



Managing Expectations Through the Holiday Season

Presented by:
Kara Barton, MSW, LCSW

Marie LeGrand:

Good evening everyone and welcome to the MSAA's live webinar: "Managing Expectations Through the Holiday Season with Kara Barton." I would like to take this opportunity to thank you for joining us this evening. I'm Marie Legrand, Senior Director of Mission Delivery and Health Equity for MSAA and your host for the program. Before turning it over to our speaker for the evening, I would like to take this opportunity to go over a few of the services that MSAA provides and some of the housekeeping items.

Now, 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. Additionally, MSAA provides equipment and cooling products designed to improve safety and mobility and to also help with heat sensitivity. We also offer our MRI access program that will help cover the costs for individuals who are in need of MRI services and who qualify for assistance. We provide a variety of educational programs, including webinars such as this one, and on demand videos, online tools, publications and digital resources, that includes the 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 offers support through community connection to help you stay connected with other members of the MS community. To learn more about MSAA's programs and services, please do visit our website or give us a call to speak with one of our specialists.

Throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit questions throughout the program, and we'll do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future programming and content. A link to the survey will also be included in the chat box.

Please note that this program is for educational and informational purposes only and does not constitute as formal recommendations. Please do speak with your doctor or health care provider if you have any questions or concerns.

We're so extremely grateful to have Kara Barton back with us, who will provide us with ways in which to prioritize what's important and how to integrate rest into daily living and reduce challenges that occur outside of our day to day routines. She will also provide tips for managing stress around the holidays while living with MS. Turning it over to Kara Barton. Kara Barton is a clinical social worker at the Keck Medical Center of University of Southern California in the Department of Neurology and in Private Practice. She provides resources and referrals for neurology patients and their families and psychotherapy for individuals, couples and families. She has facilitated various support groups for caregivers and people living with epilepsy, multiple sclerosis, Parkinson's Disease, a writing group, a mindfulness meditation group, and is certified as a trauma-informed yoga instructor. Kara is one of the coordinators for the Parkinson's Center of Excellence, providing support and resources to people living with Parkinson's disease. She works from a strength based trauma-informed perspective with self-compassion and mindfulness tools to expand capacity for coping with the unknown and the unexpected. Kara finds joy in connecting with people and connecting people to resources that improve quality of life. She has developed and produced a short documentary, "We Live Among You," about ableism and the invisible symptoms of Multiple Sclerosis, which she hopes to expand to include more profiles of people living with illness and invisible symptoms. Welcome, Kara.

Kara Barton:

Hello. Welcome, everybody. I'm sorry I got stuck with a grammar intervention, and now I feel totally incompetent and I want to hide under a rock. So I'm a little afraid of starting now because I got segued out of my center. So I'd like to start first asking everyone just to take a moment to get grounded in where you are right now, because we are here. We've made it in front of our computers. Maybe you're in your car. Maybe you're hiding in a closet. I don't know. But we all just did our best to get here today. And so what grounding means is that you are able to center from your body with what is actually happening. So not from a place of worry or fear about what's happening.

So assess if you're safe. If you're feeling like there's a threat pending, then maybe you need to be somewhere else besides this environment. But if there is no threat and your nervous system is a little disregulated, just take a moment to feel your body sitting on this furniture or in the car or wherever you are, and locate your breath, take a breath, and notice what it feels like to just give yourself this time that we have together to honor the question of what do you usually expect from this time of year and what is going to serve you best in order to get through this and actually be in a good space?

So notice how you're sitting, where you're sitting. Notice what your breath is doing. And maybe if you're feeling a little off center, just take a couple slow breaths and you can bring your parasympathetic nervous system in to... like a parachute, I remember it with a parachute... to calm yourself down. You know, whatever you have to do, whatever you were doing before you got here, and whatever you have to do next, you don't have to be doing right at this moment. So just allowing yourself to take a break and give yourself this time to be here together and focusing on what does this even mean to manage holiday expectations.

So I am a social worker, a licensed clinical social worker, and I am located in Los Angeles, California. And I have been working in the Neurology Department at Keck Medical Center of USC for, I believe actually this week, maybe yesterday was my 16th anniversary of working here. I work across divisions and diseases, but MS is pretty dear to my heart. So I run a support group and I work with a lot of people who are living with MS. And one of the reasons I picked

this slide is because whenever I'm out in nature and I look up at the sky, it reminds me how small my life is. It reminds me that we're all floating through space together on this planet, and we don't even know the half of it, right? Like we... every time they develop a new shuttle that goes out in the world and looks deeper into the universe, we figure out that we're even smaller than we thought we were. So looking at the night sky can actually be a reminder of how small our world is. And yet we're obsessed with ourselves, right? Because we're trying to stay afloat, spinning on a planet in the middle of the universe. So I think it's a good idea sometimes to get some alternative perspectives.

So this is such a challenging time of year for so many people for so many reasons. And so what is ahead is a way of asking yourself here, you know... we're in it, right? Like we did Thanksgiving. Halloween is over. And we have all these other holidays that are coming up. And depending on your belief system and your family orientation, you may or may not be participating in these things or you may or may not be able to do it the way you always have. So what I like about thinking about this now is you can plan, you can actually strategize for how you're going to do this.

When I talked about getting grounded in your body and in the present moment, you know, when we take time to plan and to strategize with an understanding of where we're coming from and what our strengths and weaknesses are, we can better prepare for what's ahead. And this time of year is tricky because sometimes we know, because we've done it every year with the same people, and sometimes we don't, like, this may be your first holiday season with MS. It may be your first holiday season where you're not in charge because you have a new daughter in law or because you can't cook anymore or because... fill in the blank. So what I do, I was talking with Marie and thinking about the questions that everyone will have, is I want to acknowledge that I am in a very specific region of the country. We have states that have different resources than other ones, so I don't have all the answers. What I'm offering you tonight is an opportunity to reflect and consider what of these things I present you resonate for you, and what can help you think about preparing instead of being ambushed by what's ahead. You know, not everybody participates in this season and what is called for when it comes to celebrating, whether you participate or not, it's happening around you. So think about from this lens for this evening, what are the things that we that I present that actually resonate for you and make sense for you. And then you can put your questions in the chat and I will do my best to field those with Marie as we get towards the end.

So again, back to this idea of preparing, take some time with yourself to reflect and to ask yourself some basic questions. What am I expecting from myself, right? What have I always done that I want to keep doing? And are there reasons that maybe that's not going to work this year? May not be forever, but maybe this year it's not going to work. So much of what we deal with when we're talking about chronic illness is losing a sense of identity, losing a sense of what we attach ourselves to in terms of an identity. I'm the one who always cooks. I'm the one who always plays Santa or wraps the gifts or does the shopping. We can fill in all the blanks. What if you're not? So what do you expect from yourself and what's a realistic expectation? And maybe there's some grief and loss in there. So there's going to be some feelings, right? There's going to be some gloominess about making changes to to how you move forward.

Then we go to what is expected of you from others. So you always cooked the turkey or you did the ham and the turkey or, you know, you host it every year or, you know, you were the one that bought all the gifts or you were the one you, you, you and people like to tell us what to do, don't they? And they like to keep us in a box. People like to say, this is how it goes, this is what we do. And sometimes they aren't open to change. So if you are asking yourself, What do other

people expect from me and is this still sustainable, there's the sustainability question, but there's also the desirability. Do you want to keep doing this? Maybe you always hated it. You know, you do have a right to vote on your own participation and happiness. How do you feel about these expectations? How do you feel about showing up and doing the same tradition every year? How do you feel about passing on traditions to the next generation? How do you feel if you can't do those things?

There are feelings here. This is why people get drunk at holiday parties. This is why people eat too much. This is why people sleep too much or they get depressed because there are feelings and we're not very good at dealing with feelings. Most of us don't even know how to label what we're feeling. We were not well trained as children and we were trained by the untrained. So we're all just doing the best we can. So this is a great opportunity to ask yourself, you know, do you look like that little face that has no expression? Like, do you know what you feel? There's so much pressure to be happy and joyful and grateful. Like, what if you're not, you know? Asking and knowing those answers can help you decide what's next for yourself.

And then do you want to do something different? Like maybe it is time to pass the baton, not because you're more disabled, because you're just done. Right? Or maybe you did that for 25 years and now it's something else, right? Or maybe there's some new tradition, or maybe your belief system has changed. So what an opportunity to be curious. And really, I encourage you to do this without judgment. It's not about you're good or you're bad or you're enough or you're not enough. It's about what is expected, what is possible and what makes sense. You know, sometimes it just, it doesn't make sense. I actually find that people who really need things should get things they really need and people who have access to everything they need maybe could restructure what gift giving means. Should we be breaking our backs and our wallets trying to get people gifts when they actually have everything they need? So I'm just having some trouble seeing my screen because of where this bar is. Okay.

And then what is in your power to control? Yourself. Now, maybe not your body. Like maybe there's stuff going on with your body from living with your diagnosis that is so unpredictable and difficult to manage. But your emotional response or your response to what shows up is something that you can work on controlling. I'm not saying we all always have control over it, but you can't control what other people do. And I mean, maybe you can pick some toddlers up and move them out of the room or strap them in with a seatbelt. But you don't get to control other people. You have to work on controlling yourself. And that's why asking these questions is so important. What is it that triggers you this time of year, that makes this year difficult? What is it about this time of year that leads you to making unrealistic New Year's resolutions? Asking, being curious, looking within, and then you can make a plan and assess what's going to work for you.

So I just thought these pictures were great because they represent so many parts of what we expect, right? Like we don't expect dogs to get into our gifts or children to be eating, you know, licking on the decorations. And then people think they're going to climb ladders and do the lights because that's what they always did. And again, the expectations culturally are so high for us to perform into these roles of being happy and joyful and generous and kind. And we may not feel that way. And it's not a crime. Now, how you manage that could be criminal. But that's why we want to weigh in early and ask ourselves what am I looking at and what am I expecting and what are people expecting of me and how can I plan better? And it may be that you have to sit and cry a little bit, that you know you're not going to have the best house on the block anymore or your, you know, your brother in law is going to put up the lights this year instead of you.

So what areas of expectations elicit joy or dread? So again, so much pressure to be happy, but there are so many reasons that people really struggle with being happy and joyful at this time of year. So, clearly, finances can be really challenging for people, you know, what is your budget? Do you have disagreements about what kind of gifts are you giving or who's giving the gifts? Or do people leverage around gifts and what's available? And we don't all have the same financial fluidity as the people in our families. Right? Everybody's got different capacity to pay for things. Probably, not always, but it's not often something that's easily talked about. And then some of us, you know, if you don't, or if you aren't dealing with young children in the family, maybe, you know, why are you still doing this, right? Like, are people willing to do secret Santas? Are people willing to do something different? Do you need to be the one that says, hey, you know what, I don't need anything this year, or if you really want to spend any money on me this year because you love giving gifts, this is what would make me happy. And then there's always going to be the people that don't listen to you anyway. So maybe you learn how to disengage emotionally from the outcome because they're not paying attention to you anyway. It's about them. So these are kind of those nuances.

Socializing, right? What are the agreements? Whose parties do you go to? What does your partner expect of you? What about your children and the PTA and work? And you know, there are so many demands on us and we have to ask ourselves, how do we want to spend this one precious life? Right? How do we want to spend our time and energy? So having those conversations, I had a client that I worked with whose husband was a minister, and she had a progressive illness. And she had to say, look, you've got these four events, which ones do you want me at, which one can I leave early from, and do I have to go to them all? Like, let's just talk about it in real talk. Let's not beat around the bush. What do you need? What do you expect and what am I able to do? You know, if somebody you really love is getting married across the country or having a celebration or a bar mitzvah or a significant birthday, you might throw yourself under the bus and know that when you get back from the event that you are going to have to recover. But to throw yourself under the bus without realizing that's what you're doing is borrowing trouble you don't need to borrow. So having really open conversations about what's expected and then what you feel like you're capable of. And then, you know, like I tell people, if you want to go to a wedding and you don't know if you can go, you can just reach out to the bride and groom and say, look, I don't know if I can come, so I'd like to pay for my plate. And then if I don't come at least it's not an expense that you have to bear. And then if I come and I miss the meal, it's no big deal. It's covered, you know, or I can only come to the church or to the event, or for one hour, you can ask for what you need.

Parenting, you know, you've got your own childhood history. People get traumatized around their histories. You know, some people were raised in families that weren't very happy at this time or grew up in poverty or grew up around, you know, substance abuse. This can be a very challenging time or those things are happening right now in your family and you have to pretend everything's okay. So when you're parenting, what do you need to consider in terms of participating in events that your children might be involved in? Maybe it's time to call in the troops and you ask your sister or your cousin to do something or you agree with your partner that you're going to split the responsibilities, you're not going to both go to the events. But just tuning in and starting to ask the questions can allow you to be more intentional about what you're participating in. We want you to be conscious. We don't want you going unconscious for the holidays, right? That's another problem. That's another presentation. But we do want you to be intentional, clear minded about what your choosing to do and not do. I mean, the collective "we," right? The "we" that wants you to be well.

And then what's your emotional state? Today actually is going to be the shortest, one of the shortest days of the year because of the moon eclipsing Mars, and the sun is going down early. Do you have seasonal affect disorder? Do you notice that you get super depressed in the winter time? Do you get serious grief and depression and loneliness around this time either related to your history or the expectations or disappointments that have never resolved? If you know what you're heading into, you can think about where am I going to get information in order to be better supported this time around? Right?

And then the need for rest. So when you have commitments that exhaust you, are you able to listen to your body? Do you know what your body needs? And I saw some of the questions that were kind of filtering in before the presentation and I was just thinking about how, you know, if you have a chronic illness and people know, you don't have to be a burden to somebody, you just have to know what you need. And if you need to take a nap after you eat or before dinner or before the gifts are opened, or, you know, you can lie down and rejuvenate for 20 minutes, you just need to know which room is available. You need to know if you can come late or leave early or you know, what are the expectations? It reminds me I have a family member who didn't get a card for a gift for the holiday and his partner went ballistic on him and he had no idea what was happening. And then she explained that in their family, they do cards, like this is a thing they do, and in the card, you know, you kind of sum up all the love and all the stuff. But he didn't get the memo, so we if don't educate people about our needs, we're going to get stuck, you know, and we're going to have a hard time.

So these are just some slides, some pictures just to show, you know, there's, you know, money and celebration and being happy, you know, the end of the year. And what did you used to do? How do you find... time is ticking away, right? It seems to go faster the older we get. And then what's going to happen on the other side of the party when, you know, Cinderella, when the carriage turns back into a pumpkin. Right? Are you broke? Was it worth it? Sorry. Yeah. So... what happened? Sorry. I'm going in all the wrong directions. So I think we need to sit with the "Are you broke?" and "Was it worth it?" for a moment. Just because planning is so important with finances, we don't want you to get stuck somewhere where you don't want to be.

And so here are just some basic tips. You know, being kind to yourself, figuring out your own needs and how to get them met by yourself. You know, maybe what you need is not such a big ask and maybe you have the answer. Let go of trying to control what other people say or do, you know, if the person you don't get along with is going to be sitting at the dinner table, can you figure out how not to be close to them and sit at the other end? Know when to say "no" or "yes" for yourself and not out of some antiquated obligation that you just, like, do... you don't even know why. And knowing when to ask for help. You know, we live in a country that is known for being generous and we have people who volunteer all the time, but nobody wants to be on the receiving side. Right? Have you noticed that? So does that mean we judge people that need help, you know, oh, I'm happy to help, but don't help me. I'm beyond help. Right? Like I'm better than that. We all need other people. We all need people to do their jobs invisibly around our entire neighborhood and community, because if they didn't do them, we would notice, you know, we'd have overflowing trash bins. We'd have lights not working, we'd have all kinds of disruptions. So we rely on people to do their jobs so we can be okay. And we take care of each other, that's part of being human. Now we know that the balance can get tipped and be a little off, but it doesn't mean that you can't have some opportunity to take care of yourself and think ahead. And part of that is knowing who to ask, right? You don't want to be asking the people who don't really like to do that. So you got to know who your allies are.

Knowing when to delegate. Right? Knowing who could maybe do it better this time or maybe this time you decide which restaurant we're going to or you decide if we're going to do gifts or we're going to play the white elephant game. And then another protective measure is to disengage or forgive yourself and others, like either don't participate or if you're going to participate and you know the climate, don't go in pretending that somehow magically over the past 364 days, somebody figured out that that thing they do drives you crazy. You can't bank on it. So what do you do to take care of yourself knowing you're going to participate or maybe choosing not to? Not that there aren't consequences, but then sometimes we have to save ourselves. Right?

And then counting your blessings. So I think this can feel so trite and so reductive. I am not saying ignore horrible things and pretend everything's okay. Absolutely not. I would never say that. What I'm suggesting is if you cultivate... biologically, we are built to look for what's not working because it used to kill us. But now everything can feel so threatening. So when we notice we're agitated and riled up, can we ask ourselves what's working? Oh, you know, I have a cup of tea. And, you know, my friend called me today and, you know, one more week and I'm on holiday break. How do I refocus so that I can be aware of what's working? Because joy and sorrow do not exist in vacuums. They exist simultaneously. And it's up to us to center the things that make us happy, that make us grateful. And again, that doesn't mean not feeling the grief and the loss and the sadness, but making room for both so that you don't just get sucked into the vortex. Right? And then set your own time frame. Are you going to come late? Are you going to drive yourself? Are you going to ask for a ride? Like what are you going to do in order to take care of yourself? Okay. That grammar police person just popped in my head and noticed the comma there, so I'm sure I was going to write something else, but I didn't and I left the comma. So I would like you all to know that I'm human and I make mistakes. Okay? Just want to put that out there for the record.

So what does rest look like for you? And I know for a lot of people with MS, rest is not restorative. So you don't rest and pop up and then want to run the marathon. Right? So how do you cultivate a rest schedule that works for you? Here are just some other ideas - you can pass the recipe on or the responsibility on to someone else. You can create new traditions, like what do we do now that the children are grown up? Or that we all live in different cities? Or, you know, just get through it. Sometimes you just have to get through it. Sometimes you're not going to go to all the parties and maybe you're going to sleep or read or watch a television marathon of Twilight Zone. I don't know. Pick one. We just watched Game of Thrones, right? We hadn't watched it at all. Amazing how you can just whiz through that, right? Sometimes you just need to get through. You know, if this is a loaded time of year for you, maybe you just need a pass and maybe that's okay.

Moderation and mindfulness, you know, what are your usual traps? Do you drink too much or eat too much or shop too much or, you know, lock yourself up and don't do anything and it's really better for you to show up. But how do you find the balance and atune to what's really going on, not just your fears and your anxieties, but the reality of what is going on. Sometimes discussions about expectations can be so liberating because everybody's been sucking it up for so long. It can be freeing to plan ahead and redistribute work, maybe start early, get some help, give up the tough stuff. I worked with a woman once who told me that there was a salad that she used to make and her brother would always say, I hope you're making the salad. And somehow it took like 12 hours to make it. And I just checked in with her recently, I'm like, you really got to tell me what this salad is about, that it's so amazing. And she doesn't do it anymore. It's over. They ate that salad enough times. If somebody wants to make the salad, they can spend 12 hours making the salad. But she's not doing it anymore. And then making plans ahead

of time and setting boundaries. Like, I'm willing to go to three of your four parties, minister husband, who I love, and I'm only going to stay an hour. Or I am definitely going to be at the Christmas Eve dinner, but I can't be, you know, I'm not going to midnight mass. Right? Set up a program and let people know, so nobody's yelling at you for, you know, disappointing them. Like clarify the expectations.

I just found this so fun that I like to share it. You can do something unmaterialistic or less materialistic, like make gifts or call someone or invite someone over or volunteer. There's a great program called Golden Talk, where elderly people who are homebound need companionship and you can call them and you can comfort them and listen to them talk. What a beautiful gift. You can offer your time. Oh, I'm editing now with all my horrible grammar. You can offer time, company... of your company with someone. Investigate creative alternatives to traditional celebrations. You know, there's a place called the Center for the New American Dream, and they talk about doing something handmade or second hand or lend a helping hand. Time, giving somebody time, or giving somebody a hand-me-down. Like maybe it's time to pass those things on.

So many ways we can get creative, you know, we can take walks, we can sit in the contemplative environments that we live in. Where can you access nature and get centered? There are studies now that "awe" actually is therapeutic. You know, like I talked about being under the stars. Like when I look at the stars, my problems just feel so minute. Where can you go? You know, the ocean, the mountains, you know, when you look at the rocks that the mountains are made out of, like how many millions of years did it take for them? How many millions of earthquakes to push those rocks up? You know, the winter can be such a contemplative time to be at a beach. And just some little... I love this little, you know, Christmas tree made out of tea bags. There are so many things we can make for fun, for gifts, just to have a new experience. And then it's such a lovely time of year to express love and gratitude or share some nostalgic memories with people. You know, I used to be a pen pal to so many different people and even pen pals go to email now. So what is it like to get a handwritten note in the mail? Because all we get is bills, right? And junk mail. But it's so lovely to get something and maybe utilize some of that stationery that's yellowing at the edges.

So finally, I want... one of my favorite gifts to myself and to other people is the gift of poetry. And it's just such a great time of year, when it's cold and dark, to take a cup of tea and a book of poems. And so I wanted to share this winter poem, and then there's another poem because who can have enough poetry? So this is called Winter Stars by Sara Teasdale. I went out at night alone; the young blood flowing beyond the sea Seemed to have drenched my spirit's wings- I bore my sorrow heavily. But when I lifted up my head from shadows shaken on the snow, I saw Orion in the east Burn steadily as long ago. From windows in my father's house, dreaming my dreams on winter nights, I watched Orion as a girl above another city's lights. Years go, dreams go, and youth goes too, The world's heart breaks beneath its wars, All things are changed, save in the east The faithful beauty of the stars. And that was written in 1920. So still holds true right? I don't know. I haven't checked Orion this week, but I think it's still out there.

And then this next poem is just something that I feel like when we are struggling in the holidays, it's such an opportunity for us to remember that we are a part... we are spinning on this planet together. And so I offer you this poem by Rosemerry Whatola Trommer, and it's called "Belonging." And if it's true we are alone, we are alone together, the way blades of grass are alone, but exist as a field. Sometimes I feel it, the green fuse that ignites us, the wild thrum that unites us, an inner hum that reminds us of our shared humanity. Just as thirty-five trillion red blood cells join in one body to become one blood. Just as one hundred thirty-six thousand notes

make up one symphony. Alone as we are, our small voices weave into the one big conversation. Our actions are essential to the one infinite story of what it is to be alive. When we feel alone, we belong to the grand communion of those who sometimes feel alone- we are the dust, the dust that hopes, a rising of dust, a thrill of dust, the dust that dances in the light with all the other dust, the dust that makes the world.

And so I offer you this presentation as a way to maybe come in from another angle and see what is possible. And I wish you so much grace at this time of year, whatever that means for you.

Marie LeGrand:

Oh, thank you so very much, Kara. This was amazing. This was such a wonderful presentation, and I'm pretty sure it resonated with a lot of individuals, especially around this time of the year, when it can be very stressful and it can be very busy with everyone trying to get in everything at the last minute. So I truly appreciate you sharing your expertise with us and your thoughts.

We will now take time for some questions. Just a reminder to please be sure to type in your questions. We had a few come in prior to tonight's webinar, and we'll go ahead and start with this one: "So, how do I communicate the need for my safety to others due to the risk of COVID?" Oh, you're on mute.

Kara Barton:

You missed my wicked laughter, as if I have the magical answer. I think that so much about communication is starting with yourself and saying I am really struggling. Right? I am really confused or having a hard time or super vulnerable or whatever it is about your own position. So it is not about telling them what they have to do to keep you safe, it's about you saying I have certain needs in order to feel safe, so I'm happy to come, but I'm going to sit on the porch. Or do you have an outdoor heater or, you know, again, it goes back to finding what is it that you need to feel safe. Now, you don't get to tell everybody that they have to mask and they can't be indoors. You may have to say I can't come because I'm not safe. But first you have to tell them what you need to be safe and you might be surprised.

Marie LeGrand:

That's true. You know, different individuals feel differently about that, but it's important to voice how you feel, especially as someone living with a chronic condition, such as MS. You have to always look out for yourself, first and foremost. So thank you, Kara. Now, do you have any suggestions for staying stress free while traveling during the holidays, especially going to the airport or going to rental companies? You know, Enterprise Rent-A-Car, you know how busy that can be. So do you have any suggestions for staying stress free?

Kara Barton:

Oh, boy. Well, traveling stress free - go unconscious and get shipped in a box. I really... I think traveling is so challenging. And one of the greatest things you can do is really think of where in the process do you have particular needs. You know, if it takes you a lot of energy to load up the car or drive or walk through the airport, then maybe you organize a ride. I would say again, planning. Maybe use the wheelchair so that when you get out at the other end, you, you know, you're not exhausted. You have the energy to get up and use the restroom. Maybe it means that you are, you know, talking to your doctor about what kind of medication you can use to sleep if you get jetlag or, you know, what exercises can you do in a plane to keep your legs from

throbbing? You know, look at all the places in the process of traveling where you think there are going to be glitches and then you can piecemeal problem solve for where that's going to be. I mean, for some people, MS or not, like maybe you just never again stay in that person's house. You're always going to get a hotel room, you know, it's personal.

Marie LeGrand:

Yeah. Yeah. Well, since we're on the topic of energy, there was a question that came in about energy, so you can share your thoughts with us. "What really works to get more energy? Also, what works for cognition?"

Kara Barton:

Well, I'm not a doctor. I would like to say that. I think that to me sounds like part of what you can talk to your neurologist about and part of what you can talk to your occupational therapist about. One of my favorite terms is energy conservation. You know, again, if you have seven parties to go to, but you're useless because you go to all seven, maybe you go to one or you go to two for one hour each. Right? The first thing to do is understand where your most energy comes from. Right? The mornings, is it in the morning? Is it in the evening? Do you get a second wind after lunch? But also... so it's very personal. And then what do you do about cognition? There is so much science out there about that, but if it doesn't work for you, it doesn't matter. So the question is, you know, are you noticing that your cognition is impaired when you eat too much sugar or when you don't exercise or, you know, some of it's disease progression. So you definitely want to be working with either a speech therapist or an occupational therapist because that's their domain. They can help you with cognitive interventions. And then listening to your body. Right? Stop overriding. When your body says it's tired, maybe you should listen.

Marie LeGrand:

Yeah. So on that note, how would someone go about in saying no to holiday gatherings without letting their loved ones down, or how do they politely exit, for example, when they're feeling unwell at a party?

Kara Barton:

Well, again, I think it's about planning. I mean, if everybody's planning to go to Disneyland, maybe you need a hotel room. If everybody's planning to go to midnight mass, maybe you say, oh, my favorite memories are going to midnight mass with you all. I can't do that anymore. Light a candle for me. You know, I'll sit with you until 10 p.m. and then I'm going to go home.

I think the place to start again with communication is start from the place of appreciation, of beautiful memories, of your desire to be with everybody the way you've always been. And then you get to say without the "but," the "but" cancels all the good. I would love to go to mass with you. I have had so many beautiful memories. And you know what? My body's not the same. And I find that when I stay up a certain amount of time, I can't function the next day. And I really want to be there for, you know, the opening of the presents for Johnny's first Christmas. So I'm going to pass on mass, but I'm going to be so present the next day.

Marie LeGrand:

Yeah. Now, one individual just wrote in, "but I feel when my needs are expressed, people just don't understand and imply you are too much. This is not my problem, but it's hard not to take it to [heart]" What do you think?

Kara Barton:

Ooh, I totally understand what you're saying. You know, some people are not interested in your comfort and they're not interested in your problems. I don't know why. Maybe they're narcissists, maybe they're busy. Maybe you're the identified complainer in the family. What I'm suggesting today is don't go in and ask people to do stuff for you so you feel okay. I'm telling you, you have a right to say this is what I need, I'm going to bring, I'm vegan, I'm going to bring my own meal, or I can't eat sugar anymore, so I'm going to bring a side dish where I know I can get something I need. Maybe not asking. One of my clients goes to Al-Anon and I just love the saying, stop going to the hardware store for bread. If you know your audience is at the hardware store and you're looking for bread, you are going to be so disappointed every single time you ask for support. Go to your allies. If they think you're too much, they're going to interpret every single thing you do as too much. Maybe you are. I don't know. That's where you sit with yourself first. Okay. But then asking yourself, you know, why am I waiting for them to make me feel comfortable? I'm going to prepare.

Marie LeGrand:

Yeah, good point. Now, what is the best way to remind people that you need help getting around during the holidays to be with family? So for individuals who perhaps, you know, may be in wheelchairs or scooters, walkers.

Kara Barton:

Well, I think it's also really important, again, to identify who your allies are, like who wants to be helpful, who's loving, you know, if all you hear from people is, you know, you're complaining, or you don't look sick, or whatever. You know, what you hear when you have MS, find out who is willing and able to help you.

So maybe you have a child who's in between jobs and they're feeling badly because it's the holidays and they can't buy gifts, you can say, "You know what, honey, I'd really love it if you were my escort for the, you know, 12 days of Christmas, or I really want to go see that wonderful Nutcracker exhibit, or whatever it is. Your gift to me this year could be your time and your being my chauffeur." Right? So identify very specific things that you need so that you can get a yes or no answer. Right? I, you know, I'm not going to be able to come if I don't have a ride, can you swing by and pick me up?

Marie LeGrand:

Yeah. You touched briefly on grief during your presentation. So for someone, or individuals who are experiencing that, how do they handle grief during the holidays,? You know, it can be very triggering for many, you know, especially if you've lost a loved one, and that's usually the time of the year to spend with your families and your loved ones. So how can someone go about in handling grief during the holidays?

Kara Barton:

Well, you know, everybody's grief is different. And I think, you know, grief can be about losing parts of yourself as your disease progresses. Grief can be about what you never got. Right? Like you never had the perfect Christmas or you never had Santa or love or you never felt like you belonged. And often at this time, grief is about the people that we used to spend this time with. So sometimes it may mean you just need to be sad. Maybe you drink a cup of tea and watch that movie and you cry. Maybe you pull out the old family albums and you find the person in your family who wants to revisit that with you so you can share that grief and lighten the load a little bit. The only way through grief is through it.

Now, if we move it over and pretend it's not there, it will come back and suck us in. So maybe, you know, as you, especially when you're approaching a holiday for the first time, or an anniversary of the first holiday without that person, maybe you develop a new tradition. You know, you name a dish after someone or everyone goes around the table and says their favorite memory of that person, like you can hold presence for the loss, maybe, depending on your community. Right? Some people can't do that. But you find your allies.

Marie LeGrand:

Yeah. So let's talk a little bit about individuals who have two sets of family, you know, husband, wife, partner. So how do I divide my time between my family and my spouse's or my partner's family? It's always a challenge.

Kara Barton:

Well, and again, I think it's often a challenge whether you have MS or not. This is just being human. So the question becomes, you know, again, I think back to that first question, if people think you're being dramatic or you're too much or you're a burden, they may not be able to hear what you need to say. So I think your first step is to find out how much of an ally your partner is, your family... who in your family understands how fatigued you get, who in your family understands that you can't be there for the whole event, and then you align with those people.

And then maybe, you know, again, this is what couples do. Like, should the partner in the family who is not from that family have to go head to head with the mother in law? No. Maybe the son has to do that. Coming to an agreement like I can't do it anymore, honey, I need you to tell your mom, like, those days are over, we're going to do this instead. Or you can give her two concrete choices. Right? I can't do the 12 hour salad anymore, but I can do this or this. What do you prefer? And you offer real options that don't take you out, right? Like something that you can genuinely offer. And then it's all about negotiating time. And when you don't have energy because you're fatigued, you don't lead with, "Woe is me, I have MS, I can't do anything," you say, "I can't wait to see you for the holidays. And I'm so excited that we're going to get together. And I'm also really struggling. I'm not the same person I used to be. How do I show up in a way that supports the family but also allows me to rest when I need to rest?" Right? Like again, appreciation as the lead and then what you need or what you're going to do for yourself to sustain yourself.

Marie LeGrand:

Wonderful, wonderful. Well, I wanted to leave just about a minute or two to get any last words from you, because this has been such an amazing and insightful program and presentation. Do you have any last words for our audience?

Kara Barton:

I think the first thing is most of us spend our whole lives wanting to be understood. And if we're lucky, maybe we get some people who really get us. Even the people with MS aren't going to get your MS the way you get your MS. Your doctors don't get it, nobody is going to get it because no one is in your body. But you don't have to wait for the world to get you in order for you to be happy. Your joy, your happiness gets sourced from within your own self. Nobody is going to perform to your expectations. That's really just not how the world works. So my suggestion is, you know, take a look at the poems that feed your soul. Take a look at the mountains or the beaches or the photographs that remind you of what it is to be you and what it means to be human at this time and really cultivate joy for yourself, regardless of what other people are doing.

Marie LeGrand:

Yeah, well, thank you so much again, Kara. This has been so wonderful. I know there are many other questions that people have, but this concludes the webcast and tonight's webinar was recorded and will be made available on our website. Please visit MSAA's calendar of events for our upcoming webinars and events. On behalf of MSAA, we would like to thank you very much, Kara, for taking the time and providing us with the tools needed to manage stress during this holiday season. And as we close out our program for the year, this will serve as a reminder for us to incorporate rest into our day to day, something that we should always remember, not just through the holiday season, but through the entire year. So thank you once again.

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