

Public Comment
Julie Sellers

To whom it may concern,
I am one of many sufferers of this debilitating illness named after physical ailments. (Chronic Fatigue Syndrome) Diagnosed at Mayo Clinic Rochester MN 2010.

I want to know why we can't find a better name for this illness. If I only had the symptoms of being chronically being fatigued, I probably wouldn't complain. To describe my ailments and put what Chronic Fatigue Syndrome in a better perspective for the many people that just don't understand.

I shift between feeling well to feeling sick, having relapses every couple months.....I am diagnosed with (SVT) Supraventricular Tachycardia, Polyclonal Hypergamma Globulinemia, (POTS) Postural orthostatic tachycardia, myofacial pain syndrome, fatigue and malaise. I suffer with a lot of pain, weakness and sometimes my legs feel like they have lead weights attached to them. On other occasions it feels like I don't have legs at all...I need to physically think about putting one foot in front of the other. I have also learned to modify my life to deal with my symptoms as they come and go. I fight everyday and learn not to take advantage of a good day or I regret it for the rest of the week.

If I have to go to the ER for my heart symptoms, I frequently get treated as if I am not really sick or this is anxiety. (I am not diagnosed with anxiety.) Even if they give me additional antianxiety medicine to ease their mind, it does not stop my irregular heart beat. Only the heart medication helps..... because my irregular heart rate is because of MY HEART not MY HEAD.

As a patient with this illness I have learned to keep the doctors that understand my illness, close...because it is humiliating to be treated less than human by doctors that don't understand this illness.

So many people suffer and so many CFS patients eventually develop cancer. If a patient with cancer came into see a doctor. The doctor would sent them home telling the to do graded exercise and you will start to feel better. Right! Cancer patients are treated for cancer. Stroke patients treated for stroke. MS patients treated for MS. Chronic Fatigue Syndrome sufferers are treated if we are chronically tired or it is IN OUR HEADS. What about all of the other symptoms?

I have read some of the Medical journals out there. Why are we not coordinating research and figuring out the common denominator. Is it a virus? Is this contagious? Is this a death sentence? As a sufferer, of this illness.....My last wish would be to figure out this illness. Even if it takes donating my body to science.

Thanks for taking the time to read what I have to say!

Sincerely, Julie Sellers
ME/CFS sufferer since 2010