

News

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Patients share ways of dealing with daily challenges at MGFA conference



by [Marisa Wexler, MS](#) | April 4, 2023



Life with [myasthenia gravis](#) (MG) often means finding new ways to do things that used to be easy but now are more challenging.

In a [workshop](#) at the [MG Foundation of America](#) (MGFA) National Patient Conference, a group of panelists discussed how MG has impacted them, and shared some tips and strategies that help them navigate life with the disease. The conference took place March 26–28 in New Orleans.

The workshop, called "[Little Things Make a Big Difference](#)," was sponsored by Alexion, a part of AstraZeneca, which markets the MG treatments [Ultomiris](#) (ravulizumab-cwvz) and [Soliris](#) (eculizumab).

Jennifer Yates, a professional stylist, moderated the panel, which included three MG patient advocates: Seferino "Sef" Castro, Aimee Zehner, and Liz Plowman.

MG brings 'a drastic change' to your way of life

All the panelists said that living with MG had changed the way they go about their day-to-day lives. For Zehner, who lives in New York City, her **diagnosis of generalized MG** means moving a lot slower.

“We move at warp speed in New York. But what speed does an MGer walk at, or move? Snails,” Zehner said. “It’s such a drastic change ... that shift from who we were before the diagnosis and then the aftermath of like: What does this mean for me? How am I gonna move forward? How am I gonna get ready every day?”

MG forced her to find ways to adapt a fast-paced lifestyle, she said, and to accept that there are some things she can no longer do as she once could.

“It hurts, emotionally, to not be able to do things the way that you did before. You have to think things over so strongly,” Zehner said. Even with getting around physically, “it’s not just like, ‘Oh, I’m gonna hop on the subway and I’m gonna meet you there.’ No. No. I need special transportation to get there. I have to use the wheelchair in the airport, I’ve learned ... ’cause there’s no way I can drag my heavy luggage.”

Plowman emphasized the importance of finding adaptive strategies to navigate life with MG, saying she had to completely revamp her morning routine to manage **symptoms of her disease**.

“I started life-hacking the heck out of my bathroom,” Plowman said. For example, she found a way to prop her arm firmly on a bathroom wall so she could more easily put her hair in a bun. Likewise, after switching to an electric toothbrush, she discovered that resting her elbow on a counter allowed her to better brush her teeth.

“That was really the thing, going through those activities that I had taken for granted and figuring out how to do them in such a manner that did not fatigue me out, could still get it done, and not be wiped out just trying to get through my morning routine,” she said.

Another helpful adaptation, recommended by an occupational therapist — the “masters” of life-hacking — is propping her elbows on a pillow while typing at the computer to avoid muscle fatigue, Plowman said.

Panelists noted that adaptive equipment, such as shower chairs, can make navigating daily life with MG a little easier. Castro, who has **ocular MG**, began wearing an eyepatch and found it very helpful in managing symptoms, even though some people were rude when he started wearing it in public.

“Unfortunately, there was a lot of negative comments. ... There was a lot of, ‘look at the pirate,’ ‘Halloween’s over,’” he said. “Children [were] OK, but adults, they were a little harsh. ... It was kind of sad to hear that my future adult friends were actually the ones causing harm. ... It was a little depressing.”

For ocular MG patients who might be considering an eyepatch, his advice is “don’t be afraid.”

“Go to your local pharmacy, get yourself a patch. ... Try it on, don’t be afraid. Walk around your house, walk around your park. ... Get used to it, and don’t be afraid to bump into things, that’s gonna happen,” he said. “But your body’s gonna get used to it, your peripheral vision’s gonna grow, and it worked for me.”

Practice self-care and show yourself grace

All panelists stressed the importance of being kind to yourself, keeping expectations realistic, and prioritizing self-care, which Yates defined as “taking care of your physical health and mental well-being through a variety of habits or routines.”

“I feel like MG has brought me to this world of adaptation and spontaneity. ... I have had to modify how I do things, kind of come to peace with, you need to slow down and be realistic,” Zehner said. “Because there is no rushing for me, personally, when MG is really active.”

Plowman also noted the importance of “just making sure I was showing myself some grace, and being kind to myself and not putting pressure on myself to be out the door in fifteen minutes, because it wasn’t gonna happen. And being OK with that.”

A major part of self-care with MG is making sure to get enough rest, Plowman, which required a change to her outlook.

“Pre-MG, I was very much of the mindset ... sleep is for the weak. Right? I’ll just keep pushing, keep pushing, give me some more coffee, I’m good, keep going,” she said. “That shouldn’t work anyway, but it certainly does not work in a post-MG world.

“I learned really quick that rest is treatment,” Plowman added, saying that staying rested is how she ensures having enough energy to do meaningful things, like spending time with her two daughters.

Castro said that major aspects of his self-care include meditation, and listening to empowerment affirmations in the morning while he makes his bed, like keeping a positive mindset throughout the day.

“Meditation is my go-to for self-care, and I would strongly recommend it,” he said, noting that meditation doesn’t require any fancy props, just time to sit with one’s own thoughts.

“Your meditation might be listening to the most craziest rock band — that’s mine. Or you could actually just take some yoga,” he said.

Stay active, but do things ‘a little differently’

Plowman, who is a physical therapist by profession, noted that staying physically active is important for MG patients.

“I think it’s a common misconception that in myasthenia gravis ... all movement is bad, or all muscle contraction is bad. But that’s absolutely not the case,” she said. “However, with MG ... it’s not that it can’t be done, it’s just we have to do it like everything else with this condition, we have to do it a little differently.”

Working with professionals like physical and occupational therapists can help patients in gaining movement abilities and in finding new ways of staying active, she said. Physical therapists focus on improving motor function (balance, muscle and core strength, etc.), while occupational therapists are more focused on fine motor skills and developing adaptive strategies for day-to-day life.

“We do have a lot of professional overlap. ... Physical and occupational therapists are both movement specialists, we just focus on different kinds of movement,” Plowman said. “I like to use the analogy that, if you’re in the hospital, your physical therapist will get you walking down the hallway, the occupational therapist will make sure you’re dressed first.”

For MG patients who want to be more active, Plowman’s advice is to “start low” and “go slow.”

“Start with just something simple, something that you enjoy doing, whether that’s walking, whether that’s playing with the dog, whether that’s dancing. ... Just those little activities,” Plowman said. “Just do a little bit and then, of course, rest, don’t kill it. But just find those little ways to incorporate those things that make you happy.”

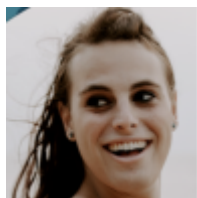
Castro likes to stay active by going on roller coasters at amusement parks, and taking selfies to work his arm muscles. Zehner, who spends a lot of time making art and singing, said she found dance to be a good way to get moving.

“I love to dance, even if I don’t particularly dance great. I can hold a beat, and I can still move my body. These hips can still wine,” she said.

In addition to finding individual ways to manage daily routines, self-care, and healthcare, the panelists emphasized that support from family and friends can make a big difference in navigating life with MG.

“Luckily I had a very strong support system from my family, my friends, and my husband ... they all helped me understand and kind of grow and accept myself,” Castro said. “That’s what made me strive to keep going and never give up.”

About the Author



Marisa Wexler, MS Marisa holds a Master of Science in cellular and molecular pathology from the University of Pittsburgh, where she studied novel genetic drivers of ovarian cancer. Her areas of expertise include cancer biology, immunology, and genetics, and she has worked as a science writing and communications intern for the Genetics Society of America.

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