

Testimony

Anonymous

Please Help Me and Others Like Me. ME/CFS Has Taken My Life Away.

The manner in which many physicians and some friends and family members have treated me since the sudden onset of my illness has been shameful, inexcusable, and from my point of view, mean-spirited. The reason for this is because the picture that has been painted of the ME/CFS patient has been one of doubt, as to whether or not this illness is real. This devastating illness is frequently looked upon as being a psychiatric illness or no illness at all, I imagine, most likely by those who may never have suffered from any chronic illness, and are quite smug about their own convictions and beliefs about judging other people's health status. It is a persistent picture, one that has not been able to be erased from the thoughts of many if not most people, despite convincing recent news reports and new research findings, pointing to the uniqueness of the ME/CFS illness. The fact remains, despite what anyone else in the world believes, I have been suddenly and severely disabled as the result of a flu-like illness that took place over five years ago.

Life before ME/CFS. To make a long story short, I had a happy normal childhood, happy adulthood and had enjoyed excellent health for 54 years. I had, and have, many interests such as enjoying classic music, creating art, visiting museums, volunteering in my community, working on animal welfare issues, walking around New York City, organizing events, and many more. I have received several awards and certificates of recognition for my work. Like any patient with my personal history would, I resent any reference to psychological problems or childhood adversity as a possible contributing factor in becoming a disabled person as the result of a viral infection.

Onset. My downhill health spiral began with an intestinal and "flu-like" illness. A seizure followed. I then became so ill I felt as if I was collapsing even though I was bedridden. I remained basically bedridden for months and could hardly walk from one room to another. My elderly mother had to stay at my home and bring food to my room when my husband was at work. My vision was blurred and I was so fatigued I could hardly speak. I had chills

and fever for months. Intermittently, I would have bouts of being unable to move my legs and was stuck in bed for hours. Over the months that followed, I realized that I could not walk properly. I was shuffling my legs and walking very slowly. The level of fatigue that developed was so disabling, walking was very difficult, and still is. I thought I had developed a sudden onset of Multiple Sclerosis. Two neurologists have declared that I do not. I developed POTS, and have had sudden tachycardia episodes. One such episode landed me in the emergency room with a severely elevated heart rate.

Fortunately, the inability to move my legs has subsided, my vision is no longer blurred, and I can speak to friends on the phone for quite some time. I no longer shuffle my legs while walking, but when I walk the short distance that my illness allows, I walk much more slowly than a healthy individual. Most days I remain homebound due to the severe level of fatigue.

Robbed of a normal life after developing ME/CFS. Can you imagine that instead of recovering from the "flu" you actually become more and more disabled as time goes on as the result? (Can you imagine how **horrifying** it is to realize that you have emerged from the "flu"-as a disabled person?) I can tell you it is absolutely horrifying, and nothing less than that. Can you imagine being healthy all of your life, only to find that you needed a wheelchair to go from point A to point B? (I have refrained from submitting to being pushed around in a wheelchair, except to visit a doctor in a large hospital) I live within my limitations. Imagine many people and physicians dismissing you as merely tired or worse, making up symptoms? You lose many friends and some family members, and you spend most of your time alone, all alone. You must deal with the endless monotony of being homebound for the most part, day after day and year after year with no end in sight. I live trying to suppress the terrifying thought that is lurking in my mind all of times, that is, will this illness ever go away?

Most of my past activities have been stripped away from my life. I used to easily walk 100 blocks in New York City. I can no longer walk more than 2 blocks or so on a good day without suffering a severe setback, collapse and experience the worsening of symptoms. For years I did not have the stamina to walk down my short driveway. I am basically homebound and do not have the stamina to socialize very often, and for the first four years or so, not at all, ever. I had been virtually couch bound for most of the day for many

years. I spent much of my time staring out of my window and dreaming of returning the self that I knew for 54 years; a very active, upbeat and outgoing person. I have missed many friends and family gatherings. I cannot make appointments to see friends. My muscles are weak and I am severely fatigued, morning, noon and night. Resting does not help, and activity makes my symptoms worse. The more I try to use my muscles the weaker they become. I believe that I am very deconditioned, but any efforts to try to fight this lead to an undesirable effect. This illness cannot be fought. I am terribly fatigued and feel like I still have the "flu". My husband makes sure though, that I do go out on my "good" days by driving me around town and elsewhere "to see the world". I can also on occasion walk around a small store or visit my local library. I did once visit a very small museum, but did suffer the consequences.

What I think ME/CFS is. I think the sudden onset cases are indicative of a neurological illness, and a distinct illness, most likely as the result of the immune system's effect on the brain and spinal cord. I sometimes wonder if this is the result of an ongoing viral infection in the brain. I think it is an organic brain illness or disease, which share many of the symptoms of Multiple Sclerosis and other serious neurological diseases, despite the fact that there is no laboratory test to confirm this illness. I also think that since it has been reported that women are mostly affected by *ME/CFS*, that estrogen has something to do with this. I have read that estrogen has a protective effect on the immune system. If it is true that women between the ages of 40-59 are mostly affected, then perhaps the lower estrogen levels means that the immune system may be weakened as a result and not as effective in combating viral illnesses and the immune system must work harder to do so, and so doing damages the central nervous system.

Illness not recognized whatsoever by most physicians, and if it is, they are very misinformed. The only advice I have been given by most physicians is to join a gym or ride a bicycle despite my explaining the symptoms of this illness and the limitations place upon it's victims. I have been ridiculed and sneered at. Most think I should just push myself. It is very hard to listen to this without outwardly becoming very upset, but I just sit there a "take it" because I know they do not know anything about this illness and the more I explain it to them the less they believe me. It just saddens me to visit with any doctor that I have so far seen. I doubt that any

physician treats MS, Parkinson's or any other seriously ill patient the way MS/CFS patients are often treated. I know there are a handful of experts in this country to see, but they are located far away from my home, and some that may be in my area do not accept any insurance or are not on my medical plan. Since there is no 'cure' for "ME/CFS" I do not want to spend perhaps thousands of dollars to see a ME/CFS doctor that is not on my plan.

What needs to be done. Doctors must be trained to recognize all of symptoms and possible symptoms of ME/CFS sudden and gradual onset cases. Doctors must be trained that post- exertional malaise is the hallmark symptom of ME/CFS, and that advising a patient to exercise will certainly lead to a worsening of symptoms, so much so, that a patient may become bedridden as a result for quite some time. I think it is preposterous to have wait 6 months before being diagnosed. I believe that all psychological studies must cease, as ME/CFS is not a psychological illness. Since there seems to be no way to prevent this illness from occurring and no way to determine who is vulnerable to succumbing to it, then there must be more effort devoted to educate the public and physicians about it; emphasizing that it is indeed a real and devastating illness. Of course, more funding and finding a way to attract talented and unbiased scientists to investigate the pathophysiology of ME/CFS is sorely needed.

Prognosis. Since at this time no one knows the cause of this illness, I do not think that anyone can determine who will or will not recover. The thought of never walking again, enjoying the museums and city is a nightmarish and petrifying thought, a thought that I live with every waking hour. I must visit the museum in my dreams or memories of it. I am as desperate as any other victim of a devastating illness or accident to return to the previous level of health previously enjoyed. Other than having to accept oneself as a disabled and very ill person, one of the worst aspects of having ME/CFS is that there is none or very little support from most of those that you need and expect it from. Thank goodness my husband who I am with since 1970 knows what I am going through and is very supportive. My 86-year-old mother also knows. She can hear it in my voice over the phone. She is heartbroken to know I cannot enjoy the things I have done in the past and that I suffer almost every waking moment.

Closing Comment. I had never known, before becoming ill, that it was possible to be a person with an ebullient personality, a love of life and

beauty, and have such a horrible illness befall me suddenly as the result of a viral infection.. I had never heard of ME/CFS before becoming ill. I hope and dream of recovering, but they are dimming as the years pass me by. Only time will tell whether or not I will ever walk the streets of my beloved New York City, or comb the beach for beautiful pebbles and seashells, ever again. I worry that my life will remain a "virtual" one for the most part, one that is lived sitting in front of my computer watching the world go by, forever.