

MSWS: Episode 4 – Understanding Care Partner Burden and the Impact on Workplace Productivity

On Screen Logo Animation	00:00	MSWS Multiple Sclerosis Work Space
Announcer VO:	00:08	The following podcast is not designed to provide legal or HR advice, but is intended to provide a general overview of the topic.
On-Screen Super:	00:09	Understanding Care Partner Burden and the Impact on Workplace Productivity
On-Screen Super:	00:17	Mary Schaefer, SHRM-CP, PHR Speaker, Trainer, Coach, Consultant and Advocate for a ProHuman Workplace
Mary Schaefer:	00:15	Hi, I'm Mary Schaefer. I'm a human resources professional that specializes in bringing more humanity to the workplace. I'm here with Lara Krawchuk today, welcome Lara, can you tell us a little bit about yourself?
Lara Krawchuk:	00:28	Thank you Mary. I am a clinical social worker, in private practice at Healing Concepts LLC in Westchester, Pennsylvania. And I specialize in supporting families facing physical illness, uh, grief and loss and trauma.
On-Screen Super:	00:30	Lara Krawchuk, MSW, LCSW, MPH Lecturer at University of Pennsylvania School of Social Policy and Practice Nationally recognized expert on coping with physical illness
Mary Schaefer:	00:45	Thank you. And so given today our discussion is about care partners, can you define for us what a care partner is?
Lara Krawchuk:	00:54	Yes. A care partner is someone who is providing emotional care and sometimes physical care for someone living with MS. They could be doing a variety of activities ranging from grocery shopping to childcare to scheduling medical appointments, to sometimes some physical care and of course, emotional support.
On-Screen Super:	00:55	Care Partner – Someone who provides emotional care And sometimes physical care for someone living with MS.

Mary Schaefer:	01:17	So Lara, given what you've told us about the role of a care partner, tell me about some of the challenges for a care partner.
Lara Krawchuk:	01:24	Sure. Being a care partner is very challenging. It can really range the gamut from being stressful to being satisfying to being completely overwhelming. Some 40% of care partners experience depression, but they can also experience a whole range of emotions ranging from satisfaction and pride to sorrow, depression, anger, really anything can be experienced by a care partner. And it's important for them to recognize their own mental health and wellbeing.
Mary Schaefer:	01:59	That makes sense, that makes sense. What about the number of care partners?
Lara Krawchuk:	02:04	There are a lot of care partners. We have underestimated the prevalence of MS in this country and we now know that the numbers are close to a million people living with MS. Therefore, if you just do the math, there's a lot of care partners out there that need tending too and need support.
Mary Schaefer:	02:22	It sounds like the care partner has a lot going on given their situation, what advice would you have for a care partner?
Lara Krawchuk:	02:30	A care partner has a great deal going on. And the first thing I would say to the care partners is to broaden their circle of care as much as possible. To bring in as many family members, community members and that could range anywhere from the medical team to even clergy therapists, support groups. Broaden that circle of care, give everyone a role. It's very important. The other thing that care partner can know is that the workplace be a good partner. So if they voluntarily disclose that this is going on for them, the human resource managers can really help point to appropriate resources in the community and that can also be an important partnership.
Mary Schaefer:	03:15	Are there any specific care plan benefits for employees who are care partners?
Lara Krawchuk:	03:21	Absolutely. The most important benefit that people should know about is the family leave act. It's called F-M-L-A. Most people think that, that's really about taking off time after you've had a baby or adopted a baby. But it's really much broader than that. It's available to people who are facing illness to take time away from work and still have their job protected when they return. So one of the things that can be talked about is how to tap into that FMLA benefit. It can also be helpful to talk about

advocacy groups that can help families navigate this illness process and tap into benefits that are out there.

- On-Screen Super: 03:28 Ensure that employees are aware of Family Leave Act (FMLA) benefits that can include job protection for employees who are taking care of loved ones.
- Lara Krawchuk: 04:06 So some excellent advocacy groups include the Multiple Sclerosis Association of America or MSAA and the National MS Society. Another one is there are some national caregiving alliances as well and these are excellent resources and have staff available to help both families and HR providers understand kinda how to navigate the system when they need it. It's really essential that care partners get the support that they need because otherwise they're at risk for extreme stress and burnout. And burnout related to caregiving duties is estimated to cost American businesses some \$13.5 billion dollars each year. So not unsubstantial.
- On-Screen Super: 04:10 Human Resources organizations can help employees to connect with advocacy support organizations like Multiple Sclerosis Association of America (MSAA) and the National MS Society (NMSS).
- On-Screen Super: 04:47 According to the Society for Human Resource Management (SHRM), caregiver "burnout" costs American businesses over \$13 billion each year.
- Mary Schaefer: 04:56 What would you say to caregivers around how employers or HR can help out with their needs?
- Lara Krawchuk: 05:02 Many employers, particularly the larger ones, have access to employee assistance programs and employee assistance programs can be really critical in providing some short term, crisis oriented support to families. So care partners can actually call in or sometimes go in and meet with an EAP provider to give some guidance around resources and actually give some emotional support. So those can be really essential.
- On-Screen Super: 05:28 Ensure that information about Employee Assistance Program (EAP) benefits are readily available to all employees online or via telephone.
- Mary Schaefer: 05:37 It sounds like the care partners focus on their own self care is really important. What else would you want to say about that?
- Lara Krawchuk: 05:45 No doubt about it. Self care is important and employers need to understand that care partners are in crisis. They're under

incredible stress sometimes both at work and at home. Little things that can be done that aren't hard to provide are flexible start and end times so that the care partner has a little extra time to get into work or hap- perhaps leave early to take their loved one to a doctor's appointment and some dedicated quiet space where that care partner can go to unwind so that they have a moment to themselves. Those can really make a difference.

- On-Screen Super: 06:02 Employers can support care partner employees with flexible start and end times, extra time to get to work, flexibility to attend doctor's appointments with spouse, dedicated quiet space to unwind and have privacy.
- Mary Schaefer: 06:20 Tell me about the proactive steps that employers can take in support of employee caregivers?
- Lara Krawchuk: 06:27 One of the things that employers can do is create a resource guide. There are a lot of excellent resources out there. AARP has some good resources, the Caregiving Alliance Network has good resources. The one that we're familiar with in Philadelphia is the Philadelphia Corporation for Aging. So creating a resource guide to point people in the right direction when they're having care partner duties can be a really effective and simple step to take.
- On-Screen Super: 06:29 An employer-provided Resource Guide can be a valuable resource for providing guidance to employee care partners. AARP and Caregiver Action Network (CAN) have information worth including.
- Mary Schaefer: 06:57 That sounds really helpful.
- Lara Krawchuk: 06:58 Yeah,
- Mary Schaefer: 07:00 It sounds like employers and what care partners are experiencing in the workplace there's a big disparity around the perception of what g- what's going on and the impact on care partner's performance. Do you think that they're afraid to disclose what's going on because of potential impact on their careers?
- Lara Krawchuk: 07:20 Absolutely. Care partners are afraid to disclose. They are afraid of consequences from that disclosure. They're afraid of not putting, being put on big projects. They're afraid of salary consequences. They're afraid of losing their jobs. And so it is important for workplaces to set a culture where it's okay to say that you need this support and then to actually provide it.

On-Screen Super:	07:40	It's critical for employers to create a culture where is it okay to ask for help in locating support resources for care partners.
Mary Schaefer:	07:47	That culture is important.
Lara Krawchuk:	07:48	Oh, absolutely.
Mary Schaefer:	07:50	In addition to the stress around a concern over a loved one's diagnosis, it sounds like care partners have additional stress for all kinds of reasons.
Lara Krawchuk:	08:02	Absolutely. The stress of trying to take care of someone you love trying to work, trying to take care of kids at home is enormous. Females tend to have higher levels of medication due to anxiety and some depression and men report higher levels of physical ailments. Though I would say as a psychotherapist, they struggle just as much emotionally, but they report it differently. And so it's important for all of those needs to be taken care of. Again, using a collaborative approach.
Mary Schaefer:	08:40	Do care partners ever feel compelled to leave the workplace altogether?
Lara Krawchuk:	08:45	Unfortunately, yes. Sometimes in the peak earning years and the peak years of their upward trajectory at work, they feel like they have no choice but to leave the workplace. And this is really sad. They feel often that the costs, the literal cost of hiring good help at home is completely out of reach. And sometimes they feel like they can't find trustworthy, reliable, accessible help even if they could afford it. And so often care partners are forced to make the very tough decision to leave and stay at home to take care of their loved one. It's really tragic.
Mary Schaefer:	09:30	Sounds like yet another reason for it to be important for employers to attend to care partners who are their employees to attend to their needs and pay attention to what's going on.
Lara Krawchuk:	09:40	Really essential.
Mary Schaefer:	09:42	Lara, I'm aware that there may be flexible spending account options that are relevant to caregiving.
Lara Krawchuk:	09:49	Yes. Sometimes caregivers can use their FSA to help pay for medical costs at home and it's often something that they forget that they even set aside money for, on a pretax basis. So it's really helpful to remind them that they can tap into this.

Sometimes they even have a credit card that they use to pay for medical related expenses. It can be a substantial resource.

- On-Screen Super: 10:09 It's helpful to remind employees about the existence of the Flexible Spending Account (FSA) and the role the FSA can play in helping them set aside pre-tax money for medical expenses.
- Mary Schaefer: 10:18 It sounds like a really valuable benefit.
- Lara Krawchuk: 10:20 Yes, it is.
- Mary Schaefer: 10:21 What advice would you give decision makers in companies that puts policies in place to support caregivers as employees?
- Lara Krawchuk: 10:31 The first thing that I would recommend is that employers realize that some of their most talented employees are struggling with being care partners and they're struggling in silence because they don't feel safe in sharing their truths. So the first thing is to recognize that this is a prevalent problem. It probably exists many times over in their organizations. And maybe the first step would be, to find out how prevalent it is, do an anonymous survey, find out who in the company is being a care partner, what the burdens are, what the things that they need are, and start to put policies in place to meet those needs. This is a quality of life issue. It's a human issue and it's an issue that all employers should really care about and take steps to make sure that they're adequately supporting.
- On-Screen Super: 10:31 Employers should know that it's likely some of their most valued employees are care partners – and may be struggling as a result.
- On-Screen Super: 11:03 Conduct an anonymous employee survey to get a handle on the number of people that might be affected. Find out what they need and put policies in place to meet those needs.
- Mary Schaefer: 11:30 All of that makes sense to me. And particularly coming from an HR perspective, I would think paying attention to job descriptions, defined career paths and benefits packages are some really practical things to look at would also be valuable from an employer's perspective.
- On-Screen Super: 11:38 Employers should review job descriptions, career path definitions and benefits packages with an eye to care partners and ensure the needs of this group are included/being addressed.

Lara Krawchuk:	11:48	Yeah, and really listening to the needs of the employees. That therefore the anonymous nature of a survey can be really helpful because they're running fearful and they need support.
Mary Schaefer:	12:02	It's important to take into consideration.
Lara Krawchuk:	12:04	Yeah.
Mary Schaefer:	12:05	Lara, thank you so much for spending time with us today. I really enjoyed our discussion.
Lara Krawchuk:	12:09	Thank you, Mary.
Announcer VO 2:	12:10	Thanks for your time today. For those listening, be sure to check out the MS-Workspace website at ms-workspace.com . There you'll find resources that can provide additional support to employees in your organization as well as a very unique MS estimator tool that can help give you a sense of the impact MS may be having on your company right now. So visit that MS-Workspace website and thanks again for listening.
On-Screen Animation	12:10	(ms-workspace.com screen shots)
On Screen Logo	12:35	MSWS – Multiple Sclerosis Work Space ms-workspace.com
On Screen Logo Animation	12:39	MSWS Multiple Sclerosis Work Space
On-Screen Super	12:49	How many adults in your organization could have MS? Get your estimate at msestimator.com
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