dysfunction can be broken down into primary, secondary, and tertiary reasons for sexual dysfunction. And again, our research out of the Mellen Center at Cleveland Clinic shows us that up to 64% of individuals experience sexual dysfunction. And then we're going to spend the majority of our time tonight talking about mood.

So I want to walk you through one of my patients. So, of course, her name has been changed, and that's definitely not her picture. But this is Sarah. She's a 31 year old married mother of two small children. She's a full-time labor and delivery nurse from Pittsburgh, diagnosed with relapsing-remitting MS six months after the birth of her child. She complains of weakness in her left arm daily, vision issues, severe fatigue, incredibly high expectations of herself, significant anxiety and feelings of frustration and inadequacy, racing heart, ruminating negative thoughts, and feelings of hopelessness. She frequently over uses benzos and wine. She's upset that people cannot see her disease, and the expectations of her are that she's a healthy person. So six months into her MS diagnosis, she continues to worry, is having difficulty sleeping, and having adherence issues with her MS treatment plan. So keep her in mind because she's a combination of many of my patients that I've seen over the years.

As we start today, I'd like to I'd like to read to you a poem. This is by Emily Kingsley called “Welcome to Holland.” And this is one of the first ways that I introduce what I do to my patients. So let me read this to you. When you plan your life and meet your significant other, it's like planning a fabulous vacation to Italy. You buy a bunch of guidebooks and you make your wonderful plans. The Colosseum, the Michelangelo David, the gondolas in Venice. You learn some handy phrases in Italian, and it's all very exciting. After months of eager anticipation, the day arrives where you pack your bags and off you go.

Several hours later, the plane lands. The stewardess comes in and says, Welcome to Holland. “Holland?” you say, “What do you mean, Holland? I signed up for Italy. I'm supposed to be in Italy. All of my life I dreamt of going to Italy.” But there's been a change in the flight plans. They landed in Holland and you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place. It's just a different place. So you go and you buy new guidebooks, and you must learn a whole new language, and you'll meet a whole new group of people you would have never met. It's just a different place. It's slower than Italy. Less flashy than Italy.

But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills. Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy. And they're all bragging about what a wonderful time they had there. And for the rest of your life you will say yes, that's where I

was supposed to go, and that's where I had planned to go. But the pain of that will lessen and you will understand that you lost a significant dream. But if you spend your time mourning the fact that you didn't go to Italy, you may never be free to enjoy the very special, lovely things about Holland.

And so when I first start working with my patients, I give them a copy of this poem and remind them that this is... that you are... you had a... you had to go to Holland instead of Italy. And it's a loss of a... it's a loss of your dreams. But there are wonderful things in Holland. And so we work from that framework.

So let's talk a little bit about multiple sclerosis and what I see in my practice. So first, let's talk about chronic disease. Chronic diseases are amongst the most common and costly conditions in the United States. 50% of all adults have at least one chronic disease and 30% of 18 to 44 year olds have a chronic disease. And that's an important statistic because the majority of our patients with MS are diagnosed around that time frame. One in four adults have two or more, and seven of the top ten causes of death are chronic disease. So the overall estimated cost is $2.5 trillion annually.

What's important about depression? Well, there's a very high prevalence of depression in chronic neurological conditions. Depression can contribute to lots of things, but specifically significant morbidity issues, decreases in quality of life, disability, decreases in adherence to treatment, apathy to treatment decisions, cognitive complaints, relationship stress, and suicide. I think what's important that we recognize is that depression is one of the most common symptoms of MS, but it is also one of the most treatable symptoms of MS.

So from a prevalence statistic, what you're looking at here are the blue bars being the MS population and the green bars being the general population. The first bar is depression. And so what you see is that people with MS have about 3 to 4 times as likely chance of developing a depression during some point during their disease trajectory. Anxiety is a little bit more difficult to measure because there's a state and there's a trait. So from my perspective, I think of anxiety as a lot higher than the 36% listed here. But this is what our data is telling us right now. Adjustment disorders are at about 22% of the population, bipolar 13%, and psychotic disorder at about 3%.

So let's talk about the dynamics, the dynamic challenges of chronic illness. So one of the things that we talk frequently about are role reversal and identity shifts. There's everyday life changes with the spouse and the partner, so maybe one spouse has to go back to work. One spouse has to come home from work. A child may have to move into a nursing role. So all of these role reversals. There's often... sorry, there's also emotional reactions that we, that are very difficult. So people can have grief and depression, anxiety, worry, all kinds of different emotional symptoms. And what you see to the right are the stages of grief. And so these are pulled from Kübler-Ross's theory. But what she shows is that there's all these different types of symptoms that one may have as they're going through the stages of grief.

So I want to talk with you a little bit about collaborative medicine, and you'll see on my screen is a picture of an elephant. And the reason I'm sharing this is because I want to share with you a fable called The Blind Men and the Elephant. So many of you may have heard this, but this fable goes that a group of blind men heard that a strange animal called an elephant had been brought to town. But not one of them was aware of its shape and form. Out of curiosity, they said, We want to see this elephant, inspect it by touch and know what it is. So they sought it out and when they found it, they felt it about.

In the case of the first person whose hand landed on the trunk said, This is like a thick snake. For the next one whose hand reached its ear, It said it seemed like it was kind of a fan. As for another person whose hand was on its leg, he said, The elephant is a pillar, like a tree trunk. The blind man who placed his hand upon the side said, No, it's a wall. Another felt its tail and described it as a rope. The last felt its tusk, stating that the elephant was like a smooth spear. The six men fell into this great argument about the nature of the elephant. And they all called each other crazy because they... they knew for themselves what they had held true in their own hands, but because they had never valued each other's opinions, none of them understood the elephant. They began to argue about the elephant and every one of them insisted that they were right.

It looked like they were getting agitated and a wise man was passing by and he saw them. He said, What's the matter? And they said, We can't agree with what this elephant is. Each one of them told what he thought the elephant was. The wise man calmly explained to them, Well, actually, all of you are right. The reason every one of you is telling it differently is because each one of you touched a different part of the elephant. So actually, if you look at the elephant as a whole, it has all of these features for which you've said.

And so the moral of the story and why this is so important to how I practice medicine is that to move forward in an interdisciplinary treatment of MS, so, from my perspective, I'm a psychologist. I touch one part of the human, the neurologist touches another, the physical therapist touches another. But that we all work together and we all value each other's opinion and how to formulate the best care for any individual with MS. So for example, this is our interdisciplinary team at the Cleveland Clinic Mellen Center. The patient is in the middle, surrounded by all of these different types of treatments that we all value and we all know contributes greatly to the success of our patients.

I want to spend a few moments talking about what we see most frequently at the Mellen Center and Behavioral Medicine. So the top three things that we see are anxiety, stress and depression. So let's talk first about anxiety. Anxiety is common, yet it is frequently overlooked. It usually goes hand-in-hand with depression. There are several subtypes of anxiety: generalized anxiety disorder, obsessive compulsive disorder, panic, specific phobia, post-traumatic stress disorder, and adjustment disorder. So there's less attention paid to anxiety in the literature than there is depression.

I want to talk a little bit about adjustment disorder in clinical practice. So adjustment disorder is basically having a normal reaction to a very difficult situation, is the way that I describe it to my patients. So it's the development of anxious or depressed symptoms in response to medical symptoms or disease that occurs within the first three months. It's characterized by marked distress and significant impairment in social or occupational functioning. And there's lots of different ways that we can treat it. No one size fits all, but here's some examples. One of the things that I like to share with my patients is the three by three by three rule. And this is something that over time I've seen with my patients.

So basically it's this - for the first three weeks of the diagnosis, it's all the person is thinking of. Basically, their hands are in front of their face and they can see nothing else. Then the next three months, the person is able to look into the future, into the world, into what they're doing on a daily basis. But they still have this periphery of their MS and it's still kind of overruling everything. And then by the next three months, so that's about six months in, their MS is kind of

way out here and they've kind of adjusted to what they're going through going forward on a normal path.

So let's talk a little bit about stress management. This is my area of research, so I get really excited talking about stress management. But I think first what we need to talk about is that the effects of stress on the body, chronic effects of stress on the body are significant. It affects almost every major organ system, from mood to cardiac system to the immune system to the GI system, the sexual system, our bones and our joints. So the chronic effects of stress on the body are wide, and it's very important that we recognize that and we find ways to manage it.

Let me tell you a little bit about what we do in my clinical practice. So we've been running a study for the past ten years on the outcomes of our stress management protocols. So our stress management protocol is a four session protocol, and we'll share the contents of that in the next slide, but in it, we teach skills of education, cognitive behavioral therapy, breathing skills. It's short term and we treat people every 4 to 6 weeks so that... we want them to practice outside of the office. Because if we can teach you what to do inside the four walls, the four safe walls of therapy, it's not as impactful as them taking it outside into the world, into, you know, where stress is on a daily basis.

So let me share a little bit about what we do. In session one, we do psychoeducation and introduction, and you'll see to the right there's a picture of a pulse oximeter. So we're measuring the biocentrics or the biofeedback of the individual. We're measuring saturated oxygen, we're measuring breath rate and we're measuring heart rate. And our goal is to see these things drop over time when we're teaching these skills so that we know that the person is moving from sympathetic nervous system into response, into parasympathetic nervous system response.

In session two, we review the nervous system and the stress response. So we do a bunch of things about hyperventilation response, Serial 3 breathing, which is something that I will teach you guys at the end of this today. In session three, we're doing visualization and guided imagery and we make this very specific to each individual person. So we help them to write their relaxation script. And then in session four, we're doing mindfulness and distress tolerance.

So let me show you what our results have shown. And I'm so grateful that we're able to present this to share as a platform at our annual conference that is coming up next week. And it was chosen for our platform, which is just a very big honor given that this research, I think, is pretty... it's pretty good. So what we found, we had 124 patients complete at least two sessions. And across time in the stress management program, a net improvement was seen on all measures except for pulse. So we saw a net improvement in anxiety and depression, in saturated oxygen and in breathing rate. And so we're very, very proud of this data that shows us that people are able to kind of come out of their stress response and go into kind of their rest relaxed response.

So let me talk last about depression here. So when we think about depression, we know that it's very common, but it's also very treatable. It's difficult to distinguish between the symptom and the syndromes, and it differs from normal grieving. What we find in the MS population, irritability is greater than tearfulness. So a lot of times on, you know, normal TV or mainstream media, you hear of depression as being kind of tearful. And that's usually not what we see. We see it as more irritability. It's more common in females than in males, but the strength is greater in males. And stressful life event is the strongest predictor of developing a depression. Individuals with chronic disease are at a greater risk than the general population. And as we said earlier, cognitive decline can be linked to depression and anxiety. The suicide rate can be as high as 7.5 times higher than the general population. So if that's something that crosses your mind,

there are many ways to get help. Start by making sure that you tell somebody and you can call the National Suicide Hotline number.

Major depressive disorder is something that we see pretty commonly in our practice. So this is a disorder of depression where you have five or more of the following for every day for at least the past two weeks. So you have to have either sadness or irritability, as I said earlier, and loss of interest in some things that you once enjoyed. Also coming with that is guilt, energy, concentration, loss or gain of appetite, psychomotor agitation, sleep problems or suicidal thoughts. So let's talk about some of the treatment considerations.

So we're going to focus on cognitive behavioral therapy in the next slide, and that's probably the most sought after and most used therapy. It understands the connection, helps people to understand the connection between thoughts and moods. But Kübler-Ross describes the stages of grief and loss. Grief is personal and not linear at all. So somebody could move through these stages, such as meaning their emotions, such as shock, denial, anger, depression, and they could go all over the place. It looks more like a mountain to me than anything linear. They can go forward and backwards and have grief one day and they can have acceptance another day. And really a person's resiliency impacts the movement in this model. That... Kübler-Ross believes in adaptation, that we want people to adapt to where they are today. So think about the poem “Welcome to Holland,” we want people to adapt to the fact that they're now in Italy versus staying in Holland. And so we want people to understand what they can do rather than what they can't do. That's adaptation. So what can I still do rather than what can I no longer do?

Some of the other things that we do are behavioral therapy, which is our stress management protocol. We do group therapy, which is supportive and interpersonal. And in the Mellen Center, we have some really unique support groups. We have a regular general MS support group which meets weekly. We have a young professionals group, we have a caregiver support group. We have a men's MS group, we have a sleep and fatigue group, and we do a shared appointment with neurology and the newly diagnosed patients. So we're highly involved with the neurology group, but also with support groups.

So let's talk a little bit about cognitive behavioral therapy. So cognitive behavioral therapy, otherwise known as CBT, focuses on the relationships between thoughts, emotions and behaviors. Emotions and the interaction of all of these on mood. It's relatively short term in duration, it's about 6 to 16 weeks in duration, and there are different modes of delivery. In fact, we've seen that since COVID, we deliver most of our care via telemedicine nowadays. Now, the person does have to be in the state of Ohio, but you know, most of our patients no longer want to come all the way to Cleveland Clinic. As long as they're in the state of Ohio, they're welcome to come to our groups or to do any form of therapy with us. In cognitive behavioral therapy, we can incorporate relaxation, stress management, breathing, visualization and mindfulness based interventions. And as I shared earlier, it can also be delivered via group format.

So I'm a psychologist, which means I do not prescribe medications, but I do know a lot about them. And I think it's important that I share some of this with you. So there are different pharmacotherapy classes and sometimes treatment with pharmacotherapy is recommended for people with depression. Some of the common antidepressants are listed here and in their specific classes. So we have the SSRIs, which is recommended as the first line of treatment, and then the SNRIs, which is recommended when people have pain, anxiety and depression. And then every once in a while we recommend a benzodiazepine.

So I want to share with you what frequently comes up in my practice. So people are sent to our offices and they frequently say, They're telling me it's all in my head, doc. And so I love to describe to them the Descartes Mind-Body Dualism. So Descartes was a philosopher. He was, he did his work in the 1600s and he was a dualist and believed that the mind exerted control over the brain. And at the mind was distinct from matter. He believed that there were two kinds of substance matter, which is the essential property that is spatially extended, and mind, of which the essential property is that it thinks. He did not believe that the mind and body were connected. He was gravely wrong. His belief was that the mind is nonphysical or that the mind and body are distinctly separate. His theory of Mind Body Dualism separated the mind and the body. Many philosophers have since described arguments against this theory, but it's important to understand their original belief of mind body separation.

Now, what we understand is that the mind and the body are very closely tied. So a person's thoughts, feelings and behaviors are closely tied to their physical symptoms. So let me help you to understand this. So I want you to pretend that earlier today I went to the corner market and bought some lemons, a cutting board and a knife, and I'm going to slice those lemons and they're oozing with juice. They're sticky. And now I'm going to give each of you a piece of the lemon. And please pretend to put that into your mouth and bite down. I want you to notice that the juice is going down the back of your throat. Notice any sensations in your body and in your mouth. Next, I want you to imagine that I had a piece of tinfoil and I'm going to crumple it up, give it to each of you, and I want you to place that your mouth and bite down. What's happening in your body and in your mouth?

And next, if you're like me, you come home and there's Amazon packages all over your door or your garage and you open it up and inside is styrofoam. And what I want you to do is I want you to stick your fingers into the Styrofoam and move the styrofoam around, and notice what's happening in your jaw. And finally, imagine that I have long fingernails and there's a chalkboard behind me. And I want you to imagine that I'm scraping my fingers down the chalkboard. And again, notice what's happening inside of your body. And what's really interesting right now is that I'm probably... well, I know I'm not in the same room with you. There was no physical stimuli that I actually gave you. And I'm probably not even in the same state with you. But yeah, you were probably having a physical reaction to the memory of each of these physical, physical beings.

So what I want to do now is I want to do an experiment with you. I'm a psychologist. You know, I love experiments. And so what we're going to do is I'm going to get out my stopwatch and I'm going to ask you to just count your breath for the next minute. Okay? So get in a comfortable position. And when I tell you to start, just count your breath and keep that in your head. Begin.

Okay, stop. And I want you to keep that number inside of your head because I'm going to give you some data now. Okay, so for anyone who had 12 breaths or higher, that is considered hyperventilation in my field. So the average person breathes two times the norm, causing lower brain oxygen levels. Hyperventilation reduces oxygen delivery to all vital organs in the human body. So what we can see is that normal breathing is where our brains are oxygenated and hyperventilation pulls the oxygenation away from the brain.

So now what I want to do is I want to teach you a skill called diaphragmatic breathing. So remember, at the beginning of the presentation, I said that with my stress management protocol, we teach the skills of breathing. So I'm going to end today by teaching you two skills. One is diaphragmatic breathing. So the diaphragm is the large muscle located between the chest and the abdomen. So it's kind of that U-shape underneath your lungs. Okay. So the benefits of

diaphragmatic breathing are vast. It improves venous return to the heart, leads to improved stamina, expands the lung's air pockets, helping it prevent infection, increases oxygenation in the body, and is an excellent tool to stimulate the relaxation response. So, again, just practicing by placing... I know you can't see my where my hand is right now, but you place your hand underneath your lungs and one hand on your chest and you try to kind of figure out where you're breathing from.

What we're going to end today with is called Circular 3 Breathing. So what Circular 3 Breathing is, is that it's using the diaphragm to do diaphragmatic breathing, but it's also counting. So we start by inhaling for 3 seconds, we hold for 3 seconds, and we exhale for 3 seconds. And I will let you in on a little secret. The hold is where the magic occurs. So for most individuals, what we do is, it's like our breathing pattern looks like this - It's in, out, in, out, in, out. And what we can do to stimulate the relaxation response is to practice placing that hold there. So Circular 3 Breathing is again inhaling slowly for 3 seconds, holding for 3 seconds, and exhaling slowly for 3 seconds.

And so what we're going to do is we're going to practice this together and I'm again going to time you. So we're going to do this for one full minute. And I'm again going to time you. I'm going to walk you through the first cadence, which is the first circle. But my cadence is probably different from yours. So I'm going to let you take over from there. But each circle is considered one breath. So now what I'd like for you to do is in this next minute, I want you to count how many times you performed a circle So that would be one breath. Okay? So get back in that comfortable position. And I want you to think about breathing from the diaphragm. And here's what we're going to do. We're going to start now in... two, three, hold... two, three, out... two, three. And take over in your head.

Okay, stop. If you want to drop into the chat, how many breaths you had per minute, that would be wonderful, because my guess is that most of you were around six breaths per minute. And so this is a way that we can take your breathing or your sympathetic nervous system. So the sympathetic nervous system is that fight or flight response, and we can take it down and turn on the parasympathetic nervous system response, which is the rest or relax. Okay. I'm going to check out the chart here. And I'm hoping that the magic occurred at the hold. So let's see here... alright! I see lots of sixes, fives, six, six, five. I'm right. So the magic occurs at that hold.

The other thing that's really beneficial about the circular breathing is that it gives you something to focus on. So if you want, I'm going to pause on this slide. If you want to take a photo of it with your phone. I think this is a great reminder to us to breathe and to use the circles. So we're focused on the breathing. So it's a distraction technique and it's also a relaxation technique. Shutting down that sympathetic nervous system. Love seeing all these responses. Sixes all over... Whoa, I see a four on there. Amazing. Five, six, seven. I don't see anybody back at the 12 range. So this is wonderful. Yes. So people who practice... So Maria said, "I practice yoga and I'm familiar with this breath." People who practice yoga or wind instrument players or runners or swimmers are very, very good with this type of breathing. So this is one of my favorite breathing techniques. So when I get stressed out, I use this, I use this technique as well. Five, six, fours... Casey got a two. That's amazing. This is amazing. So, trained singers, too. Wonderful, wonderful. Well, thank you all so much for sharing that.

So as I wrap up the didactic portion tonight and go into the questions, I'm going to go on to our summary. So when we think about MS, we know that mental health conditions are highly prevalent, specifically depression, anxiety and stress. But they're also very treatable conditions of MS. Something that I say very frequently is that MS takes so much from us, don't let it steal

your joy. I want you to remember the parable of the blind man and the elephant, blind men and the elephant. And that is that when, you know, like at Cleveland Clinic, we are all medical specialists that work together to understand the entire human being, including the high prevalence of mental health disorder. So it's very important that you have a team of providers that work together for you, and that treatment of mental health disorders is a necessary component of patient care and leads to better outcomes in life.

And finally, I can't forget to mention how powerful the mind and the body are. And so when we did those exercises with the lemons and the aluminum foil and the chalkboard, these are things that probably elicited a physiological response in your body, despite the fact that I'm probably in a different state from you, definitely in a different room, and you definitely didn't have the stimuli in front of you. So the mind and the body are so closely tied. So it's important for us to take care of those. All right. So I am going to stop sharing my screen and I would love to entertain any questions that may have come across.

Marie LeGrand:
All right. Well, thank you so, so very much, Dr. Sullivan, for this wonderful presentation. As Dr. Sullivan mentioned, we will now take some time for questions. Just a reminder to please be sure to type your questions into the chat box. We did have a few that came in prior to tonight's webinar, and we can go ahead and start with this one. “Self advocacy in health care can be stressful. How can I manage this without worsening my MS?

Dr. Amy Sullivan:
Yes. Self advocacy is very, very stressful. So stress impacts MS. We know this from correlational studies. In fact, the father of all MS, when he was first describing MS, described MS as stress affecting this particular patient, that he was first diagnosing. So we’ve know this, you know, for decades, well, more than decades, centuries, actually. We know that stress impacts MS. But self advocacy is so vitally important. So when we're thinking about health care, I think that what we have to recognize is that we are our best advocates. And if it's too stressful for you to do that, bring along a loved one or somebody that you care about to do this because sometimes they can help to self advocate for you. I think utilizing some of the stress techniques that we talked about tonight is important, but also writing down your thoughts before you go into an appointment is important.

Marie LeGrand:
Thank you for sharing and you brought up some really good points. I know for a lot of individuals, it can be stressful, you know, to sit down with your health care team. You know, you had a set of questions you wanted to ask and you've forgotten them. So writing them down is important. And having someone there to advocate on your behalf is also important. So thank you for that. So now how do you combat stress when it's part of everyday life?

Dr. Amy Sullivan:
Right? Stress is a part of everyday life. And we're... certainly I'm not saying that we can get rid of stress, because I'm an expert in this, and you saw me all get stressed out at the very beginning of this presentation. I get stressed out, who has been practicing in this field for 15 years. But what I'm very good at is pulling myself out of that stress. So I'll get very anxious and then I can pull myself right out of that by using some of these techniques. So I think that we have to recognize that we live in a world that is... there’s stress around us. Just turn on the news and you're probably hearing something that you get stressed about. I actually advocate not watching the news, to be honest with you. Your family members, your children, your jobs, the

stock market, whatever... finances, anything can stress you out. It stresses all of us out. But I think what's important is that we allow ourselves to recognize that, yes, we're experiencing stress. But what's more important is that we find ways to cope and manage our stress.

Now, stress management and coping is not a one size fits all type of treatment. I think what we have to do is figure out what works for us. And in fact, we may have lots of different tools in our tool belt for different situations. So one day you may need to, you know, do some breathing techniques. Another day you need to, may need to binge on Netflix. Another day, you may need to call your best friend and process out some of this. Another day, you might be lucky to see your psychologist. I think there are lots of different ways that we can cope with stress, and sometimes it's even important for us to find coping skills for different situations. So stress is always going to be a part of our lives. What's important is that we manage that.

Marie LeGrand:
Thank you. I was actually going to ask if you had a preferred technique over another or if that all depends on the situation, the circumstances.

Dr. Amy Sullivan:
Yeah. So my favorite is definitely the Serial 3 Breathing, which I taught you all. That to me is very important. My second favorite, however, is mindfulness based therapy. So mindfulness based therapy is learning to stay in the present moment. So if we go ahead to the future, it may bring about anxiety or fear. If we go into the past, it may bring about regret, remorse, depression. But if we stay in the present moment, which is basically all we have anyway, right? We learn how to stay grounded. And the best way for us to do that, to stay in the present moment, is to poll on your five senses. So what am I seeing? What am I smelling? What am I hearing, what am I tasting, and what am I feeling? And that's a grounding technique which can pull you into the present moment.

Another one that I love truly is gratitude. So I use this on a very regular basis 3 to 4 times a day. I think to myself or I write or I journal what I'm grateful for, and there's so much to be grateful for. And so those are the ones that I use. But I think, you know, every person has their own skills that are important to them, their own way of responding to stress, their own way of responding or having coping. And so it's important for each person to find their own

Marie LeGrand:
Wonderful. Thank you. How can one deal with the discouragement and stress of decreased ability?

Dr. Amy Sullivan:
Yeah, that's hard. That's hard. So, I hope you remember in the slide we were talking about the kind of grief and acceptance model, and this is the Kübler-Ross theory. So I adjusted this from her theory, which is, you know, kind of losing somebody. So hers is from death and dying, whereas mine is more from acceptance or adaptation to a disease. So I adapted my model of chronic disease from her model of grief, because I think that we still have to grieve what we've lost. So it goes back to kind of that poem of “Welcome to Holland,” you know, you have lost... there's a lot of loss that comes with a chronic disease. Chronic disease changes so many things. It changes what perhaps your future may look like. It changes relationships in the family dynamic. Right? So the stay at home spouse may have to go to work and the person that was working may have to come home or the child may have to move into more of a caregiving role.

There are so many changes that come with a chronic disease. So I think the grieving process is very important.

But what then we have to do is shift to the ability. So what can we still do versus the disability, what we can't do? So I think that's a long process in therapy. You know, that probably takes an individual 3 to 6 months to get through that process. And I think it's really important to have a trained expert who knows how to help the person process the grief while also helping the person then realize that adaptation. So what can they still do and what might their life look like with the adjusting path, not taking away the feelings of sadness, being able to process those, but moving into the gratitude of what we can still do.

Marie LeGrand:
Good point. Does MS cause lower stress threshold?

Dr. Amy Sullivan:
No, I think life causes lower stress threshold. You know, there are theories about just kind of chronic stress and having one thing toppled on top of the other. Top it on top of the other. In fact, there is a theory on post-traumatic stress disorder in the medical population, and that is that, you know, what we used to think about post-traumatic stress disorder is that this happened to veterans who, or soldiers, who are at war, people who are in horrible, traumatic situations across their lives. And that's what we used to think post-traumatic stress disorder was. But now we understand post-traumatic stress disorder also comes with medical diagnoses. And so meaning that there are chronic stressors with medical diagnoses. So going to the doctor's office can really increase your stress, or having to go to the grocery store if there's ambulatory issues or having to take a step back from your job or go on disability or asking somebody to help you, there's chronic stressors all around.

But this also happens in lots of different categories, lots of different life experiences. So somebody with cancer may have the same thing, or somebody who lost a spouse may have chronic stressors that are piled up on top of each other. I just think it's really important to manage our stress with MS, because what we know is that stress greatly increases the likelihood that you'll have more gad-enhancing lesions, T2 lesions. In fact, there's a study by David Moore and his colleagues of 2012 from Neurology, where David Moore and his colleagues looked at individuals who went... so, this is the first class-1 study of stress in MS, and what he did was he put randomized people into two groups. One was a treatment group, and the treatment group was stress management. And the second was just kind of the holding group. So the second group did not get the treatment, the first group did get the treatment. So those that went through the treatment, in the end, they had fewer gad-enhancing lesions and T2 lesions than those that were in the control group. And what's important about that study too, is that those effects did not... didn't stay after the person stopped the stress management techniques. So what's really important here is that we practice stress management on a regular basis. If you remember my research, we describe that we do it every 4 to 6 weeks, and that's because we want people to be practicing that outside of our four walls of therapy. So it's really important that somebody practices stress management on a regular basis.

Marie LeGrand:
Wonderful. So I'm going to pivot a little bit. I wanted to ask a question around individuals who are care partners. There is one question in particular regarding someone who is living with MS but who is also a care partner. Do you have any suggestions for care partners and also for someone who is living with a MS and also a care partner in managing stress?

Dr. Amy Sullivan:
Yeah. Yeah. Well, I think care partners are incredibly special people and I say that because they're putting the needs of somebody else above their own. And this is what almost every care partner does, right? We put the needs of whoever you're caring for above your own. That can be very dangerous, though. So what the literature shows us is that if if the care partner does not take care of themselves, they're more likely to get sick, they are more likely to have chronic disease, they are more likely to have problems at work, so possibly losing some financial gains. So it's incredibly important that the care partner take care of themselves. But it also... the care partner literature also shows us that individuals that are in a caring role have more stress. So it's more, it's vitally important that the person that is in the caregiving role takes care of themselves from both a psychological perspective and a physical perspective.

At Cleveland Clinic and the Mellen Center, we recognized this need, and so we developed a caregiver support group. And it is full every single week that we have it. It's a wonderful resource for people to be able to talk about the stress that's in that role, because sometimes it's very hard for the person in the caregiving role to talk to their partner about how they're feeling because they fear that it might make their partner feel bad. So they have to have an outlet. There has to be someone that they can talk to about the way that they're feeling, because truly it comes down to the airline steward's analogy, which is in the event of an emergency, if the oxygen mask falls, it's important to put on your oxygen mask first before caring or putting on the oxygen mask for the person next to you.

And that's kind of an analogy for life as a caregiver, it is so important to take care of yourself first before anyone else around you. Because if you go down and you get sick, then there's no caring for anybody else. So making sure that we take care of ourselves is just vitally important.

Marie LeGrand:
That it's so true. And that's definitely an analogy that, you know, I think sometimes we need to think about, you know, like when you're, what you said, the flight attendant lets you know, okay, you have to put on your mask before you can put on someone else's mask. So you have to take care of yourself. If you're not able to do that, how can you care for someone else?

Dr. Amy Sullivan:
Yeah, absolutely. Yeah.

Marie LeGrand:
Thank you.

Dr. Amy Sullivan:
Sure.

Marie LeGrand:
So let's talk about treatments. What types of treatments are available for mental health disorder and will this interact with an individual's MS treatments?

Dr. Amy Sullivan:
Mm-hm. So I think first and foremost, let's differentiate between kind of mind-body treatments. So these are the types of things that I do. These are empirically validated treatments like cognitive behavioral therapy, behavioral therapy, interpersonal therapy. So these are non

pharmacological interventions. So most of the time people want to try a non-pharmacological intervention first before they get put on a medication. Sometimes people are very successful with cognitive behavioral therapy or interpersonal therapy or stress management, and then sometimes we need to add a little bit of a pharmacological treatment.

So the pharmacological treatments, as we had mentioned earlier, the most utilized are the SSRIs. So those are a class of medications which are called selective serotonin reuptake inhibitors, SSRIs. The second most utilized class is an SNRI. So these are serotonin norepinephrine reuptake inhibitors, and sometimes those are used for pain, anxiety and mood where the the SSRIs are used mostly for mood issues. There are some interactions very, very rarely. And so it's very important to consult with your neurologist or your advanced practice provider, whoever is prescribing your disease, modifying therapy. But they're very rare interactions. And in fact, there's only a very small handful of interactions that I can think of. Most of them are very, very safe.

Marie LeGrand:
Okay. There were a couple of questions that came in. So one that stood out was, “I just got diagnosed today. How do I handle being positive and not crying in front of my kids? Should I take off work tomorrow?”

Dr. Amy Sullivan:
Yes. The answer is absolutely. You should take off work. You should care for yourself and you should allow yourself the grieving process. And I hope that the poem “Welcome to Holland” stood out to you. You can look that up online. It is a beautiful, beautiful poem. I think what I see very frequently, I see people, you know, day one of their diagnosis, day two of their diagnosis, and they're really, really struggling. Remember that 3x3x3 rule, it's all you think about for the first three weeks of your diagnosis. Really, truly. But what I can share with you over years and years of treatment, I have so many letters to me to prove myself right, is that, you know, 15 years of treating just MS population, and I'm so very, very blessed to treat just people with MS, but 15 years of data shows me that individuals over time are really grateful that they were diagnosed with a chronic disease.

In fact, I myself have had my own medical issues, and I can tell you today that I am very grateful that I've had them because it changes you, it changes your perspective and it changes you... It changes the way that you think about the world. And I have 15 years of patients that letters after letters after letters who will tell me that, you know, of course, in their first year, they're not happy about this diagnosis. And it's very scary to them. But, you know, year three, year four, year five, they're writing me, telling me, you're right. This is something that changes my life for the better. I look at the world differently and it's a beautiful, you know... that poem “Welcome to Holland,” Holland is a beautiful place.

Marie LeGrand:
That was wonderful. Thank you so much for that. We'll take one last question. And this one has to do with sleeping problems. Are there any suggestions to help with sleep problems?

Dr. Amy Sullivan:
Oh, gosh, there's so many, I think, yeah, so first thing we have to understand about sleep is that sleep is a restorative process. So you have to expend the energy in order to need the sleep. So the sleep is restorative. So what I typically find with some of my MS patients is they may be moving around less. And so they're not expending as much energy, still... in fact, I worked with

a patient on this today, still expecting to sleep the same amount. Also, as we age, we need less sleep. And so I think what we typically see with our most patients is that they're needing less sleep because they're possibly aging and needing less sleep because they're moving around less often. And so it's important that we just, we know that up front.

Second, I think there are sleep hygiene rules that I like to help our patients with. So those would be things like no electronics before bed, within an hour before bed. If somebody, you know, likes to eat late at night, that's probably not the best thing to do because eating revs up your metabolism and you have to digest your food. Drinking even before bed is not a great idea because then you have to get up and go to the bathroom. So there's lots of different sleep problems. It's hard to know exactly what this person is talking about. Are they having insomnia? Are they having difficulty staying asleep, difficulty falling asleep, difficulty initiating? It's difficult to know specifically what that person is asking for, but there are sleep hygiene things that we can certainly teach people. Yeah.

Marie LeGrand:
Okay. That's good to know. I know that's one of the, you know, many things that I've heard from individuals, you know, especially when dealing with stress and not knowing how to handle it and having things running through your mind constantly and not necessarily knowing, you know, who it is that you can speak with. Or who you can turn to regarding that.

Dr. Amy Sullivan:
Yeah. Absolutely. And I'm just going to answer this last question that I see on the screen that says, “What can we do to keep doing some things we love?” I think this goes back to finding things that you can still do. Don't let MS steal your joy. So figuring out what you can still do, if you can still hike, hike. If you can still pet your dog, pet your dog. But figuring out what you can do versus focusing on what you can't do, I think is incredibly important. When we start focusing on what MS has taken from us, it just brings us into a very negative place. And like I said earlier, I prefer to stay in gratitude. So what can we still do and where can your new path lead you and what are you grateful for? So focusing on those types of things.

Marie LeGrand:
That is wonderful. And I think that is such a great way to end the program this evening. Thank you for those last words. Dr. Sullivan, once again, this was an amazing and insightful program and we can see from the chat that it was extremely engaging and, you know, people had a lot of questions and I wish we had more time, as always, to get through all of the questions. But we're at the the last of the hour. So this concludes the webcast. Tonight's webinar was recorded and will be made available on our website. Please visit MSAA's calendar of events for our upcoming webinars and events. And on behalf of MSAA, once again, we'd like to thank you, Dr. Sullivan, for taking the time and providing us with the tools needed to better understand the impact of stress on MS.

And so our wonderful audience, we would like to thank you for joining us this evening. Please do take a few minutes to complete the brief survey, which will appear on your screen momentarily and know that we are thinking of the entire MS community and hope that your families continue to stay safe. Thank you and have a good evening.

Dr. Amy Sullivan:
Thank you. Bye bye.