



**National  
Multiple Sclerosis  
Society**

**MS Learn Online  
Feature Presentation  
Medical Self Advocacy: Getting More from Your HealthCare Team  
Featuring Marion Brandis, MA, RN, BSN**

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**Tom:** Hi I'm Tom Kimball

**Tracey:** And I'm Tracey Kimball, welcome to MS Learn Online. While MS affects all of us differently, the one thing I think we all have in common is a feeling of uncertainty and a loss of control over our bodies and our lives. The one thing we can take charge of, though, is receiving the care and treatment that we need.

**Tom:** This three-part series is called Medical Self Advocacy - how you can advocate for the medical care you need and deserve.

**Tracey:** In this episode, Medical correspondent Kate Milliken sat down with Marion Brandis, a nurse with the National MS Society's New York City chapter, to talk about "Getting More from your HealthCare Team".

**>>Marion Brandis:** When I think of self-advocacy, I think about empowerment. I think about somebody's ability to articulate for themselves what it is they need, and who they are. What you need has to always be in the context of who you really are, what you like to do in your life, and what quality of life would mean for you, and what's important to you. And you have to advocate for -- one should advocate for one's self in all the different realms of life.

So, physically, in terms of wellness, and spiritually and emotionally and intellectually, in all of those realms. So, all of those things really need to be addressed if someone is going to be truly self-empowered in seeking medical care or just a good quality of life in general.

>>**Kate Milliken:** Awesome. Unfortunately, in the world of MS, in kind of more progressive states, there is a point where sometimes a doctor will turn to a patient and say, "There's nothing we can do." What would you recommend to that patient or that person who is in that state to move forward as an advocate for themselves?

>>**Marion Brandis:** Right. I'm always saddened when one of our members tell us that my doctor said to me, "There's nothing more I can do for you." That makes me very sad in my heart, because I know that's not really true. Well, it may be true that that clinician really has nothing more they can offer that person.

So, I often explore with that person, maybe there's another clinician you might want to investigate being cared for by. Is there another system of care that might work for you better?

MS care is a very complex situation for a lot of different reasons because it is such an intensive disease to work with and to treat people with. So, sometimes a single practitioner, and this is not at all meaning to be -- to over-generalize, but sometimes a solo practitioner, or somebody who is seeing many different kinds of neurologic illnesses doesn't have the resources to really care for the person through the entire trajectory of their illness.

So, sometimes a different setting. The MS Specialty Care Centers are often a good example of a setting where somebody who is progressing more with their disease will be able to go and find clinicians who say there are lots of things we can do for your illness.

So, I really don't, with the right person, I don't believe there is ever nothing that can be done. There is always a piece of equipment that could be helpful to that person to assist them in their activities of daily living. There is always some kind of support out there. There are legal services, employment services, and many of the things that we have at the chapter. We're very fortunate in New York to have a lot of those services.

But even if it's not within your chapter or even within your doctor's office, reach out into the community. Find out more about your community resources. And really an MS specialized nurse is one of the best people to help coordinate those kinds of services. But, again, not everybody has access to that.

So, I guess my point is, if somebody has a clinician who says, you know what, there's really nothing more I can do for you, your disease is progressing and your treatments aren't working so well right now, then I would say be very skeptical about that answer and look further. Look further, and this is the place where self-advocacy comes in. It's so important.

You know, that patient knows who -- that person with MS knows who they are. They know what their life has been and who they've been. Who were they before the disease? Who have they been over the last number of years as things have changed? What are their roles? What things have they lost? What are they missing? And then question, really, is there something that can fill those gaps in and bring me back closer to the quality of life I was living before, to that meaning that my life had?

**>>Kate Milliken:** Sure. So, let's pretend that I'm someone with MS and that I'm really shy. And I do have MS, but I'm not shy. So, let's say that I was. What would be the thing that you would tell me to do, to say, "Hey, you have every right to be an advocate. Here's some of the things that you could talk to about your doctor to step up to the plate for yourself?"

**>>Marion Brandis:** Again, I think it's really important to find some means that's comfortable for you. If speaking is not the means, in particular, speaking off the top of your head, for example, you might want to think about making lists for yourself that you would bring with you to a medical visit. So that your goal really would be, even though I'm a shy person, I need my doctor and/or nurse, nurse practitioner, all my clinicians to really understand who am I at my core, so that they can really tailor the treatments. Whether it's the actual medications or other kinds of recommendations and referrals, and how they really look at me as a whole person. Tailor them to me. So, if I can't speak, which sometimes I have that issue sitting in front of someone with a white coat. I get a little tongue-tied too, believe it or not. So, often I bring in a list. I'll write down the things that I know are a major concern to me that are my priorities.

Now, those priorities of mine may not be the clinician's priorities. So, it's always a little bit of a dance there. How am I going to get that clinician to really listen to me? How can the patient get the clinician to really listen to them, to understand what matters most to the patient, when the clinician also probably has a medical agenda for that person?

>>**Kate Milliken:** And let's talk about it from your perspective, because you're a nurse and you deal with people with MS all the time. So, tell us how it helps you to have a patient that's an advocate. Does it make your job easier?

>>**Marion Brandis:** Yes, so it does. It really does. If the person -- actually, very often, when people get to me at the chapter, it turns -- their question it seems, to begin with, the reason they called us seems to be some kind of a medical question. But what I often find is that engaging them in a conversation and asking them, again, from that place of curiosity, a little bit more about who they are, how did they come to us, what else is going on their life, that sometimes it's not the question they were calling with.

So, the empowerment comes in the fact that they reached out. They knew something was bothering them, that they wanted more information, more support, more something. So, they reached out to us, and then I'm able to respond to them by helping them sometimes just navigate the medical system, or just navigate around what their issues are and connect the pieces for them. And help them really, in fact, help them understand better why they called.

>>**Kate Milliken:** Yes. I almost feel like there's something about advocacy that really introduces a real personal element to the whole process of going through the disease. Instead of just medical, medicine, technical, clinical, that advocacy kind of introduces a whole other field to the process.

>>**Marion Brandis:** Right. And I think it's important as much as we can, or at least for me, from the perspective I come from, to demedicalize the illness sometimes. There are so many, as we said before, there are so many other aspects of living with MS that don't just have to do with the disease process and treatment, but just reaches out into so many other aspects of a person's life.

So, again, knowing a person in that sort of holistic sense that we like to talk about in nursing is good medicine, too.

>>**Kate Milliken:** Well, Marion, thank you so much. It's so nice to hear somebody from kind of the medical side be so positive and encouraging for people to step up for themselves. So, I really appreciate it.

**>>Marion Brandis:** You're welcome. My pleasure.

**Tom:** Ms Brandis really makes some important points about self-advocacy.

**Tracey:** I agree. And I know that when I take a more holistic approach to my MS, I feel much more in control of my body and my life.

**Tom:** Our series on Medical Self Advocacy continues with episodes on Palliative Care and Disability Care Centers. Be sure to check them out.

**Tracey:** Thanks to Marion Brandis for helping us understand how we can get the most from our healthcare team, and thank you for joining MS Learn Online.