



Multiple Sclerosis
Association of America

MSAA Podcast: Caring for the Care Partner – Episode 7

Host: Peter Damiri

With special guest: Amy Sullivan, PsyD, ABPP

Peter Damiri:

Hello, and welcome to the Multiple Sclerosis Association of America's podcast, "Caring for the Care Partner." I am Peter Damiri, Senior Director of Content Development for MSAA, and your host for today's program. Today's program is part of MSAA's MS Awareness Month campaign spotlighting *Improving Mental Health and Wellness*. I am honored to welcome our guest presenter, Dr. Amy Sullivan. Dr. Sullivan is a board-certified staff clinical health psychologist and the Director of Behavioral Medicine at the Mellen Center for MS Treatment and Research at the Cleveland Clinic. Her clinical interests focus on individual, family, and group work with patients and family members affected by multiple sclerosis. Dr. Sullivan, thank you so much for being here and sharing your expertise with us today.

Amy Sullivan:

Thanks so much, Peter. I'm so glad to be here to discuss this important topic.

Peter Damiri:

Thank you. Well, our theme for MS Awareness Month this year is *Improving Mental Health and Wellness*, which is so important in managing MS, especially given the stress and anxiety brought on by the COVID-19 pandemic. And certainly, this affects people living with MS and their care partners. So, before we talk more about the role of a care partner, can you touch on the importance of overall wellness, both physical and emotional in the management of MS?

Amy Sullivan:

Absolutely, Peter. So, I think it's really important to bring in what you just talked about which is the pandemic. So, in a time like right now, I think we need to really focus on how important having overall wellness is during a time of physical concerns. But I am more concerned with the mental health concerns. And as I've said frequently, I feel like this may even be at a crisis level for mental health. In fact, I just saw an article today talking about the increases in depression with COVID patients as well as we've seen many articles citing that mental health concerns have increased.

So, this pandemic and this time that we're in is contributing to a lot of uncertainty, certainly due to the of the pandemic, but also because of thoughts about the vaccine, getting it, not getting it, having the availability to it. Certainly, many of us have dealt with loneliness and isolation, which also contribute to mental health needs and the need for us to take this very seriously. So, for my

patients, there's just a multitude of factors I feel, that are influencing their overall health and well-being.

When we look at their overall well-being, I think it's important to understand that wellness is multifaceted. So, when we say multifaceted, it looks like having wellness in several different areas. One is physical activity, which is something that we're all very aware of. Another is nutrition or having a healthy diet. One that I'm very passionate about and that we will speak a lot about is mental health or managing stress. Another is sleep and making sure that we're resting, relaxing, and recovering. Another is having a routine. And then finally, spirituality, if that's something that is important to somebody. All of these contribute to our well-being and our wellness. And so, I guess one of the things that I want to stress is that this is certainly important for everyone, but especially for our care partners. Because our care partners are at risk for not only, you know, burnout, you know, we really have to make sure that they're taking care of themselves because they are so focused on the care partner.

Peter Damiri:

Yes, exactly. Those are great points. Thank you. So, moving into our topic, can you describe what is meant by being a care partner?

Amy Sullivan:

Absolutely. So, by definition, a care partner is an individual who helps with physical and psychological care for a person in need. Some of the things that I think are important for us to remember is that it's often a family member. So, it could be a spouse or a partner or a child or a parent providing the role of the care partner, as well as being in the care, needing the care role. The care partner provides a wide variety of assistance for activities of daily living, including bathing, toileting, dressing, transferring, cooking, eating, meds, doctor's appointments, et cetera. And I'd just like to share a couple of statistics with you if that's OK.

Peter Damiri:

Sure.

Amy Sullivan:

So, 66% of care partners are females, and 65% of care recipients are females. Isn't that interesting? And then this is something that I found interesting, too, the care partner generally doesn't do less than 20 hours a week in their role. And many of them also have jobs. And what we have to remember is that the care partner is typically unpaid. So, some staggering statistics regarding the care partner.

In addition, I think it's important to talk about the fact that caring for someone, so being a care partner can be profoundly fulfilling, as individuals will generally move closer together when challenges arise. But it can also be very daunting and even challenging due to the chronic nature of the disease, in some cases. And so, I thought that was interesting to point out.

Peter Damiri:

Yes. Very insightful. I appreciate that.

Amy Sullivan:

Yeah. And if I could just mention one more thing about the care partner is that when we think about caring for somebody, you know, one of the things that come up frequently in the literature

is caregiver burden. And so, caregiver burden is this multi-dimensional response to the physical, psychological, emotional, social, and financial stressors associated with caregiving.

Peter Damiri:

So, these are great points. And as we know, MS is very unpredictable with many stages. Given this, would you say there are different stages of being a care partner as well?

Amy Sullivan:

Absolutely. So, I think we have to think about the natural ebb and flow of life and that is taking care of infants and the elderly, and that's just kind of what human beings do. But when we think about the care of an adult with a chronic disease, just like you said, it can be unpredictable and unexpected. And so most chronic diseases are unpredictable, as you stated. So, each family I think, is going to have their own unique reaction to the disease as well as how their life is impacted.

So, when we think about family identities or how a family displays their values, I think we have to understand that the family identity may shift, the family rhythm shifts, and we call this "role reversal" in my field. And so, role reversal looks like a working spouse coming home to now stay home or care for somebody at home, or a stay-at-home parent now or partner now going into the workforce, or a child taking on some nursing responsibility roles. And so, I think it's important that we recognize that all of these role reversals can present challenges.

So, in many ways, a family will benefit from progressing through a grief process. And when we think about the grief process, we think about grief and the changes in the family identity or life as the person once knew it. And Kübler-Ross is somebody that I really follow, she's well-known for her work on grief and acceptance, and I really like her work. And so, what she talks about is how a family may engage in changes, and then there are several emotional reactions that follow that. And the emotional reactions vary from each person. The cycle is not chronological, but it can look something like, you know, somebody having shock or denial or anger or bargaining or depression and eventually moving into acceptance. And for me, I don't really like the word acceptance. I like the word adaptation, which means that there's still a lot more that a person can do, we have to adapt to our environment instead of accepting the environment, I think acceptance is kind of passive versus active. But again, it's not chronological. And no one person is going to progress through a stage that is, you know, it's unique to each person.

Peter Damiri:

Right. Absolutely. Thank you. So, let's talk about the needs of a care partner. In your writings, you mention the term "trifecta of self-care", can you elaborate further on this?

Amy Sullivan:

Absolutely. So, when I think about the trifecta of self-care, I think about how healthy relationships are successful only when they're reciprocal and mutual. And we think about that in all relationships, you know, a significant other. I think it's really important that we think about reciprocal mutual relationships. And so, in this case, the person that's being cared for, or the MS person, may have significant needs but so does the care partner. I think that we really have to focus on the needs of the care partner.

So, the trifecta of self-care is really looking at the needs of the care partner, and it involves three important aspects. One is emotional support. So, when we think about caregiving, we know that it can cause really a plethora of mood symptoms, maybe feelings of sadness, grief, and loss. All

of these are very common to the needs of our care partners. And I think it's very common, therefore, for our care partners to need mental health help. But it's very uncommon for them to seek that help out. And I think it's really important that we talk about this because if, you know, a care partner is not taking care of their own mental health needs, they're not going to be able to take care of anybody else.

Peter Damiri:

Right.

Amy Sullivan:

Yeah. So, the second part is wellness activities. So, engaging in wellness behaviors such as what we talked about before, kind of those pillars of wellness include activity, nutrition, sleep, mental health, spirituality, and having some sort of routine. What we know about engaging in well-being activities is that it really enhances the overall health, both physically and mentally, of the individual.

And then finally, caregiving essentials. So, the trifecta, I think, is so important because it mentions all of these different components of providing care. So, caregiving essentials are, you know, most people come into a caregiving role with really little to no previous knowledge of these skills. And so, it may take a little bit of time for them to learn about an approach or how to be a caregiver. And so, when we think about these essentials, I think it's important to learn how to do the role. And organizations such as yourself, are great resources for the care partner, as is the neurology office. And then many neurology offices are partnered with behavioral medicine services, such as myself, and I know in my practice we offer a caregiving group just for the caregiver. So, you know, again, I think it's really important to take care of the individual who's in the caregiving role.

Peter Damiri:

Thank you for that. Dr. Sullivan, I was reading your chapter about the caregiving career. Can you talk more about that?

Amy Sullivan:

Absolutely, Peter. So, when we think about the caregiving career, this is really a philosophical model of caring that I like. And this is described by Linda Grim. So, it has three phases, and the first is called the encounter phase. And this is where the individual confronts the diagnosis, they grieve the loss of their previous life or their future dreams. And in this phase, new skills are acquired. The second part of this phase is called the enduring phase. And this is where the care partner is submerged in the role, often to the detriment of their own health. So, the key to this stage is learning how to cope with the isolation, the grief, and how they still maintain their own identity and their own health as changes to life dreams are occurring. And then finally, is the exit phase. And this is where the care partner's role is relinquished after either the death or institutionalization of the patient. And in this role, there can be significant grief for the loss of their partner or the caregiving role. But there may also be some relief in not having to do all of the caregiving roles. And these are all very normal responses, both grief and having some relief. And so, I really liked this model of caregiving called the caregiving career.

Peter Damiri:

Well, that's great information. Thank you for that.

Amy Sullivan:

Yes, absolutely.

Peter Damiri:

Unfortunately, we often hear about the realities of care partner burnout. Do you have any guidance or suggestions on possible ways to avoid this burnout?

Amy Sullivan:

Absolutely. So, when we think about caregiver burden, again, I think it's really important to look at the multi-dimensional facets of it. So, it's both physical and psychological. And so, I think when we think about it, I think it's important to talk about first maybe the economic burden. So, when we were speaking earlier, we noticed that no less than 20 hours are devoted to this care partnering role. I think that's staggering because most individuals that are in a care partnering role are also working. When we look at the literature, the care partner is more than two and a half times as likely to live in poverty. The average family that's in a caregiving role spends about \$5,500 in out-of-pocket expenses a year, and that's about 10% of the median income.

Isn't that something that I think is staggering for us to think about? But, you know, care partnering reaches far beyond economics, and it may have an impact on their health as well. Many individuals that are in care partnering roles have increases in stress and increases in stress hormones. Some of this may lead to increases in blood pressure increases in glucose and a weakened immune system. And this effect can actually be seen up to three years post-caregiving role. And then the literature also shows us that about 70% of care partners forego their own health and appointments. And in addition, most don't participate in those general well-being practices that we have focused so much on today, which are those nutrition, those activities, those stress management types of things. And so, the care partner is at greater risk for physical and psychological illness.

Peter Damiri:

Yeah. Excellent points. And it does make sense that the care partner is so focused on providing the care that they're not paying attention to their own health needs and physical and emotional needs as well, right?

Amy Sullivan:

Absolutely. Yeah.

Peter Damiri:

And you mentioned taking time for yourself and other activities, maybe taking some quiet time, reading a book, or going for a walk. I would imagine they're some of the tips and suggestions that would help the care partners as well.

Amy Sullivan:

Yeah. And when I think about the tips that I provide to individuals that are in caregiving, I think it's all individualized. And so, each person is going to respond to their own kind of stress management techniques and what helps them. But in a chapter that I wrote that was published by Dr. Rae-Grant, Dr. Fox, and Dr. Bethoux at the Mellen Center, I did come up with some caregiving tips to avoid burnout, and I wondered if you wanted to hear some of those.

Peter Damiri:

Yeah, that would be fantastic. Thank you.

Amy Sullivan:

Yeah. So, the first one that I suggest is really becoming educated about MS or whatever the disease is that the individual is taking care of. And so, I think, you know, the more one knows about the disease, the more empowered one will feel and the more comfortable they will feel in these role changes. So, when they're at the neurology office asking as many questions as they need and remembering that no question is a stupid question, they're all just really important questions.

Second, as you mentioned, is taking care of yourself. So, this brings us to what the airline stewardess says, and that is, you know, in the event of an emergency, if the oxygen masks fall, it's important to put on your own oxygen mask first before helping those around you. And I think this philosophy is perfect for caregiving. If you're having unhealthy emotions or you're physically unhealthy or spiritually unhealthy, I think you're going to be of really less help to somebody else.

Third is to practice healthy living. So, it's really focused kind of on that wellness approach that we've talked about today. So, making sure that your nutrition is healthy and making sure that you're exercising or just plain having some activity, making sure that you're involved in your own interests.

Fourth is staying social. So, connecting with others in similar situations is very powerful because you no longer feel isolated and you can learn from others, and that's why the caregiving support group that we offer at the Mellen Center is so incredibly successful and helpful because they're able to kind of normalize their behaviors, learn from others, and meet people who are in similar situations like them.

Five is accepting help. And I remember when we first had children, this was something that was really told to us. And I think this applies throughout the lifespan. So, accepting help, it's really difficult to ask for help from others, but realizing that you need a break and that others really want to help you, and making sure that you're not the only one burdening everything in the caregiving role.

Six is acknowledging your emotions. So, if you're feeling hopeless, worthless, helpless, sad, anxious, fearful, whatever it may be, make sure that you acknowledge these and also realize that these are normal emotions and reactions to the situation.

And seven is allowing for healthy expression of your feelings with each other. So just because you're now a care partner doesn't take away the relationship that you had in the past. You're still a spouse or a parent or a child, et cetera. And that comes with the responsibility to speak respectfully and openly.

Eight is allowing for a caregiving holiday. So, this simply means taking some time away. You're a better care partner to your loved one if you're able to take some time away.

And nine is encouraging healthy independence of your loved one, to helping the loved one to be as independent as he or she can for as long as they can, knowing that this may involve assistances or devices or new technologies, that making sure you're seeking those out.

And then finally, ten is seeking help through local organizations such as yourself, Peter, with the MSAA, and I think that these are places where we can get help and information and just really needing some guidance towards available resources.

Peter Damiri:

Well, that's great information. Thank you for that. Well, Dr. Sullivan, you have provided such great information and helpful insights today on this extremely important topic. As we wrap up our program, what are some of the key takeaway messages you want to leave with our audience today?

Amy Sullivan:

Yeah. Well, first of all, thanks so much for having me to talk about this important topic. And I think one of the things that I always like to stress is that I think it's important to normalize that we have mental health needs and getting that mental health help. So, as I said, it's very common for somebody to have mental health needs, but it's uncommon for especially care partners to seek that help.

I also know that, as we discussed today, there are significant rewards and challenges of providing care, and there's that risk of being overburdened, and with overburden comes some significant challenges to our physical and emotional health which really is concerning because if the individual and the care partnering role neglect their own physical or mental health care, they really can't be available to the person that they're caring for if they're not healthy. And so, I really can't stress enough how important it is to take care of yourself throughout this process. And again, using that airline steward analogy as a goal, and that's that, you know, in the event of an emergency if the oxygen mask falls, please put on your masks first before helping someone else. And we should really all aspire for this because if we can't take care of ourselves, we really are not going to be valuable or helpful to anyone else.

And then finally, in the field of MS, I think we're lucky to have such excellent resources and help from the MSAA and different organizations where individuals can really reach out for help so that they know that they don't have to do this alone.

Peter Damiri:

Well, thank you for that. Appreciate it. That's such great advice. And we really do appreciate your time and your expertise here today. So, this concludes our podcast, "Caring for the Care Partner." On behalf of MSAA, I would like to once again thank Dr. Amy Sullivan for her helpful knowledge and insights on this topic and thank Gradwell House recording for hosting us today and producing the program. Please note this podcast, along with additional information on multiple sclerosis, can be found on our website at mymsaa.org. Once again, thank you for listening.