

Living Life with MG

Meridith O'Connor

Typically, when I compose articles to promote awareness around Myasthenia Gravis (MG), I tend to write from the perspective of an expert; aiming to teach an audience about something that may be unfamiliar to them. However; this article is different.

I do not have to try to illustrate what it feels like to wake up every morning knowing that some part of my day will be consumed with fatigue and weakness. I do not have to attempt to describe the humiliation that creeps upon me when I sense my speech start to slur or when my eyelids begin to weigh heavily. I do not have to depict how or why this disease has forced me to feel shame, guilt, and discomfort. Why do I not have to do this? Because I would gamble that the majority of you have probably felt one of the things I just mentioned from one time or another, and in reality, describing such feelings and emotion does not even begin to scratch the surface of our individual experiences with MG.

Therefore, this article has almost been a challenge for me to write because for most of my diagnosis I have been required to defend my experience or explain the impact this disease has had on my life. Today I do not have to do that because you know; you get it. You understand.

My goal behind this particular article is to hopefully remind you that you are not alone in this illness, and to validate your experience living with MG. For so long I was doubted, and although my official diagnosis with MG provided confirmation, the validity of my experience continued to be questioned, and I never want anyone to feel that their experience is not real.

I have lived with Myasthenia Gravis for over 12 years now, and I am at a point in my life where my disease has become manageable. My disease remains chronic and I am confronted with challenging moments every single day.

Most recently, I graduated with my master's degree in social work from one of the most renowned programs in the nation. Prior to being diagnosed I had huge dreams; I did not necessarily know what I was going to do with my life, but I knew that I had the intellect and tenacity to succeed. Yet after I was diagnosed, my aspirations were always second-guessed; and not just by others, but by me. Can I actually do this? Is this a realistic goal? Am I truly capable?

MG constantly influences your decision-making capacity and compels you to question your ability to be the person you hope to be. MG makes you undesirably attuned to your fear of failure and your self-efficacy.

Deciding to take the risk of accepting my offer to the master's program was one thing, and actually accomplishing this achievement was another. These last two years were extremely grueling and strenuous, balancing my health and academia, but nevertheless I did it. I completed something that a lot of people probably thought I was not capable of doing, including myself at times. Although there was doubt, fear, and apprehension, there was still something

within me that believed I could do this. There were of course times when I did not think I could; did not think I was cut out because I would be overcome with the reality of my health.

The fact of the matter is, MG is relentless and it will continue to put you in a place of uncertainty. Remember to recognize this and know that it is okay. However, do not let this disease or anyone convince you that you are unable to live the life you were meant to live. Remind yourself of the unpredictability of this disease, but do not let that determine your destiny. Advocate for your needs, assert your authority over this disease and do not be ashamed about your reality. These are tough tasks, I know; ones that I myself struggle with daily. But I can, and I will, and I hope you do too.

About the Author: Meridith O'Connor is a patient in our St. Louis group who recently graduated from Washington University in St. Louis with a Masters Degree in Social Work with a concentration in healthcare. Meridith was diagnosed with MG in 2005 and regularly writes for The Mighty.