Multiple Sclerosis Association of America

Webinar Transcript

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Presenter: **Amy Sullivan, PsyD, ABPP**

MSAA Host: **Peter Damiri**

Peter Damiri: Hello, and welcome to the multiple sclerosis association of America's live webinar, "Managing Depression and Anxiety in MS." I am Peter Damiri, Senior Director of Content Development for MSAA and your host for tonight's program. On behalf of MSAA and our guest presenter, Dr. Amy Sullivan, we thank you so much for joining us tonight and hope everyone is doing well and staying safe. As you may have read in our recent announcements, March is recognized as MS Awareness Month and MSAA's theme this year is Improving Mental Health and Wellness. A very important yet often overlooked topic in MS care, especially as we continue through this pandemic. Tonight's program continues our series of digital educational events on this topic, which also includes a podcast with Dr. Sullivan on "Caring for the Care Partner," an archived webinar on "Finding Purpose in Life," presented by Dr. Adam Kaplin and much more. All of this great content can be found on our dedicated MS Awareness hub at MyMSAA.org.

Also, tonight's program continues our new virtual display hall, which is mentioned in the chat box with the link. This online resource details some of the products and patient assistance services offered by our selection of sponsors. MSAA would like to thank Biogen, Genentech, and Sanofi Genzyme for taking part in this new virtual opportunity.

As you may know, MSAA is a national non-profit organization dedicated to improving lives today for the MS community. Listed here are just some of our many free programs, including our cooling equipment, and MRI programs, along with our COVID-19 and MS Pathfinder tool, which provides ongoing updates on the coronavirus and the recently approved vaccines.

Also, please know, MSAA has extended our Helpline hours to 8:00 PM Eastern between Mondays and Thursdays. To learn more, please visit MyMSAA.org, or give us a call at 1-800-532-7667. And finally, please know tonight's webinar will be archived to our website within a few days. For the Q & A session, please type your questions into the chat box on the screen, and we'll address them at the end of the presentation. Also, if you're having any technical issues, please type your concerns into the chat box as well.

At this time, I am extremely honored to introduce our special guest presenter, Dr. Amy Sullivan. Dr. Sullivan is a board-certified health psychologist and Director of Behavioral Medicine, Research and Training at the Cleveland Clinic's Mellen Center for MS. She is passionate about physician self-care, burnout, diversity in leadership, and psychological health. Her clinical interests focus on individual, family, and group work with patients and family members affected by multiple sclerosis. Dr. Sullivan, thank you so much for being here tonight and helping us learn more about this very important topic.

Dr. Amy Sullivan: I'm so thrilled to be here tonight, Peter, and with all of you on the phone today. It's such a strange world that we're in, and I think we're all starting to get used to these Zoom-type of meetings. And so, I just appreciate the opportunity to be here today. So, today I am going to be talking with you about mental health, and this is definitely my passion. I've spent the last 10 years of my career in the Mellen Center for MS at Cleveland Clinic. And my clinical specialty is solely focused on MS care, specifically caregiving, depression and anxiety for and adjustment disorder for the MS patient.

So, if I were with you in person today, I would love to do this next experience with you. But I'm not. So, what I'm going to have you do is I'm going to have you look at this person with MS. And in your head I just want you to think about who this person is, describe this person. So, this person has MS. What are some of the adjectives that you would put onto this person? How does this person feel? And just take a moment and think about that in your head.

So, again, if I were with you in person, you would be shouting out to me in a room. And many of the things that you would shout out would be things that are invisible symptoms. So, possibly the person experiences depression, or anxiety, possibly fatigue, maybe some relationship issues, maybe some cognitive symptoms, maybe some pain, insomnia, maybe even sexual dysfunction. So, when we think about invisible symptoms, I think it's important to point out that sometimes these are the most debilitating symptoms of a chronic disease, in particular, MS.

So, let me give you some statistics here. So, with regards to fatigue, the way that it's been described to me over the past 10 years in my clinical practice is the MS patient will say, it's like having a 24/7 flu. Constant fatigue. The literature tells us that about 90% of our patients have some form of fatigue. When it comes to cognitive symptoms or cognitive complaints, between 40 and 65% of our MS patients will experience some sort of cognitive complaint. This specifically effects processing speed, and what we know about the cognitive symptoms is that depression may exacerbate these symptoms. So, again, very important to pay attention to symptoms of depression and managing them.

Pain is prevalent in up to 86% of our patient population, and sexual dysfunction occurs in up to 64% of our patient population. So, things that are the most oftentimes the most debilitating are these invisible symptoms.

I'm going to introduce you to a patient of mine. Of course, all identifying information has been changed. And actually, this is a collaboration of several different patients. So, I'm going to

introduce you to Sarah. Sarah is a typical patient that would come to my practice. She's 31 years old, married, she's the mother of two small children. She's a full-time labor and delivery nurse from Pittsburgh. She was diagnosed with relapsing remitting MS six months after the birth of her first child. Sarah described the weakness in her left arm daily. She has vision issue, describes severe fatigue, has incredibly high expectations of herself, has significant anxiety and feelings of frustrations and inadequacy. She describes physiological symptoms of anxiety, such as racing heart, and she describes some cognitive symptoms of anxiety, such as ruminating negative thoughts and feelings of hopelessness.

To cope with these anxious feelings and these feelings of inadequacy she frequently overuses benzodiazepines and wine. Sarah's main complaint to me is that she's upset that people cannot see her disease. So, a lot of invisible symptoms and people expect that she acts like a healthy person, quote, unquote. Six months into her MS diagnosis she continues to have worry and anxiety, and is having difficulty sleeping and having adherence issues with her treatment plan.

This is a very typical patient that we would see in the Mellen Center. I want to share with you a poem that was written by Emily Kingsley. And I think you're going to understand why I share this poem with you, but this may have been a similar experience for you when you were newly diagnosed. So here's the poem. 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 make your wonderful plan to the Coliseum and Michelangelo's David, the gondolas in Venice. You learn some handy phrases in Italian, and it is all very exciting. After months of eager anticipation, the day arrives where you packed 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 plan. They landed in Holland and therefore, you must stay. The important thing is that they haven't taken you to a

horrible, disgusting place. It's just a different place. So you go, and you buy a new guidebook. And you must learn a whole new language and you'll have to 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 Rembrandt.

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, yeah, that's where I was supposed to go. And what I had planned to do, and the pain of that will lessen. But you 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, very lovely things about Holland.

And again, this was written by Emily Kingsley and it was written in response to the fact that she had a developmentally disabled child. And so, she had planned all of her life, what she thought her life would look like and it changed. And she learned how to see the very beautiful things about the life that she now had versus the life that she had expected. And I imagine that this is very similar from a very similar experience from what many of you have had as you've been diagnosed with MS. Adjusting the expectations and adjusting the life that perhaps you're mourning.

So, let's talk a little bit about the patient experience. So, chronic disease is amongst the most common and costly conditions in the United States. These are statistics from the CDC, which reports at about 50% of all adults have at least one chronic disease, 30% of 18-to-44-year-olds have a chronic disease. So, the young population right now, what we know about MS is it's usually diagnosed around that timeframe as well.

One in four adults have two or more chronic diseases. And seven of the top 10 causes of death are chronic disease. The overall estimated cost is $2.5 trillion annually. And one of the things that we know is that wellness and preventative medicine can decrease these numbers. And one of the

other things we know is chronic disease is very uncertain, as I'm sure you can all address with your own MS.

So, let's talk about depression. Depression is highly prevalent in chronic neurological conditions, such as multiple sclerosis. It may contribute to significant morbidity issues, decreases in quality of life, disability, decreases in adherence to treatment. When we're thinking about treatment, we have to think about treatment from a holistic standpoint. So, this is not just decreases in adherence to DMTs. This is decreases to adherence of all treatments, of speech therapy, psychological therapy, PT, OT, et cetera. Can also cause apathy in treatment decisions. So, slower treatment decisions, cognitive complaints, relationships, stress, and unfortunately, suicide. Depression is one of the most common symptoms of MS, but it's also one of the most treatable symptoms of MS.

So, I wanted to share with you some of the prevalence rates of MS versus the general population. So, when you're looking at this graph, the left-hand bar graph, in each of the dark blue, is the MS population. And then that teal to the right is the general population. And so, what's important that you see here is that the MS population has prevalence rates of depression at about three to four times that of the general population. Anxiety you see is elevated. Anxiety is a very difficult thing to measure. One of the reasons is because it's difficult to tell if a person is experiencing a state of anxiety or a trait of anxiety. So, are they experiencing a moment of anxiety, or is this more of an anxious personality?

Adjustment disorder, as you can tell, about 10 times the amount in the MS population. Bipolar disorder, we have 13 to 4.5%. And then psychotic disorders about two times the amount. So, important for you to just kind of put this in your head so that you know how prevalent mood disorders are in the MS population.

When we look at chronic disease challenges, I think it's important that we always remember that invisible symptoms are so very, very difficult to deal with. As we had said earlier, many with the

case of Sarah, many people look at somebody with a chronic disease with multiple sclerosis, and they say that you look fine. You're not losing your hair. You don't have a cast on, you're not walking with crutches, et cetera, something that they could see. Many of your symptoms are very, very invisible symptoms. The challenge is also that you have to make difficult treatment decisions. So, some of the DMTs come with difficult side effects and you have to weigh the risks and the benefits. You have to decide if you want to make difficult disclosure decisions. So, for example, if you're newly dating somebody do you disclose that you have MS? Do you disclose to your boss that you have MS?

And then, if you choose to disclose how do you deal with the reactions of others? I think it's also important to learn how to communicate limitations and needs. It's very important that you're able to say that, you know, if you're having a day where you're not feeling well, having extreme fatigue and you don't want to go on that two-mile walk, that you're able to say, I'm just not in the mood for that. Or if you need some help with something you say to your significant other family member or friend that you might need some help, and that's very difficult to do. And then, it's important to plan for uncertainty. So, financial planning, estate planning, disability, insurance policies, SSDI.

When we think about the dynamic challenges of the chronic illness, one of the first things that comes to my mind is what we see in families, which is this role reversal or this identity shift. And what that can look like is an everyday - their everyday life changes. So, a spouse that was one at the office is now coming home and staying at home. A child who, you know, was a 9-year-old and having, you know, just playing outside all the time is now having expectations of helping at home. This can also look like emotional reactivity. So, it can look like a bunch of different emotions.

So, what you see there to the right are the stages of grief from Kubler Ross. And so, one of the things that I want to point out is that the stages of grief are not linear. They - each person kind of goes into the stages of grief at their own time and with their own emotions. And so, at one point, somebody could experience depression, and then they could be angry, and then they could deny

that this is happening, and then they go back to depression. It's not a linear model. And so, there are a number of different emotional side effects or emotional symptoms that one may experience. And this is important to put those all out there so that you're aware of them.

So, let's look a little at collaborative medicine and why it's important to have emotional support involved with your overall MS care. And so, I'm going to start by sharing with you the parable of the blind man and the elephant. And this is an Indian fable. That's how the six blind men that come across different parts of an elephant in their life's journey. Each man creates his own version of reality from his own limited experience and perspective. And so, let me share it with you. There were a group of blind men from India, and they heard that a strange animal called an elephant had been brought to the town, but none of them were aware of its shape or form. Out of curiosity, they said, we must inspect and know it by touch of which we're capable.

So, they sought it out. And when they found it, they felt it. In the case of the first blind man, his hand landed on the trunk. He said, this thing is like a thick snake. For another one whose hand reached its ear. He said, it's like a fan. As for another person whose hand was upon its leg. Said the elephant is a pillar-like tree trunk, the blind man who placed his hand upon its side said, no, the elephant is definitely a wall. Another that felt its tail describes it as a rope. And the last felt its tusk. Stating that the elephant is hard, smooth and therefore must be a spear.

The six men fall into this great argument about the nature of the elephant. And they all called each other crazy because they've each held the true elephant in their own hands. But because they never valued each other's opinion, no one ever understood that the elephant that they began to argue about in fact was right. It looked as though they were getting agitated. A wise man was passing by and he saw this.

He stopped and asked them, what is the matter men? They said, we cannot agree to what the elephant is like each one of them told what he thought the elephant was like. The wise man, calmly

explained to them when in fact all of you are right. The reason every one of you is telling it so differently is because each of you touch the different parts of the elephant. So, actually, if you look at the elephant as a whole it has all of those features with what you said, you just need to put it together.

I love this because to me, this speaks about collaborative medicine. So what I take away from this is that to move forward in collaborative medicine or interdisciplinary medicine we need to value the perspective of others while holding true to what we understand ourselves. So, from my perspective, I understand the brain and mental health and emotions very, very, well. But I work closely with nursing, with primary care, with neurology, with emergency medicine, with PT, OT, and all of us bring our own unique biocentric approach to the patients and to the medical team. And I think it's important that we learn how to hear each other's perspectives.

So, this is a picture of our interdisciplinary team at the Mellen Center. The patient is always at the center of the team and the patient is touched by all different disciplines and we respect and we honor each of the disciplines because each one of those disciplines plays an important role in the patient care. I also want to explain to you how important worldview is. So worldview, I think, is a very important concept to understand.

Worldview is basically the fact that each person comes into any experience with their own existential, fundamental cognitive orientation of the world, a microcosm, a culture, a group of people, et cetera. Worldview is likely very diverse in nature. Thus, in interactions with others, we ask that each person is open to evaluating their themes, their values, their emotions, and cognition in a non-judgmental way. We ask that they're open to hearing other people's processes and understanding where others come from. And this kind of goes back to the parable of the blind man and the elephant where we all see the world through our own lens and our own experiences. So, with the bio-psycho-social model of care, which is what I just showed you. It helps us to guide the

patient and see the patient as a complete picture - honoring what each specialty brings in. We're all biological, psychosocial creatures and all of this needs to be addressed.

When I think about my practice, I think about the top three things why one would come to my practice. And like I said, I've been in this field for quite some time. And so, these are the top three things that we deal with: anxiety, stress, and depression.

So, let's talk a little bit about anxiety. Anxiety is common, but it's frequently overlooked. What we know that anxiety usually comes hand-in-hand with depression. So, when somebody has depression, we should always be looking for anxiety as well. There are several subtypes of anxiety, generalized anxiety disorder, obsessive compulsive disorder, panic disorders, specific phobias, PTSD, and adjustment reaction. There's less attention paid to anxiety in the literature than there is depression.

So, adjustment disorder is the development of anxious or depressed symptoms in response to medical symptoms or disease that occurs within three months. Adjustment disorder is characterized by marked distress and significant impairment in social or occupational functioning. And the treatment is that we normalize, we empathize, we provide education, adjustment management techniques, and at times medication.

I also think that the three-by-three-by-three rule is incredibly important in describing adjustment disorder. And so, what that is, is if you could see me right now I have my hands up in front of my face as blinders. So, the first three weeks of the diagnosis, the MS disease, it's kind of right there in front of your face. It's like the only thing that you think of. And then, by three months it kind of moves out to the periphery. You can still see it. It's still a very prevalent thought. You're still able to - you're still seeing it very often, but you're also starting to think about other things. And then, by three years, as you can see, my hands are kind of by my ears right now, because what that means

is it's still there, still something that, you know, is there, you know you have it, but it's not the thing that you think about all of the time.

So, I love the three-by-three-by-three rule because it helps you to understand the time it takes to adjust to a new diagnosis or perhaps functional decline or a shift in diagnosis, whatever the change may be. So, let's talk about stress management.

One of the things that I can't leave out is the fact that we are in a pandemic. And what you'll hear me say over and over and over again is we're not only in a physical health pandemic, but we are in a mental health crisis right now. I've never seen my practice as full. I've never seen the severity of symptoms like I'm seeing right now. And for the past 12 months, actually, it's just been this mental health crisis that we're in. And so, I wanted to spend a few moments just to talk about what that looks like. So, when we think about our emotional health during the pandemic, there are waves of emotion and there's an uncertainty. There's an influx of information. Sometimes we don't know what's right information, what's correct information, and what's incorrect information. There's more social distancing than ever to keep us safe, but that certainly creates isolation, loneliness - can create some anxiety and depression. And for many there's economic uncertainty, this all leads to decreases in wellbeing and psychological health and increases in uncertainty, depression, anxiety, and stress.

Speaking of stress, let's look at the effects of stress on the body. And I really love this slide because it shows you that stress does not only affect you from an emotional level, but stress plays an important role in all of the major organ functions in the body, organ systems in the body. So, everything from the brain to the cardiac system, to the immune system, to the GI system, skeletal system, to your bones and your joints, stress plays a major role on our body. So, it is not just the mind. There is a mind-body connection, which we will talk about later in this presentation.

So, what do we do at Mellen Center for stress management? Well, we've developed a four-session stress management protocol where we teach skills of education, cognitive behavioral therapy, and breathing skills. It's very short term. In fact, our data, our outcomes data shows that within three sessions, our patients are actually seeing significant decreases in anxiety and depression. And the most important thing is that we do this every four to six weeks. We spread our sessions every four to six weeks because we want to teach our patients the skill. And of course, if they do it perfectly in our office, it doesn't matter if they can't do it perfectly outside of the office, right? Or even some perfectly outside of the office. So, what's important for me is that I teach them the skills and that they then apply them outside of the office. And then they come back with data in terms of how they were able to utilize their stress management skills.

And finally, let's look at depression. So, when we think about depression, what we know that it's one of the most common symptoms of MS, but it's treatable. It's often times difficult to distinguish between symptoms of depression and symptoms of multiple sclerosis. And our next slide will talk a little bit about that. It does differ from normal grieving. Symptoms are usually more irritability than tearfulness, and I've seen that over and over and over again in our MS practice. Oftentimes even the care partner will say to us, you know, it's like walking on eggshells when I'm with my partner - a lot of irritability and very infrequently is there cheerfulness. It's more common in females than males, but the strength is greater in males. We also know that stressful life events are the strongest predictor to developing a depression. So, for example, an MS diagnosis, an MS progression and then, there are a ton of other life stressors that can occur there.

We know that individuals with chronic disease, specifically MS, are at greater risk than the general population. And remember that prevalence slide that I showed you earlier, which shows that depression is about three to four times as great in the MS population than in the general population. We know that cognitive decline or cognitive complaints can be linked to depression and anxiety and depression and anxiety may exacerbate cognitive complaints. Depression is also a predictor

for slower processing speed. And this statistic is the one that really shakes me the most. And that is that the suicide rate is 7.5 times higher than in the general population.

These are the symptoms that one must have in order to be diagnosed with major depressive disorder. So, I guess what I'll say before we cover this is if you remember that prevalence slide. So, it showed that up to 54% of patients may have a depression. These are people who are diagnosed with this disorder that you're looking at here on the screen. There are others who have symptoms of depression that are not included in that prevalence data because that's the diagnosable disorder. Okay. So, what you'll see is that it takes a lot to be diagnosed with major depressive disorder. So, what we're looking at here is that one must have at least five or more of the following symptoms nearly every day for at least two weeks. One of which must be sadness or what we describe as irritability in the population or loss of interest in things that they once enjoyed.

Also, we see symptoms of guilt. We see loss of energy. We see loss of concentration or cognitive complaints, loss or increase of appetite, psychomotor agitation, or retardation. We see sleep problems and suicide. Again, you all know that many of the symptoms overlap with some of these and that's why it's important to have a behavioral health clinician or mental health clinician be able to confirm or deny that a person has major depressive disorder and get them the right treatment if they do. So, here are some treatment decisions. So, first and foremost, we use a therapy called cognitive behavioral therapy. We'll focus more on that in the next slide, but I just wanted to mention it here, that it is understanding the connection between thoughts and mood. We've talked about Kubler-Ross's theory already when I showed you the diagram of the different emotions.

So, this is the grief acceptance. And in my practice we like to call it the adaptation model. I don't necessarily agree with acceptance. I think people get to a point where they say, I guess I just accepted it. That's very passive to me. I would like for people to get to a point where they realize that not only do they accept the fact that they have multiple sclerosis and they may have some limitations, but that they adapt their life to still live the best life that they can. We do behavioral

therapy, which is, are some of the things that I was sharing with you about the stress management protocol. So, different types of breathing skills and I'll do one of those with you later in the session. We do a group therapy. So, at the Mellen Center we're very fortunate to have a large behavioral medicine team. And we do several different groups. We have six actually in the Mellen Center. We have a young professionals group, a caregiver support group, a men's MS group, an MS support group, a neurocognitive group, a sleep and fatigue group. And then we also do several shared medical appointments with our neurology team for the newly diagnosed patients.

There's also a lot of community support such as MSAA, Facebook groups, et cetera. I thought that it was important to spend a little bit of time looking at cognitive behavioral therapy. So, cognitive behavioral therapy focuses on the relationship between thoughts, emotions, and behaviors and how emotions interact with all and help to formulate the mood. So, it's relatively short in duration, about six to 16 weeks.

There are different modes of delivery and can be delivered via telemedicine, which we've really learned this year how to use pretty effectively, and for that, I'm very, very, grateful. We can incorporate relaxation, stress management, breathing, visualization, and mindfulness-based interventions, and it can also be delivered in group format. So, it's a highly effective form of psychotherapy. And as I shared with you earlier, our outcomes show that with only three sessions people are experiencing decreases, significant decreases, in both depression and anxiety.

So I will spend just a few moments looking at pharmacotherapy classes. So, the first line would be the SSRIs for the first line of treatment for anxiety and depression. Important to make sure that your doctors know everything that you're taking because there can be potential medication interactions and then some side effects. The second line are the SNRIs. So, these are typically recommended for people who have pain and depression and anxiety. And then, the third line would be benzodiazepines. And they're not used as often because they can be become addictive and habit forming.

I'm going to give you a coping with stress, my fast five. So first, wellness is imperative. When we think about wellness, we're looking at all of the pillars of wellness, right? We're looking at activity, we're looking at healthy eating, we're looking at rest, recharge, recover. So, maintaining those healthy diets, moving, having a routine, incorporating spirituality, if that's important to you, having a wellbeing approach, and sleep. Number two is taking a break from media. So, disconnecting from media. Staying informed from a trusted source. So, having one 30-minute block in the morning and one 30-minute block in the afternoon or PM, and that's about it. We really have to protect our children and our elderly from incorrect information. And we have to provide age-appropriate information to our children. Rest and recharge is so very, very, important. So, this is about shutting down that sympathetic nervous system or that fight or flight response and turning on that rest, recharge, recover. So, in order to do this, we need to sleep, we need to rest. So, therefore, it's important not to watch news outlets within an hour timeframe of going to bed if they rev you up.

Limit stimulants, alcohol, and nicotine before bed. In some cases limit exercise as well, because it can stimulate you. It's important to stay on your normal sleep-wake cycle. So, on the weekends, you know, not varying too much from that. I always recommend worry journals to people who can't shut their mind down when they lay down for bed. Have you ever noticed that when you're lying on the couch and you're watching a movie with your family, it's so easy to conk out, but when you go up into your bedroom and there's nothing on there's all it is are thoughts that are playing through your head. It can become very difficult to fall asleep. And so, in this case, we recommend a worry journal. So, then, perhaps it's important to come up with a wind-down routine. So, maybe a bath, a cup of tea, some prayer, some meditation - whatever that looks like for you.

Number four is connecting with others. So, reaching out to family, friends, and colleagues. One of the best ways to overcome burnout is to connect with others, particularly connect with those we know that are isolated. Perhaps sending a card, setting up Facetime, Skype, et cetera. Just becoming creative and connecting safely.

And then, finally, doing some stress management techniques. There are lots of them and it's not a one size fits all. So, breathing techniques, visualization, mindfulness, but what's important is that you seek mental health help if you notice that worries, anxiety, isolation, et cetera, are becoming unmanageable. So, I get this very often. People come into my office and they say, so doc, are you telling me this is all in my head? So, let me tell you a little bit about Descartes and mind-body dualism. So, Descartes believed that there was a disconnect between the mind and the body. His belief was that the mind is non-physical and that the body, which is physical, is distinctly separate. His theory of mind-body dualism separated the mind and the body, and many philosophers have since described arguments against this theory. But it's important to understand the original belief of the mind-body separation in order to understand the mind-body connection, which is our understanding now. This understands that a person's thoughts, feelings, and behaviors relate to those physical symptoms. So, let me show you an experiment where maybe you'll buy into this.

So, I want you to imagine that prior to me coming here today that we're all in the same room. And then I have a cutting board and it has some lemons and I have a very sharp knife. And I'm just going to slice those lemons and they're oozing with juice. And I'm going to hand each of you a piece of my lemon. And what I want you to do is I want you to take that lemon, put it in your mouth and bite down on it. Notice what's happening in your body. If there's a physiological reaction. Next, imagine that I have a roll of aluminum foil. So, I'm going to tear a piece of aluminum foil, and I'm going to give it to each of you. And I'm going to ask you to put your fingers in it, crumple it up, and again, put it in your mouth and bite down in it. Just again, notice what's happening to your body.

Next, if you're like me, you come home and there's all these Amazon packages lined up at your door and inside of your Amazon packages are usually Styrofoam. And so, what I want you to do is I want you to take that Styrofoam, break it apart, stick your fingers in there. Probably screeching some when you stick your fingers in there. I want you take it again, put it in your mouth. Finally,

imagine that there's a chalk board in the room and I'm standing right in front of you with this chalkboard. And I scraped my nails down that chalkboard.

What I am imagining, and again, I'm not in the same room with you. I'm probably not even in the same state with you. You can't see me. But what has happened is that without you even experiencing the stimuli, without even seeing the stimuli, you're likely responding to that stimuli in a physiological manner based on a memory, right? So, you know what it feels like to put a lemon in your mouth and your body probably is salivating from that. You're probably cringing with the thought of the aluminum foil and the Styrofoam. And you're probably tensing up with the thought of my nails going down the chalkboard. All of this is the mind-body connection. We respond physically to a memory or an experience that we once had.

Does this actually work? So, now, what I'd like to do is I would like for you to engage in this breathing exercise with me. So, what I'm going to have you do is I'm going to have you just get in a comfortable position and just breathe. So, I'm going to time you for one minute and I would for you just to count your breaths and breathe. Okay. Ready? Begin. Okay, stop.

So, I want you to think about a couple of things. First and foremost, what were the thoughts that were going through your head? Were you thinking this is the longest minute ever? When is this going to end? Or are you thinking this is actually really nice to have a minute to focus on myself? Neither of which are the right thoughts. It just wants you to be honest with what you're thinking. The second thing I want to know is - it's so hard not having an interactive audience - but the second thing I want to know is if you had greater than six breaths per minute.

Okay. So, my goal is for people to have six breaths per minute or less. And I guess I'll take up to 12, because of this. What we know about hyperventilation and the field of psychology is breathing more than 12 breaths per minute. So, the average person breathes two times the normal level, which causes lower brain oxygen levels. Hyperventilation reduces oxygen delivery to all vital organs

in the body. And what you're seeing here is that it reduces oxygenation to the brain as well, which can cause several problems, right? It can cause concentration difficulties, cognitive difficulties, stress, anxiety, et cetera. So, what I'm going to do now is I'm going to talk to you a little bit about diaphragmatic breathing. So, diaphragmatic breathing. So, the diaphragm is this large muscle located between the chest and the abdomen. And there's a lot of lymph nodes located just below the diaphragm.

So, that green upside down U is the diaphragm. There are a lot of benefits to diaphragmatic breathing. It improves the venous return to the heart. It leads to improve stamina in both disease and athletic activity. By expanding the lungs' air pockets it improves the flow of blood and lymph. It helps prevent infection of the lung and other tissues. It increases oxygenation in the body, and it's an excellent tool to stimulate the relaxation response that results in less tension in an overall sense of wellbeing. So, diaphragmatic breathing is really learning how to pull that breath from our chest, which is where most of us breathe, into the diaphragm. People who are really good at diaphragmatic breathing are people who have played wind instruments, are in choir or sing, are endurance athletes, are people who practice yoga on a regular basis or mindfulness on a regular basis.

So, what I'm going to do is teach you how to get six breaths or less in one minute. So, this is a way of breathing that I created called serial-three breathing, or circular breathing. And what it is, is we start on the inhale, but we do a slow, steady three-second breath in. So do one, two, three, and then you hold your breath for three seconds. One, two, three, and then you exhale for three seconds. It's one, two, three. So, we're again, going to practice this skill that you can take with you. And this is the last thing that we'll do today, before we take questions. But I wanted to leave you with some tools of relaxation and stress management that you could use outside of here. So, again, I'm going to time you for one minute, and I want you to follow this pattern. So, I will walk you through the first cadence. And then I want you to go through your own cadence as mine may be difficult more different than yours. Or at different speeds than yours. And I want you to count, so

your nine-second breath, all the inhale, the whole exhale would be one breath. Okay. So, we're going to start now. In - two, three. Hold - two, three. Out – two, three. Go ahead and take over.

Okay, stop. So, in my experience, you probably were able to focus more on this breath because you didn't have the ability to distract with your thoughts because you're focused on the continuation or the circular-three breathing. And so, that's a wonderful thing when we can be mindful and in the moment. So, this is a form of mindfulness meditation. I would also assume that most of you got six breaths or less and perhaps some of you even got fewer than six breaths or less. So, when people become really good at this they turn this into a square. And what I mean by that is that they start the inhale, they hold, they exhale, and then they hold again. And so typical, normal breathing is in-out, in-out, and that's not a way to stimulate the relaxation response in our body. But the hold is. So the hold is magic.

The more you can practice or participate in the hold of breath the better and the more relaxed you'll be. I hope you enjoyed those. We are at our summary section and knowing that this is, you know, mental health disorders are very common, yet very treatable conditions. Knowing/remembering the parable of the blind men and the elephant that all medical specialties work together to understand the entire patient, including the high prevalence of mental health disorders. And the treatment of mental health disorders is a necessary component of patient care and leads to better outcomes in quality of life. So, we're at our question section and unfortunately, I was not able to keep up with the questions. And so, I'm going to ask Peter, if you can give me some of those questions and I'll answer those for the next 10 minutes?

Peter Damiri: Sure, absolutely. Thank you again, Dr. Sullivan, excellent presentation. Well, we did have quite a few questions that came in and several questions were around understanding the difference with anxiety and depression in MS. Are anxiety and depression caused by MS or do people just struggle being anxious and depressed because they have MS?

Dr. Amy Sullivan: Yep. So, it's what came first, the chicken or the egg? And that is a very common question that I get in my practice. Yes, anxiety and depression are both caused by MS and a reaction to MS. So, to me, it doesn't matter where the anxiety or MS came from. What matters the most is that we treat it. So, if you're experiencing anxiety or depression it's very important to seek care because what I say very frequently is: “MS steals so much from us don't let it steal your joy.”

Peter Damiri: Excellent. Thank you. We actually had a special guest attending this webinar, which is Dr. Adam Kaplin, who presented earlier on our Purpose in Life. And he posted this question: How do you deal with the stigma that surrounds mental illness, both with patients and care providers?

Dr. Amy Sullivan: Dr. Kaplin, thanks so much for joining today. I was just sharing with somebody just today, actually, they asked: Whose research will I always follow? And I mentioned you as that, so it's just an honor to have you here today. So, my whole Twitter handle, so, if anybody's interested in following me on Twitter it's @DrAmyBSullivan, is about normalize and not stigmatize. Why that's important to me is because I trained in New York and Atlanta. In New York and Atlanta, your therapist is kind of like, they live with you on your shoulder. Their thoughts are with you constantly. And then, I was recruited to the Cleveland Clinic and I realized, boy, there's quite a stigma here in the Midwest. And so, my goal has been really to de-stigmatize mental health. And so, I think we've done a really exceptional job of that at Mellen Center.

Because what we have done is within the first session, so, the first time a person has been diagnosed with MS they're offered one of our shared medical appointments. And in that shared medical appointment is the neurology team and my team. There - it's so important that we de-stigmatize and just make it a normal part of care that we've put ourselves, Dr. Vernell had put ourselves - put the behavioral medicine team into the first initial appointment. The other thing that we do is we talk about our services in terms of stress management. So sometimes it might be scary to hear the word bipolar disorder. It may be difficult to hear the word depression. But I think people hear the word stress constantly. And so, we've really kind of made our bread and butter

based on our stress management tools. And so, we've worked very hard to normalize and not stigmatize mental health and hopefully we will continue to do that over the course of time. So, thanks, Dr. Kaplin.

Peter Damiri: Yeah. Very good. Sorry. No, go ahead.

Dr. Amy Sullivan: I did see one question in here that I wanted to address. So, I'm just reading the very end. I'm so sorry if I'm not going back to the beginning, but there was a question in here. Somebody had asked about breathing and it made you lightheaded. Betty asked this. I very appreciative that you brought that up. So, if I were teaching this in my office, Betty, I would say it's normal to get lightheaded if you don't typically breathe this way. But it's scary to get lightheaded. So, I would have people stop the breathing exercise if that was happening and then start again, and then gradually make small improvements. And again, like I said, many people who are wind instrument players, or people who are singers or people who are endurance athletes, they know how to do that diaphragmatic breath.

And they've probably breathed six breaths per minute or less on a given day, but most of us don't do that. So, I can tell you from my experience, that happened to me as well when I first started doing this even though you know, I've been an athlete my entire life and I've played the flute my entire life. So, it still made me lightheaded. And so, what I did was I gradually started incorporating this. But now, you know, patients will say to me, can you show me what it's like to breathe inappropriately so they can see it? And I can't even do that anymore because I've learned how to use the diaphragmatic breath.

Peter Damiri: Great. And a similar question on breathing: Do you believe breathing is a key in managing anxiety?

Dr. Amy Sullivan: A hundred percent yes. I think we have to learn. So, what ends up happening from a physiological standpoint is if we do this choppy chest breathing we're not pulling the breath into the diaphragm and therefore we're not oxygenating our visceral organs as well as our brain. And our brain takes this as a, it's almost like our brain is saying, stop, stop. I'm hyperventilating. The brain isn't getting enough oxygen. And so, the brain sends anxiety symptoms and we've had very difficult times those anxiety symptoms. So, once we learn how to pull the breath from our chest into our diaphragm, we really help to reduce anxiety and shut down the sympathetic nervous system response.

Peter Damiri: Great. And breathing might be the response that you're going to give to this next question, but it is: I never had panic attacks until being diagnosed with MS. What is the best way to deal with panic attacks?

Dr. Amy Sullivan: Yeah. So, panic attacks, I think we first need to understand the etiology as well as maybe what's triggering those. So, we use a lot of cognitive behavioral therapy in managing panic attacks. So first we have to understand what brings about the panic, and then what's the thought that comes. So, whatever that person says brings about the panic, there's usually an irrational or dysfunctional thought that comes right before that. And then, that causes the panic. So, it's important for us to really dissect the thought process. And this occurs over time too because people usually can't identify that thought process. And then we're able to, once we can identify that, help them to restructure their thoughts and then provide stress management techniques such as breathing. But there's also a very good skill called mindfulness that we utilize to help the person stay in the present moment.

So, typically, with panic somebody who's going to a worst-case scenario and as Mark Twain would say, typically the things that, you know, he worried about throughout his life never came to fruition. And that's what we try to teach with panic. So, we try to help people to understand the here and

now, which is mindfulness, and to help them to stay here instead of going into the future wherever that fear may be.

Peter Damiri: Okay. Thank you. Here's another question. I know exercise is helpful to fight off depression and anxiety, but when I exercise, I experience extreme fatigue and neuropathy in the ankle and feet area. Do you have any helpful advice on this?

Dr. Amy Sullivan: Yeah. So, one of the things that our physical therapist would say is: have you explored all forms of exercise? So, many people think that exercise is, you know, simply running or lifting weights or something really intense. And exercise does not have to be that. Exercise can be movement and movement can help us with fatigue. So, believe it or not, it's helpful to incorporate exercise to help decrease fatigue. So, some of the things that we would suggest would be possibly yoga. Not hot yoga, but maybe restorative yoga. Or finding a pool that one can cool their body temperature, core body temperature. Maybe walking. So, maybe doing things that aren't so strenuous and that will be helpful for the individual and will help actually with fatigue management. It also helps with mood. And in fact, I can share for my fellowship I did a study. The study that I did for my fellowship was looking at exercise over the course of 30 minutes, three-times per day.

And so, we had individuals doing a real slow walk on a treadmill in 10-minute spans. And what we found were that even these really slow speeds. So, the speed that we took people up to was 3.2 miles per hour, which is about the speed of a bride walking down the aisle, significantly reduced anxiety and depression. So, in only 10 minutes. So, I thought that that was a really powerful study because it showed us that you don't have to even do the 30 minutes all at once. You can do them throughout the course of the day.

Peter Damiri: Yes, absolutely. If anxiety is treated with medication and counselling, and is well controlled, does it still increase cognitive decline?

Dr. Amy Sullivan: No. If it's well-controlled it should not.

Peter Damiri: Terrific. And we're running up against the hour. So, I want to ask one more question and then give you an opportunity to provide any last-minute suggestions or take-home messages to our audience. So, the last question is: How do you know when it's necessary to seek professional help?

Dr. Amy Sullivan: Yeah, so, that's a question I get asked very frequently and what I would say is: when it starts to impair your functioning. So, when you notice that you're depressed or anxious or irritable, and those start to impair your functioning, it's very important to seek mental health care. Also, when you're withdrawing or when you lost interest in things that you once enjoyed, seek mental health care. Again, MS steals so much from us, don't let it steal your joy.

Peter Damiri: Absolutely. Great information. And again, any last suggestions or take-home messages for our audience tonight?

Dr. Amy Sullivan: No, I just really appreciate you guys joining. Thank you, Dr. Kaplin for that question for me. You know, for me, the normalize and not stigmatize is just really something that I'm so passionate about. And I hope that all of you on here realize that it takes a very brave person to talk about mental health issues, but it is very normal in the MS population to have mental health issues. So again, if you find me on Twitter, I'm @DrAmyBSullivan. So, D R A M Y B S U L L I V A N. And we talk a lot about normalize not stigmatize and mental health care.

Peter Damiri: Well, that's great advice, thank you so much. Well, that does conclude tonight's webinar, which as a reminder, will be archived to our website within a few days. Once again, I would like to thank Dr. Amy Sullivan for her time here tonight and helping us better understand and manage depression and anxiety in MS. I would also like to thank Biogen, Genentech, and Sanofi Genzyme for supporting our new virtual display hall. As mentioned, MSAA has additional programs on our

theme of Improving Mental Health and Wellness. So, please visit our MS Awareness hub at MyMSAA.org to learn more. And finally, we ask you to take a very brief survey that is coming up next. Your feedback is very important to us and will help us secure funding for future programs. So, on behalf of MSAA and Dr. Amy Sullivan, thank you so much for watching and please stay safe.