



MSAA Podcast: Exploring Relationships & MS – Episode 1

Host: Andrea Griffin

With special guest: Miriam Franco, MSW, PsyD, MSCS

Andrea Griffin:

Hello, and welcome to the Multiple Sclerosis Association of America's podcast: "Exploring Relationships". I'm Andrea Griffin, Vice President of Communications and Marketing for MSAA and your host for today's program. Today's program is part of MSAA's 2019 MS Awareness Month campaign on MS and the family, spotlighting the topic of relationships and MS.

I am honored to welcome our guest presenter Miriam Franco: to the program, who will be sharing with us her expertise and insights on fostering healthy relationships for couples living with MS. Dr. Franco is a psychologist, social worker, certified guided imagery practitioner, and a multiple sclerosis specialist. Miriam, thank you so much for being here and giving us your time today.

Miriam Franco:

It's a pleasure to be here.

Andrea Griffin:

To begin, we often hear that when a person is diagnosed with multiple sclerosis, it doesn't just affect the individual but those around him or her. What is one of the first things you do when working with a person who has MS who has a partner?

Miriam Franco:

Whether I'm working with an individual or with the couple directly, I make sure we spend time learning how MS is for them. It's necessary for the person with MS to understand their disease. And this is very hard to do initially. When you first get a diagnosis, it can take one to two years to start to feel like you're starting to know your disease, what it's like for you.

You're also trying to adapt to major medication aimed at reducing and slowing relapses in MS progression. And typically, by the first or second year, you've started to inform some people in your circle about it. Hopefully, you're starting to not just react to having the disease, but you're beginning to respond to how to grow into the challenge. And I find that growing into the challenge, becoming a person with MS, this really takes time, and it continues throughout your life course.

There's always a relearning, a re-shifting, because a chronic illness like MS requires fluctuating adaptations and some resilience to cope well with it. So, I find that part of being a couple requires knowing yourself. A relationship doesn't protect you from yourself. You take yourself wherever you go. So don't expect your partner to understand it if you don't.

You may have to become aware of new needs with MS. You certainly will need to observe your capacities, your realistic limitations, and how to problem-solve and negotiate your needs with your partner. It's really always lonely when you struggle with anything that can make you feel different from others, or that threatens your former sense of self or your ideas about how your life should unfold.

Andrea Griffin:

Yes.

Miriam Franco:

So of course, social support and spousal support are always essential, and support from your partner will help your relationship to weather some storms and reduce some isolation.

I find, Andrea, that more than people are comfortable admitting, often the partner with MS has hidden fears that loved ones may not be able to stay the course and they may not be addressing this, or they may unwittingly pull away from protecting a partner. So how you need support, when you need it, how your partner feels about it, and how to balance the support in the relationship, provide the larger context for how support is experienced among couples. And again, this is something helpful to explore in couples counseling.

Andrea Griffin:

That's a good point, Miriam.

Miriam Franco:

So, the first part of developing good social support requires self-education, self-advocacy, and carving out a sense of self over time with the disease.

Andrea Griffin:

Let's talk about that education piece, and where do people start?

Miriam Franco:

Well, what I often experience is how shocked each partner is by how much they don't know or understand about MS. If you think about it, most people don't know someone personally with MS, and when they do, they typically know of one person, and that forms the basis for their impression. And there's not really a common knowledge base. And then some aspects of MS are really hard to understand. Many report, for example, that it's very difficult to convey what physical fatigue is like to their partners. This is complicated by the fact that the word fatigue has about 20 medical synonyms, like being tired, or sleepy. So...

Andrea Griffin:

Yeah, sorry. I was just going to add, and we certainly know that fatigue is a significant issue for so many people with multiple sclerosis. And it is not just a matter of being tired. It's so much more than that.

Miriam Franco:

Yes. In fact, the best description I've been able to come up with is bone-wearying fatigue that's experienced as a whole felt body state. But sometimes the mental, the psychological, and cognitive symptoms of MS are even more challenging to understand and identify than the physical ones. Take, for example, Andrea, mental fatigue. Many with MS experience mental fatigue more than the MS community and practitioners tend to grasp or identify. Mental fatigue can require rest periods, but it doesn't necessarily require lying down or getting off your feet. Rather, it may require slowing down multiple sources of input, like lots of people talking at once or feeling like you're taking in too much information at once, or there's too much clutter in your visual pathway.

If there is cognitive difficulty or mental fatigue, I can't recommend enough the importance of getting connected with MS social workers or psychologists. They really are just as important a member of your team as are other MS specialists. An MS-experienced or certified social worker, a psychologist, or even a psychiatrist can greatly help people with MS and their partners to first understand what it's like to have MS for that individual. And because cognitive issues are not well understood by the person experiencing them, and they often have so much fear about talking about them, the MS mental health practitioner can really help with this.

Andrea Griffin:

Absolutely. Miriam, we've talked a lot about communication with one's partner. Let's talk a little bit about communication when children are involved.

Miriam Franco:

OK. Well, it's difficult to answer this question because so much depends on the age and the developmental stage of the child. Children of appropriate age, I believe, should be told because otherwise an emotional secret is created in families. Secrets actually increase anxiety, and they promote distrust in the child that their parents or significant figures can handle or make contact with distressful or painful topics. Children do need to be taught about privacy regarding who they share this information with.

Balance or symmetry in parent-child relationships is also important here. It's OK for children of a reasonable age and capacity to help a parent manage their MS in some way, as long as this is not a rigid, ongoing role. All families sometimes require their members to temporarily take on a caring or helpful role that they may not do otherwise. But the key here, Andrea, is not developing repetitive patterns, wherein the child or the teen is rewarded for their adult capacities and contribution to the family, to the cost of letting go or relinquishing their natural child-like dependencies. So, children need to be uneven, drop a stitch, to still be silly, not responsible, or just at times just plain self-oriented. If they become too accommodating, responsible, or pseudo-mature, they run the risk of becoming a parentified child and they'll have difficulties in relationships later in life. So, role flexibility here is key. It's those patterned asymmetries you want to watch out for.

There are some marvelous books and guides on how to talk to your child or your teen about your MS. Major organizations, like the MSAA, provide these. And this is also something that can be discussed in a support group or perhaps a weekend program for couples that some of the MS organizations offer.

Andrea Griffin:

Thank you for touching on that, Miriam. We know that many of our listeners out there have children, and they are trying to figure out how to best communicate multiple sclerosis, and the challenges associated, in an age-appropriate way. So, thank you for touching on that. I want to move on to talking about the symptoms. And so you touched on, earlier, fatigue, which we know is certainly a significant issue for many people with MS. I want to talk a little bit about symptoms and their impact. Can you touch on how certain symptoms of MS can cause difficulties in relationships between couples and ways to address them?

Miriam Franco:

Yes. I think the first thing to remember for many folks is that neurologists do not typically spend time on symptom management. Your neurologist has to focus on the progression of your disease, your MRI report, and how your medicine is working. An MS nurse, if one is available, or an MS-experienced social worker or psychologist may be able to help you start to talk about symptom management and how it's affecting you and your relationship.

Some of the more embarrassing symptoms like bladder or bowel issues or how to manage sexual relations aren't always easy to learn online.

Andrea Griffin:

Right.

Miriam Franco:

And even if you do understand them, it can be hard to know how to talk about this effectively with your partner.

Andrea Griffin:

Sure.

Miriam Franco:

And this may not be a high skill set already established in the relationship, but it will become an important one to learn. Rather than allow fear, resentment, or distance to build up. I also find that for women with MS, most gynecologists are not prepared to help them with bladder or sexual concerns. If you do have pelvic health specialists, nurses, or physical therapists who are trained or certified in this area, the specialty, they can be terrific in teaching you ways to manage bladder symptoms, decreased sex drive, best ways to manage intercourse, and many concerns that can arise, and they can discuss them in particular detail as it fits your needs.

Andrea Griffin:

Mm-hmm. Very important point.

Miriam Franco:

So, let's again examine one of the major symptoms to manage in MS, which you mentioned before, Andrea. It's the most common one - Fatigue, and how it may impact a couple. So physical fatigue and, for many, mental fatigue, can negatively impact the couple system because it can interrupt almost any activity. Bone wearying fatigue can occur for some the same time every day, that 1:00 to 2:30 sudden drop in the afternoon where you feel like someone turned a switch on your back and all of a sudden you got to rest, you got to get off your feet. You sort of go kerplunk. For some, it becomes a predictable time of the day over time. Yet for so

many, it varies, and it's not always daily. And this can create temporary havoc, and sometimes resentment, not often shared by the other partner.

It's hard to have sudden bouts of fatigue because most people have planned days and others they're responsible for. They hate to have to take rest periods because it pulls them away from an activity or from their life, or it requires a sudden change and transportation changes. And these time-outs remind you that you have MS. So, when you feel tired, it's hard to sustain a good feeling about yourself. Our first sense of self is a body self, so when the body doesn't feel so good, the rest of us doesn't either. And women have a tendency that when they don't feel good, they think and feel that they're unattractive. So, there can be a sense of loss or guilt that your illness is impinging on others, not to mention deep frustration.

Andrea Griffin:

So certainly, fatigue impacts so many facets.

Miriam Franco:

Yes. So sometimes what I do for couples and for the person with MS is I try to first get them to accept their fatigue and the necessity to take rest periods. I tell them, remember, this is your body speaking to you. I try to encourage them to make these enhanced rest periods. Shift their framework. Use it as a time to experience deep relaxation. Expand your belly breathing, your meditation, or your guided imagery practice. If you can't use it as a time to get deeply relaxed, then practice belly breathing. Learn to accept and breathe into these time-outs. And I think the people around you will come to feel more at ease also because you're normalizing them. You may also be able to keep a phone nearby, listen to music. I think you have to also consider pacing for major family events or date night with your spouse because fatigue requires flexibility.

Also, drinking alcohol won't help because it acts as a depressant on your respiratory system. So, watch your alcohol intake when you're experiencing fatigue. Mental fatigue, though, is far more common in MS that many people don't realize, and many with MS struggle, to even understand their cognitive issues so they often don't even understand mental fatigue.

Andrea Griffin:

I'm glad you're touching on that because I wanted to talk a little bit about the cognitive issues and the impact that they may have.

Miriam Franco:

Yes. 50 to 60% of people with MS have some cognitive issues, no matter where they are in the disease course because it really has to do with the location of your plaques or lesions. So cognitive difficulties are so hard for those that have them to identify clearly.

Andrea Griffin:

Sorry, I didn't mean to interrupt, Miriam, and I think it's an area that is often misunderstood in general. I think for symptoms around mobility issues, people can see that, they can see what's going on. It's hard to explain to others about cognitive challenges.

Miriam Franco:

That's right. And also, the people that have them are fearful about sharing or talking about them. So, to clarify, cognitive fatigue can take the form of feeling as if you can't focus when several people are talking to you or there's too much in your visual field to scan, or maybe your head

and around your eyes feels achy. You feel like you can't get information in, like you can't pack it in.

Andrea Griffin:

The processing is difficult.

Miriam Franco:

The processing is difficult. You may even feel that your thinking process is strained. You could even feel dulled or lightheaded. You may need to withdraw a little, but you're typically not resting your whole body unless you're experiencing physical and mental fatigue together. Most don't distinguish the type of fatigue they're experiencing, and therefore their partner's in the dark. So mental fatigue may not require the same length of time of rest as physical fatigue does, but I do think the person experiencing mental fatigue needs to cue other people.

And specifically, like, I need to talk a little slower, or perhaps let's shift and not talk for a few minutes rather than passively continuing the discussion or activity and hiding it.

Andrea Griffin:

So going back to the point about communication.

Miriam Franco:

Right. But an important thing to remember is you're always trying to get better at meeting distress, though you may have to talk about hard, painful, or difficult topics. The most and the best practice is to meet distress with your partner, it tends to actually create more sense of trust in the partnership, that we can touch things, even if we don't know what to do with them yet.

The other problem is if you act as if you're OK and you're really not, typically your partner picks up the disconnect but doesn't know how to process it. So, this often leads to misunderstanding, confusion, or your partner attributing something motivational on your part. And this can blossom, and you really want to interrupt this kind of pattern.

Andrea Griffin:

And can ultimately cause some other issues within the relationship.

Miriam Franco:

Tension within the relationship. Right. Now, another thing about fatigue that we do need to talk about, Andrea, and I know you've experienced this and come across this often is that when you're working with a mental health practitioner who understands MS, they can help you tease apart how depression could be impacting short term memory or your fatigue. And so, depression really is three to four times more common in MS because it's connected to the physiology of the disease, the actual structure of the disease process.

So sometimes MS is causing fatigue or impacts your short-term memory. Sometimes it's depression and you wouldn't have a way to know that. Unfortunately, depression still is underdiagnosed in MS, though depression is highly treatable. So, if you can get your depression treated, you can tease apart what's causing the fatigue and cognitive issues. Also, treating depression improves your quality of life because depression also lowers your sex drive and performance. So, working with an MS health practitioner, you may be able to receive some

counseling and be on an antidepressant. Exercise, too, over time has been found to regulate depressed mood.

Andrea Griffin:

Thank you for touching on the topic of depression, Miriam, because I think often it's underdiagnosed, but it's also not discussed very openly, so thank you for touching on that. You know, we've talked a lot about communication in general and even some of the symptoms and how those can impact communication. Let's talk a little bit about the differences between men and women and their communication styles and how they express their feelings differently.

Miriam Franco:

Well, there certainly are differences.

Andrea Griffin:

Yes.

Miriam Franco:

Before I address them, I do need our listeners to be aware that I'm going to apply broad stereotypes here, because the question calls for it.

Andrea Griffin:

Yes.

Miriam Franco:

That's not to imply that all men or women with MS fit these patterns or fit them neatly. There is considerable research on gender differences and chronic illness. Women attend to existing health concerns. They engage in preventative behaviors, and they sustain treatment interventions more often than men do.

Men generally take longer to report symptoms, it takes them longer to get evaluated for MS, they start treatment later, and they adhere less to treatment routines. And this is especially true for younger men between the ages of 16 to 44. It's not surprising given societal messages and pressures that men receive about being masculine, that we would find this appearing in their health behaviors.

Men still tend to be stoic or stick to getting information or trying to know how to solve or fix a problem. Being overwhelmed by the illness may be perceived as threatening to their breadwinner role, their ability to protect their loved ones, or even, I find, their fear of feeling and being overwhelmed. In other words, sometimes when men experience a heightened or an occasional raw, emotional state, it's equated to vulnerability, and that's perceived as a weakening process, versus just seeing it as having an occasional feeling state. So, feelings of sustained anger and grief or fears about sexual functioning, lead to shutting down responses because they think they're going to experience a perilous state, not a temporary, necessary reaction that will shift. So, experiencing it gets equated to being it.

Men's difficulty expressing feelings and needs is, of course, terribly frustrating for women. Plus, men with MS, like men with other chronic illnesses, tend to rely on other females, wives, sisters, or mothers, to talk about their MS, certainly not other colleagues at work or other men. So, for many men, the realization of having to use a cane, and being seen in public also gets equated

to lower status, because being strong is often associated with a physical image of stature and, again, associated with masculinity.

So, usually, it's women that start sounding boards for men with MS. When men do talk to other men with MS, they talk about sports, they hang out, they pal around. They may not talk about the disease itself.

Andrea Griffin:

But that's OK. And that's important to have that network or that support system. Would you agree, Miriam?

Miriam Franco:

I do because I often recommend that wives not confront this because it's best to recognize that hanging out with other men with MS is still a viable means of social support. And you may find that the men aren't, like, talking to each other, like, 'how's your MS going?' But what they will do is give them information. They often refer them to a good MS specialist. I think it's just helpful for them to be around other males, whether they're talking about the disease or not because it reduces isolation and it also helps the wife to not have to carry the management of the husband's disease. And I think that's freeing. So, they don't have to be in an MS support group, but they do need to be with other men that help them strengthen their feelings of camaraderie and masculinity.

Sometimes what you can do as the woman partner, the female partner, you can help make a suggestion about how to manage an MS symptom. Like, let's say there are mobility issues, and your husband needs to take a child to some important activity. Once you've figured out a way to do that creatively, then you might try asking him what it would feel like to figure this out. That's when you might hear about how much relief and worry he had, previously.

Women, on the other hand, want to express themselves and have others hear them or comfort them. If your partner does need to express their emotions with you and you have little skill in doing so, it's important to do it gradually with rules in place. It's very overwhelming for people who have difficulty expressing feelings to try it in an open-ended format. So, time limits matter here. Agree to signals for a timeout or when to take a rain check or when to talk about it later because things are getting too frustrating. It's also really helpful to have a beginning and an ending, and smaller doses more often is a good rule to follow.

Andrea Griffin:

That's a good point. Smaller doses. So, taking things in pieces, not trying to address every topic within one discussion.

Miriam Franco:

Right. And sometimes anger is the first thing that men feel comfortable sharing. Anger has a way of bearing witness to something significant that has happened to you. It's a way of sometimes mobilizing yourself. 'I can't stand with this disease is doing to me. I'm not going to give in to it. I'm going to kick it.' This is an understandable response. As long as it's not pushing other people away. So, it may be important to validate anger versus the way it's being expressed. Having male peers here who can model new ways to do this with MS could be helpful. And there are some MS organizations that have online male chat rooms and support groups.

I also want to say again that couples therapy can be very helpful here, and it doesn't have to be long-term. Getting help is often assumed to be a shaming or a blaming experience. But in couples work, it's the relationship that's the patient, not the individuals. And remember, most people need help learning how to live with the disease. It's unfair to expect yourself to know how when you've had no preparation for it.

Andrea Griffin:

Very good point. Very good point. Thank you for that, Miriam. I want to talk a little bit about stress and anxiety. Most people, to a degree, experience some level of stress and anxiety in their lives. What are some of the strategies you offer to help manage the anxiety that comes specifically with MS and its impact on couples in a relationship?

Miriam Franco:

Certainly. As you know, depression is part of the disease, but anxiety comes with living with the disease. And most people just don't fare well with change and things that impinge on their sense of control. So, some anxiety and stress are to be expected, and we're all built for this. The problem with anxiety and stress is when it's sustained, but it's no longer needed for a situation. So, it continues to pile up or build up. And it's building up in the body. So without having periods of interrupting it, or breaking it up with intervals of deeper relaxation or lowered reactivity. So, the problem isn't specific stress. It's not weaving in and out of higher stress-responsive states to lower, less reactive states where your body and mind recover and regroup. So, the fight or flight response that's triggered by sustained anxiety or stress takes a toll on the body, it interrupts healthy sleep, and as we all know, stress exacerbates MS symptoms.

So, most folks know when they're highly stressed or anxious and if they don't, their spouses do. They know little, though, about how to practice deep relaxation. Some people don't even know what it's like to be deeply relaxed. And it's more than just distracting yourself with an activity. So, the first thing I teach anxious individuals, or couples, is to learn how to live in the present.

Andrea Griffin:

Very good point.

Miriam Franco:

Anxious thinking tends to escalate into over-anticipation about the future. And we tend to view the future based on how we're feeling in the present. And we really don't know the future, but we like to think we do when we're anxious because we can ascribe fearful negative outcomes to it. And though that's painful, we can at least control it.

The best way to start interrupting, dwelling on the past, or over-anticipating or catastrophizing the future, is to practice belly breathing or what we call diaphragmatic breathing. As you learn to slow your exhale, you usher in the relaxation response. And this consists of expanding blood flow, bringing more oxygen to your muscles that release muscle tension. It slows the heart rate and breathing rate, and it creates what's called a present focus, or what some people refer to as a meditative state.

I first practice this with clients, I breathe along with them. And then I have couples sit and face each other for maybe 15, 20 minutes, sometimes half an hour. And they have to meet each other's gaze and just match their exhales to the other's. This creates a wonderful feeling of holding with or bearing a present focus with the other. It's a very containing experience, and it tends to open up empathy and empathic resonance between people.

Andrea Griffin:

I think that's an excellent message, just focusing on our breathing. Something we sort of just take for granted and do. But there's probably a lot of shallow breathing going on for all of us.

Miriam Franco:

All day long. Most people are really sort of breathing at a half trot all day long. I also find that anxious people tend to have very active, anxious imaginations and lots of thoughts running through their head, but they have a hard time sustaining most forms of meditational practice because when you have a lot of, what we call, mental chatter, or sometimes referred to as monkey brain, what happens is it's hard to be alone in your own head. And if you have cognitive issues, sometimes meditational practice is seen to be too stressful or just requires too much of a higher level of skill to be successful with it. So, the neat thing about relaxation and guided imagery is that first you relax your body and once you relax your body, you don't have to clear your mind with each breath, your mind will continue to have movies on your mind or get distracted.

But as you relax and enter a deeper state of relaxation, if you start to use sensory images, like imagining an ideal place of relaxation, a safe place, somebody easy to love, these sensory images come up, like, for most Americans, it's going to the beach. So, what happens as you deepen your relaxation response, and you bring in sensory images, your body starts treating it, the body starts taking in the healing property of that beach.

And the more you practice it, the more it reverberates like deep-depth charges in your body. And it's fun and it's playful. So, what's happening is that you're sort of turning on your own natural pharmacy and you're really learning how to interact with the images. And the images in this state are more vivid, more immediate, and more emotionally charged. So, you tend to interact with them in a playful way, and you tend to shift your perception and your behavior more quickly, rather than being in a left-brain state where you're worried about 'how long will this last? Do I deserve it? Who's going to take it away from me? What's going to happen next?' ET cetera, et cetera. You have more of an experience of a felt body state of being in an experience.

So, these techniques, just like yoga, enter through the body first, and they can be very helpful in coping with stress, anxiety, and MS because these techniques increase short-term immune function which is great for autoimmune disorders. You can also practice this with your partner. So you're not talking to each other, but you're doing it side by side, and then afterward you're sharing the images you have.

Andrea Griffin:

I think that's a great point. That's something that couples can do together.

Miriam Franco:

So, just learning to interrupt this automatic pilot response of our anxiety and stress, kicking the fight or flight response down is very helpful. I call it weaving. Even if you don't get into a deep state of relaxation, you're really learning to kick that fight or flight, that anxious, stressful response down. And it's good for your body. There really are so many things out there that people can try now that are more right-brained and allow them to reduce emotional or interpersonal upheaval. I do have a suggestion, though, when you do have to discuss a hot topic and you're anxious about talking to your partner, it's really important to not expand your focus of concern or worry. When people are anxious, they tend to think in all or nothing, black-

or-white terms and exaggerate how bad or large things feel. Because mood always affects perception. So, keeping tasks or topics focused on the present, and breaking them into smaller bite-size units is very important for couples. Also, one step at a time. Problem-solving one step at a time. Allowing and normalizing feelings of loss of control, while allowing the effects of loss to be grieved and expressed are just really helpful to couples.

Andrea Griffin:

Excellent advice, Miriam. Thank you so much. We really appreciate your time and expertise in speaking with us today. Well, that concludes our podcast, "Exploring Relationships." On behalf of MSAA, I would like to thank Miriam Franco: for the excellent information, she has shared with us on this very important topic. I would also like to thank Gradwell House Recording for hosting us today and producing the program, and our funding partner, Sanofi Genzyme, for supporting this podcast as well as additional programs as part of our MS Awareness Month campaign.

This podcast, along with additional information on multiple sclerosis, can be found on MSAA's website at mymsaa.org. Once again, thank you very much for joining us.