

Public Comment
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Fatigue is a word that doesn't do much to convey the enormity of the experience of living with ME/CFS. Since I first became ill, twenty-seven years passed, or stated another way -- one half of my life. I have vague memories of days, weeks, months, and even a year when I did not spend much time away from bed. Even when I am able to venture out of my bedroom, which is quite often these years, the cognitive problems are equally or even more personally debilitating than the isolation. The light shows and disorientation occurring within my brain (or eyes and/or ears) became background static that would ebb and flow with stress, movement, and stimulation. People around me can understand a bad flu, however it is much more difficult for others to comprehend or be patient with the consequences of looking well but having difficulty utilizing my marbles or keeping my batteries charged.

Staying focused is another challenge with fatigue as demonstrated last Sunday. I was making my regular pilgrimage to the guru's at the apple store when I forgot to pay attention to where I was going, made a wrong turn and found myself nearly home forty-five-minutes later. Somewhere towards the end of that journey I realized that I did not recognize my surroundings. I kept driving until I did. Struggling to keep on track or return to track is an every day momentous challenge. Vast amounts of time often seem like a flash as every thing takes so long to do: fill out the form, find a note, put on a shoe, remember what I was doing.

My jewelry box holds a small emerald pin and a faux-gold-medal; relics won in high school speech competitions. These testify to my former ability to remember easily, reason succinctly, and present compelling arguments with ease. But, since the onset of the illness, during the bad times my attempts at conversation are a source of embarrassment as all too many times I am not able to remember what I was thinking while simultaneously attempting to decode the words spoken to me. There was a sense of old Rolodex cards flipping deep in the head as I waited for the meaning of words to emerge one at a time. The effort of attempting to converse was really only an exercise for often I could not possess more than a few words at a time. Not many people crossing my path possess the time to wait while I struggle to comprehend questions or comments and then form sentences. When I can engage sometimes I am off topic, incomplete, or intense. Functional communication was much worse several years ago. Eventually language became less of a problem unless pushed beyond my energy envelope.

When visual distortions of past years became less difficult, auditory problems began as memories of buzzers, beepers and other mechanical noises repeated mercilessly through my days and nights. I sometimes woke to check the sump pump and kitchen appliance doors unable to distinguish between the real noises and the memory of noise. Perhaps these are not common symptoms mentioned within the CFS community but many of us develop additional problems that are also not present in our family histories, such as Hoshimotos thyroid or Para-thyroid, gastrointestinal problems, prolapsed mitral valve, or POTS, and frequent thirst, and sexual dysfunction.

Perhaps some of what I experienced is a failure of the immune system and endocrine system to behave appropriately, I certainly had astronomical titer counts, sore throat and years of swollen

glands, but not always. For a while I experienced what felt like a swelling inside my head – body pain ever changing in nature as well as location -- and the inability to process medications, or environmental exposures -- and yes sometimes stress related lapses in composure. Later came the sleep disturbances and mini seizures.

We all have heard the story of the blind men describing an elephant by feeling only one part. Endeavoring to understand the nature of this illness is similar to that. I continuously try to assemble a comprehensible drawing using sketches by blindfolded artists who have only one random part they had access to explore. For if you have four people with "ME/CFS illness" (isolated from all the other patients that may have been given the "trash can diagnosis") we may present as differently in a single moment of time from each other, as we do from ourselves on another day, or week, or month, or year. I do not experience my life or my illness as I did 27 years ago, and neither does anyone else with ME/CFS whom I have observed over the course of these years.

Personally, I do not see the process of this disease as either static or uniquely presenting itself upon the individual members of our ME/CFS community. In other words, I see the illness as a complex whole body experience that is loosely predictable over its evolution. I also think someday we will look back and recognize a relapsing and remitting progressive pathology. It seems to me that this illness follows a particular course with some variation that many of us commonly experience. This is neither due to nor equitable with getting older.

We risk further marginalizing our predicament if we cannot find ways to group together with other patients that share similar experiences albeit different origins. By grouping together we become more relevant to the general population and possibly better able to share resources rather than competing for them. If I understand the research community, we may come from different places, but many roads lead to Cincinnati.

Thank you for your time and this opportunity to share my thoughts.

Lolly

Fell ill July 5, 1985 about 9:00 AM

Diagnosed with Myalgic Encephalomyelitis that same morning in the hospital with many of my study abroad classmates, we were unintended participants of a known epidemic in Mainland China.