



In It Together: Love and MS Relationships, Communication, and Intimacy

Presented by:
Jessica Thomas, LCSW

Yahaira Rivera-Bobadilla:

Hi. Good evening, everyone. Welcome. We're so happy that you're here with us tonight. Thank you for joining MSAA's live webinar, "In it together: Love and MS, a Conversation about Relationships, Communication and Intimacy." This webinar will be presented by licensed clinical social worker Jessica Thomas. My name is Yahaira Rivera, and I'm the Director of Mission Delivery and Program Development for MSAA and your host for the program this evening.

Before passing it to our speaker, I would like to take a moment to share some information about MSAA and go over some housekeeping items and reminders. 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, an equipment and cooling distribution program with products designed to improve safety and mobility and help with heat sensitivity, and an MRI access program. Both of these programs are available for individuals with MS who qualify for assistance. We also offer educational programs, online tools, publications, digital resources and support through community connection to help you stay connected with other members of the MS community. All of our programs are available nationwide. To learn more about our programs and our services, please visit our web site. mysaa.org.

And now I just want to share a couple of reminders. During tonight's program, you will have the opportunity to ask questions by typing them into the Q&A icon on your toolbar. As time permits, we will do our best to answer as many questions as possible during the Q&A portion of tonight's webinar. Please note that this program is being recorded and will be made available on demand on the MSAA MSi website in the upcoming weeks. Know that at the end of this program you will have access to a brief survey. We ask that you please complete it. Your feedback is so important and you help us develop future programming and content. A link to this survey will also be available in the chat box.

And this is just a friendly reminder that this program is for educational and informational purposes only and does not constitute any formal recommendations. Please speak with your doctor or healthcare provider team if you have specific questions and concerns.

And now I would like to introduce you to our speaker this evening. Jessica Thomas brings over 19 years of experience as a clinical social worker helping patients and her partners in urology, oncology and chronic illness. Most of Jessica's expertise is in the field of mental health and emotional wellness for people living with multiple sclerosis and other neurological disorders. In addition to her professional experience, Jessica has over 20 years of living with multiple sclerosis. Welcome, Jessica. We are so honored to have you here with us tonight. Thank you.

Jessica Thomas:

It is a true pleasure to be here this evening or today with everyone and we're going to be talking about some important topics. And it's timely. It's, you know, we had Valentine's Day a couple of weeks ago, but we're going to talk a little bit about love and MS. And so, before we get started, I just wanted to, you know, give accolades to MSAA. They are a great organization. I have been helping people with MS for a very long time. And I have referred people to the Cooling Program, to equipment loans, as well as the MRI program. There's a lot of really great resources. And I have been so impressed at the art program, that I wanted to share a little bit of my artwork, and so I am sharing that in today's presentation as we walk through the the journey of "We're In It Together: Love and MS." And we will see that often if you think of a flower arrangement or think of a beautiful group of flowers, they're all pretty, but what makes them beautiful is all the different pieces and how they complement one another. And so as we do today's presentation, we're going to break down relationships and MS and with communication, intimacy, and relationships in general. And we're going to really focus on each part, but to know that they all sort of make the relationship. So we'll move on to the next slide.

So I always like to introduce myself, I had a pretty great introduction, but I like to tell a little bit of my story in a very quick way. So, 20 is the amount of years that I will have been married this year, and out of that period of time, 19 of those years have been spent as a clinical social worker helping people living with disease. I was a social worker prior to, but I worked in a different setting. But when I was diagnosed with my own illness, I decided to work in the field of helping people with the emotions of disease. And then 18 is the number of years that I really have been dedicated more to MS more than anything. And then 17 is the number of years that my son turned. So, usually my story is pretty easy to tell. And between the years of 20 and 19, I was diagnosed with MS. So, a lot happened in a couple of years of my life when I was in my twenties. But today's program, what we're going to do is that we are really aiming here to talk a little bit about relationships, offer you some practical advice and strategies for maintaining healthy, fulfilling relationships despite challenges that might be posed from MS or from just a general challenge in a relationship. So we're going to move to the next slide, and we're going to talk a little bit about MS.

So, because there's a physical impact and then there is an emotional impact. And so to understand MS, you know it is an autoimmune disease that causes a lot of different things to happen in your body. I don't want to make this an MS 101 conversation. But with MS there can be changes in your physical ability, there can be changes in cognition, and there can be changes in vision, with walking, etc.. It's a wide range of symptoms and some of your symptoms are visible where you can see them. So if you're having problems with your gait or walking, that's something that's visible and it can be seen. But sometimes cognition can't be seen or fatigue might not be able to be seen. And mood changes are definitely often not able to be seen. And so it's important to know that MS has a lot of different symptoms and it can impact the relationship and how it can do this is in a couple of different ways.

MS has a pretty profound emotional impact on people. And when we are first diagnosed with the illness all the way to dealing and coping with a disease that is sometimes progressive. So some

of the emotional challenges that can be associated with MS can be the uncertainty. Just not knowing what day to day is like, it can be an unpredictable nature and that can cause feelings of anxiety or stress. Also feelings of fear, fear of progression, loss of independence and just the unknowns. And then there can be grief, coping with the loss of abilities, changes in your lifestyle and the impacts of MS could really lead to feelings of grief. And understanding those aspects is really important to know for people that are affected by disease, but also for the people that love them.

I always say that my my husband, and my son, to some degree, they carry some of the weight of my MS. And it does impact some levels of our relationship, and MS can be, I think, a positive impact, it can make you stronger, but it also can make things a lot more challenging. And MS can strain relationships with your partner or with your family or friends as a disease may require adjustments in roles and responsibilities as well as emotional support.

And I, when I give presentations, I've worked with patients in a clinical setting as well as working for MS organizations, and I also lead a monthly mental wellness chat. We talk about how MS impacts our relationships. And so I'll share maybe a couple of my own anecdotes, but one of the things that I would say is that, you know, after my MS diagnosis and after having my son, my husband and I had to figure out how to work together well as a team. And so we highlight the, you know, some of the emotional and psychological impacts of MS, you know, with all the different emotions that you're feeling, it is not uncommon for your partner sometimes to feel those, too. I know when I have went through and my own diagnosis journey, I had a lot of anxiety, my husband did not. But, when we've had to make big decisions or and have had to work together as a team, my husband's had to pick up a little bit more of the burden with my son, like getting him ready in the morning when he was younger, etc.. And so it's important to know that the people that love you, if you're living with MS, you know that they can experience a level of emotional strain, too. And because they witness some of the challenges that you're going through, they bear some of the weight of making treatment decisions, even having to bear some of the stressors, and sometimes they may even feel helpless and overwhelmed by changes that are in the relationship. And so it's important to really be able to talk about how the emotional health is for both you and the person that loves you and to make sure that you are doing positive things for your relationship, even in the face of challenges with MS sometimes.

Some changes that can happen in our relationships is the changes with roles and responsibilities, and sometimes changes with daily tasks and decision making. And sometimes the uncertainty in itself can make it difficult to kind of plan for the future. And that can be challenging. I always share, my husband and I moved into a house that had a master on the main level, and the reason why we did that is I had a really big relapse when my son was young and that brought to the forefront some of the fear and the concern about what and as would be like for the future. And so we had to face some of those concerns, and one of our choices was to change our living arrangement.

These challenges can really strain our relationship and it really requires both you and your partner to adapt and find ways to support each other. And we'll emphasize today the importance of communication, understanding, and support from not only your partner, but to your partner as well so that way we can have healthy communication. So, communication is essential in maintaining a healthy relationship when MS is involved. It's important for both partners really to be able to openly discuss their feelings, their concerns and their needs related to MS. Understanding and having empathy for our partners is important. And because the disease is invisible, sometimes it's important to make sure that we're communicating the symptoms that

we're experiencing as well as our partner understanding and valuing and and believing what we're saying as well.

So, statistics and studies essentially say that the insight on prevalence and the impacts on MS and relationships, for example, or the studies can actually give us good insight on this. For example, studies have shown that couples affected by MS may experience higher levels of relationship dissatisfaction and lower levels of intimacy compared to couples without chronic disease present. So knowing that chronic disease is present and that MS is present in your relationship already gives you an awareness that you'll have to work hard, and sharing this information is important because it can help to normalize the experience that when you have a chronic disease in a relationship, it's a little bit harder. It's not impossible to work through things. It's not impossible to work on intimacy and communication. It's not impossible to have very great relationships. But they might take a little bit more work because there's another variable. And what we know is that marriages are hard, relationships are hard. Sometimes they're beautiful, they're great. We all want them. But they're tough and they're tough for the general population. And so having a chronic disease in it just elevates it a little bit more.

And so I'm going to, within today's presentation, also answer questions that were pre-submitted as I get going. So we're going to stay on that healthy communication style, but we're going to talk a little bit about relationships real quick and some of the questions that we had from that. So... and statements, a couple people added statements. I'm going to say them because it is really important to me as a therapist, as a clinician to tell people, to reassure them, that they're not alone. And so if it's a statement, I'll just let it be. But if it's a question, I'm going to answer it. So, for starters, someone had stated the fear of being in a relationships due to medical conditions. So that person has a fear of being in relationships due to having MS and a medical condition. And that's something that many people may agree with, it might be a scary thing if you don't already have a relationship. I know early on in my own diagnosis, I went to counseling. I was really worried and I felt very sad for my husband. We were newlyweds and I was so worried about how MS would impact our marriage. And that was something that was going to have to take time to sort of see. But, but that was the scary thing.

So we had - upon meeting someone, how should I share my diagnosis with them? So this varies person to person and it is definitely a very delicate thing. You know, I know that you can't un-tell somebody once you tell them. So it's always about finding the right time, and maybe it's related to the level of relationship you have, the intensity of the relationship, and going with your gut, what feels appropriate. I don't think there's a right answer or a wrong answer to this. I just think that it is helpful eventually if you are in a relationship with someone for them to know about some of the challenges that you may have or know that you have a diagnosis of MS, because that doesn't define you, that's not everything about you. But when you decide that it's time to tell someone, just making sure it's the right time to tell.

How do you know if a person is truly okay with your disability? If a person loves you, I think that love looks like that they accept you no matter what your ability and disabilities are. But in healthy relationships, open communication is incredibly important, and having a really good open conversation with your partner is important, so that way you can talk about these hard questions and talk about these things.

How is a marriage maintained with so many limitations of MS? One thing I have learned as a therapist and as someone who's worked with people living with MS for a long time is that there are a very large amount of marriages that are very strong and are very successful in the face of MS. And I remember early on in my own journey, my own diagnosis, kind of latching on to some

of those people and some of those examples and seeing that. And I think that some of the foundations about communication and intimacy that we're going to talk about is going to touch on that. And I think that also, while MS might provide limitations, that they find ways to still have a strong relationship. And I think that that is a choice. And having things about their relationship possibly that are MS free. And so we're going to talk about different levels of intimacy, that kind of thing, but maybe things that they enjoy together - parts of their lives that they may travel or they may experience different things. They may participate in art together. There might be other things that help to provide some level of balance.

When and how do you tell someone that you've started dating that you have MS? So I'm going to go back to saying that this is something that is different for each and every person that you'll probably ever come in contact with. And if you're new to dating, it can be very challenging to figure out when do I tell someone that I have MS? And so, you know, I would say, it's a big deal to share it. And it's important to share it when you're ready. And I think inside you would know when it's time to share. But if it's the right person, it's not going to matter if you have MS or not. They are still going to be accepting of the beautiful person that you are, the individual that you are, and what you bring and the things that you can bring to the table.

So all in all, in relationships MS should not define your relationship, but it will give you some potential challenges because it's a little bit harder to navigate a relationship sometimes when MS is part of it. There's a lot of unpredictable things and a lot of things that not only you will experience but your partner may experience as well. So why is communication so important? We're going to stay on this slide for a little bit. So effective communication, and so we're gonna talk about some healthy communication strategies. So communication is important because a lot, and I'll just talk in the realm of MS, but it's important because so much of the disease is invisible. So we need to be able to communicate things that are not invisible. Also, a lot of M.S can impact your day to day, and we need to be able to communicate so we can work well with our partners. Communication is really hard sometimes in general for people just in general. So we're going to talk a little bit about effective communication strategies and this is really helpful for any relationship, but I'll dig a little bit deeper into like romantic relationships too.

So communication strategies, there's effective communication, which we'll start with active listening. Often in the practice of active listening, you want to concentrate on what the other person is saying. So instead of having your phone in front of you or having the TV on or even having something in your mind that you want to say in response to what they're saying, you kind of stop and you really fully pay attention to what they're saying. One of the best things that you might be able to do if you're practicing active listening is to rephrase or paraphrase what they just said. So, if I, for example, had asked my husband how his day was and he said, I had a really busy day, and so I might say, So it sounds like you had a really full day today. And that's an example of of active listening.

Also expressing our needs and concerns. It's important with individuals with MS and also their partners to openly be able to communicate their needs and their concerns honestly with each other. And this can help to prevent misunderstandings and resentments or keeping one person from assuming something.

Validating each other's experiences. When you're validating each other's experiences, you are essentially understanding and acknowledging that the person that's living with MS has challenges that can be challenging to both people. And this can help build trust and strengthen the emotional bond between you and your partner. So it's good to have open dialog about MS. I like for MS to not be the feature in every relationship all the time, because it's enough of a

feature. I like to imagine that MS should be kind of over here and so that way you can kind of see the things that are in front of you. You can pay attention to your partner. But MS is always going to be here. You're going to be able to see it in your peripheral vision, you're going to be able to experience it because you have symptoms, if you're like me. But we want to keep it here. We don't want the MS to be in the forefront of everything.

But I also like the idea of open, balanced communication. And so how I used to say this is that there is a circle of truth or a circle of trust. And there's a movie called "Meet the Parents" that kind of mentions a circle of trust, but this is a little bit different. So to explain it, it would be the person with MS, in this case, I'll just say myself, that I have as a pretty strong understanding with my husband that if I am experiencing anything that I need him to know, I'm going to tell him. So that's a given between he and I. And so what that does is that keeps him from having to guess or assume or think things are going on with me when they're not. Because if they are going on, I'm going to share that. And so that allows him not to second guess or wonder or be concerned. And then at the same time, if I tell him I'm not, you know, in my experience, I haven't been feeling good, etc., that I trust that he is going to accept it and understand it and know, even if he can't see it, that's my reality. And so that keeps me from being able to and know that he's going to be there and understand if I say something that it's really happening, that he's not going to be questioning it.

So for communication, we we want to encourage open conversations and honest conversations, and giving yourself space to discuss, at times, how MS is impacting your relationship and even having a safe space sometimes to talk about fears or frustrations or needs. And this can help both you and your partner be understood more. And then also leaving space to address difficult topics, encouraging you to address these topics related to intimacy, roles, responsibility, future plans, symptoms, and allowing a space for open and honest communication and trust will help you to prevent, again, misunderstandings and also be able to build a stronger, more resilient relationship together. That is one of the gifts that I will say is that while MS presents to be a challenge in relationships, sometimes it also is an opportunity to be resilient and to grow together more.

So maintaining, for communication, maintaining a positive atmosphere, space to express gratitude. Making sure that you are expressing gratitude for one another and the positive aspects of your relationship, even in the face of MS related challenges. And also finding humor. Studies really suggest that difficult situations related to having something like MS, that laughter can be a powerful tool for coping with stress and strengthening bonds. However, it's really important to be sensitive to each other's needs. But I'll share, even in the questions, I went through some of the questions with my spouse tonight before the program, and we even had a little bit of humor because one sounded, one question sounded like it came just for me. And then also, for communication, if you're realizing that you are struggling with communication, that you are finding that you are both short tempered, you're arguing, you're misaligned, you're having a lot of misunderstandings, or if MS is presenting a lot of challenges for your relationship, and you need to breathe together, you need to learn to work together more as a team, I encourage you to seek professional support. You know, going to a counselor will help you to work through strategies to communicate with one another and even strategies to live with MS together. That was a part of the role when I was a therapist full time, that I did, is that I worked with couples to kind of help, it might have been a newly diagnosed couple, but I would see both of them. And as they were kind of, you know, just figuring out how to wrap their head around this diagnosis in this life together now with MS included. So when you're implementing communication strategies, this will strengthen your relationship and it also will help you to

improve your ability to cope with challenges from the disease and really, overall, enhance your quality of life.

So we're going to move on to some of the communication questions that we got from the presentation... or sorry, from the registration. And so how to be less argumentative with your spouse when you're having an awful day? This is a really good question. So sometimes when we have a bad day, that bad day kind of sticks with us, Right? And this is kind of a... it may be an awful day that's an MS stay or maybe not an awful day. At first when I read this, I wasn't even thinking about MS. When you're having a bad day, I think it's important to know that if things are not going your way, if things are difficult, that you are always responsible for how you respond, even if your awful day is physically related and you're having an emotional response, you're always responsible for how you respond. And that's really tough because when you feel bad, it's hard to be super nice. You know, it's hard. So there are some strategies that I believe can be helpful, because we're not as resilient when we're having a bad day.

So what things can we do that can help us to be more resilient? So that's one thought, you know, is that taking a little bit of time before you and your spouse are kind of together for the evening. Is it decompressing? Is it doing art therapy? I talk about that a lot, because I think it's beneficial. Or is it practicing gratitude, or is it journaling, getting everything off of your chest before you go home or before you are interacting full time for the evening with your family and spouse. It also is okay to kind of give the weather report of how you're feeling. You could say today was a really hard day and I'm kind of struggling a little bit. And so I'm going to be really careful in how I react to things. And so, that might change, you know, you might not want to have extra touchy conversations that evening. You might want to limit some of the things that create a little bit more irritation. You might even want to do something that makes things a little bit easier, you know, for dinner or whatever, just make the evening a little bit lighter. Or, you might want to do something that allows you to have a little bit of lightness in your evening if the day has been really hard. And letting your spouse know that you need to take care of yourself or you may invite them to join with you. But, it's okay to have bad days, it's okay for them to feel gross. It's okay and it's understandable that that creates kind of a tension within you. But then it's our responsibility to figure out how to mitigate that. So what resilience strategies can we put into place.

So then we have: "How do you cope when trying to focus on your life with MS and its progression without any support from your spouse for more than two decades, almost three decades? So this person doesn't feel like they're getting any support from their spouse and feels like their MS at the same time is progressing. And, I think that this is, you know, relationships are very unique. And so what I would say is that this may be a really great opportunity to go to see a counselor together, to work with a therapist, possibly. And then, if your spouse is not willing to, maybe for you to individually go. So, that way, you can't always control what the other person does, but you can control yourself. And so that would be my clinical recommendation.

When I get tired... this is the one my husband said that reminded him of me... When I get tired, I'm so irritable. I pass that frustration on to my husband and then later I feel sad. Okay, so this is a statement I clearly can identify with a little bit because when I'm really tired, I'm irritable, too. I'm, you know, I just don't feel good. And then when I'm tired, I'm not emotionally resilient. So one of the things that I think that can be beneficial with this is learning to communicate it. So, communicating with your spouse. So on these days, instead of my husband just seeing the irritable, because that's what he would see, I say, You know what, today I am really tired and I need to go take a nap or I need to rest. And just doing that can make me a little bit less irritable.

But then also making sure that I am responsible for my self care and my ability to manage some of that.

Now, fatigue is a big part of my life and I know it's probably a big part for many other people's lives that are watching this. And so, you know, fatigue is going to be present a lot. So what can I do to help be a little bit more resilient? So some of it is those resiliency factors, but then also it's that self-care and that communication. And so, and then being internally aware, when you do a body scan, you realize, okay, I'm really tired, okay, what do I need to do to help mitigate that? That might help you to kind of stop and pause for a minute instead of being tired, not talking about it, and then you end up being irritable, which is what people see, and then you feel bad that that happened. So I would encourage you to communicate, talk about it, and then also find things inside that you can do for yourself to help mitigate that. And you might not be able to relieve the tired, but what self-care and grace can you give yourself to help feel a little bit better or more resilient during that time, even including possibly resting?

How can I make my husband understand my MS challenges? So this is a lot about communication. I also am a big proponent of if you have people in your circle that have MS, it's good to have for you guys, maybe to go on a double date. Early on in my own diagnosis, I encouraged my husband to hang out with some of my friends' husbands too. So we would go on some dates together. But I just wanted him to be around other people that maybe would understand what he was going through as well, because I needed the connection of a friend with MS, but I wanted him to have that connection too. And I think through that, also going to educational programs or attending webinars like tonight's webinar with MSAA, really important. I encourage you to have your spouse listen to some of these programs, because if they can hear other people's experiences then also be able to hear other professionals talk, then they will start to understand it a little bit better as well. And if you have the opportunity for your spouse to interact with another spouse, that to me is kind of magical because that can help the level of understanding.

The next one is: How can I get my husband to realize that even though I keep a calendar and write notes, I do not purposely forget to complete tasks.? And that is a lot about communication. So, with this person, I would recommend talking with your spouse and maybe even sharing some resources on cognitive challenges with MS. And you can also maybe problem solve some strategies to help. It might be that the notes are not effective. It might be that there's other things that may be helpful for you. And then there's always the opportunity to see a neurocognitive... a neuropsychologist, sorry. And that might be helpful as well. But again, communication, communication, and communication. But, I think including your husband maybe in some education about cognitive challenges can be helpful as well. And then finding maybe some strategies and tools to help with that.

So then we have: How do you communicate to your loved ones the problems you have with the invisible symptoms like fatigue and cognitive issues? So, MS is often like an iceberg, and I'm sure many of you are familiar with this, the top being what people can see, the bottom, the iceberg is so much bigger, and it's what people can't see. There may be ways to explain some of the symptoms and challenges that you have. But I do think that including your loved one and communicating with them about how it feels for you, but then also giving them the opportunity to receive professional information and education that supports what you're saying as well. And then helping them to see kind of what their perspective is, you know, because I think it's an important way to work with your spouse is to really share your experiences. You might not be able, they might not be able to wear them, they might not be able to understand that. You know, I'm so thankful my husband will never understand fatigue is like for me. But he does know that

fatigue impacts both of us. And he does know that fatigue is there and it's a part of my journey. And so I think being able to communicate, they may not fully understand, but it's the idea that they understand and believe the symptoms that you're experiencing. And this is where it's also important to have other people in your life that are living with MS ' a friend, or maybe you go to a support group, etc., because it's really important to be able to communicate with people and people that understand what you're going through, because some people in your circle and people that you love intensely, like I love my husband, he'll never be able to understand that. So we're going to move on to the next slide. I'm going to take a big sip of water real quick and we are going to talk about intimacy.

So what is intimacy? So this is a really a broad range. So intimacy really encompasses physical, emotional and psychological connections between people. And so there's different types and I'm going to go through some of them. Physical intimacy involves physical closeness and touch, and it can include having sex, but it can also include non-sexual activities such as cuddling, holding hands or hugging. And this is an important feature. And usually most people think about this type of intimacy. Then there's emotional intimacy. And this involves sharing feelings, thoughts, experiences with another person in a way that fosters closeness and vulnerability. And it's often about being open, honest and supportive with your partner and feeling understood. There's intellectual intimacy, and this involves sharing ideas, thoughts, and intellectual pursuits. And so this could be around hobbies and interests, etc. Then there's spiritual intimacy, and this involves sharing beliefs, values and spiritual practices with your partner. And it's about engaging with your partner on a very deep level.

Then there's experiential intimacy. And so this can be when you're sharing experiences or creating memories together. So this might be with traveling, trying new activities or spending quality time together. And this kind of intimacy can really strengthen bonds and create a sense of adventure and excitement. There's conflict intimacy, and this is working through navigating with disagreements and conflicts in a way that strengthens the relationship. There's creative intimacy, and this involves expressing creativity or imagination, and this might be doing creative projects, exploring new ideas, or simply just enjoying each other's creativity, and this can really foster playfulness and spontaneity. There's recreational intimacy, and this may include leisure activities such as like hobbies or exercising, playing sports. And each type of intimacy is really important for building and maintaining a strong, healthy relationship. And by nurturing different aspects of intimacy, you can deepen your connection. So we're going to move on to our next slide, and we're going to talk about maintaining intimacy.

So with MS, MS can impact intimacy in a couple of different ways. It may lead to changes in libido, your sex drive, sensation, or the physical ability to engage in sexual activity. Fatigue, muscle weakness and other symptoms might also affect your desire, the sexual desire and function. There may be an in some areas of physical affection MS can actually, you know, be impacted. So, mobility issues and muscle stiffness, pain can make it challenging for people with MS to engage in some forms of physical intimacy. But there's important ways that we should think about how do we maintain intimacy. So MS can provide some challenges in the actual physical sexual level of intimacy. But how about some of the other ones? So maybe we can explore new forms of intimacy. So exploring new ways of being intimate that doesn't require physical exertion. This can be verbal, emotional intimacy. This also can be sharing fantasies, engaging in like a sensual kind of talk as well as non sensual forms of touch and affection, communicating openly and honestly about sexual needs, desires and concerns. Now, I'm going to note here I'm not a sex therapist at all, but it's important to be able to openly communicate and to be able to understand each other's needs and find ways that both of you can feel satisfied. Seeking professional support. So I would recommend, and I did recommend when I

was doing therapy full time, for patients to seek the support of a therapist who specialized in sex. And so a sex therapist who specifically could talk about the challenges within intimacy and help to build other things around intimacy. And these professionals can provide guidance and strategies for maintaining intimacy despite the challenges of MS.

We're going to stay on this slide right here. So, for some of the intimacy questions, this is a statement: Feeling unattractive. I feel so unattractive with incontinence. This is a real thing, and I want to share that this is something that, again, that you are not alone, that there are many people that experience incontinence, and yes, that probably is not a very sexy feeling, but it's important to know the things that make you attractive are not that. And while that makes you feel unattractive, it may be helpful to focus on the things that do help you to feel attractive because the incontinence is just a small part of you. It is important to talk with your partner about it and to have open communication, but I do want you to know that while incontinence is a bad thing, it doesn't make you a bad thing.

How do you adjust to intimacy as your MS gets worse? You know, I think as people age, as people, as disease progresses, sometimes it does, even in the lifecycle of marriages, intimacy changes, and if you are dealing with a lot of physical changes with your MS, it's important to communicate with your partner about it. It's really, really important to talk about intimacy. Talk about the levels of intimacy that you miss, what your partner misses, where would you like to strengthen your intimacy. It might be through other areas of physical touch and connection. It may be through other activities, but it's important to talk about, and I encourage you to always make space to talk about some of the hard things, because if we don't talk about them, they stay there and they grow and get worse. But there are things that you can do. You can also talk with your doctor as well, and I always want to note that.

When you have a low sex drive and haven't had sex with your husband in months. So if you have a low sex drive, this is something that can happen for many reasons. It happens with women when they're aging, it happens with men sometimes, it happens with people, generally with MS, without MS, and sometimes people that are on antidepressants, etc.. It's important to talk with your husband and talk about it. Again, it might be a big elephant in the room that's uncomfortable. But if you're dealing with a low sex drive, there may be physical reasons or maybe medical reasons, so it's important to kind of uncover that, but also to talk with your husband and have open communication about that. And even if you're struggling in areas of physical intimacy and sexual intimacy, maybe there are other areas that you guys can work on.

How common is it for partners to lose interest in intimacy after a MS diagnosis? So again, this is a very individual question. I can tell you when I was first diagnosed, I was a newlywed. And so I should have really had a high libido. But guess what, MS kind of put a big rain cloud over that. And the reason is it's hard for you to deal with a MS diagnosis. And I had a lot of anxiety and my mind was not on intimacy. It was on what is my future going to be like? So for me, it was a part of my adjustment cycle and grief cycle to the diagnosis, and that can be a common thing for people. But, an MS diagnosis should not change all of your feelings of wanting intimacy. We are human beings first and that's a natural thing for us to want. So I would encourage you to know that if you're newly diagnosed, it may not be a feeling that's... for me, my libido recovered, but it was hard to be a newly diagnosed person in my twenties and not really have that much of a libido because I was anxious. So it's important for you to talk to your partner about it, but also to maybe see a counselor, too, if you're concerned about it from a longer range, because you may be still working within the adjustment of your diagnosis.

And this is a statement: Suffering from erectile dysfunction. I don't want a future partner to think I'm not sexually attracted to her. Any advice? Communication. So the right partner, the right person for you is going to be someone who loves you and accepts you, but they need to understand you, and that's going to be an invisible thing that they're not going to understand, because that's something that you'll need to share.

50 years, married, 40 with MS, we love, hug, and kiss, but rarely physical intimacy. Is this okay? This may be okay for you. Yes. So, you know, it's important for you and your husband as a couple to kind of know and discuss what works for you. Some people have a lot of physical intimacy and some people don't. And, you know, as people get older and there's a life cycle, you know, to intimacy as well, and not that it stops, but with the ebbs and flows of life, you can see the desires change with hormonal changes, with life changes, with aging, etc.. But making sure that you are cultivating a relationship that does have intimacy and different levels of intimacy.

So we're going to move on to our next slide. And this one is "What Does Love Look Like with MS." And so I think with MS love looks a lot of different ways. So one might be a high level of emotional intimacy. Maintaining with MS, you know, love can look like having really good communication and a level of understanding and connection and sharing your feelings, thoughts, vulnerabilities with your partner and feeling accepted and understood in return. Also, love looks like building emotional intimacy. Love can be a really deeply personal and multifaceted experience, but it also also involves feelings of affection, care, compassion, connection towards one another.

And so love manifests itself through emotional connection, physical affection, respect and support, shared experiences, communication, commitment, unconditional care, growth and development, mutual respect and trust, and sacrifice and compromise. Overall, love is really complex, and it can take on many different forms, but it's really... love can look very different for everyone. For example, what love looks like for me tonight was my husband got pizza for dinner and he actually got me M&Ms too, on request. But love can look like making treatment decisions together. It can look like having hard conversations, discussions around parenting. It also can look like having fun and silly conversations. Love will look a little bit different from person to person. We'll move on to our next slide.

So your questions matter and clearly I embedded them within today's presentation. I answered, I think every single one that was provided and I would love if you have any questions, so please feel free to ask.

Yahaira Rivera-Bobadilla:

Thank you, Jessica. Thank you for talking about these important topics and for taking time to answer all of the questions that we received during the registration process. We do have a couple of questions that came in tonight during the live webinar, so we're going to start with this one: What should you do when you present your spouse with the symptoms that you're experiencing and your spouse accuses you of making excuses?

Jessica Thomas:

So there in that case, that can be very challenging because what's happening is there's not a circle of that trust, right? Because we've got to be able to when we share that this happens, even if you don't see it or understand it, that you know it's real for me. And and so I would encourage you, you know, that... a couple of things. Counseling may be helpful, because sometimes counseling can help in those situations. Also, attending educational programs together, because they may not be understanding the whole different ways that MS can look

like. And I think when we... knowledge is power, when we know more, we can accept that more. But, I do encourage you to seek both of those. But you cannot change your husband's level of understanding. You can only try to provide as much information and resources to help him understand or help her understand. Sorry, it's a partner. It wasn't a husband.

Yahaira Rivera-Bobadilla:

Thank you. We do have another question, Jessica, about someone that recently got divorced. My husband didn't want to deal with it. I just got divorced because of my MS. How can I trust and love again?

Jessica Thomas:

So this is a journey I think many people experience. And you know, when the divorce rate is high, and it's higher with MS, when MS is in the picture, or a chronic disease. It's a personal journey, and one benefit that I would say is that sometimes when we are... So, I was married first and then diagnosed, and so that is a little bit different. I felt like my husband had no choice. All of a sudden he married someone, and here. But when you're going back out and you're dating again, there is a variable that's kind of cool, is that you have the opportunity to build love and trust with someone at your pace and they can know about your MS and you can decide if there's someone that is going to be there for you or not, because they can show you during that dating process and during that relationship and that friendship process, you know, and communicating, etc.. And you can decide what's right for you. And then I always say, whenever in doubt, go to counseling, too.

Yahaira Rivera-Bobadilla:

Thank you, Jessica, for that. And for people who are listening today that perhaps they're not dating, they are not married, and they just want to build stronger relationships with friends or finding support, what will be your advice?

Jessica Thomas:

I would say... so, thinking about... so, if we take the physical, like, the sexual intimacy and put that aside, and thinking about the communication, so thinking about that piece, that circle of trust, I think that's important for any, you know, for relationships that you're building. But if you're trying to build friendships and trying to... you just want to expand your support, you want to expand people in your life, think about those different levels of like intimacy and thinking about ways to connect with other people through experiences, through hobbies, through exercise, through things, learning people in different ways. And as you get to know them and decide if you're letting them in on your MS, your experiences, etc., know that any healthy relationship should have that level of trust in it and that open communication. And so, if internally you don't feel like you're getting a level of support or understanding, even after trying to communicate with someone, finding what relationships are healthy for you and your MS and healthy for you in your life.

Yahaira Rivera-Bobadilla:

Thank you, Jessica, for that advice. And one last question: What is the best way to rekindle the spark with your spouse or partner when it feels gone?

Jessica Thomas:

So there's... one, It takes two to work. And relationships change over time. They have life cycles, too, right? Things can be very exciting in the beginning, and then you get used to your partner, which can be comforting. And then, so some... I think that intention is incredibly

important. So making effort with all your relationships, you know, making effort with friends to connect with them, making effort to go on dates sometimes, you know, making effort to do something special, even if it's small, making an effort to do something that's MS free, you know, if it's watching a movie or holding hands or finding little things. What things give you joy? What things to give your partner joy? What's fun to them? What's fun to you? Because if you're both doing something fun, you'll feel a little bit more of a spark and more of a connection. So what things connect you.

Yahaira Rivera-Bobadilla:

Thank you so much, Jessica, for this insightful and candid conversation. I love all the advice and strategies and tips that you gave us tonight. And also I want to thank our audience for participating and for being here with us learning alongside Jessica. This concludes our webinar. On behalf of MSAA, thank you so much, take care, and have a wonderful evening. Bye bye.