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Shared Goals, Shared Gains: Align With Patient Preferences

Dr. Edmundson:

This is CE on ReachMD, and I'm Dr. Christyn Edmundson. Here with me today is Dr. Wolfe.

In this episode, we're shifting gears to the patient experience. When it comes to treatment planning in gMG, how do we make sure that we're not just hitting clinical targets, but also aligning with what matters most to the person in front of us? Because when patients are part of the decision, we see better adherence, greater satisfaction, and improved outcomes.

Dr. Wolfe, when you're discussing treatment options with patients, how do you bring their preferences into the conversation and help them weigh trade-offs without steering the decision for them?

Dr. Wolfe:

It's a great question, Dr. Edmundson, and this has really been highlighted lately with shared decision-making with the patients and their families and so forth, and just the individualized nature of treatment in myasthenia gravis. It's not the only disease where we have to do that, but myasthenia gravis, I think, is one of those diseases where we really have to focus on the individual, and that can involve clarifying what success looks like to them. For instance, in an ocular versus a generalized MG patient, there may be different elements that we really need to focus on. Managing uncertainty, expectations around remission, tapering or flares, emotional readiness to continue or pause therapy cycles, and then educating the patient and their caregivers on what things the patient might experience, whether that's on the good side or the bad side. And I can tell you, early in disease states, especially, patients can be very uncomfortable and worried because they just don't know what to expect. They don't know the disease that well. They don't know what types of things may recur when their disease gets less controlled. Over time, they often figure that out if they have those problems. But early in the disease state, it can really, really create a lot of anxiety, both for the patient and their caregivers.

Using tools like the MG-QoL15r or the PASS mechanism that was actually invented at the University of Toronto can be quite helpful in gauging how the patient is doing. Comorbidities, a desire to start family planning, pregnancies, work demands, needle fatigue, time off work. All of these can factor into what kinds of medications we actually use.

The route and frequency of the administration, such as, is it weekly sub-Q or IV infusion, say every 2 weeks or every 8 weeks. Patients may have preferences about that depending on where they live, what facilities they can access, their venous access, and so forth.

Tolerability, convenience, the speed of onset, how convenient it is for them, and the types of support they have at home, that can also factor into shared decision-making for the patient.

Dr. Edmundson, in your experience, where does the breakdown in interdisciplinary communication happen? How do you use, for instance, advanced practice providers and nurses in your practice to try to optimize care for our patients?

Dr. Edmundson:

Yeah, that's a great question, right, especially in something like myasthenia, where we're seeing patients every few months or so, a lot can happen between visits, both for the better and sometimes for the worse. In my own practice, we don't have APPs working with us, although I've seen that model used successfully in some of my colleagues' practices. I'm really fortunate to have a fantastic team of nurses that I work with, and they are really, really helpful in responding to patient concerns in between visits, right? I am, of course, also available as well, but it's so nice to have nursing support that can get on the phone and really dig into what's going on with a patient and then summarize for me such that I can either give input or reach out to the patient with some idea beforehand of what's going on.

And one of the things that we will often do, one of the tools we'll often use when a patient is calling with changes in between their visits, is we use the MG-ADL, right? It's a patient-reported score, so my nurses can get on the phone with a patient and either talk them through an MG-ADL score or even send them an MG-ADL score via MyChart that they can fill out and send back. So, in using a combination of sort of a patient subjective experience as well as some objective outcome measures to better understand concerns that are coming up for patients between visits, I find is a really successful way of sort of partnering with other healthcare providers and responding successfully to patient concerns.

What's your experience been like in this, Dr. Wolfe?

Dr. Wolfe:

My experience has been similar. We have a great group of medical assistants and nurses that help. The other thing that I'll point out is some of the patients in our routine clinic were in clinical trials, and so our research coordinator often has a very tight relationship with them and often also helps, even once they're outside of the trial, in ensuring that we're taking care of them properly and so forth.

Well, that wraps up this discussion. Thanks for joining us for a look at how patient-centered decisions can shape more effective and sustainable care.