



Elevating Your Well-Being: A Conversation about Multiple Sclerosis and Mental Health

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Yahaira Rivera-Bobadilla:

Hello, everyone. Welcome and thank you for joining MSAA's live webinar, "Elevating Your Well-Being: A Conversation about Multiple Sclerosis and Mental Health" with MS specialist Dr. Barry Hendin and psychiatrist Dr. Holly Hendin. Tonight's webinar is part of our MS Awareness Month programming on improving lives through supportive connections. My name is Yahaira Rivera and I'm the Director of Mission Delivery and Program Development for MSAA and your host for the program.

Before getting started, I would like to take a moment to share some information about MSAA and go over some housekeeping items and reminders. As you may know, MSAA is a leading resource for the entire MS community, improving lives today through vital support and services. Our services include a national helpline providing English and Spanish services Monday through Friday, 8:30 a.m. to 8 p.m. Eastern Time, an equipment and cooling distribution program with products designed to improve safety and mobility and to help with heat sensitivity, an MRI access program for individuals with MS who qualify for assistance, educational programs, online tools, publications and digital resources to help you stay informed. We also offer support through community connection to help you stay connected with other members of the MS community. All of our programs are available to people living with MS nationwide. To learn more about MSAA's programs and services, please visit our website, MyMSAA.org.

And now I'm going to share a couple of reminders. Please note that during tonight's program you will have the opportunity to ask questions by using the Q&A icon on your toolbar. As time permits, we will do our best to answer as many questions as possible during our conversation and during the Q&A portion of tonight's webinar. And know also that this program is being recorded and will be made available on demand on MSAA's video library within the next couple of weeks. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and helps us develop future programming and content. A link to the survey will also be included in the chat box. Also a friendly note, please know that this program is for educational and informational purposes only and does not constitute any formal recommendations. If you have specific questions or concerns, please speak with your doctor or healthcare provider team.

And now it is my pleasure to introduce you to our guest speakers for this evening. Dr. Barry Hendin is a highly accomplished neurologist and MS specialist. Dr. Hendin has coauthored more than 30 medical articles, given more than 50 presentations to physician academies, and

has been the principal investigator for more than 115 clinical trials. After 45 years as a neurologist with Phoenix Neurological Associates, Dr. Hendin is now Director of the Arizona Integrated Neurology MS Center. Dr. Hendin is also the Chief Medical Officer for MSAA. Also joining us tonight, Dr. Holly Hendin. She's a board-certified outpatient psychiatrist with the Dignity Health Medical Group at Saint Joseph's Hospital in Phoenix, Arizona. And she's also an assistant professor of clinical sciences at Creighton University School of Medicine at the Phoenix campus. She has published and presented research on various topics, including the psychological challenges of multiple sclerosis. Dr. Hendin is interested in cultivating behavioral health wellness through medication management, as well as nontraditional strategies. Please join me in welcoming Dr. Barry Hendin and Dr. Holly Hendin.

Dr. Barry Hendin:

Thank you.

Dr. Holly Hendin:

Thank you so much.

Dr. Barry Hendin:

Well, I might begin. So the discussion today is about mental health and multiple sclerosis. And I thought, although Dr. Holly Hendin will be talking about the more formal mental health challenges and diagnoses, depression and anxiety, for example, I thought I would talk a bit about the journey of an individual patient and the challenges to people's mental health that can occur as part of that journey from the very beginning through a lifetime. Those will be the challenges, when I get done talking about the challenges, what I'd like to talk about is the hopefulness of the future and how much we've already advanced, how much better the life of an individual with MS is today than it would have been 30 years ago or 50 years ago when I began practicing as a neurologist. And so, first the challenges and next the favorable discussion of optimism and hope.

So we know some things about MS before it's ever diagnosed. There's a period prior to the diagnosis of MS that we call the prodrome I think you've been told often if you have MS that your MS began before your first diagnosis. And when we go back in the literature, we can see that for a year and as long as five years beforehand, people are hospitalized more frequently, in emergency rooms more frequently, seek mental health assistance more frequently, and are on medications for mental health more than they were prior to that time or more than a controlled population. So something's going on in the biochemistry of the brain and in the wiring of the brain in people with MS even before they're officially diagnosed. Adding to that is the challenge that people with MS will often say that they were not immediately diagnosed with their first symptoms, that the first tingling and numbness may have been ascribed to something other than MS - growing pains, stress - and brushed off. It may lead to a lack of confidence in the whole medical system when the diagnosis is delayed.

Having said that, when the diagnosis is made, it presents its own set of anxieties and concerns. Although people presenting for the first time to my office with a diagnosis of MS may appear perfectly poised when the surface is scratched, it's a terribly disconcerting time with a great deal of anxiety. The anxiety is, "What about my future?" "What will become of me?" "Will I be able to work for a lifetime?" "Will I be able to marry?" "Will I be able to have children?" Will I be able to travel and enjoy my life?" Or in the usual phrase, "Will I end up in a wheelchair?" A lot of the concerns that would have been appropriate prior to 1993, prior to medications being available, some of those pessimistic outlooks were realistic. Today, the outlook is so much more

optimistic, but people will still be fixed on a time when we weren't as able to control relapses and progression. They may read things that make them more concerned. They may have relatives from another era who didn't do as well. And so I think sometimes at diagnosis there is great concern above and beyond the realistic sense of what MS is today.

Having said that, the neurologist or clinician who sees them will often recommend a medication. And then there are concerns about medication. So although some patients are very eager to get on a medication, patients are often very fearful about the medications and side effects and may have heard things inappropriately about the medications that we use as neurologists. So it takes some real patience and explaining about the risks of MS and the risks of our medication and the fact that the medications we're using have evolved to more and more effective medications with fewer side effects and increased benefit to risk profiles.

Having said that, the concerns thereafter are if the neurologist recommends a medicine and the patient is interested in getting that medication, what about navigating the insurance companies and payors who sometimes have step edits and say, No, that's what you want, but it can't be provided. So that becomes the issue of navigating the whole medical bureaucracy. Does your clinician answer phone calls? Do people return phone calls to get back with you? Does your clinician know MS and can they answer your questions? Does your payor or insurance company allow you the medication that you have agreed upon by shared decision making with your clinician?

And then the other things that evolve over a lifetime - What about the workplace? What about navigating work and work demands, which sometimes can be excessive for anybody, especially for MS, when issues like fatigue and cognitive slowing or processing may occur? What about relationships with supportive spouses or partners with nonsupport of partners and family members? How do you navigate that? How do you navigate your community? And so, many issues. What about planning for pregnancy? Family planning? What about planning for your later years? Retirement? All of those become part of the journey of MS and I really want sort of to pay a compliment to the people living with me who've gone through all those challenges, often successfully, occasionally with a challenge that gets the better, but with hopefulness about what we can do together.

Then what about the future? I said I'd begin with the challenges and end with hope. I have been a neurologist for 50 years, and so the day I entered medical school, there was not a CT scanner in America, much less an MRI. There was not a therapy for MS. The specialty was very underpopulated. Not a lot of people were MS specialists because not a lot of people wanted to be in a field where we had such primitive tools. I will tell you that this is a... no one wants to have MS. It's not a choice. But when one does get the diagnosis of MS, it's such a more optimistic time today than it would have been 30 years ago. We have such better tools for diagnosis and understanding of MS. We have such better therapies. We have specialists in good numbers to deal with the issues in a highly knowledgeable way. Research keeps on answering the unmet needs so that we've gotten better and better at getting effective therapies for relapse reduction. We're now trying to work on an unmet need, which is progression. And I will tell you that I have said both in a lecture format and to patients in front of me, you need to expect more from us.

There was a time when there wasn't much you could expect from your neurologist. Today is not that day. There's much more that you should be expecting from your neurologist or your clinician, much more that we should be expecting from ourselves. There is no time when I see a patient and say there's nothing we can do, whether that thing we can do is a disease modifying

therapy to reduce relapses and progression, whether it's a symptomatic therapy for depression or anxiety or bladder or walking or spasticity, whether it is connecting with the right specialists, the urologist, the psychiatrist, the psychologist, the physiotherapist, etc.. There's so much more we can do. And again, if there's something to say, future has gotten brighter, will be brighter still. There's a lot that we can do together. Do expect more from us. Thank you.

I don't know... So I think it looks like I'm going to turn this over to Dr. Holly Hendin, who will talk much more specifically about mental health and psychiatric disorders and MS. I'm actually so delighted to be sharing this program with Dr. Holly Hendin, my daughter, and to be able to share all of this with you. Thanks.

Dr. Holly Hendin:

All right. Well, thank you so much for having me here tonight. It's really an honor to be able to speak to so many people all at once, even if it's in this remote electronic format. But I think it's really wonderful to see how many people showed up to support themselves or a loved one with MS and to think about how do we focus a little bit on wellness and mental health and try to make your journey a little bit more hopeful and successful.

So as my dad, Dr. Barry Hendin, was saying, it's true that mental health issues are experienced with higher incidence in the population of people who are diagnosed with MS, that there can be a mental health prodrome, so prior to getting the diagnosis of MS, as he pointed out, that people often were experiencing depression, anxiety in higher rates than the population of people who were not diagnosed with MS, whether it's a prodrome, whether other things were going on that it's hard to know. But we do know that there is that relationship. And then additionally, why might there be more mental health issues in a population of people diagnosed with MS, so all the challenges that my dad spoke so eloquently about are real and they impact mental health and well-being, the nature of the disease itself, the symptoms of fatigue and pain, difficulty walking, brain fog.

Those are just some of the symptoms that can get people feeling really down about themselves, can be isolating, can make it hard to participate in the things that people have really enjoyed in their lives and the ways that people define themselves. So their identities are being challenged by the very symptoms of MS. And then additionally inflammatory processes just in general are related to mental health issues. So depression, anxiety, bipolar disorder, all of these come with inflammation, and the inflammation tends to recede when they are well treated. So, a plug for really thinking about, What am I experiencing? Is it just sadness and challenges with the diagnosis, which would be kind of, in psychiatry speak, like an adjustment disorder? Or is it really more like two weeks or more of a very down mood and feelings of guilt and difficulty sleeping and maybe thoughts of suicide?

There was a recent study in the UK on an MS, or a population of people who were diagnosed with MS, and out of the 2000 people that they surveyed, only 9% had brought up to their MS provider that they were experiencing mental health issues. So the first thing that I just want to say is please, please bring up your issues to your provider, whether you think it's silly, whether your family is telling you maybe it is silly. If you feel like there's something going on, please bring it up because we won't know how to help you address issues if you don't bring it up to us. And 9% of 2000 people, I mean, it's still, you know, like 200 people, but a thousand plus people who didn't bring it up and who are suffering. And there really is no need to suffer alone.

There are psychiatrists out there if you want to think about medications, and then psychologists, counselors, therapists, social workers who are there for the counseling aspect of mental health. So those are definitely available to you. I think an earlier question was how do I know how to get established with somebody who knows about MS in particular? And although there might be

through Google searches, ways to find those people, I think your first resource would be your MS team, your neurologist, and that office asking them, do they have psychiatrist, psychologist, counselors that they like to work with? And then if that's not something you feel comfortable with or not available, then to look online.

One of the tools that I really like to tell my patients to utilize is, and I know it's strong in Arizona, which is where we are, but I know that it's everywhere, but I don't know how strongly the database is supported in other parts of the country, but it's called Psychology Today. So, in person, Psychology Today is a magazine, but online they have a database of providers, and the providers themselves keep their profile updated. So it's really useful because not only is there a database there, but it is searchable and filterable. So, if you said I want a psychiatrist who has experience in chronic illness and who has training in, let's say, acceptance and commitment therapy, which is a really wonderful type of therapy for people with chronic illness, it's basically accepting the limitations of what you are struggling with and then committing to living your healthiest life and doing the things that you still can do, you could plug those into the search engine of Psychology Today, the database, and then all those providers will come out. You can also filter for your insurance. You can filter for, Gosh, I don't feel comfortable going into people's offices, can I do this by Telehealth? You can filter for location of the office. So I really think Psychology Today is a wonderful resource available.

And then there are definitely medications. So that was called acceptance and commitment therapy. A.C.T. is the little acronym for it. There's medications that are available, that's my specialty, it's more like medication management. So SSRI, serotonin reuptake inhibitors like Prozac or Lexapro, so fluoxetine or escitalopram. SNRIs, the serotonin and norepinephrine reuptake inhibitors, these can be very helpful for helping people manage depression and anxiety. Usually it takes a little bit of time. We would say like 4 to 6 or 6 to 8 weeks, definitely for them to become effective because although the medication is in your body, your receptors need time to modify, to accept them, and then to work the way that you want them to work.

One of the types of therapies that when I'm speaking to patients who have been diagnosed with MS that I like to think about with them is a type of therapy called RTMS, which is repetitive transcranial magnetic stimulation therapy. It's a type of therapy that is FDA approved for treatment resistant depression. So you have to have been diagnosed with depression for your insurance to pay for it. You have to have tried three different medications and worked with a counselor. But if you are still feeling depressed at that point, your insurance will pay for TMS and the benefit of TMS in a population of people diagnosed with MS is that it really helps not just with depression, but with concentration, cognitive ability and with energy. And so you can see how there might be a nice place for options to benefit you that maybe are not completely fulfilled by medication management alone.

So TMS is available. So there's a type of treatment that is available for depression called ketamine, or ketamine assisted therapy is another one. So all of these are available to you. Unfortunately, ketamine is not generally covered by insurance, but it does have a lot of effect on pain management, depression. It's really the only legal psychedelic. It's not actually a psychedelic, but the only legal psychedelic medication that you could be utilizing right now with a provider to have psychedelic assisted therapy outside of clinical trials. So there's... I think ketamine has a lot of promise in terms of the pain management. That could be a really helpful component for people who have been diagnosed with MS.

And then there is also psychedelic assisted therapy. It's probably, we are hopeful that it's going to be approved for treatment in the next year or two. MDMA is probably the first one that's going

to be available. But psilocybin, which is the chemical inside of magic mushrooms, psilocybin is available, psilocybin assisted therapy is available, legally, in certain countries and then also in certain states, and those states are trying to open up the treatment and psilocybin might actually show some utility in terms of helping with remyelination or some of the inflammatory processes of MS and depression.

So those are all reasons to be hopeful in terms of medications and what you could do for your mental health. I would say that when anybody comes to work with me, the first thing that I want them to do is get established with a therapist. So medications can take you a little bit, they can help to, I always say, buffer some of the things that you're experiencing, but even just anxiety, let's say a medication will never take away your anxiety, nor would I really want it to, because I believe that anxiety serves a really important purpose. And so you really need anxiety in the way that, let's say, a cook needs to be able to feel his or her fingers while they're cooking so they don't burn them. Anxiety is there to help protect you as well. So, experiencing anxiety will still occur. Experiencing sadness or depression will still occur even in the context of medications. And then all of the other parts of what I think everybody is here for tonight start to come into even more importance. So, I'm talking about wellness and I'm talking about therapy. I don't know if we want to take a little break for questions or whether I should just keep going.

Dr. Barry Hendin:

So, what's your thoughts?

Yahaira Rivera-Bobadilla:

Yes, we do have a plethora of questions that are specific to what you both discussed so far. So we can take a little break for questions and we'll continue our conversation. We received questions about if the location of a lesion on the brain affects mental health.

Dr. Barry Hendin:

Sure. I'm going to give you a couple answers that may sound internally contradictory. There have been studies that have tried to associate specific depression or anxiety with specific brain lesions. For example, frontal lesions or temporal lesions. But my view is that it is less on the specific place of a lesion than on the more diffuse changes that occur in MS. So those diffuse changes are the inflammatory change, diffuse inflammatory changes that Dr. Holly talked about, but also diffuse lesion load and atrophy. They affect fatigue and cognition and mood. And so, yes, there have been studies that have supported localization of lesions. I think it's much less important than the general brain changes that occur in MS.

Yahaira Rivera-Bobadilla:

Thank you, Dr. Hendin. And then we have questions also about the family dynamics. My family knows about my MS and my mental health issues, but they just don't get it, I'm afraid, somewhat being that I'm grandstanding. Any suggestions for that?

Dr. Barry Hendin:

Sure. I think for any chronic illness, it's not just the the individual who has that, but really the whole family is involved favorably or unfavorably in the issue of of chronic illness or MS in this particular setting. So if you said what's the solution? I mean, there are a lot of potential solutions, but it begins with education. So I'm always thrilled with the fact that people bring in their partners or their children. And it's an opportunity to talk with the partner or the parent or the child about what MS is and what MS isn't, to dispel misinterpretations and misunderstandings. I sometimes bring up a movie, a Japanese movie called Rashomon, which is a movie based on

the idea that the truth is not held by one individual, but rather by finding out and canvassing everybody who witnessed or is involved in the event. And so I take advantage when there are family members there, saying to the family members, let's don't forget the patient is central, but let's find out everybody else's perspective. What do you think about what's going on? What do you see? What are your concerns? So I think having others there in the conversation and utilizing the other people there for education and for education of the clinician and education for the family is hugely important.

Yahaira Rivera-Bobadilla:

Thank you, Dr. Hendin, for that great advice. We also have questions about what is research saying nowadays about correlation between MS and Alzheimer's?

Dr. Barry Hendin:

Dr. Holly, would you care to weigh in on that one?

Dr. Holly Hendin:

Sure. We were lucky enough to be able to see some of the questions that you all posed when you signed up, and so we were able to kind of get ahead of the "that's such a great question, let me look that up and get back to you." So I think what we both decided was that definitely MS is related to cognitive changes and that anybody can develop Alzheimer's or dementia, especially later in life, and that it's hard to tease apart where exactly cognitive changes turn into dementia, per se. There has been some research that suggests that maybe people with MS do have a higher incidence of dementia. But...

Dr. Barry Hendin:

Do you want me to... I think that Dr. Holly is pointing to me to follow through. So, the most common cognitive changes of MS are processing speed - how quickly you come up with the answers, how quickly you sift information. I think it can lead to problems with multitasking. There are some problems with memory and executive functioning. MS does not cause Alzheimer's disease and Alzheimer's disease does not cause MS, but because Alzheimer's disease is common, people with MS can get Alzheimer's disease in the exact same proportion as the rest of the population. But as people age, they can say, I've had these problems with processing speed, etc., etc. The fact that I'm aging, which produces some of the same problems, makes things seem as if they're compounded.

So we do believe that there are cognitive changes that occur in half the people with MS, they're not Alzheimer's disease. In some people, they can follow into the stage of dementia like they can in any other individual. Interestingly, what MS doesn't do is generally change intellect. So intellectual capacity is generally not the target for MS, it's these other features. It's a broad answer, but the answer is people with MS have cognitive changes. It's not Alzheimer's disease, but all of us are vulnerable to everything else, whether you've got MS or don't.

Yahaira Rivera-Bobadilla:

Thank you. That answers the question and clarifies some of the misconceptions, as well. So, thank you so much, both of you. We have questions about depression and about bipolar disorder. So if someone is receiving treatment for one or the other, would that interfere MS treatments or DMTs? Or how is that related? Both of them?

Dr. Holly Hendin:

I mean, generally not. I would say that whenever I'm prescribing somebody a medication, I'm always looking to see what other medications they're on. And then I do a drug-drug interaction. You know, I just run it quickly on my computer just to make sure that I'm not going to be interfering with anything. But I haven't really come up with anything. I also tell my patients, you know, also ask your pharmacist where you pick up your medication and let them know what other medications, because pharmacists, they just have a wealth of information about drug-drug interactions. And so, but I would say that sometimes there are interactions kind of like if somebody is taking Gabapentin for, you know, like peripheral neuropathy and I want to give them Escitalopram and then there'll be a little interaction that comes up that says both of these could maybe make you a little bit sleepy. But that's generally the extent of what I see. But I will pass this over.

Dr. Barry Hendin:

Sure. So, I want to take even as a slightly different angle, I know that somebody had previously asked the question, do these medications cause depression? So the fact is it's been looked at. In the early days, there was some question as to whether the interferons, the Avonex, Rebif, Betaseron, Plegridy, would cause depression. The answer is when looked at over the years, probably not. So, the data looks like it's the opposite, that some of the medications that control MS are neutral, but some of the medications that help to control the MS process, the disease modifying therapies, actually may improve depression because they reduce inflammation, because they improve your physical and psychological well-being. So I would say, by and large, our MS medicines don't cause depression, are either neutral or sometimes cause improvement. Though early on there was concern in another direction.

Number two, I think sometimes we do get polypharmacy - people who are on just multiple, multiple medications. And that means medication for pain and spasticity and mood and anxiety. And when there are too many medications on board, those too many medications can create their own load. They can add to burdens on mood and cognition. So somebody ought to, as Dr. Holly said, take a look at the whole medication polypharmacy group and make sure that you, the patient, you the clinician, are not guilty of unnecessary polypharmacy. It can add to the burden.

Yahaira Rivera-Bobadilla:

Thank you. Thank you both for that information. We have a question about if MS can worsen preexisting suicidal ideation.

Dr. Holly Hendin:

Yeah. I mean, I would say that thoughts of suicide are very common. When somebody is depressed, it's actually in our diagnostic and statistical manual, which is what we use to kind of create the criteria for diagnosing somebody with a certain psychiatric disease, that thoughts of suicide is one of the symptoms of clinical depression or a major depressive disorder. So anything that can worsen your depression can also worsen thoughts of suicide. And what I generally tell my patients is, well, a) please speak up about it. If you are experiencing that, there really is no need at all to suffer in silence. And 988 is now in addition to 911, which is our usual emergency line, 988 is specifically for mental health emergencies. So if you are experiencing thoughts of suicide that you think you might act on, call 988 right away. If you are just wondering in general about thoughts of suicide and how MS interplays with that, I would say that in general, thoughts of suicide tend to come up for people who feel like they are trapped or stuck in a situation and they don't have a good way out.

And so I would say that lots of different situations can create that feeling of being trapped. But what I tell my patients is just keep in mind that there are so many, so many, many, many, many, many other ways to feel like you are not trapped beyond ending your life. And I had an attending in residency who used to say that suicide was a permanent solution to a temporary problem. And I'm not saying that MS is by any means a temporary or easy problem, but there's so much available, there really is so much available to be helpful to people who are struggling. So I was thinking about why people come into their neurologist's office and I say like, I'm fine. I can do this by myself and I don't want help. I'm going to do it alone. But then I think, like if you were going to climb, let's say, Mount Everest, would you really say, I'm fine, I'm just going to climb this on my own? Like, no. You would train for it and you would have people around you to support you. And trying to get to a place of wellness is kind of the same. Like there's so many people there to help guide you. If you are brave enough to be able to bring it up and start that process.

Yahaira Rivera-Bobadilla:

Thank you for that beautiful and hopeful advice, Dr. Hendin. And with that said, how about if we continue our conversation and we talk about how can our participants elevate their well-being despite all the challenges of MS and mental health?

Dr. Holly Hendin:

Perfect. Yeah. So one of the first things that I say to any of my patients besides it's wonderful to meet you, so glad you're here, thank you so much for being here, let's talk about medications, and then getting them established with a therapist. But what I really like to talk about is wellness and the things that you could be doing or trying to do to really help create wellness. So there are physical things. There are things like trying to really cut down on substances. So I can't tell you how many patients I have that come into my office and tell me, I don't know why, but I just can't sleep at all. And then I say to them, How much caffeine are you consuming? And they'll say like, you know, like three pots of coffee all day long, up until like 8 p.m. And then I'll say, That's why you can't sleep. Or at least it's part of it, like caffeine will increase your anxiety and make it so much harder to fall asleep. So reducing caffeine, cutting back on alcohol, even cannabis, which can be very helpful. It's a personal subject, so it can be helpful for many people. But cannabis can also create, depending on what you were using, difficulties with racing thoughts and sleep and anxiety, paranoia, sometimes hallucinations. So really trying to bring the substances that you are utilizing on a day to day basis to a much lower level.

And then really engaging in a healthy diet. I know these sound like things that maybe your grandma would tell you, but it's true. Like a healthy diet, there are diets that can really lower your inflammation levels and help with your gut. And unfortunately, you know, getting rid of sugar and carbs or at least keeping them to a lower level really helps with that. Yoga, Tai-chi, chair yoga, mindfulness, meditation, these are things that you can really utilize in terms of lowering overall stress. And as you bring stress down, wellness kind of blossoms. So, if you're able to, getting some exercise, and it can be just walking 15 minutes a day, reaching out to a therapist, and then one of the things that I think that we've all really thought is something to make as a really critical point is keeping connections with yourself, with your family, with your therapist, with your neurologist, psychiatrist, friends. It just, it really makes a big difference to stay connected with others.

And if you are limited in mobility, then connecting online is perfectly valid. There have been studies that have shown that online engagement with therapy can be just as effective as in-person therapy. So and I would say connection to friends is the same. We have these days so much more ability to connect with loved ones with a video chat than we ever have. And so I

think sometimes it's difficult to start the process and you do have to kind of push yourself a little bit past your comfort zone and say, I look terrible today, I don't really want them to see me like this, or today is just not a good day, but you have to kind of make the decision - my wellness and my well-being are really hinging on this and this is important for me. So definitely staying connected.

And then I, you know, I'm just a really big fan of mindfulness and mindfulness practice. And I would say that there is a really wonderful book called "The Mindful Way Workbook." It's got like a little eight week program. You go through it on your own, you practice those... all of the little exercises that they provide for you. And it really is a way to check in with your body to calm yourself. And it may sound, again, maybe like a cliché, just calm down or do some yoga, but actually yoga and mindfulness really lower stress levels. And by lowering stress levels, again, like wellness just kind of blossoms up in its place. And so anything that you can do to ground yourself, I like to tell people like a simplest grounding technique I ever learned was to just close your eyes and then say to yourself, Where are my feet? That's it. You just say, Where are my feet? It's not even like, do I feel my feet or what do my feet feel like or anything. You just say, Where are they? And it just immediately, I don't know why, but it grounds you.

Another way to ground yourself and bring yourself back into the moment is thinking about your senses. Anything that you can touch, that you can hear, that you can see, that you can smell or taste will bring you back into your body. So in MS as with many chronic illnesses, I think people are not really wanting to be in their bodies. Like they're like, No, I hate my body. My body has betrayed me with this illness. But the more that you are able to befriend your body and connect with your body, that's where the wellness really is. And that's when the stress goes down. The pushing against things and the trying to say like, no, no, no, I don't want to get into my body. I hate my body. That's where stress rises. And then the kind of like, let me see if there's an avenue to befriend my body. That's where stress really lowers. So I know we're going very quickly over all of this, but I would say there are kind of like the guides that will help you get up Mt. Everest.

There are so many therapists out there, so many counselors who are just waiting for you to come into their office and say, I've heard about mindfulness. Could you teach me about it? Or I've heard about acceptance and commitment therapy. What is that? Or somebody in the chat mentioned DBT, dialectical behavioral therapy, another really wonderful, wonderful type of therapy. So I just want to kind of say and end this with there's so much out there right now for you if you take that step to reach out for it. And it really, all that takes is for you to show up into your neurologist's office and say, I would like a referral to a psychiatrist, to a counselor, please help me. And like I said in the beginning, if you're too shy to do that, you can Google it on your own. Psychology Today is really a wealth of information that you can also reach out to your insurance.

Dr. Barry Hendin:

As you say, Dr. Holly... So, first of all, thank you. That was really good. It shouldn't surprise you that in an MS neurologist's office, many of the same issues come up and many of the same answers with less sophistication. And so I see myself talking about exercise, but having to remind people, that doesn't mean you have to go to the gym and do something where you wear yourself out and can't function for the next two days, or over eat, but rather your 15 minutes walk, five or six times a week, that's exercise. Eating healthy. I tell people, I used to tell people about weight. I'm much more inclined today not to talk about weight, but to talk about healthy eating and that there is not one magic diet, but rather the concept that eating healthy has not just dividends 20 years from today, but dividends today in terms of mental well-being, physical

well-being, feeling more energy, feeling better. So exercise, eating healthy, staying connected should be part of what neurologists are talking about in their office with patients as well.

Dr. Holly Hendin:

I agree.

Yahaira Rivera-Bobadilla:

And speaking about that, we received a question, What happens when my neurologist doesn't hear me or he just gives me 9 minutes for a consultation and I'm not able to share these issues with that doctor? What can they do?

Dr. Barry Hendin:

So that's... it's a sad reality. So I have sort of two answers. One is that, general neurologists, right now, have very significant time restraints. It is common for general neurologists to have 15 minutes for patients. And when you have gotten done talking about the MRI and the disease modifying therapy and maybe one other subject like your bladder, there's not much time to talk about more. So I sympathize with patients and I sympathize with general neurologists, the patients who don't get the answers and the neurologist who doesn't have the time. So I would say that most MS neurologists do, in fact, spend more time as a matter of course, we certainly do in our office. And that is what we think is the most common pattern across the country. An MS-focused neurologist tends to set aside more time. And the other answer is when you have a neurologist who doesn't listen, you've got the wrong neurologist. So, I hate to take to say that, but there are things... I began the conversation with the statement, You need to expect more from us. You need to expect more from us. And if you don't get it, it may not be the right fit. Holly. Dr. Holly.

Dr. Holly Hendin:

I agree. I would say it's perfectly fine to actually say to the neurologist, I have more that I want to talk to you about. What should I do about that? And then they will probably say to you either, well, let's talk about it right now, I have 5 minutes or 10 minutes. Or they will tell you, let's set up an appointment for next week or two weeks from now or whenever they have availability, which sometimes can be a little bit challenging. But I would say that in terms of like this slide and advocating for yourself and your voice matters, I would say that healthcare really has become increasingly the system that is really minimizing the amount of time that doctors have to spend with patients. But I always, always want my patients to be telling me what they're experiencing.

And I agree that you've got a good position or neurologist or psychiatrist if they want to hear from you. And if you bring something up and they seem to be kind of minimizing it, then you might need a different provider. That being said, please advocate for yourself. I think your voice and your advocacy will serve you well, and it kind of goes back to that original question about like, what if my family thinks I'm just grandstanding? I would say, tell your family I'm not just grandstanding. Like this actually is important and I need to bring it up. And, you know, if for whatever reason your provider is not receptive, then you find you advocate for yourself by... you vote with your feet or with your Telehealth and you go see a different provider and find somebody that maybe has more time to spend with you.

Dr. Barry Hendin:

I liked your answer very much. And your answer began with advocacy. And that is first to say, there's more I need to say, there's more I need to hear, more that you need to hear. So a lot of it begins... in our office, we have a face sheet that lists all the problems the patient may have. And

so I have a GPS, I know what to focus on. But otherwise, if you're depressed, you say so, if it's your bladder, you say so, and if there's not enough time, you say so. And if you're listened to, you're in the right place. If you're not listened to, you can vote with their feet.

Dr. Holly Hendin:

Yes. And I would say the opposite to when your provider, and it doesn't matter what provider we're talking about here, but when they do listen to you, I would say that really thanking them for that, it just helps to train your provider to do it more often, to ask the question. I always try to ask at the end, like, is there anything else we haven't covered? And if they start to bring up something new at the very end, then I'll say that's really important. I really want to talk to you about this. Let's make an appointment as soon as possible so we can keep going on this if we're out of time. And if we're not out of time, then I want to hear, I definitely want to hear about it.

Yahaira Rivera-Bobadilla:

I love that. Thank you so much. Great advice and great information. With that said, we can continue with our presentation. We have about 10 minutes left and we would like to go over some advice for our audience about supportive connections.

Dr. Holly Hendin:

Sure. So I think we touched on this earlier and it really is, it really is not to be downplayed that connections can really be important for everybody, not just people who are struggling with depression or anxiety or people who have been diagnosed with a chronic illness, but everybody benefits from connections. And people who have a chronic illness or people who have been diagnosed with MS I think will benefit the most in terms of really not... I think what happens with an illness is that you not only feel like you are the only person in the world who has this illness, although you know it's not true, but you feel that. And then in response to that feeling, there's an isolation. So again, kind of like with the advocacy, just know that it's normal to kind of isolate and it's normal to feel like you are the only person. But there are 189 other people here today, or maybe minus the four of us, so 185 other people. And that's just a small amount of people who are going through probably almost exactly what everybody else here is going through. So know that you are not alone.

Really make the effort to build a community around yourself if you can. If you have a really wonderful friend who can organize something like that for you, or a really wonderful partner who could organize kind of a community for you, then I think it's really important to kind of capitalize on that, if you can. I would say that the more that you put into your relationships, the more you will get out of them and that if you don't speak up and let people know that you want to spend time with them, then it's possible that they might leave you alone, especially if you are kind of giving off a signal of "I just want to isolate. I'm not feeling good." So, it's almost like taking a medicine, like it's scary and most people don't want to do it even if they know that it's good for them. But trying to build connections wherever you can and then trying to take the steps on a daily basis for connecting with at least one person. That being said, it could be almost anybody. I mean, the best connections are the people where you feel really seen and heard and validated. But if you go into a coffee shop and you say to a barista, I really like your hair, or this coffee is amazing, you would be surprised, people actually want to connect. We are humans, we're designed to connect with each other.

And so looking for those small connections everywhere versus this idea of like, I'm alone, I'm isolating, nobody wants to be with me. It really is kind of like, can I shift my thinking to what would happen? Sometimes I'll tell my patients, like, just do it as an experiment. This is kind of

like, what would happen if...? If you told that person at the supermarket that you liked their sweater or if you called up an old friend that you haven't spoken to in a while, or if you sent a text to somebody saying, I'm so grateful for you... what would happen? And almost always it's positive. So it really, again, it sounds like maybe something your grandma would tell you. But it's true that having connection and support really, really does help you out in terms of overall well-being. So if it doesn't come naturally to you and if you aren't feeling like you're in the mood, then think about it like a medication or think about it like an experiment and just see what would happen, what would happen if I did that. And then you never know, but almost always it's positive. That being said, I would say if you find a therapist, therapists are really, really good also about not only providing a connection but also helping you foster connections in your life. So that's another avenue.

Dr. Barry Hendin:

Wonderful. I agree entirely. I think we are born that way. And I think that it's something we should further, It's natural, but even when it's unnatural, we should do it.

Dr. Holly Hendin:

Yeah. And even if it's, you know, over a, you know, a video call or even if it's a phone call or even if it's a text, it's not ideal, you can't see them and touch them and hug them, but it's something. So trying to add little bit of that everyday to your life will pay back. People will then start connecting you, or getting back to you, and then connecting to you in that same way that you're connecting.

Yahaira Rivera-Bobadilla:

That was just wonderful. Great advice and a great way to take this message as a takeaway message for tonight's program. We have about 3 minutes for Q&A, and we appreciate that you have been addressing questions that they submitted during registration, during tonight's live webinar, so thank you so much for taking the time for answering questions. We have one question that caught my attention, and it's about - please explain ways to find happiness and move forward with this disease. Letting go of the past and the life that I had once. So what would you recommend to this person? What is your advice?

Dr. Barry Hendin:

Dr. Holly?

Dr. Holly Hendin:

I mean, for me, that question is really about grief. It's how do I grieve the loss of this identity that I had, that maybe I still have, but I don't feel like I have. How do I grieve my career? How do I grieve this future that I thought I was going to have? And so grief ebbs and flows. The pain stays with you, unfortunately, it is just part of being a human and being a loving human. But the more that you build around the grief, then the grief doesn't get smaller, but it gets smaller by comparison because you build a life around it. So first and foremost, connect with a therapist, I would say, and really start to think about grief and grief processing.

And then gratitude is another practice that I think is just so important, letting people know that you're grateful for them. Again, what a connection builder that is. And it also feels good for you. But in this case it would be: Can you find gratitude for where you are right now? Are there things that you are grateful for right now that you can start to build from, to start to rebuild? This is the future that I still want to have. And that's kind of part of that acceptance and commitment

therapy that I was talking about. So grief therapy, acceptance and commitment therapy. There's some really good trauma therapies out there as well.

Dr. Barry Hendin:

Yes, I agree. By the way, this is not quite the answer to the question, which I think you, you answered beautifully. I sometimes say that at some point in my life I'd like to edit a book, not write one, but edit a book in which my patients, now age 30 or 40 or 50, could write to their younger selves and say, This is what I thought the day I was diagnosed with MS, and here's what I've learned. And so many will say to me, the journey I feared wasn't really... it didn't come to pass. I thought it would be so much worse. And even when people have had hard times, there's often gratefulness built in. And that is, I've learned to survive it. I've learned to overcome it. And so there's something about the human condition with gratefulness and a little wisdom that allows us to look back in a more circumspect and grateful way. Happy way. Someday, maybe I'll edit that book. But it really is the letter of patients to their younger selves, people with MS to their younger self saying, This is what I've learned and it wasn't as bad as I thought it would be, it was much better than I thought, in most cases, and often I've been very grateful for the lessons learned. And often, the odd statement, I've been grateful for my MS. I've been blessed. So you may not expect to hear that one, but you do periodically, that life can be looked at from multiple perspectives. Gratefulness helps.

Yahaira Rivera-Bobadilla:

I love that thought about the book and like telling yourself, Dear younger me, What have I learned with MS? Thank you so much, both of you. Once again, on behalf of MSAA, thank you, Dr. Barry Hendin and Dr. Holly Hendin for this candid and wonderful conversation about mental health and multiple sclerosis. We are grateful for both of you for your time and effort for all the insights and tools that you shared with us tonight.

Yahaira Rivera-Bobadilla:

Thank you to our wonderful audience for participating, for being engaged with so many questions and comments in the chat. Thank you so much. We hope that this program has brought meaningful knowledge and tools to help you continue elevating your physical and emotional well-being and building resilience and building supportive connections in your MS experience. This concludes our webinar. This program was recorded and will be made available on demand on MSAA's video library within the next couple of weeks. Please take a few minutes to complete the brief survey, which will appear on your screen momentarily. On behalf of MSAA, thank you everyone, and have a wonderful evening.

Dr. Barry Hendin:

Thank you.

Dr. Holly Hendin:

And thank you, too.