



Living Your Best Life: Tips and Coping Strategies for Those Living with MS and Their Care Partners

Presented by:
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Melissa Barnhill:

Good evening everyone. Welcome and thank you for joining MSAA's live webinar Living Your Best Life: Tips and Coping Strategies for Those Living with MS and Their Care Partners, presented by Elizabeth Nager. My name is Melissa Barnhill and I am the Director of Mission Delivery and Community Engagement for MSAA and your host for tonight's program.

Just a little background about MSAA and some housekeeping items before we get started. As you may know, MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the entire MS community. Our services include a national helpline, providing English and Spanish services Monday through Friday, 8:30 a.m. to 8 p.m. Eastern Time, as well as an equipment and cooling distribution program with products designed to improve safety and mobility and to help with heat sensitivity. In addition, MSAA offers an MRI access program for individuals with MS who qualify for assistance. We also have educational programs, webinars, and on demand videos, online tools, publications and digital resources that includes the just released Ultimate Treatment Guide, which is now available on our website. This interactive guide describes and compares 19 FDA approved MS treatments and will help people living with MS make informed decisions and choices. MSAA also offers support through community connection to help you stay connected with other members of the community. All of our programs are available on our website at mysaa.org or give us a call.

During tonight's program, you will have the opportunity to ask questions by typing them in the chat box. We will do our best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and it helps us in developing future programming and content. A link to the survey will also be included in the chat box. Please know that this program is for educational and informational purposes only and does not constitute formal recommendations. Please speak with your doctor or healthcare provider if you have specific questions or concerns.

Now, without further ado, I would like to introduce you to our speaker this evening. We are extremely grateful to have Elizabeth Nager join us tonight. Ms Nager has specialized in working with people diagnosed with MS since 1982. She provides therapy to individuals, couples and

families. She has led groups for both people newly diagnosed with MS and people experiencing progressive disability due to their MS. She also led therapy groups for caregivers who support people severely disabled by MS. In addition to working with people who have MS, she also works with patients with other neurological diseases. Elizabeth enjoys working with people who are motivated to create healthier patterns of coping to their current life challenges. Welcome, Elizabeth.

Elizabeth Nager:

Thank you so much, Melissa. I truly appreciate that introduction. And I want to thank MSAA for sponsoring this event this evening, and to everyone who has logged on to the discussion this evening. So everyone here this evening has signed up for a talk on living your best life. And I'm going to start with a question for everyone who is here this evening. What is your best life? How do you define this? Now, there's no magic wand here. No one has won the Powerball drawing. Either you still have MS or care for someone with MS. We still have winter, and certainly where I am, it's about ten degrees going down to five degrees tonight. And your in-laws are still your in-laws. So I want you to think about how would you describe your best life?

Now, I expect that each person will have a different answer, but there will be common themes. So what is your best life? I've come up with a list of questions to help you think about what this means to you specifically. So let me start with what part of your life do you enjoy? What makes you happy? What brings you joy? What are you really good at? How do you spend your leisure time? What activities relax you? And spending mindless hours on the computer does not count, because there are way too many people spending too many hours every day on devices as life passes them by. Is there something that you truly want to do? Are there dreams or goals that you have ignored in your life? And what stops you from following your dreams? What is holding you back? And what will motivate you to change? Is there anything that you regret not doing? Are there things that you do but don't like doing? And what are the things that you like to do but have not been doing? What do you want to change in yourself? What do you think you need to improve on? What makes life meaningful for you? What is most important in your life? And what is one thing that you can do right now to change your life for the better?

I realize this is a big list of questions, but I think it's really important that we identify what truly is my best life. Too many people go day by day, and certainly we all have cooking, cleaning, laundry, grocery shopping and putting one foot in front of the other. And it's a week, it's a month, it's a year, and all of a sudden it's five years and we've gone through the motions without really thinking about what is my best life. So I'd like you to consider if you knew you only had one year to live, what would you change about your life? It's a pretty profound question. If you had only one year to live, what would you change about your life? And whatever the answer is, I would like you to consider what is stopping you from making those changes right now. Can you make these changes starting today? And what would be a good first step? If we don't identify it, it will never happen. So we need to first identify the very basics, what is your best life?

So it's really hard to live your best life when you feel overwhelmed with stress. And this past several years with COVID and politics, I don't need to tell all of you what stress feels like. And that's on top of the normal stresses of living and the stresses of having a chronic illness. Many people cope by drinking or other drugs, by compulsive shopping, by gambling. But these certainly would never be considered healthy ways of coping. So I've made a list of ways that we can cope in much healthier ways. And I'm going to go over this list, but I'd like to first start with an exercise, a breathing exercise. So we can go to the next slide.

So I'm going to teach this strategy. It's pretty quick. And what I like about it is that it's easy. You can do it any time or any place. There's absolutely no cost to this. No equipment needed and no side effects. So I want everyone to sit comfortably in your chair and we're going to go over a three step process to learn this breathing technique. It's called diaphragmatic breathing. I want everyone to put your hands on your belly, get comfortable, just hands on your belly. And I want you to breathe deeply through your nose. And as you breathe in, I want you to pretend that your belly is a balloon and you're blowing up that balloon. So I want you to take a couple of breaths now, breathe in through your nose and make sure that your belly expands, really expands.

So try this a couple of times. Belly up and down where you can see your belly expanding, where you can feel it that your belly is expanding. The reason why we do this is that we want to be breathing deeply. We want to breathe the way babies breathe naturally and the way animals breathe. As life gets stressful, as we come into adulthood, all the stresses, we start breathing in a very shallow way and we stop belly breathing. And guess which is the healthier - the way babies and animals breathe, truly emptying your lungs completely by doing that belly breathing. So again, in through your nose. Breathe deeply. Belly up and down.

Now, I'm going to add something to this. I want you to breathe in through your nose. Hold for a few seconds and breathe out through your mouth and breathe out like you're blowing out birthday candles. In through your nose. Hold. Breathe out through your mouth, hard, like you are blowing out birthday candles. And you can still feel your belly going up and down as you breathe in and out.

Third part of this, as you breathe in, I now want you to think the words to yourself, not out loud, think to yourself "I am..." hold and breathe out and say the words to yourself "...in control." So we're going to do this three times. Breathe in through your nose. Hold. Breathe out hard, like you're blowing out birthday candles. Second time. Breathe in. Think the words "I am..." Hold. Breathe out, "...in control." Third time. Breathe in. "I am..." Hold. Breathe out, "...in control." Take a second here and think, how do you feel? Is there any difference with doing this very simple breathing technique? Now, again, we want to breathe in deeply. We want your belly to go up and down because as you do this, you're actually stimulating your vagus nerve, which helps your body to go into the rest and relax phase. Simple technique, again, that you can use any place.

So for both people with MS and their care partners, I have come up with a list of, again, strategies that will help to manage stress in a positive way, in a healthy way. And as I go over this list of healthy coping skills, I would like you to consider how many of these suggestions are you currently doing, and which one of these tools would be fairly easy to incorporate into your life? So the first one we went over already, and that is diaphragmatic breathing. Next one, can you allow time for reflection in your life? Ask yourself what is missing from your life and what would it take for your life to be fulfilling, meaningful and productive?

Do you make time for friends? Is there an old friend that you would like to reconnect with? Do you call friends to both celebrate the successes, the good times in life, and to talk about the challenging times in life? It's interesting, when I ask my clients this question, many times, the answer is, I don't want to call my friends when I'm down. I don't want to be a burden. But I'm happy to listen to my friends when they're going through a tough time. Most people, when it's a true relationship, do not mind that "give and take" with friends, of listening to both the good times and the challenging times. That if it's a true, genuine friendship, you are not being a burden. Even more so, being emotionally open and vulnerable is how we truly connect with other people. There was a study in 2015 that said Loneliness and social isolation increase the

chances of premature death by 50%. Fifty percent. And isolation is as damaging to your health as smoking 15 cigarets a day. That's pretty powerful. We all need other people in our lives.

Can you write in a journal? This is another way to get the emotions out versus keeping everything bottled up inside, which we know is not good for you. Can you pursue your passions and activities that you love? When was the last time that you had fun? Kids have fun all the time. When you listen to kids playing outside, you listen to the laughter, and it is so wonderful to hear. When was the last time you had a good belly laugh or laughed to the point that there were tears streaming down your face, that the situation was so funny? This certainly is harder in the pandemic, but not impossible.

I'd like you to be able to identify your strengths. What has worked for you in the past? When you are under stress, what can you do that you know will relax you? Know your vulnerabilities and triggers. Most people are not at their best when they're hungry or tired or overwhelmed, and family often gets the brunt of these nasty emotions. Alternative options include telling a family member, "I'm not in a good place right now." Asking for what you need, which might be "I need time alone, I need to work through this, I need a hug," or "can we please talk? I just need to sort this through." And you begin each day by identifying a daily goal. What is the priority of the day? Again, if we don't identify and set goals both for the day or for life, there's too much of a chance that life will pass us by and we'll get to the end and have regrets.

So what is the priority each morning? And if fatigue is an issue, you need to be careful about not adding too many things today and certainly being able to pace yourself through the day. Now many people with MS, if fatigue is an issue, and especially if fatigue is just starting to be an issue, many people will try to fit everything in to the morning, when people with MS generally have more energy. And so it gets to be noon, 1:00, And of course, they are exhausted. And what we find is that for everyone, but especially for people with MS, that if you take breaks, you're going to accomplish much more during the day than if you try and do everything at once and exhaust yourself. So, for example, you want to work for 45 minutes and maybe take a ten or 15 minute break. Again, be active for about 45 minutes and take that break. And if you do this pattern throughout the day, you will accomplish much more by adding in those breaks.

I encourage for coping that you make yourself a priority. You cannot be a good partner if there is no time set aside for yourself. And this is true for both partners. And I want to remind you what happens in the airplane when the beginning announcements are being said and they talk about if there's an emergency and the oxygen masks come on, who do they encourage to put the mask on first? It is you. You take care of yourself first so that you can be there for other people.

Can you make your relationship a priority? Make time for your partner. Make time to communicate. Not talking can be misinterpreted easily as not caring. And we certainly know you can be encouraging without coming across as nagging or blaming, especially if you focus on being kind to your partner. Oftentimes in life, we're more polite to strangers than we are to the people who we love. So can you develop the pattern of being kind to your partner more often? And as you are striving to live your best life, can you help your partner to live their best life also?

Another strategy for coping - recognize that you do not have to be perfect. It's okay to ask for help and it is okay to receive help. And this goes for both partners. I'd encourage you to look at your ability to adapt to change. Are you rigid or flexible when it comes to necessary changes? For example, if your neurologist told you that it was time for a cane or time for a self-catheterization, how would you respond to that? Now, again, there's going to be shock initially and the inclination is, no, no, no, not me. But over a short period of time. Are you flexible and

accepting the resources and the tools that really will help you to live a better quality of life? And again, this goes for both partners. If your partner with MS starts using a cane, as the well partner, how do you see this? Is this an embarrassment or do you understand this is a tool that your partner needs to live a better quality life?

And I would encourage you to look for ways to improve your life on your own. Do you set healthy boundaries? Do you need to be more assertive? Can you say no to others when life gets too busy or when your energy is down? Can you exercise on a regular basis? Can you walk, bike, yoga or chair exercises? And I've heard hundreds of people through the years tell me, "I can't exercise, I have MS. My energy level is terrible as it is. There's no way I can exercise." But what we know is that exercise increases your energy level. Not only that, but we know that exercise will help with sleeping. It will help with your mood. It will help with constipation. And how many people with MS suffer from constipation? Exercise decreases pain perception by releasing endorphins and exercise also helps memory by increasing the blood circulation to the brain. Those are tons of reasons to start exercising, if you are not already, let alone the reasons of trying to prevent other chronic illnesses or conditions that can happen as we age, like heart disease and high blood pressure.

And so, speaking of health, are you getting enough sleep? This is another healthy pattern that not only will help you physically and mentally, but can help to stave off problems in the future. We want to strive for the range of sleeping about ten at night to seven in the morning. And there's something called good sleep hygiene, which you can Google. But one of the basic premises of good sleep hygiene is that there needs to be a routine. You need to go to sleep at approximately the same time each evening and wake up at approximately the same time each morning. And it doesn't matter weekdays or the weekend. But you want to try for approximately the same time and don't get out of whack with what's called your circadian rhythm. Human beings are meant to be awake when it's light out and asleep when it is dark out. Think back to the caveman, that is what comes naturally and what we should be doing. If you get less than 6 hours of sleep for one night, we know this can disrupt both your mental and physical well-being. One night of less than 6 hours of sleep. If, for three nights in a row, you get less than 6 hours of sleep, there will be a decrease in the positive emotions, an increase in the negative emotions, and there will be an increase in the severity of physical symptoms. Those are mighty fine reasons to work on your sleep hygiene.

Most people also can do with drinking more water. Many of us are walking around, slightly dehydrated, and dehydration makes people feel tired. It makes us have trouble concentrating and trouble focusing. It makes us have poor mental and physical energy. There are many people who have headaches where the headaches go away if the person just starts drinking more water. Being slightly dehydrated can also cause people to be moody and irritable. And if you take lots of pills, and most people with MS are taking several medications, I encourage you to take these pills with a full glass of water. Not only is this another time of the day that it's easy to get more fluids into you, but if you do not drink your... excuse me, take your pills with a full glass of water, you are more likely to come down with a good case of acid reflux. Take your pills with a full glass of water.

Obesity in adults with MS is associated with more rapid disease, worsening, and disability. You need to watch your weight. Childhood and adolescent obesity, which means a BMI of greater than 27%, doubles the risk of, kids who have a parent with MS, doubles the risk of being diagnosed with MS. You need to be careful about healthy eating patterns, and part of healthy eating patterns means don't skip meals, food is energy for your body. So I propose to you that you look at - can you improve what you eat by 10%? I'm not asking for a total change. Can you

increase foods that we know are good for you, fruits, vegetables, grains, can you eat 10% more of these and can you cut out 10% more of the junk? Whether that's chips, sugar, whatever it is that you know is your downfall. Can you cut out 10% more and increase the healthy foods by 10%? I had a client that I spoke about eating and this very topic of improving the diet by 10% last week, and this week in our meeting he said, Well, I'm still eating at the fast food restaurants occasionally, but instead of getting fries, I ordered a side salad this week. That is success. You don't need to cut out everything that you consider to be not the best. But we're looking for improvement here.

Research shows that people will have better mental health if we spend 2 hours a week in nature. Now, wouldn't that be nice if we all lived on a nature reserve or had the ability to go hiking at a beautiful state park every week for 2 hours? Doesn't happen always. But can you get outside a little bit more and just be aware of the flowers and the trees around you? We just had a major snowfall in Minneapolis yesterday. And despite the slippery roads, it was absolutely gorgeous outside. If you can't get out and walk in nature, can you sit at a window and look at the trees? Look at the blue sky. Look at the cloud formations. And if you can't do that, the research showed an incredible thing - if you even look at a picture of nature, you will benefit from this.

Research also shows that the brain lights up with music the same way that it lights up with drugs. Isn't that incredible? Listening to music lights up the brain the same way as people getting high on drugs. Do you have a sense of spirituality in your life? Now, this might involve organized religion, or not, but I think spirituality gives us a way to find peace and calm in this chaotic world and being spiritual allows us the belief that we each matter and that we are all connected.

Another coping strategy is to figure out what you can and cannot change. And what you can change, can you take action on this? Can you identify goals for the next six months? One year? Three years? Five years? And as you're setting goals, make the goals reasonable and specific. For example, if one of your goals is to be healthier, what would be reasonable and what would be specific? So let's say you choose. I want to lose 5 pounds. That would be reasonable and specific. And you want to make sure in setting these goals that your choices support your goals. So let's say again, it's that 5 pound weight loss, are your food choices supporting those goals?

Recognize that you always, always have choices and options. You cannot change having MS, you cannot change your partner having MS, but if you feel like your doctor isn't listening to you or just doesn't get you, you can change your doctor. It's amazing how many people feel that once they start with a neurologist that they can't hurt their doctor's feelings by changing and going to another neurologist. Yes, you can. This is your life and we are trying to form the best life possible. And if your doctor is not a good match for you, then absolutely you can change your doctor. You can also change your friends if they're not supportive. And you can, again, going back to diet, change to eat healthier because you are what you put in your body.

Be honest about your attitude. In the beginning, most everyone feels shock and sadness with an unexpected diagnosis of MS, and this is for the patient and the family members. However, years later, do you still feel "poor me?" Are you coming across to others like a victim? Does there need to be a change with how you view your life? Because nobody has a perfect life and I think about the response often is, Oh, but if I just had more money, my life would be better. Even Bill Gates a year ago, with how much money, wound up getting divorced.

My final point that I'd like to make is about gratitude. Just as hard things happen in life, there are also good things happening all the time. There's an old teaching that says: "Who is a wealthy

person? One who is happy with their portion.” And again, everyone has challenges in life. It's easy to forget to appreciate what we do have. This does not contradict our desire to do better or to be better, but it is both. We can set the goal of working on ourselves and our relationships as we also appreciate and give thanks for what we do have. So I'm going to propose that you spend time each day, either morning or evening, and identify three things that you are grateful for each day. And I find in the morning it's a nice way to set the tone for the day. Or if you choose the evening, it's a nice way to end the day. And I have a belief that if you end the day by thinking about three very specific things that you are grateful for, that it will help your sleeping, that you will have a better quality of sleep.

So I think we have time here. I'd like to go through, very quickly, what is called a progressive muscle relaxation, because I want to give some very specific bodily tips for coping with stress. When you are feeling that the stress level is sky high, along with the breathing, this is another technique that you can use. And in fact, I'd like to combine the two that, when you are stressed, I recommend that you start with three breaths, like we practiced earlier this evening, again, holding your hands on your belly, breathing so that you can actually feel your belly expanding, breathe in through your nose with the thoughts, “I am...” Hold. Breathe out with the thought, “...in control.” I am in control. So I'd like to start this progressive muscle relaxation with three breaths. And now we're going to walk through this very quickly. So I would like everyone to sit comfortably, sit or lay down wherever you are, and just try and get as comfortable as you can. And now I'd like you to follow my voice. And if your mind wanders, that's okay. Just bring yourself back to my voice as soon as you realize that your mind has wandered.

Okay, so we're going to go back and forth, one side of the body to the other. And we're going to start with your right foot, left foot, and we're going to work our way up the body. So get comfortable. Again, normally I would have you do the three breaths, but for the sake of time, we're going to bypass that. And I would like you to either close your eyes, or if you would like to keep your eyes open, that's fine, but I want you to think about the toes on your right foot relaxing. And now the toes on your left foot. Feel those toes as best you can. Feel your toes relaxing. Now your right foot. Try and relax the muscles in your foot. Right foot, and now left foot. We're going to go up the body to your right calf and now your left calf. Feel the muscles in both of your calves relaxing. Up to your right thigh. It's a big muscle group. Try and allow the muscles and your right thigh to relax. Left thigh, relax, relax completely. Now feel the relaxation as if you're pulling on a pair of pants. Feel like going up your body - feet, calves, thighs, and now up to your waist. Feel the bottom half of your entire body relax, relaxing completely.

Feel that relaxation now, go up to your shoulders and allow the shoulder muscles to relax. Focus on your right shoulder, down your right arm, to your elbow, to your wrist, to your hand. Feel that right arm totally and completely relaxing. Back up to both shoulders. Left shoulder. And now the relaxation down your left arm. Feel from your left shoulder to your elbow to your wrist. Down to your fingertips. Back up to your shoulders. Feel those shoulders relax. Now the back of your neck. And feel the relaxation going up into the back of your head. Now, around the top of your head. And now feel the muscles in your forehead. Totally and completely relaxing. Feel the muscles around your eyes relaxing. Feel your cheek muscles relaxing. And now down to your jaw muscles. Feel your total body completely relaxed. Feel your body as it is relaxing, relaxing completely. Now, just take a moment and be aware of how this feels. I went through it a little faster than I normally do for the sake of time, but do you feel different in any way from when we started? And is this something that you can add into your life when the stress level feels like it is sky high?

So let's go back to the title of tonight's talk, "Living Your Best Life," and I'd like you to consider what bad habits do you want to break? What good habits do you want to increase? And only you can make these decisions for yourself. But I believe all of you have the potential to make your life more meaningful. You don't have to feel as if you are existing day to day. It is possible to truly live your best life and to help your partner live their best life also. So with that, Melissa, I think we can open up maybe to some questions.

Melissa Barnhill:

Yes. Thank you, Elizabeth, for the informative presentation. Now to continue the conversation, we're going to go ahead and make some time for questions. We have a lot that were shared during the registration process in tonight's program. The first one is what is a good place to turn to for a new therapist?

Elizabeth Nager:

Great question. Great question. Okay. There's lots of therapists out there, and as in every single field, there's excellent, very good, good, fair and not so good. And so two places I'll start with - one is ask your doctor. Because for people with MS, you want someone who understands MS, and the reason for this is so many of the symptoms of MS are almost identical to the symptoms of depression. And so you want someone who truly understands both depression and MS. And I'll give you an example of this: fatigue, obviously, can be a symptom of MS, but fatigue can be a symptom of depression also. But for a therapist who understands both, they understand the difference. For example, with depression, oftentimes a person will wake up and just want to pull the covers over their head. A person who has MS fatigue, they wake up and they've got energy and they're busy and about three in the afternoon, they're done. Those two different kinds of fatigue are very different. So you want a therapist who understands it. So I recommend talk to your neurologist. Talk to your general practitioner. If you belong to an MS support group, ask who people in the group are using and are they happy with that person. And you may also want to call your health insurance for therapists that are covered under your insurance, because people with specialties tend to say what their specialty is to the health insurance companies. So that's another way to find a good therapist who specializes in chronic illness, but in MS specifically.

Melissa Barnhill:

Great. Thank you for that. The next question is, "My caregiver is my husband. What tips can you suggest to have your partner feel appreciated day by day?"

Elizabeth Nager:

Another great question and I would start by asking you a question. How many times do you say thank you to your husband? It's such a simple thing, but we do not often show our appreciation to the people who are around us the most. We're more likely to say please and thank you to our neighbors and strangers, but not the people around us. So again, that simple, please and thank you. And the occasional "Boy, I really do appreciate all that you do for me. I'm glad that we're in this partnership. I'm glad that we're in this marriage." It goes for many people. I want to say that it goes without saying, but it doesn't. As human beings, we need to hear those words. And also, for the person with MS, what are you doing to show appreciation to the caregiver? What are their special things that would make life better that you can do to lighten their load or to make their day just a little bit happier?

Melissa Barnhill:

Great. Thank you. This one is similar to that one: “How do you get over the feeling of guilt that your partner has to do so much of the things you can no longer do?”

Elizabeth Nager:

Great question again. I think part of it is what we just talked about, showing appreciation, having a good attitude, being able to communicate that life has not gone the way that you planned, that when you got married and walked down that aisle, it's easy to say those words “for better and for worse,” however, we never really think about what “worse” will be, because you're young and pretty naive. And at that point, life looks like it's always going to be pretty much stress-free, and then the stresses start happening. So how do you get rid of guilt? By being able to talk about what life has brought. Because in the... over the course of the years, the decades together, oftentimes one person carries the load a little bit more than the other one, but over time, it changes. And usually in relationships, one person may be doing more of the physical work, but maybe the other person is stronger emotionally. But it's being able to talk about what you both bring to the relationship, what you each need from the other person, and what you're each grateful for that you receive from the other person.

Melissa Barnhill:

Great. Thank you. Another question is, “When you have spasticity, it is hard to relax those muscles. Any techniques for this?”

Elizabeth Nager:

So, spasticity is difficult with MS. So, one of the things that you can do is to try and do these exercises after you take your medication, or an hour afterwards, so that it is when the medication is at its peak effectiveness. Also, I'd recommend, what also would help you specifically to relax. Like, I went over shoulders, I spent even more time on shoulders, probably because that's one of the ways that I will manifest stress in my body, is my shoulders get so tight. So oftentimes I will do this progressive muscle relaxation. But sometimes I'll ask my husband, can you please rub my shoulders? And then after he's done it that my shoulders are a little bit looser, then I will do the progressive muscle relaxation. So I would say try and time the medication when you do it.

Another might be if you can use something that is warm, if that helps your spasticity. And again with MS, you have to be careful, for most people, about not overheating, but can you use a heating pad on warm? Can you put a sock with rice in it in the microwave for just a few minutes and use that to try and loosen up those muscles and then really focus on relaxing those muscles. Now, the first couple of times, it's not going to be so effective, but if you do the relaxation exercises every day for two weeks, my guess is you'll start to feel something.

Melissa Barnhill:

Thank you for that. Here's another one: “How do you stay positive with this disease? Newly diagnosed and have really bad days and can't talk to family?”

Elizabeth Nager:

Ah! Can't talk to family. I'd like to think that every family is wonderful, but that is not reality. So is there one family member in your immediate family that you can talk to? Is there someone in your extended family that you can talk to? Is there a good friend that you can talk to or do you need to reach out for counseling? But we all need people that we can confide in. And I'd like to say again, because I'm a therapist, if you cannot talk with family, would counseling help, would that help to improve the communication and the relationships?

Melissa Barnhill:

Great advice. "How can I disclose to my manager or superior that I'm having a bad day? Should I ask for those breaks at work as a reasonable accommodation?"

Elizabeth Nager:

Oh my! That is a good question. In my mind, that is a reasonable accommodation. And it's going to depend, probably, on where you work, on your specific manager, if it is a small company, if it's a large corporation, if it's a large corporation, you may want to go to the HR Department and talk with someone in human resources first to get their take on it, knowing that the HR department is also getting their paycheck from the corporation. And is that conversation going to be held confidential? But if you are a hard worker, if you are responsible and diligent and do a good job at work, I'd like to believe that most managers would allow those breaks, especially if they know that you are dedicated as an employee to the company and that when you're working, you are working hard and you explain to them that with the breaks you will be able to do more and longer. I'd like to believe that most managers would allow for those breaks.

Melissa Barnhill:

Okay, the next question is, "How do you get your team to realize that when you are out and about doing well then suddenly feel weak, that it's not personal?"

Elizabeth Nager:

So this, I think, comes down to describing MS to your family, and your family, I mean, every member of the family. And I recommend starting to talk about MS to your kids when they're young. And I've had clients say to me, Well, I think my kids are too young to talk about MS. How old are they? 16. 17. I recommend at about age three or four. Mom or dad has MS and that's why mom or dad's legs don't work well. And you just make it part of normal, because for your family, this is normal. This is your normal. So if you start out when the kids are younger, they will have a sense of this is just mom or dad. This is not me pushing them too hard. This is just mom or dad's body. But again, bottom line, talking with your team about "this is a good day, let's go shopping," or "I think I can manage an hour or maybe 2 hours," but first, it's being in touch with what you think you're capable of that day, and if today truly is not a good day to go shopping that you explain to your team, not today, but I'm going to try and go to bed early tonight because I know how important this is to you. And so I'm really going to try to be able to do this tomorrow.

Melissa Barnhill:

Thank you. "Any suggestions when you're having trouble going to sleep at night?" And this is our last question.

Elizabeth Nager:

So I think this is, again, a great question. And when there is the stress of living with a chronic illness, the stress of a pandemic, the stress of the politics, the stress of will the car start tomorrow? How much is gas going to cost tomorrow? I mean, there's so many things that go into causing an inability to fall asleep at night. So I like to do that progressive muscle relaxation. That's why I took the time to go over it tonight, because I think it is really important, and not only to relax our body so that everything functions at peak performance as much as is possible, but I believe that by relaxing the muscles that it will help you to fall asleep easier.

A couple other techniques. If there's something specific on your mind, some people find that if they write it down and then imagine that they're putting it in a bag or a box and they're going to

shut that box or tie up that bag and they're going to open it up tomorrow, but they don't have to deal with it now. And that you teach yourself, now is the time for sleep. It's time to shut off my mind and I'm going to go to bed right now. And it's important also for good sleep hygiene to make sure that you're doing the same routine every evening before you go to bed. Just like with little kids where you have them wash their face, brush their teeth, and three books. Now, what are you doing for that routine so that your body knows that you're getting ready to go to sleep? It's just as important for adults as it is for little kids to have that routine before you go to bed. And make sure that you're not on the computer four hours before bed. If you can be off the computer, be off. Looking at your phone for about 2 hours before bed, you will probably sleep better.

So those are just a couple ideas for sleeping. I noticed someone just wrote Chamomile tea or Sleepy Time Tea will help. Sometimes it's the camomile, for some people it's just drinking something warm before bed that will help. Some people, it's that warm glass of milk, it reminds them of things that they did when they were young before bed. But again, having that routine, if there's something on your mind, can you write in a journal? Can you talk to someone about it? So that when it's time to sleep again, you can set it aside.

Melissa Barnhill:

Wonderful. Looks like we've covered all the questions, and our time together has come to an end. Elizabeth, is there anything else you would like to share? Any last words or advice or takeaways for our audience?

Elizabeth Nager:

I would like to say that the words that I said tonight are not just words. I truly believe that everyone is capable of having a best life, and being diagnosed with MS or being the care partner to someone with MS does not mean that you will not get a best life. Life is so much more than just our bodies. It's appreciating what we do have. It's developing the relationships. It is setting those goals and meeting goals that allow us to truly have a best life.

Melissa Barnhill:

Once again, thank you, Elizabeth, for providing us with this insightful information about coping strategies for care partners and individuals living with MS. And to our wonderful audience, thank you for participating. This concludes the webcast. Tonight's webinar was recorded and will be made available on our MSAA MSI-website in the upcoming weeks. Please take a couple of minutes to fill out the survey that will appear on your screen and know that we are always thinking about the entire MS community and we hope that your families continue to stay safe.

Have a wonderful night. Bye now.