

MSWS: Episode 1 – The Impact of MS: The Effect of Chronic Diseases like MS on Your Organization

Speaker 1:	00:00	(On Screen Title: [MS Work Space Logo] The Impact of MS: The Effect of Chronic Diseases Like MS on Your Organization)
Speaker 2:	00:08	A donation has been made to the Multiple Sclerosis Association of America in support of their participation in this program.
New Speaker:	00:17	(On Screen Super: Christine Porath, PhD Professor Georgetown University, McDonough School of Business)
New Speaker:	00:17	Hi, my name is Christine Porath and I'm a professor at Georgetown University's McDonough School Of Business and I study respect and civility in the workplace, and how do we create more thriving workplaces, cultures for people. And I'm so pleased to have you here, Gina Ross Murdoch. Could you tell us a little bit about your background?
New Speaker:	00:36	(On Screen Super: Gina Ross Murdoch President & CEO MS Association of America (MSAA))
Gina Ross M:	00:37	Sure. Thank you so much Christine for having me here today. I am the president and CEO of the Multiple Sclerosis Association of America. We are a patient advocacy organization that's been in existence for 50 years next year. Really servicing those living with multiple sclerosis, whether it's the person living with MS, care partners, healthcare providers or employers. So to give you a little bit background of multiple sclerosis, it's a disease of the central nervous system where there is damage to the nerve cells. And the kind of the wrapping around the nerve cells, which is called myelin. Symptoms can range from being very mild for numbness and tingling or they can be much more severe for mobility issues. Women are three times more likely to develop multiple sclerosis than men, and it's usually diagnosed between the ages of 20 and 40, when people are really starting their careers, their lives getting going when they need to be most productive. And some of the major symptoms that impact employment and life are cognitive issues and fatigue. So that's really a concern.
New Speaker:	01:40	(On Screen Super: Symptoms may be mild, moderate or severe in nature.) (On Screen Super: People with MS may show one or more symptoms which can include numbness, tingling sensations, cognitive issues, fatigue, mobility challenges among others.).

New Speaker:	01:40	(On Screen Super: Women 3x more likely to have MS than men. Diagnosed between 20-40 years old)
Gina Ross M:	01:41	(On Screen Super: The number of people living with MS: Close to 1 million)
New Speaker:	01:41	Previously we thought that there was about 400,000 people living with multiple sclerosis, but there's a new article that came out in a publication, Neurology, that it's a little bit closer to one million people living with multiple sclerosis across the country. So more than double what we had originally thought. So when you add care partners onto this, this is a significant impact to the US economy, to healthcare, to employers. So it is a really important point that we want to bring up. In the past we thought that there was certainly a geographic component to multiple sclerosis, where you're finding a higher prevalence rate farther away from the equator. But we are seeing a multiple sclerosis in a wide variety of populations, in African American population, Asian population, Hispanic population. So there really is multiple sclerosis throughout the country.
New Speaker:	02:31	(On Screen Super: The age, gender and workplace location of individuals are key factors in determining how many people may have MS.)
New Speaker:	02:31	(On Screen Super: How many adults in your organization could have MS? Check out the MS Estimator. Visit ms-workspace.com/estimator)
Christine P:	02:32	And what are some of the consequences or the impact on people in their quality of life that have been diagnosed with MS generally?
Gina Ross M:	02:39	(On Screen Super: MS can impact work productivity due to anxiety, depression, speech issues, bowel/bladder issues, speech impairment)
New Speaker:	02:39	Sure. As we talked about, the cognitive issues and fatigue issues are the ones that really impact people working and kind of their career path. But there's other common symptoms of MS that really can impact their lives. There can be anxiety and depression, it could be vision issues, it could be speech difficulties, it could be bowel and bladder issues, it could be mobility issues. These really affect quality of life and certainly can impact performance. And as the disease, it is a progressive disease, so they can worsen over time. So that can really continue to impact quality of life as well as work performance.

And people really connect themselves with who and what they are in the workplace. So when something comes into their life like multiple sclerosis or any chronic condition and changes how they see themselves, how they define themselves, that really can have an impact on how they perform and how they view life.

- Gina Ross M: 03:33 Thankfully, we have a number of FDA approved medications currently that really look at impacting the disease and the disease progression as well as exacerbations or flareups of the disease, as well as some of the symptoms. So we do have certainly treatments available for people living with MS, looking at the disease itself, but really the quality of life and the management of MS.
- Christine P: 03:57 And along those same lines, how might the challenges like lost productivity and absenteeism impact the organization itself?
- Gina Ross M: 04:04 So it, we're looking at there's a possibility with absenteeism and presenteeism. It might be, obviously if that person is not able to be fully in the workplace, what that's going to do to their area, their department, what that might be. There also might be some resentment from other employees about somebody who was getting an accommodation. Or maybe having a performance issue and then anxiety for the person living with multiple sclerosis on kind of being the recipient of some of that anxiety or decreased performance.
- Christine P: 04:36 Sure. So let's talk a little bit more about that. What are some things that companies can do to make the work environment more comfortable or flexible for someone living with MS?
- Gina Ross M: 04:46 Well, wonderfully, there's a lot of things that an employer can do. People are moving a lot more towards telecommuting.
- Christine P: 04:52 Sure.
- Gina Ross M: 04:52 So certainly within issues of fatigue, if the job allows for it and they can actually work from home a day or two, that would be a great accommodation. Flexible work hours. If somebody is able to start a little bit earlier in the day, that certainly would be helpful. There are tangible helps that a corporation could offer for desks, chairs, those types of things. But also if somebody is having cognitive issues, if they could be in an area that's a little bit quieter so they can really focus. If somebody is having bowel and bladder issues, if they can have a desk or a workspace closer to the bathroom, those are the types of things that

employers can really do, that will make such a difference of somebody living with multiple sclerosis. But could really impact their entire population with chronic diseases.

- New Speaker: 05:34 (On Screen Super: What employers can do to help: allow telecommuting, flexible work hours, more convenient desk location)
- Christine P: 05:35 (On Screen Super: Christine Porath, PhD Professor Georgetown University, McDonough School of Business)
- New Speaker: 05:35 Yeah, I love those specific examples and I just know from my own and others research that it makes such a difference if people feel a sense of psychological safety or a sense of trust and respect. So that they feel comfortable, for example, speaking up about any issues or concerns that they're having more generally. And we know that that impacts whether it's team performance, individual performance, creativity and innovation, retention, so it drives individual team and organizational wins. And it sounds like that's really quite crucial to people that are dealing with MS or any chronic illnesses?
- Gina Ross M: 06:13 Absolutely. I mean, we all feel when we are appreciated and we feel valued, anybody would react positively to that. So I think the corporations and HR professionals have a wonderful opportunity really to create a culture of collaboration when they're dealing with somebody who is living with a chronic disease, whatever that might be. Because that shows that employee that they're valued, that the company is innovative, willing to work with them, looks at the value of their contribution to the overall success of the company. And that reverberates out, those so many other employees that may not, maybe, wonderfully do not have a chronic condition in their lives.
- New Speaker: 06:48 (On Screen Super: Create a culture of collaboration and inclusion)
- Christine P: 06:49 Right.
- Gina Ross M: 06:49 But they see what that corporation and the HR really taking a lead in creating that culture of inclusion can do. And that can have a real positive effect on overall corporation and the person living with MS and how they're viewed by their coworkers and the environments.

Christine P:	07:04	And I know one of the things that managers and leaders can do is really small steps, like saying hello, how are you doing? Acknowledging people, giving credit to people, listening very attentively. All of those small things make a huge difference to people as far as do they feel like this is someone that has their best interest at heart?
Gina Ross M:	07:25	Absolutely.
Christine P:	07:26	Do they feel like they could bring any issue they're having, much less a health issue to the table. Well, we talk about workplace accommodations for people with MS in the workplace. What does that mean generally? I imagine that that's really challenging. That making the decision about whether to disclose, when to disclose. Is there anything that you found either from the person that's been diagnosed or from the HR side of things that would allow for this to happen more naturally or allow for a better result in the conversation?
Gina Ross M:	07:59	(On Screen Super: Gina Ross Murdoch President & CEO MS Association of America (MSAA))
New Speaker:	07:59	Sure. So what we talk about is a really individual decision and there's no one size fits all for how to disclose. So we really talk to people about really thinking about what your career goals are. What is the reason that you would want to disclose? And I think it comes and what do you hope that conversation looks like on the other side of it? So really kind of thinking that through. What is the disease progression you've had? Is it based on performance? Have you really looked at how the corporation has dealt with others living with a chronic condition? Can you get a sense of the company? So there's a lot of really personal decisions and we really talked to people, again, knowing their rights. But really having a good conversation internally with family, friends, maybe their healthcare provider, and really getting a sense of what do you want that, what looks like success for you?
Christine P:	08:48	Right.
Gina Ross M:	08:49	And on the other side of it, but there really is no good time, bad time, way of disclosing. It's a very individual decision because some employers are wonderful and some really don't understand. So you've really got to think about it because people are concerned about job security, career advancement. It's a very individual decision.

New Speaker:	09:10	(On Screen Super: There is no good time or bad time to disclose – it’s a very personal decision)
Christine P:	09:10	And how about on the employer side of things? How can they demonstrate some sense of partnership as you mentioned, which is so key for anyone.
Gina Ross M:	09:19	Sure.
Christine P:	09:19	But certainly those dealing with any kind of chronic illness. What would you recommend that might impact their ability to do their job well and to feel comfortable having these conversations?
Gina Ross M:	09:32	(On Screen Super: HR professionals – get educated on what is involved in managing a disease for the diagnosed person as well as their caregiver or spouse)
New Speaker:	09:32	So I really encourage the HR professionals to become educated on chronic disease overall. Kind of the impact, again, not only the person living with the chronic disease, but the care partner. It's really in everybody's best interest, both the employer and the employee, that employer take a really active or a proactive role in the employee health. Creating a sense where there can be discussions about healthy behaviors and access to support. And all of those conversations really sets up an environment where they can enable people to live well at their corporations and go forward.
Gina Ross M:	10:09	(On Screen Super: In new employee orientation, define the role of HR as one of a true partner)
New Speaker:	10:09	The other thing that they can really do is set the bar from the first day. A lot of corporations go through orientations and they're having conversations about everything that they're going to be approaching in the corporation. And setting it up that HR is somebody who you can rely on, you can go to and really setting that culture up for the new employees from the beginning. They have an opportunity to engage employees, not only administer health benefits but really be a partner. So I think that that's where there is.
Gina Ross M:	10:36	(On Screen Super: Include actionable resources that HR professionals can make available to employees that have been diagnosed with a chronic disease (help lines, advocacy websites, etc.)

New Speaker: 10:36 The other thing that I would suggest is for HR professionals, is to get in involved with organizations like mine and there's other health organizations, patient advocacy organizations across the country that can provide them with a helpline that's confidential so they can ask questions. We have a website for information, there's publications. So certainly there are resources for HR professionals. And I said we deal with a wide variety of corporations and professionals and encourage them to rely on us as a national patient advocacy organization and therein many disease states as a trusted source of information to help them educate themselves.

New Speaker: 11:12 (On Screen Super: The Multiple Sclerosis Association of America (MSAA) offers free counseling on this topic. Call toll-free at (800) 532-7667.)

Christine P: 11:12 And many millions of employees at US based companies are covered by group health plans and prescription benefit managers. What role do these stakeholders have, if any, in providing support to companies and employees with chronic diseases such as MS?

Gina Ross M: 11:27 (On Screen Super: Gina Ross Murdoch President & CEO MS Association of America (MSAA)

New Speaker: 11:27 So a lot of the PBMs and the health plans actually do provide information and programs to both the employer and the employee. But sometimes it does get confusing.

Christine P: 11:39 Yeah I'd imagine.

Gina Ross M: 11:40 [crosstalk 00:11:40] who's calling. So, especially if you're dealing with a chronic disease, you're probably dealing with a specialty pharmacy, so you may be getting a call from the specialty pharmacy, from the payer. It is a bit of confusion.

Christine P: 11:49 Sure.

Gina Ross M: 11:49 So any way that they can help streamline that process, especially with somebody who's dealing with a chronic disease that might be dealing with a lot other things going on in their life, expediting that conversation and streamlining that would be extremely helpful. We as an organization has been involved in employer health coalitions.

Christine P: 12:07 Okay.

Gina Ross M:	12:08	And what they are is they are collaboratives of corporations, small, medium and large throughout the country, regionally based, and they come together. They're the professionals that are really focused on employee wellbeing and benefit design and all of those kind of health areas of the companies and they share ideas. They look at best practices, they look about what's impacting businesses in their particular area. So we as a patient advocacy organization have actually joined one in Philadelphia and New York. So we're at the table. We can hear the pain points for the employers, we can hear what they're struggling with and we can be that bridge of that voice between what the payer is looking at, the employer's looking at and the patient needs and try to be the translator between all of those. So I think it's also being in the conversation is critical.
Christine P:	12:52	Right. That makes a lot of sense. What questions should HR professionals or benefit managers at employers be asking of health care plans or their PBMs to ensure that they're maximizing care for their employees with chronic diseases such as MS?
Gina Ross M:	13:08	(On Screen Super: HR – Help diagnosed employees to navigate health plans so they can quickly get access to the treatment they need)
New Speaker:	13:08	So, I think that one of the things that they should be asking is, is the process for somebody who was diagnosed and accessing the healthcare, the plan as easy as possible? You're talking about somebody who's dealing with multiple sclerosis, has a wide variety of symptoms and issues. But any chronic disease, they're dealing with a lot, trying to get somebody through the process as easily and expeditiously as possible so that they can follow the protocol dictated by their doctor. It decreases some anxiety. It gets people on where they need to be. So I would say that, are they asking, are they reviewing the processes with the PBM? With the healthcare provider? With the health plan? And is this most expeditious to get person from diagnosis to treatment, to work as quickly as possible and expeditiously as possible for everyone's benefit?
Christine P:	13:58	So it sounds like being very proactive generally.
Gina Ross M:	14:00	Exactly.
Christine P:	14:01	Being knowledgeable and increasing your awareness on not only MS, but chronic illnesses given how prevalent they are sadly today.

Gina Ross M: 14:09 It is. And I also think that the wonderful thing about it is from an HR perspective and a corporate perspective, even though there may be focusing on the chronic conditions, being that type of employer has a wonderful ripple effect in all employees.

Christine P: 14:24 Definitely.

Gina Ross M: 14:24 So I think that there was certainly, is a holistic view of the way that they treat a chronic disease, has a potential benefit to their entire workforce.

Christine P: 14:34 Absolutely. And I know just working with organizations, you get a reputation for your culture. That has lots of ripple effects, certainly internally leads to greater productivity, creativity also retention is huge. You mentioned the talent aspect.

Gina Ross M: 14:50 Absolutely.

Christine P: 14:51 Keeping talent.

Gina Ross M: 14:52 Absolutely.

Christine P: 14:52 And so I think that that's huge as well, but also reputation, outside of the confines of the organization where people want to work there, they want to do business with companies that are providing these kind of safe spaces and cultures where people can really thrive.

Gina Ross M: 15:13 So I do think that there is that wonderful ripple effect of how they're addressing that. And I think that that goes towards overall reputation of the company and certainly where that might be in. I don't know where that would be in the business.

Christine P: 15:27 Yeah.

Gina Ross M: 15:28 And kind of the environment, but doing well and looking at these policies and these practices and truly living it from top to bottom, I think can only do well for the corporation, for the employees. Certainly again, feeling valued and being proud of the company that you're working for because they are proactive and innovative and inclusive certainly reverberates from within. And certainly people see that from outside.

Christine P: 15:54 Definitely. Well I just want to thank you so much for being here and educating us on how to care for folks with MS as well as the

conversations to have if you may be diagnosed with MS or other chronic illnesses for that matter.

Gina Ross M: 16:10

Thank you for having me.

Christine P: 16:12

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.

Title Card 16:40

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