



Multiple Sclerosis  
Association of America

## **MSAA Podcast: Spotlighting Care Partner Needs with Lara Krawchuk – Episode 2**

Host: Andrea Griffin

With special guest: Lara Krawchuk, MSW, LCSW, MPH

### **Andrea Griffin:**

Hello, and welcome to the Multiple Sclerosis Association of America's podcast, "Spotlighting Care Partner Needs." I am 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 care partners.

I'm honored to welcome our guest presenter, Lara Krawchuk, to the program, who will be sharing with us her insights as well as resources and tips for care partners. Miss Krawchuk is a licensed clinical social worker, therapist, and wellness educator. Lara, thank you so much for being here and giving us your time today.

### **Lara Krawchuk:**

Oh, it's my pleasure, Andrea. Thank you for having me.

### **Andrea Griffin:**

Absolutely. I want to first acknowledge the important role of the care partner. I think many people are in this role and may not even necessarily identify themselves as a care partner. It's also notable to mention that each person in a care partner relationship is unique and that the roles and responsibilities certainly vary for each situation. Lara, let's talk about some of the different challenges that care partners may face and how best to address those challenges.

### **Lara Krawchuk:**

Sure. The challenges that care partners face are really varied, ranging from the physical rigors of care to the emotional impact of caring. This could be for someone who lives with a person who has MS, or who lives down the street, or who lives across the country, or even the world. So, care partnering has a really diverse impact and range of possibilities. And one of the things I recommend is kind of identifying who your care partners are, what their roles are, and how they want to be utilized and are best utilized.

### **Andrea Griffin:**

Those are all great points. Thank you. You know, we know communication is key in any relationship and this is certainly true for care partners and those they may be helping to care for.

Let's talk about some tips to help with communicating needs for both the care partner and the person with MS.

**Lara Krawchuk:**

Communication is critical in this. Both communication between care partner and patient, and also between care partners and medical team. Communication that is overt, clear, keep it short and repeat, hit "Repeat" as often as needed. Sometimes a brief conversation is much more helpful than going on and on for hours and belaboring the same points or pushing things when the patient is not ready or not open. So, communication skills include being clear, backing off, and revisiting an issue when it's important.

**Andrea Griffin:**

Yeah, I think you make a lot of good points there. Thank you. Lara, in terms of communication, let's talk a little bit about the importance of communication with the medical team. Say, for instance, a person with MS may be having some mobility issues or even some difficulties around fatigue, and a particular mobility device may help conserve that energy and help with the fatigue. Let's talk a little bit about how that communication can take place with the medical team involving both the care partner and the person with MS.

**Lara Krawchuk:**

Yeah, Andrea, that's a really important issue. And care partners can be so powerfully helpful in coordinating communication with the medical team. So, if for instance, a family member is wondering about or noticing a need for a mobility aid, they might identify who in the medical team is their best ally, and who is easiest to talk to. Sometimes that's the doctor. Sometimes that's their nurse, or nurse navigator, or a social worker on the team. It doesn't matter who it is, but if the care partner can help identify the person who is their bridge to getting the proper information and give them a heads up, or formulate a question or two, I really recommend being very organized in your communication with the medical team. Short and sweet. They're always overstressed and over-busy. And think through what exactly it is that needs to be answered. Specifics about devices or questions about timing.

It is a great idea to take the lead in that if it's welcomed by the person living with MS. If the person living with MS is not resistant, the care partner can take the lead in starting a conversation like that to get more information, to explore issues of timing. If the person living with MS is not ready, the care partner needs to back off. Be respectful, and again, remember the principle of agency and the right to self-determination, unless there's a safety issue. But partnership with the medical team is essential. Good note-taking about what is recommended, ideas, and offerings, can also be extremely helpful.

**Andrea Griffin:**

Great suggestions, thank you, Lara. Let's talk a little bit about the importance of caring for the care partner. Certainly, if the care partner is not well, that makes it challenging to help care for anyone else. What advice can you offer on that?

**Lara Krawchuk:**

The rigors of caring are great. There is something called compassion fatigue - and compassion fatigue is simply getting worn out by caring. And this is a little different than physical caring, which has a lot of fatigue elements as well, but compassion fatigue is being worn out by the emotional rigors of seeing someone that you care about suffering or struggling, and that can stick and really have an impact on your own well-being.

And so, people need to keep an eye out for what are the signs that they're experiencing compassion fatigue. This is a term that we use in professional circles a lot for professional careers. But I think it's completely relevant for care partners as well. What are the physical signs? You know, are you experiencing muscle fatigue, or pulls in muscles, headaches, or neck tension? What are the emotional signs? Are you irritable or are you sad? Are you feeling what we might call depressed? Are you feeling overly stressed? Sometimes people have relational impact. They're snapping at the people they love. They're irritable in relationships. They're isolating, they're tuning out a lot. They're really not present. There can be spiritual impact. Anger at God, questioning. None of these things are wrong, but all of them need to be supported and addressed for there to be success in long-term care partnering.

**Andrea Griffin:**

That's a really good point around compassion fatigue. How does someone start that process? Just of identifying that this is maybe happening.

**Lara Krawchuk:**

Yeah. So, I always try to keep a baseline. So, I always ask people, "one" being totally fresh as a daisy, you feel great, you cannot wait to get up and help every day. And "nine" being you really thinking about leaving. You know, we don't want to be a "ten" where we burn out and leave.

**Andrea Griffin:**

Right.

**Lara Krawchuk:**

And so, what is your number? It's a simple scale to just say, like, 'where am I?' Notice I don't put zero on the scale. I think stress is a part of this, and it's hard so if you're a one to three, you're in really good shape. You're fresh. Maybe you had a time of respite and you're coming back fresh. Or sometimes when people are new to being a care partner, they're fresher than as time goes on. I always say pay attention to the four to six range in your numbers, because you're starting to get fatigued, you're tiring. And again, if you keep even a small notebook or something that talks about your signs of fatigue, there's no science to this. It's not scientific.

**Andrea Griffin:**

Right.

**Lara Krawchuk:**

But if you just note, like, 'I tend to get headaches when I'm feeling kind of done,' or 'I tend to get sick more often,' or 'I'm sleeping longer,' or 'I'm not sleeping well.' But if your number is in the four to six range, that's time for an intervention. Seven to nine is recoverable with help. It is cause for more concern.

**Andrea Griffin:**

Thank you for explaining that. And, you know, we'll talk a little bit about some resources at the end of our podcast. But I want to kind of stay on this topic because we've talked about identifying when that may be happening for a care partner. So once that identification has been made, what would be the next step, what would be some strategies that that care partner can take?

**Lara Krawchuk:**

So again, you want to pay attention to the four to six number range because you want to put strategies in place early enough so that you're not flat-out fatigued or feeling sometimes people say kind of crispy and done. And so, you want to take time to think through what might work for you. Everybody's different. So that could be finding someone to, if your care person needs a lot of care and you can't leave the home and that's one of the reasons that you're getting exhausted, to find somebody who can come for even two hours so that you could go take a walk. Nature is extremely healing for poor moods. You could go to a yoga class if that's something you use to enjoy. You can go to a therapist or a support group or simply go upstairs in your home and log online and there are many support groups. Not many, but there are support groups, for care partners on the Internet. So doing something that is specifically for you, sometimes people can't leave the home` but they might enjoy a long shower, a bubble bath, reading a book, or listening to music. Every person is different, but it is really important to proactively think about the things that renew and refresh you. Prayer is another, you know, talking to clergy, going to church; it doesn't matter what works for you as long as it works for you.

**Andrea Griffin:**

That's an excellent point. We have to figure out what is best for that individual.

**Lara Krawchuk:**

Yeah. And we need to be proactive in our thinking about it.

**Andrea Griffin:**

Sure. Great suggestions. Thank you, Lara. What advice can we offer to care partners who may be facing a situation where the person they are helping to care for is resistant to accepting help? And on that topic, what advice can you offer to someone who may be struggling to accept that help?

**Lara Krawchuk:**

Yeah, accepting help is really hard, especially in our society that's all about pulling yourself up by your own bootstraps. And that becomes such a problem when you're facing illness. And also, people who are experiencing illness and also their care partners are experiencing grief very often. There are many losses associated with living with MS, and very often people need to grieve those losses and they don't know how to do it, or they don't know how to language how they're feeling, they don't know how to talk about their anxiety, or they feel proud and they don't want to ask for help because of some of their physical challenges or their everyday daily living challenges. So, any of these things could get in the way of being receptive to help. It's really important for care partners to first assess safety. Is this situation something that must be addressed? Or is it something that I want to be addressed? There's a big difference between lack of safety and your assessment of quality of life. When you assess the quality of life, you have to assess people's need for mastery, self-determination, their emotional ability to engage in getting help, and what that does to them.

So, our perspective is care partners. And believe me, I have lived some of this myself with a parent who did not have MS, but who needed a lot of care, and he struggled to accept it. It was something that he had not been accustomed to needing. He had been a leader in our family and in the community. And when he needed more help, it made him angry, anxious, sad. He was grieving losses he couldn't identify. So that's very common. As a helper and a daughter, I wanted to force him to accept help, and what that did was cause tension. And that's what we see in many families living with MS, is that well-meaning loved ones, care partners, want so

badly to do something, and they push too hard. So, pick your moment, again, be really clear and short. Think through proactively what you're offering. Stay away from "shoulds" unless it's a safety issue. And when it doesn't work because the patient is not quite ready, then back up. And later, in a soft time, not a time of tension, offer again or listen to where the rub is, where the tension point is, and come up with a new way of helping. You know agency and mastery and being your own boss is important no matter what illness you're living with.

**Andrea Griffin:**

Thank you for touching on that. I think for a lot of us, it's often difficult to accept help and to ask for help. But we want to let our listeners know that it's OK to ask for help.

**Lara Krawchuk:**

It's a wonderful thing to ask for help, on the patient side of things, on the person living with MS, it is a wonderful, courageous skill to learn how to appropriately ask for help. Not only that, loved ones are looking to be supportive. So spread the helping out, find the right people for the right jobs. And learn, and I do believe it's a skill. Learn how to appropriately ask for and accept offered help. The more specific you can be about what you want and what you need and what would be helpful, the better.

**Andrea Griffin:**

Yeah, that's an excellent point.

**Lara Krawchuk:**

Take control of your own asks.

**Andrea Griffin:**

Yeah. I think, as you noted, finding the right person to ask for the right type of task is a great point as well.

**Lara Krawchuk:**

Yeah. Not everybody is equipped to be a physical care provider. Not everyone is equipped to be an emotional care provider. Some people are better off mowing your lawn for you. Some people are better off helping with the finances. Some people are wonderful at coming to doctor's visits and helping you listen and retain information. And some people can't stand the hospital or the health clinic environment. I know in my world, I'm the person who helps people grieve. I am really good at helping people identify when things are a loss and sitting with pain without trying to fix it. And so, I get those calls all the time from family members who are struggling. And that's an honor. But don't ask me to do your taxes.

**Andrea Griffin:**

Very good. Very good point. Lara, you've provided a number of helpful insights and, as we wrap up our program, we want to make sure that we provide some helpful resources for our listeners. What suggestions do you have in terms of resources and tips for our listeners?

**Lara Krawchuk:**

I think the best resource that there is an organization like MSAA because they spend a great deal of time cultivating excellent resources. So, call, ask for those resources, go to the websites, check things out. But there are a number of care provider-specific resources - The National Caregiving Alliance, the Well Spouse Foundation, that are really worth a look because they have both disease-specific and location-specific, and then more general information resources

that are really helpful, ranging from just checklists to ask your doctor to online support programs to articles about caregiving. There's a wealth of information out there. So, I encourage using the internet well, just keyword "care provider", "caregiver", things like that. They'll pop right up. So those are really excellent.

And also, as someone who puts together support groups frequently in my therapy practice, I know how hard to borderline impossible it is to get people to come live to your support groups, and so, online presence is really helpful and I think a lot of good resources are out there if you look for online group support. And I highly recommend talking to people who get how incredibly hard this is, who understand the losses you face as a care provider, who understand the anxiety of it, who can help you answer questions about 'how do I prepare for worst-case scenarios, how do I find respite, how do I care for my own fatigue?' These things from people who truly understand can be enormously valuable.

So, I can't say enough good things about group support, particularly like if it's professionally facilitated myself, because I think that adds another layer of protection should your mood be poor, should you be in trouble with depression or anxiety, things like that. Also, if you're in trouble with substance use, things like that, we have to pay attention to care providers' needs because they do struggle, they do suffer and there's no shame in asking for help if you're finding that you're in trouble.

**Andrea Griffin:**

That's great. Thank you for highlighting some of those resources. And really, our takeaway message is that there is help out there. There are resources available. There are organizations out there to assist. So, there are options.

**Lara Krawchuk:**

There are options. And one of the options is also local therapists. When you try to find a therapist for something like this, it's helpful to ask if the therapist works a lot with illness. It doesn't necessarily have to be with MS specifically, although that would be wonderful. And there are therapists out there who have experience working with MS specifically. But illness in general, it is a little bit different to work with a care provider with that kind of anxiety than, say, generalized anxiety. So, it's a good thing to call the providers on your insurance panel or find a provider who's even out of network and ask the right questions before you go in and waste your precious time with somebody who is not well-equipped to meet the needs of care providers.

**Andrea Griffin:**

Finding the right expert, the right resource, at the right time.

**Lara Krawchuk:**

Yes, exactly.

**Andrea Griffin:**

Great point, Lara, thank you. It's been wonderful to have you with us here today. We appreciate all that you have shared. We do want our listeners to know that MSAA is here to help and that we have many resources available. Please visit our website at [mymsaa.org](http://mymsaa.org) for more information.

Well, that concludes our podcast, "Spotlighting Care Partner Needs." On behalf of the Multiple Sclerosis Association of America, I would like to thank Lara Krawchuk for sharing her insights 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 EMD Serono, 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](http://mymsaa.org). Once again, thank you so much for joining us.