



**MSAA Podcast - Episode 14:
Finding Joy in the Process:
Managing Mental Health in the MS Journey
Part Three: Social Interactions and
Connections**

Host: Yahaira Rivera

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

Yahaira Rivera:

Hi and welcome to the final episode in our special series, “Finding Joy in the Process - Managing Mental Health in the MS Journey”, with mental health expert Doctor Amy Sullivan. Today we are addressing the topic of social interactions and connections. My name is Yahaira Rivera and I'm the Director of Mission Delivery and Program Development for MSAA. I'm glad that you're here, connecting with us and listening.

And I want to welcome back our guest speaker. She's a board-certified clinical health psychologist and associate professor of medicine and a director of behavioral medicine and research at the Cleveland Clinic Mellen Center for MS. And she's also a member of MSAA's Healthcare Advisory Council. Welcome back, Dr. Sullivan.

Dr. Amy Sullivan:

Oh, this has been so fun for me to do with you, Yahaira. It's been a lot of information, I know, but hopefully we're able to help some people as we go through the podcast. So, thanks again for having me.

Yahaira Rivera:

Thank you. I have enjoyed our conversations, and, I've been learning so much with you. So, thank you for that. So, let's start with talking about how does MS impact our daily lives and routines and relationships and social life as well?

Dr. Amy Sullivan:

Yeah. Yeah. I think from my perspective, when I think about the MS patient journey, it's usually someone who, you know, that I start seeing is a relatively young individual. So, this is something that people will deal with for decades upon decades. And typically, the individual that we see is working at the time of their diagnosis, maybe they're starting a family, they're maybe moving up in their career, so a very exciting time in people's lives. And then bam, this hits them. And so,

from a mental health perspective, there's certainly reason for people to experience grief or anxiety about the unknown. And so that's typically why somebody would come see me.

MS affects individuals in so many ways. So not only from the physical perspective. but we think about the invisible symptoms. So, when we think about the invisible symptoms, we know that it's kind of the "But you look so good" phenomenon. It's like, what could possibly be wrong with you? Because we have great disease modifying therapies nowadays that are doing a phenomenal job of holding off functional decline for our patients. So, people are really just struggling a lot with that "but you look so good" phenomenon. And what that means is essentially like the symptoms that people struggle with the most, those invisible symptoms, such as cognitive dysfunction, fatigue, mental health concerns, are things that other people don't see.

So when they come to talk to me, their social lives are affected because maybe they're fatigued and they don't want to go out on the weekend, maybe they want to recover, maybe their social lives are affected because people that they are associating with don't really understand their diagnosis or their functional needs, or people that they're going out with don't understand why they have anxiety about the future or why they are grieving their disease. There's so many reasons why social function may be affected. And so, I think that it's really important that we stop, and we evaluate. So, in my practice, it's an evaluation as to, number one, how the person got to where they are and why they feel this way. But number two, what their goals are and making sure that we're aligned, and that the person and I are focused together on what their goals are in therapy practice. So, how can we help them the most?

Yahaira Rivera:

Thank you. And what is the benefit of social interactions and connections when someone is managing both MS and also mental health challenges?

Dr. Amy Sullivan:

Yeah. So, I think connections are important for all of us in life. We're human beings, and I think that that's what kind of sets us apart from like a wild animal. I think for humans, connection is central to who we are. A person with MS, I think there are really unique situations and circumstances that that person is facing. So, for example, we run a weekly support group in our practice, and it is... that and our men's support group are the largest support groups that I've ever seen, honestly. We have so much interest in these groups. And so, these are places where people go to process unique needs to them, and they've developed friendships through these groups.

And I think that that's one of the most beautiful things is that they have developed friendships and they're able to even talk to these people outside of our weekly support group for them. Connections are just vital to human beings and making sure that individuals with MS are connected to someone who understands them, connected to someone who's not going to judge them for those invisible symptoms, you know, like I said earlier, the most common thing that I hear is the "but you look so good" phenomenon. It's like nobody understands what they're going through because they don't have a cast on their arm or some kind of surgical scar that shows what they've been through. But they're certainly going through so much.

Yahaira Rivera:

Those invisible symptoms; it's good to know about them and understand them. Definitely. So, Dr. Sullivan, if someone is listening today and feels alone or isolated, how can they start building nurturing relationships and where can they find that support?

Dr. Amy Sullivan:

If somebody is in Ohio, I know from my perspective, I want to mention a couple of things that we do here. Unfortunately, we can't practice across state lines. So, if you're in a surrounding state that is close to Ohio, we do have people who drive across the border and are at a coffee shop or someplace where they feel like they can talk to us. But there are a couple of really unique programs that we offer at Mellen Center that I'd like to talk about.

So, I mentioned a little bit about our groups, but I want to mention a little bit more about them because we have some very unique groups. So, we have the weekly MI support Group, which I think is just a wonderful space for people to connect and for them to feel like their emotions are normalized there. We have a men's support group, which is just for men. I think men have very unique needs, and this goes back to a previous fellow of mine, Dr. Brian Davis, who was very interested in masculinity and norms for men. And he started this group, and it has thrived under him and continues to thrive. And we're so very grateful that I started this. It's probably, between that and our MS support group, the most popular groups that we have at Mellen Center.

We also have a young professional group. So, as we were talking about earlier, when the person is diagnosed with MS, typically they're very young. They're in the highs of their life, they're getting married, they're having families, they're developing careers. And so, this is a very exciting part of life. And then boom, this diagnosis hits, and so they have unique challenges, not only being a mother or somebody who is, you know, their career is taking off, but now they have this chronic disease that goes along with that. And so, we hold that group as well. We have a sleep and fatigue group. So, we know that sleep and fatigue are significant issues. We talked about that earlier, is fatigue being one of the most difficult symptoms that individuals have with MS. And so, we have a sleep and fatigue... It's actually more of a class, but we teach people skills to manage sleep disorders or fatigue management.

We also have a caregiver support group. So, we talked on episode one about the care partner, and so I think the care partner is somebody that is vitally important in the transition of our patients across time. And they're with the person longitudinally, but they also have their own concerns. And so, what we know about care partners is that care partners tend to not take care of themselves because they're so busy taking care of the person with MS. And, the first thing we talk about in that group is about, you know, when you're on a flight and the flight attendant is initially describing the emergency protocol, and the flight attendant comes on and says in the event, in the unlikely event of an emergency, if the oxygen masks fall, it's important to put your oxygen mask on first before taking care of others. And that's I think, what we want to process in that group is how do we still take care of ourselves while taking care of a person we care for, or the person we love so much?

And then finally, we have what's called a newly diagnosed group. And this is shared with our medical providers, but it's kind of like a welcome to Mellen Center. So, we normalize up front that people likely have mental health needs as they go through this journey. I think on our first part of this podcast, we talked about the high prevalence of mood disorders in the MS population. And when we think about individuals with MS, they're three to four times as likely to develop a mental health condition as the general population is. So, depression and anxiety are very, very prevalent in this population. And so, we want to start the journey, the MS journey, for people in the Mellen Center by kind of normalizing the fact that they'll likely see a psychologist through their journey. This isn't something to be ashamed of at all, this is just something that we want people to normalize and say, "Look, we want you to take care of your mind and your body, and not one is more important than the other." It's like the parable of the blind man and the elephant - all different parts of the human being are the elephant in the

parable, are important. And we have to make sure that we're all functioning as a team at Mellen Center so that we're taking care of all parts of the person, or in the parable, the elephant.

Yahaira Rivera:

Thank you, Dr. Sullivan. We appreciate all the information, insights, and strategies that you have provided us throughout the entire series. A minute ago, you said your mind and your body are important. We need to take care of both of them. I would like to wrap up our episode with that thought. Thank you, Dr. Sullivan, and thank you once again to Gradwell House Recording for hosting us and producing our podcast series.

To our listeners, please know that you're not alone. MSAA is here and for you and we offer direct services and resources to support you in your MS journey. Please visit our website, mysaa.org to learn more. Thank you for listening and take care.