

My History with ME/CFS
Mary M. Schweitzer, Ph.D.

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In one day, October 24, 1994, my life changed forever. I was not in an automobile accident, nor was my home destroyed by a hurricane or tornado. It was a disease that struck mysteriously, suddenly, in a single day. Looking back, I can see hints that all was not well with my health. But it is a characteristic of this strange disease that most of us can point to the precise day we collapsed; the day we changed from being a person who has been sick, to an experience altogether different from anything we had ever imagined.

In my case, it was a crisp autumn day. I had driven to my office at Villanova University in the Philadelphia suburbs. Behind in my grading, I thought I could catch up by locking myself in my office on a day that I normally was not on campus. Instead, I disappeared into a fog that lasted several hours, unaware of the passage of time when I finally re-emerged. I looked down at my lap. I could not understand any of the words in front of me. It took fifteen minutes to be able to will myself to stand. Somehow I made the drive home, where I sat in a chair in the kitchen until my husband came home and took me upstairs to bed. My life would never be the same again.

I was lucky in many ways. My students gave me the diagnosis before my family doctor did, and within a few days of being formally diagnosed I found an internet discussion list where I was directed to an excellent specialist in Washington, D.C. – only a couple of hours from my home in Delaware. My husband – though clearly frustrated – never wavered in his support and care. Perhaps because of the obvious severity of the illness, no one in my family doubted that I was physically ill, and my husband's friends were supportive and kind. I already had children and had been able to spend time with them when I was still healthy. Most of those whom I would meet on my journey with ME/CFS would not be so lucky.

Trapped by an illness about which little seemed to be known, I used internet to search internationally for statistically significant, sound research programs. By 1996 I was attending research conferences, seminars, and government meetings – almost always in a wheelchair, and often too ill to be able to learn much more than what was contained in the package of handouts I dragged back home.

Internet also became a source of friendship and personal support on a level I had not experienced outside my own family in years. I became good friends with patients from Scandinavia to the British Isles, all over the United States and Canada, Australia and Japan. In the course of a decade, I have watched as far too many fell too ill or too

indigent to continue the friendship on internet. Some have died. But many remain *good* friends.

It took time to realize that I did not have an acute illness. Everyone, myself included, assumed that with sufficient rest and appropriate medical treatment I would recover from this downturn. I remember thinking that by April, I would probably be well enough to do light research. Instead, I found myself settling into a life that did not change – at least, did not change for the good

Every day was a day survived. To others, I was resting, taking it easy. But not to me. The simplest task took enormous exertion and concentration. The cognitive effort required to go online and meet with my friends tired me out quickly. If I did too much – which could be as simple as going out to dinner and sitting upright for an hour – the disease slapped me down the next day with exhaustion and pain.

How could “resting” be this difficult? My prior concept of “rest” always included some kind of activities. During previous bouts of illness, I would lie in bed reading the newspaper or a good book, or perhaps just knitting and watching TV. But now, reading was at first tiring; eventually impossible. Knitting was far too difficult, both mentally and physically. Just getting food during the day was an adventure, because I was so confused all the time.

Months and years went by in this state, or rather, continuing to deteriorate. No one except my family saw me at my worst. While observers might assume I was doing fine, my family would be watching for signs that we needed to leave and get me back to bed. Outsiders never saw me incoherent at home, or lying in a dark room listening to my movies because it was the only way I could bear the pain.

For four and a half years, morning coffee was my nemesis. Mostly, my problem was remembering where to pour the coffee – or, more specifically, where *not* to pour the coffee. It became a running gag on the discussion list how many times – and ways – I would find to spill the coffee on the floor. I would forget to get the cup, and find myself pouring the coffee straight unto the saucer, only to watch it spill unto the table and then like a pretty dark brown waterfall, off the table unto the floor. One morning I opened the silverware drawer before I had the coffee cup ready to go, and I poured the entire pot of coffee into the silverware drawer, convinced it was a cup. I *knew* something was wrong with the picture, but I could not figure it out until the pot was empty and I had set it back down. I noticed we had the waterfall again – and then I realized it was coming from the cracks in the silverware drawer, falling all around in a much *larger* brown waterfall than usual.

I didn't want to stop drinking coffee, so I finally figured out a way to pull it off. The trick, I learned, was to chant, over and over again, “saucer, napkin, cup, coffee, drawer, spoon,” from the minute I walked into the kitchen. It really did work. Except the times I forgot to do it.

When I tell people this story – to explain how sick I was – often they will smile and say, “Yes, I’ve accidentally spilled coffee.” Or, “Yes, I’ve found myself looking for a cup in the microwave.” Sure you have. Once or twice. Not every single day. Believe me, this is very *very* different. In the beginning I would get irritated when healthy people would try to sympathize by telling me they had experienced the same thing, but later I just took it as a kindness and left it at that.

Once I arrived at the recliner, I had to sit quietly for a while before I could eat anything. The effort of putting everything together usually left me pretty exhausted. Then there would perhaps be another pause while I tried to reach the water, or coffee cup, or TastyKake (left behind for me by the family). The recliner itself was an accommodation; Eric’s idea. He had Bob buy an inexpensive computer desk, then set it up next to the recliner so I could write lying flat, with the keyboard in my lap.

At first I brought the morning newspaper with me to read. But the newspapers began to pile up, because reading them was simply too difficult. Probably the saddest aspect of cognitive dysfunction, for me, was the inability to read. My mother taught me to read before I went to kindergarten. When I was a kid, I used to enjoy sitting on the floor reading page after page of a 50-year-old encyclopedia. As an adult, I got the same pleasure out of sitting on the floor of the library, reading back issues of scholarly journals. I could spend entire days lost in whatever subject I was researching. I scored a perfect 1600 on my grad records (the equivalent of SAT’s, but for graduate school). In addition to professional journals, I used to read three daily newspapers, plus the *New York Times* Book Review section and the *New York Review of Books*. And now I could barely read at all.

I finally realized how bad my ability to read had gotten when I had to abandon reading the daily comics. I cannot remember when I could not read comics – I probably read them with my father before I started school. Even today he’ll clip a favorite and mail it to me. But with the disease, I found that I was stuck, looking at the same comic strip over and over again. I could not remember what was in the first panel by the time I got to the fourth, so I just sat there, looking at it in confusion. Finally, I gave up. I looked at the pile of newspapers – saved for the daily columnists as well as the comics – and told Bob to throw them out.

Before I fell ill with CFS, I could never have imagined anything except a stroke that would have prevented my being able to continue to publish. How could I continue in any form if I could not read enough, write enough, sit in a lecture and understand enough? Who was this new person?

This was what made me disabled. This was my illness. It was not being “tired” or “fatigued.” My *brain* was broken.

Fortunately, I could still read somewhat on internet. I would converse with my friends, or work on a new website. I made quite a few websites while I was ill – it would take at least two weeks to make each one. I would have to stop and rest often, because

intellectual exertion is tiring for us – for me, not as tiring as physical exertion (which was dang near impossible), but tiring nevertheless. And in between I would just rest – in between sentences in an email message, or before taking another try at getting the html language right for the website. I stared at the tv, or stared out the window, or just ... stared. And then I would go back to the computer. That was one of my favorite parts of using a computer – no one knew about the gaps. They just saw the finished product.

In the first few months I tried driving to the grocery store, and then using an electric wheelchair so I would not have to walk very far. One day, however, I woke up with the car on top of the curb in front of the post office. I have no idea how I got there. My children took the car keys away. I would get frustrated having to be indoors on a beautiful day, so I would try to take a short walk. After a couple of blocks, I would have to sit down, confused and unable to continue. Someone would come find me and bring me home.

So my days went – on good days. On a bad day, I would never get up at all, or would lie in bed curled up under the covers. Every day of the illness I experienced pain behind my eyes and in the back of my neck. It felt as if somebody had hit me in the back of the head with a baseball bat, and someone else was trying to unscrew my eyeballs with a pair of pliers. At the same time, the glands in the front of my neck felt swollen (though my doctors told me they were not), a feeling I described as having golf balls in my throat.

On a good day, the pain was mild enough that I could tolerate it and spend some time with the living. My muscles ached all the time. It felt as if I been out running, or spent the day skiing, but of course I had not. Sometimes my muscles felt heavy, as if they were made out of cast iron. Had I been a cartoon character, when I stood up my body would have left a deep imprint in the furniture. Just for me, Mother Nature had turned up gravity about 4 times normal. Friends with Multiple Sclerosis told me they had experienced this. Why? What did we have in common?

A pain day was often payback for trying to be normal – staying too long at a ball game with my family, or trying to go to dinner with my husband at the university. I often wonder at the doctors who believe this disease is psychosomatic. Part of the rationale behind the psychosomatic diagnosis is the belief that the individual gains somehow – generally by getting more attention. With this disease, I ended up at home, alone and lonely, and in pain. I cannot imagine what could be considered a gain from that.

About a year after my collapse, on a drive home with my husband Bob and my daughter Carol from a trip to Gettysburg, we stopped at a rest area on the Pennsylvania Turnpike. Bob and Carol walked on ahead at a normal pace. I could not. I got out of the car slowly, shut the door, then walked unsteadily to the handicapped ramp. I used the rail to pull myself up, slowly, and then leaned on it as I slowly walked toward the front door. I had to plant my right foot and drag the left foot up to meet it. I was focusing very hard on trying to walk, so I did not notice that my daughter had come back to see what had happened to me. When I looked up, I could not escape the look of deep concern on her face. What on earth was going wrong?

Nothing except a crash, followed by a permanent downturn. It was the first of many over four years, until by the fall of 1998 I was too sick to even continue on internet.

My sense of balance eventually became so bad that I made it around the house by clinging to the furniture and leaning against walls. I had a golden retriever, Kelly, who would stand beside me to help my balance, and if I fell, she would wait patiently for me to use her to push myself back up again.

Stairs were always a problem. I only did them once a day. Bob made me lean against the wall so I would not try to hold on to the stair-rail, which he did not think was strong enough to hold me if I started to fall. And, of course, Kelly occupied the space next to me to help keep me propped up. But I found looking down at each step physically difficult. At first, I often tripped at the bottom because I thought there was one more step and there was not. Strangely, I never stepped out into space – rather, I expected there to be one more step. That kept me from any really bad falls. I finally developed a method of doing stairs where I felt each step with one foot – I followed the riser all the way to the next step before committing my weight to it. That worked.

I would close my eyes to focus on dressing. To do that, I had to dress sitting on the bed. I would pull the clothes on, and then sit cross-legged and close my eyes for difficult things like fastening hooks or buttons. That could have hilarious results if I did not get the right button matched with the right buttonhole. Often I put clothes on inside out, or backwards. I really didn't care, as long as I had something on. When the family got back home, Bob or Carol would straighten out my clothing for me.

At home I was having more trouble communicating with Bob and Carol. "Expressive aphasia" could be both frustrating and embarrassing – especially for someone as verbal as I had been. My husband felt he had lost his best friend, because we could no longer talk things out. I could not stay in the conversation long enough, and if I did, I could not explain my thoughts. There's a line in the movie *Bull Durham* where Kevin Costner tells Susan Sarandon that a conversation with her was like a Martian talking to a fungus [practice bat]. Well, that's about what a conversation was like with me.

When people called and asked me just to write down a phone number, I could not do it. I could not remember more than one number at a time, and I had a great deal of trouble explaining that to the caller. Eventually I got to the point where I told them to hang up and dial my husband's office phone, and leave the message themselves. I could not be reliable enough.

Later, when I would testify about the disease to the CFSCC, a committee at the Department of Health and Human Services, I would take days to write down a five-minute presentation, then count on my adrenalin to be able to read for five minutes before collapsing. It was the only way I could do it. Afterwards, I couldn't talk to anybody – couldn't say much of anything that was coherent. I would go to the back of the room and

lie down. About a half hour of lying on the floor would usually bring me back to the world, although I remember one conference where I spent the entire time on the floor.

The other part of a conversation that was difficult was that I did not always understand what was being said. I felt as if I should be saying "huh?" all the time. Eventually I would let the disease take over and allow myself to zone out – just disappear. That was preferable to trying to keep up with a conversation that might as well have been in a different language. But is one of many ways in which this disease is personally isolating – even when surrounded by people who care.

I got used to the symptom we called "the pause" long before my family did. I would walk into a room and just ... stop. I was somewhat aware that I was not moving, but I did not know why and for the moment did not even realize it was weird – it was more the responses of my family that made me realize how weird that must have looked.

When my son was studying biomechanics in college, he tried an experiment with me. I was standing in a room, motionless. He came up behind me, pushed me ever so slightly – and I took several steps. He said that his biomechanics professor had been curious as to what would happen if he tried that. About all I understood from it was that there are some types of neurological conditions where you can't move, but if someone makes the first move, you will continue it. Later when I saw the movie *Awakenings*, it was disconcerting to watch doctors and nurses do the same thing with patients who had a severe form of Parkinson's.

What, then, did Eric's small experiment demonstrate? What is it that we have in common with Parkinson's patients? Why do they pause, too? Why does a push from somebody shake you out of it? For what matter, why did I have blackouts – how did I end up on a curb in front of the post office without any memory of getting there?

The one point I want to make for outsiders – those who have never had this disease – is how *hard* all this was; how much work it took. To a normal person, it looked like I was home resting. No. I was at home, trying *very* hard to get through the day. Everything, from picking up a glass of water, to going to the bathroom – to pouring coffee in a cup – was very, very difficult. To accomplish it, I had to focus ... *hard*. The best way I can describe it is driving on the New Jersey Turnpike surrounded by eighteen-wheelers during a drenching rainstorm. Driving is normally considered an easy activity, but not in those conditions. Well, walking or pouring coffee or getting on internet *are* easy functions for the rest of you – but for a person who is desperately ill with ME/CFS, they are extraordinarily difficult, and therefore extraordinarily exhausting.

I could not even do dishes. Pots were too heavy – somehow they fell out of my hands onto the floor. I had trouble loading the dishwasher because I kept misjudging where to put a glass – I would jam it unto part of another glass and one or the other would break. Then someone else in the family would have to pick out the larger pieces and vacuum the rest from the dishwasher.

to take care of me, get food in the house, keep the house clean, try to keep the holidays cheerful.

For a long time I still believed that somehow I would get it all back. Somewhere in the back of my mind I believed I would be skiing again, some day (all evidence to the contrary). As long as I believed I would one day get well, I could accept the walls closing in on me. That worked, until the day I finally had to accept that I was never going to be the person I once was.

That happened when I realized I was not only failing to improve – I was actually getting sicker every year. My world was smaller and smaller. The pain was worse; the confusion was worse; the effective isolation from everything and everyone – even my own family – was worse.

I had to adjust my dreams so that I no longer hoped to one day be the person I used to be – that is simply not possible. But I could, perhaps, be able to walk again. I could perhaps read a book again, write an essay again. Some day, I believed, I would once again be able to understand what was said to me, and answer coherently. It would get better. I had to believe that.

At some point I began to think of myself as Braudel in prison. Fernand Braudel was a French historian who some believe to have been the greatest historian of the twentieth century. During the Nazi occupation, many of his friends were killed, and he was himself put in prison. While in prison, he wrote his masterpiece in his head. When the war ended, he put it to paper – an enormous tome of the history of the Mediterranean from its geological beginnings to the present day.

I found it comforting to believe I was Braudel in prison – except that the prison was my own body. One day I would escape; one day I would return to my unfinished research and in a burst of energy from the new-found health, I would get it published.

Early on I tested positive for NMH/POTS (a defect in the autonomic nervous system), Hashimoto's thyroiditis, fibromyalgia, and restless leg syndrome. Although I remained severely ill, treating these conditions alleviated a certain amount of the discomfort of the disease. I continue to be treated for all four conditions.

When it came to underlying causes, I seemed to test negative for everything. I tested negative for mycoplasma, Chlamydia, Lyme, and numerous immune defects. My doctor kept sending me to be tested for M.S., but the diagnosis was always negative. There was no evidence of exposure to toxins such as black mold or mercury. Then everything changed again.

In the fall of 1998 I tested positive for an immune defect called the 37kDa Rnase-L Factor. I first heard Dr. Robert Suhadolnik present a seminar about the defect in 1996. I knew the research was solid, but it took almost three years to get tested for it. Dr. Dharam Ablashi, the researcher who prepared my blood sample for the testing, also

tested me for Human Herpes Virus 6, Variant A (HHV-6A). At the same time, a lab test for Epstein-Barr came back positive – the fourth documented positive for EBV since I was 17. EBV is a serious illness (mono), but HHV-6A is truly vicious. It causes encephalitis and meningitis, and can wreak havoc in your neurological system. In the bizarre world of ME/CFS, where you test negative for one thing after another, I was elated to find real things that were wrong with me, despite the severity of the findings. A diagnosis meant that some day there might be a cure.

HHV-6A and the 37kDa Rnase-L Factor are two of three biomarkers that seem to be useful predictors of success with an experimental drug called Ampligen, an asymmetrical double-stranded synthetic RNA. (I did not have the test for the third, a low natural killer cell function.) I had heard of Ampligen on internet almost as soon as I was diagnosed – but no one could get it in the United States. By 1998, however, I could get Ampligen if I wanted it, as long as we were willing to pay the price. Because of those positive test results, and because my health was deteriorating rapidly, my family and I decided it was worth the money – and the personal risk – to try the experimental drug on a cost-recovery basis. That meant I knew I was getting the drug (and not a placebo), but I had to pay the company's costs, which were quite steep. Fortunately, my parents helped us out in the first years when the total cost was roughly \$40,000/year cash (since 2003 I have paid \$20,000 cash/year – almost precisely my after tax disability income). I began twice-weekly Ampligen infusions on February 4, 1999. While Ampligen has not been able to return me to the person I once was, for the first time in years I did not “feel” sick all the time. Instead of continually deteriorating, I began to improve.

It has been over a decade since I was diagnosed with ME/CFS. I am not normal: my immune system remains defective and it is difficult for me to fight off infections. But I have improved so much from the prison that was my body in December 1998. I have gone from a Karnovsky disability score of 30 to a 70 (where 0 is dead and 100 is perfectly healthy). Ampligen may not help everyone, but it can help some of us. The markers I have may not be positive for everyone with ME/CFS, but at least patients should be able to get tested for them. Certainly patients and their doctors in the U.S. should have access to the criteria for an M.E diagnosis, and the half-century of knowledge that goes with it.

The presents Ampligen gave me were simple things that the rest of the world takes for granted. My husband said he got his best friend back. I danced with my son at his wedding, and three years later flew to Fort Lauderdale to hold my newborn granddaughter within 24 hours of her birth. On a visit to Los Angeles, I could stroll through the night air with my daughter to see a Hitchcock film being screened at USC, where she attended film school. I walked along the beach barefoot, and hiked on a Rockies trail just far enough to lose the sound and sight of automobiles. I was no longer in prison.

When I finally did improve, however, my old analogy to Braudel turned out to be a bit incorrect. True enough, I had escaped from my own prison – but the war was still raging, and my friends were trapped in it. I could not turn my back on them.

Thus I continue to come to the CFSCC meetings – now the CFSAC meetings. I have friends now who have tested for the same markers I have, but cannot afford the medication. Patients write me or call me and ask who they can see for a physician – and I don't know what to tell them. There are only a handful of physicians in this country who understand this disease in all its severity and complexity – and they are not inexpensive. The likelihood of a woman living on her own with this disease being able to afford the type of treatment I have received is between slim and none. The vast majority of physicians have absolutely no idea where to even get started – if they “believe in” the disease at all.

That brings us to the role of the CDC in educating the nation about illness.

The difficulty the U.S. CDC has had coming to terms with this disease is mystifying. Since 1934 cluster outbreaks of what was known as Atypical Poliomyelitis and then Epidemic Neuromyesthenia were duly recorded in the United States. By the 1950s, the name Myalgic Encephalomyelitis (M.E.) had become accepted in England, Canada, and Australia – but researchers knew that was the same thing as Epidemic Neuromyesthenia.

In the mid-1980s, confronted with a new cluster outbreak roughly centered on Lake Tahoe, at the Nevada/California border, CDC and NIH chose first to ignore the outbreak, and then to declare it a new entity altogether. Although experts concluded that it was an outbreak of M.E., CDC and NIH nevertheless presented it to the nation first as “Chronic Epstein-Barr Virus,” which was quickly discarded. They then created the name “Chronic Fatigue Syndrome” (CFS), along with what is sometimes called a “garbage” diagnosis – CFS is diagnosed not by what it is, but by what it is not. Although there has always been a billing code for M.E., the U.S. government has refused to acknowledge the existence of the disease, or the validity of a half-century of research into M.E.

To complicate matters further, in 1991 a group of psychiatrists in England adopted the “Oxford Definition” for CFS. British psychiatrists use the term “neurasthenia” interchangeably with “CFS”, and consider it a type of neurosis where the patient only “thinks” he or she has the illness. Unlike the 1988 “Holmes” definition and the 1994 “Fukuda” definition, approved for use by the CDC, the Oxford definition requires only chronic fatigue for a diagnosis of CFS, and includes patients whose main problem is depression. In 1991, the NIH admitted that M.E. was an “early term” for CFS – but they also stated that CFS was probably “neurasthenia,” just as the British psychiatrists had. In the ensuing years, researchers have created even more definitions of “CFS”. The result is chaos. How can research using one definition be compared with other research based on an entirely different definition? It can't – yet the CDC and NIH have remained silent on this issue.

In 2003, Canada adopted a very extensive clinical definition and treatment protocol for M.E./CFS (to meet the WHO classification that has placed both Myalgic Encephalomyelitis and Chronic Fatigue Syndrome in the same code – G93.3, in

neurology.) I handed out copies of the 30-page summary of the Consensus Document to all the members of the CFSAC in April, 2006 – I would be happy to provide copies to new members, but I believe that since they were entered as testimony they should be available to new members now.

I know I handed a copy to Dr. Reeves, but CDC pretends that document does not exist – even though several of the authors work in the United States, and one, Dr. Klimas, works very closely with CDC. The answers are right there in front of us – the help is right there for those who need it – if only the CDC would take off its blinders and accept research and clinical advice from outside its self-absorbed bureaucracy.

I have been lucky. I had a family who could – and would – take care of me; I had access to information most patients do not; and my family was willing (and able) to bear the costs of the treatment that has given me back a life. I can only hope that all my friends back in the world of ME/CFS can some day have access to whatever testing and treatment is available for a few. I hope that eventually there will be funding so we can get to the root cause, or causes, of this illness. I hope this committee can begin to make the changes we so badly need to free my friends from the prisons in which they remain. One million Americans suffering from a severely debilitating illness, for which they receive little or no treatment, should be unacceptable in the richest nation in the world. We have the tools to move on; all we need now is the willpower. I hope this committee can find it.

Excerpts from “Slightly Alive”

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