



**National
Multiple Sclerosis
Society**

**MS Learn Online
Feature Presentation
Medical Self Advocacy: Disability Care Centers
Featuring Rachael Stacom, ANP, MSCN**

Tracey: Hi I'm Tracey Kimball

Tom: And I'm Tom Kimball. Welcome to MS Learn Online and the third installment in our series on Medical Self Advocacy. Hopefully you've taken the opportunity to watch our other programs on getting the most from your healthcare team and palliative care

Tracey: In this program we'll learn about a fabulous resource - disability care centers. Our medical correspondent Kate Milliken visit with Rachael Stacom, who's with the Independence Care System or ICS. It's located in New York City and is doing a lot of great work for people with MS.

>>Rachael Stacom: It's a long-term care program, community-based program for people who are physically disabled. So, we really target people between 21 and -- I'm sorry, it's actually 18 now, and 64. And we help people stay in the community and independent at home. And one of our biggest diagnoses is multiple sclerosis.

>>Kate Milliken: So, how would you define long-term care?

>>Rachael Stacom: Long-term care is basically when people will require care on an ongoing basis. And it's really interesting, I think when you have something like multiple sclerosis, which is primarily a progressive disease and that people will eventually need help in just doing things like their activities of daily living, which is getting up and dressed. And also things that really wipe them out, like cleaning their home and shopping. And I think it's really important for people, we've really seen a lot of -- we have a whole range of

spectrum, and I can talk about some people and how it's very different. But it's really important for people to really plan for long-term care.

>>**Kate Milliken:** Because what I think about when I hear the words long-term care, what I hear is it's the end of the line, see you later, you're going downhill, your life as your own is beginning to get funneled. And I would imagine that's not really the case.

>>**Rachael Stacom:** No. I think long-term care, I think you're right. Most people think of a nursing home, and they'll be there and that's really it. What we see is that when people really get the help that they need that they become even more dependent than what they were, because they were struggling so much to accomplish very simple tasks. And an aide, having a home attendant, can really help you deal. And that aide really becomes an extension of yourself, so you can really do things that you want to do.

>>**Kate Milliken:** So, give me an example of someone that you might be caring for right now.

>>**Rachael Stacom:** I can give you an easy example of someone who really put off getting long-term care. And right now, just to explain, Medicaid is the only insurance, really, that pays for long-term care. So, you have to go through a process of going through this, and people always think of Medicaid as poverty. You have to be poor, when actually there are things that you can do because you have a disability and trust that you can go into to really be able to access these services.

So, there's one woman who put off getting Medicaid. She is probably in her late 40s. Really, when we stepped in and brought her into our program, had a lot of fatigue, was really isolated at home because she couldn't go out. She had a really unsteady gait and we kept her --. Once we walked in, brought her in, we got her in for a wheelchair evaluation; she got a scooter, a mobility device. She was falling at home. She is able to get out and now she is really participating in community programs and going out. She goes to some of our classes that we have, too, like support groups.

>>**Kate Milliken:** How long is the -- how often is somebody coming in, usually, on a standard case, to come help with these patients?

>>**Rachael Stacom:** Well, each person is assigned a care manager, which is either a nurse or a social worker, and they're in constant contact. I think that's

the most important thing. You really have to get to know someone, and once you do and understand how they -- what their life is like, then you really make a difference. I think as healthcare providers, we always think we know what's best, and really, if you don't get the buy-in from the patient, you're going to fail.

So, we let them really decide what they want to work on, and we help coordinate their services, their medical care, making sure they get good care. We work very closely with the MS centers. And then we're in constant contact but at least monthly with them. And then a nurse comes in and assesses them as well, and looks for things that we can prevent, especially at the MS --.

In our MS program, we do a bunch of things, but mainly it's looked at preventing complications, like bed sores and urinary tract infections, things that people with -- when they accumulate disability are at risk for. And also help with symptom management. I think clinicians are very good at pharmacologically giving medications, but we really look at non-medications, where we can give them aids to help them do kind of time management skills so they can continue.

I think our goal is to really de-medicalize people so they can live their lives and not focus around their condition.

>>**Kate Milliken:** Wow! That's awesome, and I would say that I have MS, and one of the things that I had learned is that MS is such an individual disease. And it sounds like in light of the way that you're dealing with the actual care of MS for these people, your agendas and your programs are also incredibly individual.

>>**Rachael Stacom:** Yes. It's the only way you're -- if you don't understand the individual and know what they want, you'll never succeed. I think that's in everything, but especially MS, yes, because the disease affects everyone so differently.

>>**Kate Milliken:** Let's talk about people that don't live in New York. What other organizations can they get involved with or make contact with something like yours?

>>**Rachael Stacom:** I think as a consumer and someone with MS that you really have to become an advocate for yourself. You have to let people know about the disease. You have to become aware of what the disease is, so you can share that. But I think tapping into your local MS Society. We work very

closely to really outreach the people and get the services that they need. But the clinician is really important, too, and they need to know how to help you and what's important to you. So, voicing that.

Also, finding out providers that are used to people with MS. Because I think MS, as you said, shows -- can present so differently that a lot of the healthcare system doesn't really get it. So, having your clinician say, well, who do you use for physical therapy? Who understands the importance of maintenance? And kind of linking with those people, because it's really important that everyone that you deal with understands the disease.

>>**Kate Milliken:** Long-term care, again, has this kind of feeling of, oh, it's at the end of the line. As someone who actually is from the other side and organizes it, what tips do you give for people to involve long-term care in their lives?

>>**Rachael Stacom:** I would say plan. Plan like you're having -- like a fire plan in your house. You never want to use it, actually have a fire. But if you have it, then you know, okay, I know I'll be safe, we'll be okay, we know where to meet.

I think of the same thing about long-term care, that you hope that you'll never need those services and someone to help you. But to know that you can access it is really, if you need it, is really important. Because a lot of times people put that off and then they're in such bad situations and really are at risk, then, for being in a nursing home because they just can't get the services they need.

>>**Kate Milliken:** And what about the mental element of long-term care for your clients or patients?

>>**Rachael Stacom:** You know, it's funny. We don't really present it as long-term care. We just present it, really, as a community program. So, it's not something we really focus on, but I think that we just tell people we're here for you. We're going to keep you home. We're going to keep you where you want to be in the community and out there. And that we always change what we do to adapt to their needs.

>>**Kate Milliken:** What I like about imagining that is that it's really kind of a way to empower somebody instead of debilitate them further.

>>**Rachael Stacom:** Exactly. That's what we always -- we always focus on what they can do and encourage them to continue doing that.

>>**Kate Milliken:** What is the most rewarding thing for you with your job, Rachael?

>>**Rachael Stacom:** That people get to stay home and healthy, and that they can live a life not centered around their disease.

Tom : Another great resource as we learn the importance of advocating for our own medical care.

Tracey: That's right and it's important to say that sometimes we need to really lobby for resources that aren't always easy to access.

Tom : Thanks to Rachael Stacom from the Independence Care System in New York City

Tracey : And to you for joining us at MS Learn Online.