

KIMRIE M. DONOVAN, MD, FAAP – MY STORY

I am both a physician and a long-term, late-stage MS survivor. Since my mid-teenage years, I have lived with chronic, almost daily pain, and episodes that now were clearly MS flares. I am hereto categorically state that MS is a major source of often unrecognized, unrelenting, and excruciating pain for many patients that suffer with it, especially as it progresses. I honestly believe many people have never experienced anything close to the level of pain that I am talking about unless they have had major surgery which usually gets treated with “heavy” painkillers in the short run. (I have surprised people when I say that living with shingles for literally months on end in more than on dermatome (location) was mild compared to what MS can be like).

Pain is truly relative in my perspective, as I am used to a baseline degree daily that some people only experience occasionally. I also believe that some people truly experience pain more than others genetically, but I’ve also trained myself to literally “block out” some basic pain; for example, I do not feel most needles and IVs being inserted anymore. I can tolerate up to 5-6/10 pain and “get on” with my day if I have to. Early on, I was technically considered a “low risk” type of MS, except for the fact that it started in my spine, which unfortunately also meant it took many years and specialists to diagnose. Currently, imaging the entire spinal cord as well as the brain is apparently standard of care in MS workup, from what I read and learn from colleagues.

While I had some constant daily symptoms like burning, numbness, and unusual fatigue since my late teens, I did go through periods of times where I was much more active than others during my 20s and early 30s. My residency was very complicated by the fatigue that could be overwhelming. I can imagine that many of my greatly overworked fellow residents must have thought I was “lazy” since I did not have a definitive diagnosis yet. Since multiple doctors were unable to give me a clear diagnosis until my early 40s (true and, tragically, not uncommon in many patients my age and older), I just thought most people lived in pain constantly and literally were consumed with fatigue all day most days. I blamed my visual changes on my call schedule and lack of sleep. I know that my dangerously elevated cortisol level was largely responsible for my poor health and weight gain which others around me worried about and did not understand. I just “soldiered on” because I had no choice and I had two beloved children to raise on my own. But I do feel that it impacted the trajectory and quality of my career and my personality. As many people now know, chronic severe pain has dire consequences on all aspects of your life.

By my second year of residency, I became pregnant with my first child and actually felt much better than I had in years. Unfortunately, I did have to bed rest, but it was for a different medical issue. In fact, many women with MS have reported symptom improvement during pregnancy, a key insight and consideration in developing new treatments. I have recently started the Tennant Protocol for AA, as a research subject. I have especially found that Human Chorionic Gonadotropin (HCG) a hormone released during pregnancy that helps grow nervous tissue in the developing baby), in the doses suggested in the Protocol has helped me

immensely. I am no longer bed bound, I am walking once again without my scooter, the contractures are calming down, and my blood flow to my muscles has improved greatly, they are much stronger, and the pain has lessened by 75-80%.

On the other hand, menopause is the opposite for many female MS patients who experience significant disease progression including myself. I had, and still have, an amazing physician who addressed my needs and deterioration at that time, and I must credit her with saving my life at that point, but I have been left with a baseline disability called Secondary Progressive MS. I realize I have had MS for at least forty years now, but I also know that I am part of a large group of women my age and older who did not receive an early diagnosis and treatment options. We are suffering more because the disease has ravished damaged our Central Nervous System CNS, and body, and many of us live in unbearable pain.

Having the actual diagnosis of MS has allowed others to be compassionate and patient in ways that I never experienced previously. Being told "it's all in your head" more than once is not an easy thing to swallow. MS is a confusing disease for those who do not understand it well, especially how it often fluctuates so much in the initial years. For example, at one point during my first episode at age 17, I was almost unable to move and then needed a wheelchair occasionally; at other times I was doing activities with my friends and family or even ice skating despite foot pain. I remember being in a premed class and unable to focus on the material because my legs hurt so much. In other words, looking back the whole picture makes sense but without a diagnosis it was very unclear and confusing. In addition, other medical things were blamed for some of my symptoms.

In conclusion, I would like to support the Tennant Foundation when they say "some excruciating, constant pain can cast the poor suffering individual into a humbled, bed-bound state." This could not be more accurate in describing some of my last few years. I want my story to be told in order to help others.

Kimrie Donovan, MD