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Advancing gMG Care: Conversations with Clinicians at AANEM

Announcer:
You're listening to *Neurofrontiers* on ReachMD. This episode is sponsored by UCB. Here's your host, Dr. Mimi Maeusli.

Dr. Maeusli:
This is *NeuroFrontiers* on ReachMD. Today, we'll hear from clinicians who attended the Annual Meeting for the American Association of Neuromuscular and Electrodiagnostic Medicine, which took place in San Francisco in October 2025. They'll be discussing how they're addressing treatment gaps and improving outcomes for patients with generalized myasthenia gravis, or gMG.

As gMG treatment continues to evolve, how are you defining treatment success? Are you moving beyond symptom control to include long-term outcomes, like steroid independence, or are there other factors that are influencing your perspective?

Dr. Weiss:
Oh, that's a great question. So the holy grail of clinical outcomes is to get patients off of medications, but that happens so infrequently, and only typically in patients who've had thymectomy. I still feel that the outcome that I'm most looking for is to get patients a minimal symptom expression status, which is an MG-ADL score of zero to one, in conjunction with getting them off of steroids or getting their steroid dose below seven-and-a-half milligrams a day. If I can do that, I feel like I'm successful.

Dr. Alpers:
So I'd say it's more based upon individual patients. So we talk to the patients—or I talk to the patients when they come through, and we determine, what is their goal? What do they need to get back to? Do they need to get back to work? Do they need to be able to take care of their kids? And that loosely correlates with something like MSE, minimal symptom expression, but optimally, we have a desired endpoint and that's what we're working for together.

Dr. Howard:
So the goals in myasthenia treatment are changing and have been changing. It's an evolutionary process. When I first started, it was simply, "Can I get you out of the house?"—I didn't care about side effects, that was 50 plus years ago—to, "We want side effects minimum." Then we wanted minimal manifestations, little or no weakness, and reduced side effects. Now, we want you symptom free with no side effects. And the future is, I want you in very durable response for months, years to come without having to intervene with therapy. So it's an evolution.

Dr. Maeusli:
When a gMG patient says they're doing well, how do you assess whether their disease is truly under control? And what signs or symptoms might prompt you to consider a treatment change?

Dr. Alpers:
When a patient tells you they're doing well, there's a variety of factors there. That's like the concept of, "How are you doing?" "I'm doing fine." Fine is not fine a lot of the time. So that, again, comes back to, what did you used to be able to do that you can't do? So, asking and finding that specific question: can you sing with your church choir? That might have been something they wanted to do. Have you gone back to work? So looking at, they're doing fine, they're doing well—we need to define that in the scope of their life and how the disease is impacting their life.

Dr. Sinno
So that's a complicated question because we know that gMG is a disease that fluctuates. So a patient could be doing well when they

see their physician in the morning and maybe not so good later in the day. So it's exceptionally important to sort of dig in and identify what that “I'm doing well” is. Is it overall? Is it just in the day? Are we just talking about symptoms? Are there psychosocial issues that the patient is dealing with? So that is a very important question to drill down into a little bit.

Dr. Rodriguez:
In effort to see how a patient is actually doing and having a little bit more objective evaluation, I actually examine the patient and I see how they're moving. I see if they're able to get up from a chair with ease. I ask for a lot of input from family as well. How is your loved one really doing? Is he/she under-reporting? Are they actually able to get through their day or are they struggling to get through the day? I think it's important to get other folks’ who the patients live with input as to how things are really going for patient.

Dr. Maeusli:
Symptoms like fatigue, fluctuating weakness, and quality of life can be challenging to assess in gMG. How do you track these more subjective concerns in your daily practice, and what methods do you rely on to ensure you're capturing the full picture?

Dr. Shroff:
Fatigue is very challenging. There is no objective measure that we can administer or a test to measure fatigue. So yes, in autoimmune diseases in general, they have fatigue as one of the symptoms. So it might not necessarily be from myasthenia, and some patients might have other comorbidities like hypothyroid or cardiac conditions which can also contribute to the fatigue. So it's very challenging to isolate, okay, how much of the fatigue is coming from myasthenia?

Now, on the other hand, fluctuating weakness or fatigable weakness is one thing we can check in the clinic. For the quality of life, I do like the MG Quality of Life Questionnaire, which patients do answer in the clinic when they see us on follow-up, and those are routinely, regularly tracked. And I do think that gives us an idea as clinicians what's happening other than just the clinical symptoms and what else is happening in patient's life with their quality of life in doing other activities.

Dr. Sinno:
So in the neuromuscular community, the neurology community, there are a lot of outcome measures that physicians can use to track patient symptoms, like the MG-ADL, for example. However, nowadays, with the use of digital technologies, there's more and more digital capabilities where you can use an app, for example, to objectively track patient symptoms, eye movement, and phonation, to really help both the patient and the physician really understand objectively how the patient is doing, especially over time.

Dr. Rodriguez:
So if we want a little bit deeper assessment as to how a patient is actually doing, I might ask more specific questions and utilize the tools that we have for research, such as the QMG. However, your exam becomes very important, observation becomes very important, and input from family becomes very important. So you have to really spend time with the patient and really make a good observation of how they're actually getting up and moving around.

Dr. Maeusli:
How useful are tools like the Myasthenia Gravis Activities of Daily Living scale, or MG-ADL, in your practice when assessing symptom burden? Are there any limitations or areas where they may fall short?

Dr. Shroff:
MG-ADL is an important tool where patients actually answer some of the questions of their activities of daily living. And it is important because in the clinic, we are more focused on clinical signs and symptoms in our exam. But then we might not know how MG is really affecting them on a day-to-day level on their day-to-day activities, so it is important to assess that.

In addition to MG-ADL, I would say even the MG Quality of Life Questionnaire is also important. And the second thing is, most of the insurance companies do need MG-ADL to get some of the treatments approved, so it is important to administer that in the clinic. But one of the limitations is it’s subjective, so we kind of have to tune it to a point where the patients answer the questions which are affected solely by MG and not by any other coexisting conditions which might affect their activities of daily living as well.

Now, personally, I like the Myasthenia Gravis Composite score, which is a combination of MG-ADL questions as well as part of a clinical exam as well. It just gives some amount of objectivity. But overall, seeing these patients and following these patients over a period of time gives us as clinicians an idea as to how MG is affecting the daily activities or their quality of life over a period of time.

Dr. Alpers:
Oh, yeah. Yeah, there are plenty of limitations. MG-ADL was never intended to be the end-all. A patient has a hip replacement, all of a sudden they pick up three points for the ability to stand up out of a chair.

First off, you have to teach patients how to take it, how to actually do the MG-ADL properly. And then the second thing is you have to

consider other factors that are influencing them—other non-neuromuscular factors—and kind of just put the pieces together. And that's where the neurological examination comes in, and just a little bit of extra history-taking.

Dr. Weiss:
So the MG-ADL, as you may know, is a patient-reported outcome measure, and because of that, there are limitations. So sometimes patients feel that they're doing very poorly, and because of the subjectivity of that scale, sometimes their MG-ADL score is quite high: eight, 10. But then on examination, they have very few signs of disease. There's sometimes this disconnect.

QMG, the Quantity of Myasthenia Gravis scale, might, in my opinion, be a better metric. The problem with doing that metric, that scale, is that it requires a lot more time, and you can't do it remotely. And we often, for stable MG patients, don't infrequently do telemedicine visits, and you can only do the MG-ADL scale that way.

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