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Counseling Strategies in RMS: Helping Patients Cope with Progression

Announcer:

You're listening to *NeuroFrontiers* on ReachMD, and this episode is sponsored by Novartis. Here's your host, Dr. Charles Turck.

Dr. Turck:

Welcome to *NeuroFrontiers* on ReachMD. I'm Dr. Charles Turck, and joining me today is Dr. Lauren Gluck, Assistant Professor in the Saul R. Korey Department of Neurology at the Albert Einstein College of Medicine, and Director of the Montefiore Multiple Sclerosis Center. Dr. Gluck is here to discuss how we can help patients with relapsing forms of multiple sclerosis, or RMS for short, understand and cope with progression. Dr. Gluck, welcome to you.

Dr. Gluck:

Thank you.

Dr. Turck:

Let's start with a high-level overview of progressive RMS. Dr. Gluck, what do we need to know about this type of MS?

Dr. Gluck:

Multiple sclerosis is an autoimmune disease, and in its relapsing form, it is proinflammatory. However, as people transition to progressive MS, it becomes neurodegenerative. And that, in part, explains why it's a difficult target to address, in terms of medication and disease-modifying therapy. On imaging, we don't see the same increase in white matter lesions and scarring, but on high-resolution imaging and advanced MRIs, we can see cortical lesions, damage, and actual cortical atrophy. In terms of clinical symptoms, instead of having a new attack that we associate with a relapse or exacerbation or flare that can last up to weeks to months, people just have slow progression of their old symptoms, or even of new symptoms that kind of develop in an indolent fashion. It's important to advise people to monitor these things, and it's very nuanced to tell the difference between day-to-day fluctuations with stress that we often associate with pseudo-exacerbations, or worsening of old symptoms in the setting of physical or emotional stress and change over the course of months, or even over a year.

Dr. Turck:

And what do you see as some of the main points of confusion among patients, with respect to those symptoms?

Dr. Gluck:

Often, as people have multiple sclerosis for a longer period of time, they recognize that certain levels of activity and exertion make them more tired, bring out more symptoms, and they can have worse days or worse weeks, sometimes due to these things. However, it's important to create setpoints to have people understand the change over time, so to ask, "How far could you walk a year ago? Or last summer?" Or "How much could you lift, or how long could you stand over the holidays last year? Did you do as much as normal?" It can be very useful to have patients' family or friends, if they feel comfortable, bringing them into the visit, or having them come in through, video or phone visits, now that we have telehealth, to give another outsider view of what's going on. Often when we're in our bodies 24 hours a day, 7 days a week, we don't notice the fine changes but sometimes the people around us do notice these changes over time.

Dr. Turck:

Are there any other ways that you employ to clear out those potential points of confusion and to further educate patients on those symptoms?

Dr. Gluck:

So, some of the most helpful strategies that I have is if patients have reliable family members or friends that they feel comfortable

bringing into the visits, or now with telehealth, we're able to call them in, or bring them into the video visit as well and they can be a more outside perspective, or objective perspective of, "You know, Mom, sister like, this really did change over the last year." Because when we're in our bodies all of the time, we don't always notice the small changes, especially over a short period of time, and especially in the stress of going to the doctor's office. We can only see them a few times a year. Another thing that we can employ during our exams in the neurology office are timed 25-foot walks. I have markers set down in my office hallway over 25 feet, and that's a standardized measurement, particularly in research, but does have clinical applications when looking for gait changes over time, and so to check it every six months or every one-year can be useful. We can also use the expanded disability status scale, or EDSS, in the office, and watch that over time.

Dr. Turck:

For those just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm Dr. Charles Turck, and today I'm speaking with Dr. Lauren Gluck about how we can help our patients better understand and cope with relapsing multiple sclerosis progression. Now, Dr. Gluck, earlier you shared some strategies you use to educate patients on the clinical signs and symptoms of progressive RMS. So based on your experience, what kind of impact does patient education have on treatment adherence and overall outcomes?

Dr. Gluck:

I think setting expectations with patients, from your first meeting, is very important, letting them know what can happen with multiple sclerosis if left untreated, whether in the relapsing or progressive phase, and what it means to transition into the progressive phase. So, some patients have their own expectations coming in, knowing family members or celebrities who've dealt with this disease. So, I try to reset those viewpoints and expectations. Because we've only developed disease-modifying therapies for MS in the 90's, there's a lot of natural history information about this disease.. One of the highlights I say that people seem to really understand is that we can't reverse brain damage. Your brain may repair some of its deficits due to multiple sclerosis, but if you're left with symptoms from it, we can treat those symptoms, but we can't reverse them, and that's why prevention in multiple sclerosis is so important.

Dr. Turck:

Of course, communication can also help us better understand the impact of RMS on our patients, that we might tailor our therapeutic approach accordingly, but how is it that we can go about building a strong foundation for a relationship like that.

Dr. Gluck:

I start all of my new visits by introducing myself, and having the patients introduce themselves to me, outside of the context of multiple sclerosis. I want to know what their home situation is like. I want to know if they're working or if they're at home, if they have kids or if they want kids. And that helps set the tone that I know that they are not just a patient, they're a person. As a doctor who treats multiple sclerosis, this is a long relationship. Patients have MS for their whole lives, and potentially, they'll see me for that whole time. So, understanding where they're coming from, their values. As they talk, you can hear them describe other medical issues, if they've encountered other doctors before, if they have taken medication or been offered medication. You can understand a lot about how they feel about the medical system, and that helps gear your discussion, or my discussion, about necessary, or therapeutic preventative medication for MS, how to approach symptomatic medication. Some people really don't like medication and I think that's very reasonable, and so acknowledge that with them. Offer them or let them know that there are options available for pharmaceutical treatment of symptoms, for example, but if they prefer, there are other options that are non-pharmaceutical-based, like physical therapy, like talk therapy like mindfulness that can be very useful. Another important thing in multiple sclerosis populations is family planning. So, knowing where your patients are, in terms of whether and when they want to have children, and again, acknowledging those goals, and making a plan for the future, for if and when they want to get pregnant, or want to get pregnant with their partner. And I think when you talk to people in that way and make it clear that you are listening to them, and you want them to be able to meet their goals and achieve their dreams and aspirations as time goes on, they're much more accepting of your recommendations, and knowing that you want to build a strong relationship.

Dr. Turck:

And before we close, Dr. Gluck, do you have any key takeaways you'd like to share with our audience?

Dr. Gluck:

The first is, multiple sclerosis is a lifelong disease, and creating the foundations to have a lifelong relationship with your patient is important. Understanding their values in medicine, in life, their goals of family planning, is important so you can gear a treatment plan that they understand and adhere to in the best way. Another important thing to consider is that neurology is often a palliative field, where we intend to make people feel better, even if we can't cure their disease. In progressive multiple sclerosis, there's always something that can be done, whether it is helping with symptom management, improving mobility with mobility aids or recommending home exercise programs, or connecting people to resources to help them in the community. So there's always something that you can do to help your patient feel better and feel secure in your patient-provider relationship.

Dr. Turck:

Well, with those final takeaways in mind, I want to thank my guest, Dr. Lauren Gluck, for sharing her insights on how we can help our patients with relapsing MS cope with progression. Dr. Gluck, it was great speaking with you today.

Dr. Gluck:

Thank you so much for having me.

Announcer:

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