



Helping Those That Help Us: A Program for Care Partners

Presented by: Kimberly Castelo, MS, LMFT-S, CST-S, CIIP

Kyle Pinion:

Well, hello, everyone, and welcome to the Multiple Sclerosis Association of America's live webinar. Helping Those That Help Us. A Program for Care Partners. I'm Kyle Pinion, Senior Director of Education, Health Care Relations, and Advocacy for the Multiple Sclerosis Association of America, and your host for tonight's program.

On behalf of MSAA and our presenter, we greatly appreciate the opportunity to keep you updated on this very important topic. And please know that we hope you and your family are staying safe and healthy in these uncertain times.

MSAA is extremely honored to host this educational program with Kimberly Castelo, a licensed marriage and family therapist with Healing Moments Counseling. As I'm sure you know, MSAA is a national non-profit organization dedicated to improving lives today for the MS community.

Now, with over half a century of service to this incredible population, some of our free services include a national helpline, equipment and cooling products, MRI funding, an online community, webinars and many more free programs available to all people living with MS all across the country. Free! You can't beat it. Also, please know, MSAA has expanded our helpline hours to 8:00 PM Eastern between Mondays and Thursdays. And to learn more about these and all the ways MSAA improves lives today, please visit mysaa.org or call 1 (800) 532-7667. I'm going to repeat that number. That's 1 (800) 532-7667.

Additionally, I wanted to draw attention to our brand new Virtual Display Hall, which has been made available thanks to the generosity of our selection of sponsors. If you haven't already, please take a minute to click a link in the chat box to visit this new and exciting information portal, which showcases the products and services offered by our sponsors. And we absolutely want to thank our friends at Biogen, Genentech and Sanofi Genzyme for their amazing support. You'll find a link in the chat box just like that. Shazam!

It's also important that I know... that tonight's program is intended for informational purposes only and does not constitute formal medical recommendations of any kind. Please speak with your doctor or health care provider if you have any questions or concerns around these topics or others. And make sure, of course, to do that in a one-on-one setting.

And lastly, please know, tonight's program will be archived to our website very soon. For our Q&A session, please type your questions into the Q&A box and we'll address them at the end of the presentation. Also, if you're having any technical issues, which, you know is very common with, you know, these pandemic times, unfortunately, please type those concerns in the chat box as well. Both I and my amazing colleague, Alexis... we will be working behind the scenes to help address any issues you may face.

So with all that said, we are so pleased to have you join us for this timely conversation. And I'm honored to introduce Kimberly Castelo. Now, Kimberly is a marriage and family fair therapist and a certified sex therapist who has been living with multiple sclerosis for 14 and a half years. She is a mother, wife, animal lover, business owner, speaker and supervisor who enjoys helping all of those living with MS and their care partners and helping them thrive. During tonight's talk, just to provide a bit of an overview, Kimberly will address how to care for others while caring for yourself, the common cycles those living with MS and their care partners get into and how to navigate them, as well as assorted tools and resources that will help you thrive as a care partner. A question and answer time will be in the last 15 minutes when Kimberly... and Kimberly is really more than happy to answer any of those questions that we took in at the registration time, which we've got quite a few already, but also, as we go, we'll be taking questions and we'll be happy to sort of get those to her towards the end of the talk. Kimberly tells me this is her favorite part. So being able to answer and get to know her audience is a really key element of this whole presentation.

So with that said, I am so happy to introduce Kimberly to you all. Kimberly. The mic is yours, as they say. I don't know who that is, but...

Kimberly Castelo:

Thank you so much for having me. It's such an honor to be here tonight and. Kyle is right, I really enjoy the questions and answers. So I got all of those that have signed up already. All of these questions, a lot of them I think we're going to be able to answer tonight, which I'm pretty excited about. And then, if not, then if that last 15 minutes, we really want to hit home on that.

So it's so good to be here with you guys. And thank you so much for being patient with that tech... technology stuff for us that... it just happens, doesn't it? It's so hard. But we want you to know that you matter as a care partner. As Kyle mentioned, I was diagnosed with MS fourteen and a half years ago, and I don't think anyone asked my husband how he felt about it. How he felt that I had MS, what he was scared about. It was really all about me at that time. It was not about him.

And so... So the question I have is, what did you feel like when you... when your partner was diagnosed with MS? Did you receive any care? Because this disease often affects you. And like I said, for my husband, Daniel, he didn't get that kind of care. It was just about me. So what I love about this program is today is all about you and what you feel and making space to know that what this disease has done, it affects your partner, but it also affects you.

OK, so if you've ever heard of Elisabeth Kübler-Ross and the Stages of Grief, this is pretty well known that when we are going through crisis or when we're going through pain, that we go through these stages. A lot of times people think that this is linear, that first I start with denial, and then I go to anger and then I go to bargaining. But really, it can go back and forth, so I can bargain at first and then go back to denial and then I can get depressed.

Now, this is often applied to people who, you know, like if somebody just got diagnosed, I would begin to talk about and think about clinically the stages of grief that they are going through. But also the caregiver goes through these stages of grief as well. One of the questions that we had was, is that I'm feeling angry towards my partner, embittered.

And what do I do about that? And I just want to normalize that and tell you, of course, it's really normal to feel angry or sad, or depressed, because life wasn't supposed to be like this. Nobody gets married or nobody has a partnership or nobody wakes up one day and says, I'm just going to get MS. The last thing in the world I thought I was going to have was MS. So my partner didn't sign up for that. So all of these feelings are extremely normal for the caregiver to go through. All right?

And again, they're not linear. So that means my partner, Daniel, he can bargain... and bargaining means like something, like he said, "God, I would just... if you just heal my wife, then I promise I'll do this. Or if, or if she just gets better, I promise I'll just do this." Very, very normal. Very, very normal because there's a hopelessness that comes in when you're diagnosed and when your partner, who you love, is diagnosed as well. Let's go ahead and go to the next one, Kyle.

OK, so what do we do with all of those feelings? OK, how do we self-care? How do we deal with our own depression? How do we deal with our own anger? The first thing we've got to do is figure out how do we self-care? So where does our energy go?

So here we are in the middle, that "Self," right? And where does our energy go? Our energy can go up to, you know, taking care of our care partner, working, kids, cooking, cleaning. And before you know it, all of the energy has gone out of ourselves.

Somebody... Thank you, Deborah. Somebody just said they can't see the slides. So I just want to make sure that we can... We're making sure that we can get that. So where does our energy go? Thank you, Paul, for telling us that you can see them.

Where does our energy go, right? It goes outside of us. So we then... we become... we feel depleted. Right? If I'm constantly doing something and I'm not getting anything in, I'm going to feel angry, tired, depressed. OK, so let's go to that next slide, Kyle.

OK, so we have to self-care so we don't... Next slide... Burn out. And that's what it kind of feels like, doesn't it? It's like we just totally lose ourselves and we just... the depression takes over, the bitterness takes over, the resentment takes over. We just don't have anything else to give. So what do we do? Let's go ahead and look at that next slide. OK.

So before we even do that, I wanted to talk about the signs of care partner burnout, because sometimes we don't really know what that is. OK, so before we talk about how we kind of fill our cup, I want to talk about what are the signs, so that, you know, "Uh-oh, I'm starting to burn out." So the next slide will tell us that one of the ways that we feel - and Kyle, you can go ahead and turn that - Is if you're tired. This cup, I just found this... this picture, and I just loved it because sometimes don't you just feel like that cup? Like, ugh! I'm just so exhausted, I just cannot do another thing. Please don't ask me to do another thing.

Right? And then the next thing that we feel is that anger, frustration or even resentment? There's this thing that we... that happens, and I don't know if it happens to you all, but it

happens to a lot of folks, that you go from zero to sixty. So what that means is something occurs. And without even a moment, we're angry. We're reacting. Right? We are completely and totally reacting. And it might be small. It might not be that big of a deal, but we get so tired and we're so burnt out that we don't have the space. We don't have the energy to... to take a breath and not react.

OK, so anger, frustration, resentment, responding pretty quickly, angrily, from zero to sixty without really calming down or being able to understand what they're saying is another sign. Memory loss. Foggy memory. I mean, this happens to people with MS, too, but it also happens to the care partners. You know, when you go into the kitchen and you're like, what am I in here for? And it's because you've done 10 things before that. Right? You have this calendar in your mind, all the things that you've got to do in your mind, that you just start to forget what the next thing you need to do. Very common.

And then loss of empathy. Nobody wants to admit this because we all want to feel that we're empathetic, but when we're tired and we don't have a lot of space left, it's extremely human to look at our partner and go, "Ugh! Just.... I cannot. I cannot feel sorry. I cannot feel sad. I cannot feel compassion right now. I just can't." Like I said, that's not something that a lot of people would like to admit. And it's extremely human. Very, very human, when you're burnt out, to stop to be able to have compassion or empathy for even those that we love so dearly.

OK, so what do we do with that burnout? OK, so we're burnt out. We're going through the stages of grief. It's too much. We're having... we're having foggy memory. We're getting angry and responding from zero to sixty. We're tired. We just... we're having trouble remembering things. We've got to then fill back up. OK? And how we do that is five things: our biological self, our psychological self, our social self, our spiritual self and our sexual self. So the next slide here, we're going to talk about each one so we know what they are.

OK? So the biological self, we've got to make sure as caregivers that we, too, are eating well and exercising, drinking plenty of water, taking our vitamins, making sleep a priority and taking our medications. Anything that you can think about that tends to the biological self, your body, your physical body. We want to make sure that we're getting a lot of things coming in to your body that helps it function well. OK? And there's a lot of times that I'm talking to caregivers and they just haven't eaten yet because they're making meals for their... their partner. Well, that's not something coming in and taking care of their biological self. So they're going to feel food equals energy. Right? So they're going to feel depleted. So we want to make sure that we're constantly saying, "What is my biological needs need right now and how can I make space for that?"

Then there's the psychological part, OK? Being a care partner is extremely difficult. It wears on our mental health. There's grief, there's that bargaining again, there's the anger that comes up, there's the denial and finally acceptance and all of that, those feelings that we feel actually take a toll, a huge toll on our psychological health. So what do we do? Some people like meditation. OK, some people take medication for anxiety and depression. I'm a big proponent of if your brain needs serotonin, talk to your doctor about that. OK? Something that's kind of hard is to talk about your feelings.

So who do you talk to? We're going to talk about that a little bit, right? We've got to be able to talk about our feelings. We've got to be able to even be in tune with our feelings. Sometimes we're just so angry, but we're not really sure. We know we're angry, but we don't know why. Or we don't know the underlying feeling, which is "I'm angry because I feel sad or I feel burdened

or I feel hopeless." OK? And it's super important that we tend to these emotions. You matter as a caregiver, you matter. Your psychological needs matter.

And then we have that social component, right? Outside concerts and movies, and I said outside 'cause now we're in a pandemic. Right? So Zoom parties - never would have had that before, but now we're in a pandemic, so we've got to get creative a little bit. Social engagements, bingo, book clubs, friends, support groups, family, whatever it takes. We need to make sure that we are expanding our definition of support. The MSAA is a great place to get a support group and to talk to folks. Friends are great. Faith communities are great. Whatever it takes, what we want is to make sure that we're expanding our support so we can ask for help. Enjoy life.

I had a question somebody wrote in and said, "Is it OK for for me to take some time just away?" OK, it's just, you know, just to get away. What that question told me was that there's some tiredness, like I need that time away, which makes sense. Nothing bad about that. Does it make you terrible to feel like you need a break? It makes you human. It makes you very human. And so what we want to do is we want to attend to that so that we don't burn out.

And then there's the spiritual aspect, and that could be anything. You know, it can be a faith community. It could be prayer. It can be yoga. It can be rituals like going for a walk or going fishing. Again, I put meditation here - whatever... whatever you feel connects you to something. Or nothing is fine. But we want to be able to tend to that part of ourselves that thinks that there's something bigger than us out there, or that doesn't? And that's OK, too. But either way, whatever part of us, however that shows up, it's a very individualized part of us, a very private part of us, the spiritual aspects. But it's important. So, again, we want to make sure that we're getting that aspect in our lives.

Sexual. Now, I'm a sex therapist, so I talk about this all day, but a lot of times people get really, really nervous when we talk about sexual needs. But sexuality is a quality of life issue. OK, it's quality of life. It's connecting, it's healing, it's wonderful. And then when a disease like MS comes up or anything else, that kind of gets derailed. So we have to get a little bit creative, sometimes, with mobility issues, depression and all of these kinds of things. We have to get creative. OK, so one of the things that we can do is not focus necessarily on intercourse and expand the definition of sex, which could include flirting or massages, reading, sexual literature, cuddling. OK? Any kind of activity that is connecting can be sexual.

If we're mindful. OK? And this, again, can be very difficult when we're dealing with disability, because disability, we're dealing with depression, we're dealing with mobility issues. So it's really hard sometimes to tap into this part of us when there are so many obstacles. The good news is, is that it doesn't have to be a difficult thing. We can actually work through that. And expanding the definition of what sex means, which means it's more than just intercourse, it's more than just orgasm, but it's about connection and pleasure, whatever that looks like, can be very healing.

We can do a whole course on this, by the way. But why is it so hard to self-care I'm sure some of you are saying, "Well, this is all great, Kim, but this is not... this isn't going to work... to do this bio, psycho, social, spiritual, sexual model. There's no way,." And usually it's because we feel guilty. OK, we worry. What if something bad happens to our partner? "I'm never going to forgive myself." "Oh, my partner's going to get mad at me. They are super going to get mad at me." "Hey, I signed up for this. I'm married to the person or I've decided to be their caregiver. This is my responsibility." And the feeling that "no one else can do this, but me." I don't know if any of

you have thought about any of these things, but just even reading it out loud, even when I typed it, I just felt so smushed. Right? So stuck with those thought processes. So what do we do? It's hard. OK? But in order not to burn out, we need to expand our circle of support. This is really important. OK.

We have to ask people to help us. We have to go to our faith communities. We have to go to our friends. We have to go to our families. We have to make the call to MSA for help. And why is that hard? The same thing that's hard to self-care. Maybe we also think nobody wants to do this for us. We don't want to be a burden - that could be also on here. That goes under guilt. Nobody else wants to help me with this. What if... what if my friends get mad at me and stop wanting to hang out with me? And I don't want to be, you know, a "Debbie Downer." All of those things begin to kind of put us in a place where it's difficult to ask for help.

And so not self-caring, we're not expanding our circle of support - leaves us feeling stuck. And that's what I kind of felt when I saw this image and when I was making the slides, I really loved it. This guy captured because that's how I felt when I was preparing for this - feeling, all of these limitations of really self-caring for yourself. Just felt trapped, it just made me feel stuck and helpless. So we have to push back a little bit. We have to push back and say, "I'm going to tend to myself, my biology, I'm going to eat, I need to rest. I'm going to go out with my friend tonight. I need to, because if I can do that, I can take better care of my care... of my partner." Right? Let's go to the next one.

So this we could do like a whole talk on this. I'm going to drink some water for a second. Thanks for waiting for me. Sue Johnson, I love this book, *Hold Me Tight, Hold Me Tight, Hold Me Tight!* If you can get this book, I would love for you to do it. But she breaks down these communication patterns. We can't go through all of it because of time. But the whole reason why I'm bringing this up is because I want us to be able to have the tools to actually claim self-care for ourselves so that we don't burn out.

So the three different communication patterns, which she calls the demon dialogs, right, is "Find the Bad Guy." That means both partners, care partner and MS partner, they just blame each other. They're just accusing. They're blaming. Everybody's the enemy.

The second one is the "Protest Polka." One partner complains, and the other one defends. One partner criticizes, the other one shuts down. OK, that's a lot that we see a lot in therapy is the "Protest Polka," is that somebody pokes and then the other partner withdraws, somebody criticizes, the other person defends.

OK. And then the third one is "Freeze and Flee." And that one is that both partners are like, we're just not going to talk about this. We don't care. We're roommates. We're not going to talk about anything hard. And, you know, we just keep our lives separate.

OK, so if you think about it. You can kind of say, "Where do I land? Do me and my partner just yell at each other all the time?" Does one yell and then the other one avoids, defends and comes back. And that can be yelling, too, both people can yell at the "Protest Polka." Or do we just avoid hard conversations? OK?

But the truth is, is that we have core basic needs. All of us. All of us, every person on this webinar and everyone who's going to watch the webinar later, we have needs. And when those get threatened, sometimes our communication styles get hijacked. And it becomes unhelpful. But it comes from a place of "I need something." "I just am so desperate, I need something,"

and that need of mine, all the good communication skills that I know go out the window. It's hijacked because I get in this primal fear that I really need this. And I just start yelling or I shut down or I start defending, instead of really talking about my fear.

So here's a conversation, so what does this mean in real time? OK, so **MS partner**, **Care partner**. Let's see how I do here talking about this. So the MS partner goes:

MS partner:

"I'm tired."

Care partner:

"Go rest and I will go golfing."

MS partner:

"I know I can go rest, I just wanted to say it and didn't you just go golfing?"

Care partner:

"I did just go golfing, but I want to go again."

MS partner:

"Of course you do."

Care partner:

"What does that even mean?"

MS partner:

"Nothing. Forget it, just go golfing."

What are the core needs there? And I don't know if you can see a similar conversation with you and your partner. But the MS partner might need connection. I was feeling alone. I didn't know how to ask for it. So instead of saying, "Hey, I feel alone, you mind spending time with me?" They just said, "You always go golfing." The care partner needed to self-care, but didn't know how to tend to their partner and to themselves. So they're just going to shut down, they're just going to shut down. In this dynamic, in this cycle, they're missing each other. And we don't want you to miss your partner and we don't want your partner to miss you.

So here are some options. Kyle, go ahead... OK, let's go back. Yeah... So, the goal here for us is for the person who has MS in this scenario, right, in this scenario only, is to slow down and understand what they needed at that moment and say something like, you know, "I miss you. Can we spend some time together when you return from golfing or maybe before you go?"

So we've got to slow down and really understand what we need and be able to share what we need. The care partner, the goal in this scenario would also be to slow down. And affirm, we need to tell our partners that we care for them, and that getting some time away will help us be more present. When we do this, we're tending to their fear, our partner's fear that we're... that they're too much. But we're also asserting ourselves that we will be better caregivers, we'll be better partners, we'll be better people if we're able to take some time off.

So this is what it might look like: "I love you and I want to be here for you. I am feeling like I need some extra support so I can be more present at home. How about we connect when I come back home and watch our favorite show together?"

So I didn't give in to the golf... to not going golfing, but I did tend to my partner's fears and love and said I love them and I'm here for them, and also took up space that I needed some time.

And that was OK. Here's another... is this helpful, you guys? I can't see you and I can't hear you, so just tell me in the chat if you guys are following me. OK, thank you, thank you, thank you, thank you. I just I want to make sure that I'm not going too quickly. Here's another possible conversation. OK, so...

Care partner:

There's silence. (They are scared that their partner is getting worse, but doesn't want to say anything in fear it would make their partner upset).

MS partner:

"Why are you quiet? What's wrong?"

Care partner: *"Nothing's wrong. I'm OK."*

MS partner:

"Then why are you not talking to me?"

Care partner:

"I am talking to you. Nothing is wrong."

MS partner:

"You never share with me. I know something is wrong, but you don't talk to me."

Care partner:

"I am fine."

MS partner:

"Fine. Whatever."

OK, so the question here is, again, I want us to think about what are the needs that each person here that kind of hijacked the communication. The care partner is overwhelmed, maybe scared by the disease, MS is a big disease. Maybe they're afraid that talking about they're fear with their partner might make their partner upset. Have more stress. Maybe their partner will dismiss them and say, "Well, I'm the one with MS, I don't know what you're so upset about." The MS partner wants to know how to be close to their partner, wants to share with them, wants them to share with... So the communication back and forth - I want to share with my husband, my husband wants to share with me. But whenever they try to connect, there's a shutdown. And in that shutdown, fear occurs. OK?

The truth is, and I put this beautiful brain here, is because one of our basic needs is to feel connected and to feel love and to feel safe. When we do that, there is imagery from the brain that actually helps heal us, it calms us. There's something about loving and being loved, caring

and being cared for, both reciprocal, back and forth, that actually can change our brain chemistry, help us with pain, help us with anxiety. It's quite powerful.

OK, I asked Kyle before I started, when did I need to be quiet because I knew I could talk about this forever. OK, so I'm about there, so that's good. I made it in good timing. But I wanted to take... to talk to you a little bit about some takeaways that I want you to know as a care partner. It is OK for you to grieve. It is OK for you to be angry. Now, what we do with that anger is something else, that's a different conversation. But, you're human. And so in order to not let our needs, our core needs, hijack our relationship, we have to slow down, really get in touch with what we're feeling and share. That sounds so easy, doesn't it? But it is actually super hard to slow down, to go, "Huh! Kim, what am I thinking? What am I feeling? Why am I so upset right now?" And then instead of getting angry and yelling, or shutting down, I become present and vulnerable with my partner and say, "I'm tired. I'm burnt out. I'm afraid. I'm lonely. I'm overwhelmed. I need to do something different." Sounds so easy on paper and saying it out loud, but it is so hard.

We have to self-care. As caregivers, you can't be a good caregiver if you don't self-care. And I want you to remember that it's a lot of different ways to self-care well.

It's the biological - food, water, sleep.

Psychological - meditation, talking to somebody, taking our medication.

Social - friends, book clubs, support groups.

Spiritual - whatever that looks like, wherever you feel connected and hope.

Sexual - connecting, finding pleasure in your partner, expanding the definition of sex - It's not just about penetration or orgasm, it's about connection and pleasure and fun. OK? Another main takeaway is we've got to expand our circle of support. You cannot do it by yourself. You need help? And remember all of those reasons why we don't ask - we feel guilty, somebody is not going to like us, they're going to say no, what if something bad happens? Those are all normal to feel. And, we've got to expand it so that we can actually help our partners and not drown ourselves. We've got to work on that communication skills, and that book really is wonderful by Sue Johnson, *Hold Me Tight* - really helps us slow down and identify "Why when I yell, what am I actually feeling and how can I share that in a way that brings my partner closer and not farther?"

And the last takeaway is connection heals. It's powerful to be on the same team against MS and not being an enemy with your partner. But making MS the enemy and joining together. Living in joy and connection and pleasure, it heals.

So here are some resources - that book, *Hold Me Tight* by Sue Johnson, I think it's like 16 bucks on Amazon. Always talk to your neurologist. I love my neurologist. Love, love, love my neurologist. Talk to them, talk to them about how you're feeling. Talk about support. Talk about sex. They're here to help you. Please go to the MSAA. They have tons of resources. Seek out a therapist. You know, that understands disability. Don't be afraid. Well, it's OK to be afraid, I think. I'm going to correct myself - It's OK to be afraid to talk to trusted friends and family members. But can we be afraid and still lean in and try? And please talk to your faith community, if you have one. Remember, we want to expand the definition of our support. We want to expand our circle so that we don't burn out.

And Kyle, I think I ended right on time. Super excited about it.

Kyle Pinion:

Yeah, you did. Well done. Thank you. Thank you for a really amazing presentation. I apologize, everybody, for the technical snafus. Sometimes your best laid plans can go awry, even slightly so...

But I think we've done a nice job pivoting here. And thanks for working with us on this, Kimberly. I've got a number of questions that we collected earlier and questions that have come in during the program. So I thought I would try to ask a few of those with the 10 minutes we have left. Some of them will probably reiterate points that you've already sort of discussed, and hopefully I won't be retreading over too much ground. But I do find that to discuss some things does require a little bit of reiteration.

Kimberly Castelo:

Of course, of course.

Kyle Pinion:

Retention is so much stronger that way. So let's get back to burnout for a second. I think this is a really important area for care partners. One person asked us: "I find that I am approaching the all too real burnout stage, but I'm not sure we can really afford the cost of in-home care or respite care. What would you say are some practical solutions for my household?"

Kimberly Castelo:

Yeah, I mean, that is... that's real life, isn't it? That's real life. What I love about that question is that they're aware that they're right there, right? That they're right at that burnout stage. So this is where the practical things are, you're like - "OK, so I can't afford in-home care, but is there a... Is there a food train that my friends can do once a month and bring over food? Is there a way that somebody can take me and go grocery shopping or come over and watch a movie with

me?" How are the ways that we could start getting energy back into the caregiver, that's life-giving? OK? And that means we need to expand our definition of support. OK, so friends, family, faith communities, anything like that, we got to get creative. And risk asking other people for help.

Kyle Pinion:

Absolutely. Absolutely. Another question that I think kind of dives into the communication aspect, it's really more around disclosure, but... "I don't even know how to begin to explain MS to my children. I sometimes find it so complicated, I can barely explain it to adults. Are there any tried and true methods to broaching the subject without scaring my kids?"

Kimberly Castelo:

Yeah, that's a tough one, right? That's a really, really tough one. So you've got a couple things here. You've got to think about their developmental age. Right? So we want to make it really basic. And we also want to have them be able to ask questions and just ask what they're, what they're saying.

So, for example, for myself, my daughter had when she was little and she would ask me... she would see me give my shots. "Well mommy has what's called MS, and I take my shots to help to

make sure that I'm healthy for you. And I'm going to be OK and this medicine helps me." OK? If there's a disability and the child is questioning about that, what they need to know is that their parent loves them and that they can ask and be afraid of anything.

So, for example, you go "Yeah, mommy and daddy are in wheelchairs and you can always sit on my lap and we can always spend time together that way. And I love you." Letting your child know that you love them and that you're there for them is the biggest comfort.

For somebody that's older, you know, for a teenager, you can get a little bit deeper there and say, "You know, I've got MS, and it really affects the way that sometimes I move. I get numb sometimes." We just moved to North Carolina from Seattle. Seattle is a lot cooler than North Carolina. So the heat here is killing me. So I had to tell my teenage daughter, "You know, sometimes mom can't stay outside in this heat because I kind of lose my eyesight a little bit. I want to spend time with you and I want to be with you. Can we do this activity inside?" So I'm very honest about what I'm going through. But I say I'm here for you, I love you, and then I give an alternative.

Kyle Pinion:

Fantastic, fantastic, and thank you for that answer. Especially as someone who is the child of someone living with MS, it really hit home.

Kimberly Castelo:

Yeah. Yeah.

Kyle Pinion:

So "I'm finding that our social circle is shrinking due to an inability to get out like we used to. How can we better build some new, more adaptable friendships? Is social media a good resource for this?"

Kimberly Castelo:

Yeah, I mean, this is really, really difficult. It's difficult because... just in general. But the other difficulty now is that we're in a pandemic. So this is tricky and this is hard. And social media can be a wonderful way to connect with other people. You can do support groups online. You can do book clubs online. You can do all of those things.

Social media can also be tricky. So social media, you know, people just write whatever they say and they don't really speak about the other person on the other side. So with that said, yes, go out on and join an online group, connect on social media with folks. And, the big "and," to know how to really take care of yourself on social media and know when to stick up for yourself, knowing when to, if somebody offends you, what to do with that and how to self-care. So it's both. Does that make sense?

Kyle Pinion:

Absolutely. Now, we had a lot of questions that came up, to be honest, about things like transfer and practical, I think, physical tasks for caregiving. One thing I wanted to just sort of share about that, I don't mean to skip those questions, but I think those would probably be better asked to a physical therapist or an occupational therapist. And one of the things I wanted to recommend was if you have questions about that as a care partner, give us a call at MSAA, I'm actually going to change... maybe change the slide. I was going to change to the slide that had my number on it, but maybe I won't this time.

There we go! Give us a call at that 1 - 800 number and ask to speak with our client services team and they can help connect you with a physical therapist. Kimberly, I don't know if you've anything else you want to add to that.

Kimberly Castelo:

I do want to add something to that, because the part that I want to add is the emotional aspect. It's scary to move your partner and to worry about "Am I doing this right? Am I going to hurt them? What if I drop them? What if I do this?" So, we want to get you practical solutions with a PT and OT and all of those things. And there's an emotional aspect to that question. There's a lot of fear and uncertainty. So I also want to just tend to that part of you, for those of you that are asking that question. I know that really makes a lot of sense. It's at best where we could start talking about with your partner, "I'm afraid about this, I don't want to hurt you, I want to move you." And then talk about practical solutions.

Kyle Pinion:

Now, you know, we had a number of questions about about sexual activity. And I wanted to ask this one, because I think it's probably from the care partner's perspective. It probably speaks to sort of the immediacy of the issue. "Is it normal for your husband to lose his desire for his wife after her diagnosis? We have not had sexual relations in over 10 years."

Kimberly Castelo:

Yeah, that's super common. And it's super common, not necessarily because of MS, unless there's some physical issues, but really the depression and that our body has betrayed us. OK, so our body has betrayed us somehow, and then to kind of... a body being sexual is extremely difficult. This is where expanding our definition of sex begins. And sometimes, going to a sex therapist is amazing, and well, and I'm biased because I am one, but because what happens is, is that we can help you focus on what you're already doing, which could be just holding hands, or sitting on... you know, watching a show together. And how to build from that. OK? And how to regain connection and pleasure. But it's not uncommon for depression to set in and then just say, "Well, I don't think I'm desirable anymore. I don't think I can have sex anymore. My partner doesn't find me attractive anymore," even though you do. So it's not uncommon at all. And it's actually not uncommon for people without MS to struggle with intimacy after a certain amount of time.

Kyle Pinion:

Right. Absolutely. We're a little over time, but I really wanted to squeeze in two more questions because they were very good, and I think this been such a wonderful conversation. So we had a number of questions around anger and mood swings that came in before... before registration even. So I wanted to kind of zero-in specifically on that. Basically, "What is the best way to deal with the mood swings that can potentially be endemic within the MS disease course?"

Kimberly Castelo:

That's hard. So you're talking about the person with MS is having mood swings.

Kyle Pinion:

Right.

Kimberly Castelo:

OK, so there's a couple of things. Number one, we want to talk to our neurologist. Right? Because depending on what part of the brain is affected could affect the way that we respond. So you want to talk to your neurologist. You want to figure out if there's any kind of treatments that can help with that.

Secondly, it's really, really difficult. So the biggest thing is to... how do I communicate to somebody else that they've hurt me? One of the ways that I use all the time with my clients, sometimes, is just when they say something, I go, "Ouch! Ouch. That hurt. That hurt me. Wonder how that felt to your partner." So to... to talk about, "Hey, I'm on your team. I'm feeling attacked here, but I'm for you. Can you and I work together instead of against each other?" So in owning how you're feeling - "Ouch!" And then inviting to do that moment differently.

Kyle Pinion:

With that time said we're about five minutes over. So I'm going to call that a close on tonight's webinar. And I would like to once again thank Kimberly Castelo for her enlightening and eye-opening insights into this particular facet of the MS experience.

You know, we often want to put together more programming for both sides, sort of the MS relationship, not just for the patient, but also for the care partners. And programs like this have been developed thanks to feedback from care partners who've come to our programs that "We'd like more education for us." And so we're doing everything we can at MSAA to ensure we meet your needs as well.

As mentioned, tonight's webinar will be archived to our web site. And we ask that you take a very brief survey that's coming up next. It may already be on your screen. But if not, it will be shortly. And we are absolutely... we find it essential that we are creating programming that is that is relevant to you and helpful to you. So you're honest and open feedback is so appreciated. Thank you for taking the time to fill out that survey.

On behalf of Multiple Sclerosis Association of America and Kimberly, we thank you so much for joining us. Have a great night and stay safe, everybody.