

I am writing you to plead for help.

I am an almost 57-year-old woman, wife, mother and grandmother.

In 1997, I was a very happy, extremely active preschool teacher who loved her job, loved the people she worked with, loved her husband and three growing boys. I participated in life like it was a gift to be able to play through. Just think, I got to play with little kids all day and got paid for it. I danced and sang, I cheered with joy at my childrens' sporting or musical events, I volunteered my time to charitable causes and I had dreams. It was my dream to become a foster parent and bring some relief to a very stressed social system in the state of Florida. I was the kind of person that friends sought out to tell their troubles to because I was calm, serene and balanced. I was one of those people who did not have to be reminded to stop and smell the roses. That was my life.

One month, the children in our class began coming down with a severe kind of flu that kept them down for longer than the usual flu. I got a bad case and basically, that's where I became a different person. I have never been able to recover from that flu. In 1998, I was diagnosed with Chronic Fatigue Syndrome, now know as ME/CFS.

I suffer from a constant cycle of flu symptoms and pain and cognitive malfunction and digestive disorders and oh, did I mention fatigue. Yes, fatigue, but not the kind of fatigue that is even describable in words. I have tried explain what this feels like to loved ones and friends. The closest I can get is this: It feels like somehow, some way along the way, my cells got the message that they are supposed to die. My brain, on the other hand, knows that they should not. It feels like this constant battle going on in my body and sometimes the cells are winning and sometimes my brain takes a little bit of a lead. The process itself is exhausting.

I spend most of my time in bed. It is difficult for me to shower. Sometimes it is too hard to talk or listen. Friends are mostly long gone. Family tries to understand, but it is difficult for anyone to understand if you have not experienced it yourself. I am not able to participate in the lives of my children and grandchildren. That is the most heartbreaking of all.

And now, I find myself having to rely on others to do the work in the world that I was so determined to do myself. That is why I am writing to YOU. YOU are in a position to make a difference. Please help us by insisting that the CDC and NIH take ME/CFS seriously. We have waited way too long already. It is long enough. There is exciting new research that needs careful attention not negative perspectives and immediate dismissals. Please help us. The time is now. It IS the time for Change and YOU can be the one to make it happen.

Thank you very much for your time and attention.

Pat Mayer